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Social Support in Young Adult Cancer Survivors and Their Close Social Network Members

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SOCIAL SUPPORT IN YOUNG ADULT CANCER
SURVIVORS AND THEIR CLOSE SOCIAL NETWORK
MEMBERS

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information at the
University of Kentucky

By
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Lexington, Kentucky

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and Dr. Elisia L. Cohen, Associate Professor of Communication

Lexington, Kentucky

2014

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ABSTRACT OF DISSERTATION

SOCIAL SUPPORT IN YOUNG ADULT CANCER SURVIVORS AND THEIR CLOSE SOCIAL NETWORK MEMBERS

A cancer diagnosis often causes biographical disruption in the lives of young adult (i.e., 18-39; YA) survivors and their close social network members (i.e., familial, plutonic, or romantic relational partners with whom the survivor has a salient relationship; SNM). In order to integrate their illness into their lives, normatively regain balance and equilibrium, and achieve a “new normal” following a cancer diagnosis, YA survivors and their close SNMs must work to reconstruct their biographies by engaging in tangible interpersonal communication processes often used to initiate and maintain relationships. However, YA cancer survivors report facing social struggles due to the biographical disruption of their illness across the trajectory of diagnosis, treatment, and survivorship.

To learn more about their unique social experience of cancer, I conducted private, open-ended narrative interviews with 20 YA survivor-close SNM dyads, 1 YA survivor-SNM close triad, and 10 individual YA survivors ($N = 51$). I used thematic narrative analysis to determine how and why YA cancer survivors and their close SNMs communicate social support messages with romantic partners, family, friends, peers, and one another. By examining the narratives of YA survivors, their close SNMs, and the dyad itself, this dissertation explores the interpersonal communication processes used to initiate and maintain relationships across the illness trajectory by focusing on the barriers and facilitators these individuals experience in the communication of social support.

Through their individual narrative accounts, YA survivors explained why and how they perceived various support attempts from others to be positive or negative, and their close SNMs detailed their attempts to navigate the YA’s larger support network and assume the duties inherent in their newly-adopted “top supporter” role. In addition, reports from YAs and their SNMs revealed that they often engaged in mutual pretense, a unique and often unsustainable form of support that occurred between YA survivors and their close SNMs involving topic avoidance and emotional management. Implications for the advancement of interpersonal communication theory and for practical intervention

targeting YA patients and survivors, their close SNMs, and medical practitioners are also discussed.

KEYWORDS: Young Adults, Cancer, Social Support,
Biographical Disruption, Narrative

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July 25, 2014

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For Jordan and Christine

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CHAPTER ONE: LITERATURE REVIEW

Introduction and Rationale

Approximately 69,000 young adults (YAs) between the ages of 18-39 receive a cancer diagnosis annually (Skoch, 2009), and cancer remains the leading cause of disease-related death among this population (NCI, 2011). Unlike pediatric and older adult patients, who have experienced dramatic increases in survival rates over recent decades, YAs have seen little improvement in survival rates since 1975 (AYAOPRG, 2006; Couzin, 2007). In a series of reports by the National Cancer Institute (NCI, 2004) and the Adolescent and Young Adult Oncology Peer Review Group (AYAOPRG, 2006), the lack of significant improvement in YA mortality rates and other negative disease-related outcomes have been attributed to a number of factors. These include a lack of attention and resources devoted to addressing the unique YA cancer experience, limited and restricted access to healthcare and insurance coverage in this population, inconsistent treatment and follow-up care, poor representation of this age group in clinical trials, and a limited awareness and emphasis placed on prevention and early detection. Another factor, delayed diagnosis, is attributed partially to a sense of health-related invulnerability and embarrassment that uniquely marks the YA population; for example, younger YAs may be subject to social norms that showing concern and seeking a medical opinion makes them a “wimp,” so they minimize their symptoms for too long (Bath, 2012). Additionally, medical providers’ low suspicion of cancer in this population may also lead to delayed diagnosis (AYAOPRG, 2006).

Another significant factor in this population’s negative disease-related and quality of life outcomes are the unique psychosocial and support challenges that face YA patients

and survivors pertaining to cancer diagnosis, treatment, and survivorship (i.e., the stage of cancer that follows the completion of primary treatment; Macmillan Cancer Support [2008]), which are often compounded by a lack of effective and age-appropriate psychosocial and support resources (AYAOPRG, 2006; NCI, 2004). YAs' psychosocial challenges also tend to be distinct and "broader in scope and intensity than [the challenges faced by] younger and older adult patients because of the many emotional, developmental, and social changes and transitions during this stage of life" (AYAOPRG, 2006, p. ii, bracketed information added).

Theorists of human development suggest that although cancer patients and survivors experience common sets of life disruption, they attach different levels of importance to different aspects of the experience, depending on the life stage at which diagnosis occurs (Zebrack, Chesler, & Kaplan, 2010). For example, many YAs are working toward important social milestones like forming intimate relationships, finishing school, beginning a career, and having children (AYAOPRG, 2006; Gorman, 2011). Additionally, the achievement of normative developmental characteristics, such as securing financial and parental independence, establishing an identity, and planning for the future are often prioritized by young people and typically are of less concern to older adults (Hollis & Morgan, 2001; NCI, 2004). The experience of cancer diagnosis, treatment, and survivorship abruptly delays or derails the development and achievement of these important social processes and normative life plans (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011; Kent et al., 2012; NCI, 2004; Zebrack, 2000). Thus, it is important to better understand the unique interpersonal communication processes and

challenges during this disruption in order to learn how support can be effectively provided to YA cancer survivors and those who are close to them.

Interestingly, and more specific to the scope of this dissertation, psychosocial issues related to initiating and managing interpersonal communication within close social relationships in this population are particularly salient. In a recent study, healthy college students reported that they would likely engage in more discourse, information seeking, and relational intimacy with a hypothetical, same-age cancer patient (Horan et al., 2009). However, while YAs are often the recipients of perceived positive social support from existing networks comprised of family, friends, and intimate partners, they also experience altered social roles and social identities, feelings of social isolation, and difficulty initiating new relationships (Zebrack, 2000; Zebrack et al., 2012). In fact, in a recent focus group study, YA cancer patients and survivors indicated that experiencing altered social relationships in the wake of a cancer diagnosis was their primary psychosocial challenge (Kent et al., 2012). Compared to children and older adults, YA patients and survivors often lack the built-in and well-established advocacy of family and peer communities (AYAOPRG, 2006). Therefore, finding and maintaining effective social support is often particularly difficult for this age group (Miller & Hefner, 2012).

Need for Age-appropriate Psychosocial Services and Interventions

Addressing YAs' psychosocial and support needs may help to improve their emotional wellbeing as well as their health outcomes. When YAs perceive high levels of social support from pre-existing networks or newly-formed cancer-related networks, they are more likely to be able to cope with their illness across the trajectory of diagnosis, primary treatment, and survivorship (Miedema, Hamilton, & Easley, 2007; Zebrack,

2011). More specifically, the perceived receipt of positive social support can assist YA patients and survivors in experiencing less anxiety and isolation, making treatment decisions, increasing feelings of self-worth and normalcy, alleviating pain and suffering (Zebrack et al., 2010), having more time to physically and emotionally recuperate, improving their outlook on cancer itself, and maintaining a higher quality of life (Kent et al., 2012).

Yet there is still a clear need for research that speaks to specific ways to improve YAs' ability to initiate and manage interpersonal communication within close social relationships and to provide increased access to support networks. Because cancer is largely defined and understood in Western society according to the experiences of those who suffer from it during later adulthood, it is often still thought of as an ailment that afflicts those who are well beyond middle age (AYAOPRG, 2006). As a result, YAs' unique psychosocial needs in the midst of the cancer experience typically go overlooked, even by the patients, survivors, and close social network members themselves (AYAOPRG, 2006).

For example, compared to older survivors, YAs have a greater unmet need for accessing age-appropriate information during and after treatment (Thewes, Butow, Girgis, & Pendlebury, 2004). YAs also face limited access to age-appropriate psychosocial and support services that could potentially provide opportunities for peer support with other YA cancer survivors or YA close social network members; those programs that do exist are often underused by this age group (AYAOPRG, 2006). In fact, YAs are less likely to use professional mental health services or find age-appropriate professional, recreational, complementary, alternative, and online health and support

services than other age groups (Zebrack et al., 2012). The only tangible in-person support groups available to some YAs are often filled with prostate or breast cancer survivors in their 50s and 60s, who likely have considerably different concerns than the average YA cancer patient or survivor (Kent et al., 2012; Miller & Hefner, 2012; Skoch, 2009). However, YAs have expressed little interest in attending traditional support groups anyway, even if they involve other YAs (Zebrack & Isaacson, 2012), and some survivors wait over five years after the completion of treatment to seek out a group for support (NCI, 2004). YAs also sometimes feel a wide generational disconnect with big-box cancer organizations like Susan G. Komen and the American Cancer Society (Miller & Hefner, 2012), which they perceive to be stodgy or out of touch with YA-specific needs, in part because they often frame their messages in pink-drenched earnestness and prioritize the benefits of positive thinking rather than recognize more realistic emotions like fear, anger, and cynicism (Skoch, 2009).

All too frequently, the apparent anachronistic nature of the YA's cancer experience can result in stress, anxiety, depression, uncertainty, negative care-seeking patterns, poorer treatment adherence, and, ultimately, insignificant improvement in morbidity and mortality rates among this population (AYAOPRG, 2006; Kent et al., 2012; NCI, 2004; Trevino, Maciejewski, Fasciano, & Prigerson, 2011). Learning more about the YA cancer experience, particularly in regard to this population's social support needs and interpersonal communication practices, may assist in the continued development and increased awareness of more age-appropriate informational resources and opportunities for psychosocial support and peer connection.

In addition to developing resources tailored to YAs, there is also a need to improve YAs' use of available resources. Many YAs currently are unaware that opportunities for social connection do actually exist (Kent et al., 2012). One reason that YA support services are limited and largely underutilized by this population is because the current medical system features few cancer centers, programs, services, and informational resources that have been developed to deal solely with the unique needs of YA patients and survivors and their close social network members (AYAOPRG, 2006; Bath, 2012; Gorman, 2011; Hollis & Morgan, 2001; Miller & Hefner, 2012; Thewes et al., 2004). YAs often find themselves stuck in a "no man's land" between pediatric and adult oncology, because rules rarely exist that dictate where they should receive care. As a result, they are often the oldest or youngest person in the oncology ward, and the quality of their care suffers (AYAOPRG, 2006; Skoch, 2009). For example, one young breast cancer survivor complained that her chemotherapy infusion room only offered magazines and other printed information that was developed for the retirement community, which would likely not provide specific information members of this population may need about dating, fertility issues, accepting help from a parent or significant other, balancing cancer with college, or parenting young children (Miller & Hefner, 2012). Thus, many YAs have an unfavorable perception of support resources that are available.

Additionally, compared to older survivors, YAs tend to desire a more holistic approach to their post-treatment care, complementing the improvement of their physical health with a focus on psychological, social, and sexual well-being (Thewes et al., 2004). However, these needs are not often met in the current healthcare system, so YAs often

struggle to feel a sense of inclusion and to find opportunities to establish social support with other similar patients or survivors both during and after treatment (Gorman, 2011; Hollis & Morgan, 2001; Kent et al., 2012). This is particularly problematic for those YAs who are seeking palliative or therapeutic services for the possibly unique psychosocial issues that arise during the “void” experienced at the conclusion of treatment, when strict daily or weekly regimens give way to a sense of nothingness, adjustment to new disabilities or long-term side effects, anxiety over being reintegrated into family or work life, survivor’s guilt, and a lifetime of fears related to recurrence (Iannarino, 2013; Miller & Hefner, 2012; Rosenthal, 2009).

By recognizing their patients’ feelings of isolation and advocating for, providing information about, and collaborating with age-specific community services, clinicians can also play an important role in improving YAs’ access to relevant care and age-appropriate support networks (Street, Makoul, Arora, & Epstein, 2009). However, medical practitioners generally tend to be poor judges of their patients’ emotions (Street et al., 2009), and they may be particularly unprepared to deal with the unique psychosocial and support challenges related to YA oncology (Bleyer, 2007). Because current provider training and education programs do not sufficiently address YA-specific issues, providers often lack an adequate understanding of YAs’ psychosocial and communication needs, and they rarely offer YAs specialized care guidelines or refer them to age-appropriate psychosocial services or programs that could potentially offer peer support (AYAOPRG, 2006; NCI, 2004; Soliman & Agriesta, 2008). Compared to older cancer patients, YAs want more information and a more collaborative relationship with their providers (Thewes et al., 2004). Additionally, while YA patients place a high

importance on seeking out and connecting with YA peer survivors, providers do not perceive this to be a priority (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Perhaps as a result, providers are often stumped by the need to increase YAs' compliance, manage their negative emotions, and improve their quality of life during and after cancer treatment (Bleyer, 2007). Patients may also continue to feel that the discussion of psychosocial issues falls outside the boundaries of the patient-practitioner relationship and thus mask their distress or desire for social connection (Street et al., 2009).

Although they have demonstrated little interest in joining traditional support groups, even groups whose members are close in age, YAs tend to be more open to participating in social activities with other cancer patients that help them reclaim a sense of normalcy in their lives (Shama & Lucchetta, 2007; Zebrack & Isaacson, 2012). Recently, more age-appropriate models of support groups have been established as social integration programs (Bath, 2012), which are often hosted by organizations formed by YA patients and survivors, specifically for YA patients and survivors and their loved ones (Zebrack & Isaacson, 2012). These programs are founded under the pretense that YAs will come for an activity that incidentally (but not necessarily expressly) provides them with opportunities to connect with other similar individuals and leave with new valued relationships in place (Kent et al., 2012). For example, programs like First Descents provide YAs with outdoor adventure therapy trips like surfing, rock climbing, or whitewater kayaking. The I'm Too Young for This Foundation organizes informal happy hour meet-ups for YA patients and survivors at bars across the country. Other activities offered by similar programs include outdoor oncology camps, family retreats,

bonfires, tournaments (e.g., paintball, golf, poker), triathlons, and annual summits (Zebrack, 2011; Zebrack & Isaacson, 2012).

Social integration programs offer YAs opportunities for life experiences that promote the achievement of developmental tasks, like interpersonal and problem solving skills (Zebrack & Isaacson, 2012), that YAs often lack due to prolonged periods of treatment-related isolation (Zebrack, 2011). These programs also facilitate the sharing of coping skills, information, insight, fears, and concerns that are specific to the YA developmental group, all while providing YAs the chance to “meet, be, and become who they want to be” (Zebrack & Isaacson, 2012, p. 1224). Additionally, the establishment of social ties at different stages along the cancer trajectory within this context (e.g., a more experienced cancer survivor may be able to provide insight to a newly diagnosed patient about what lies ahead) may provide opportunities for the enactment or receipt of emotional support (Zebrack et al., 2006).

An increasing number of support venues are being made available on the internet in the form of online social network sites geared toward YAs. These sites provide YAs with age-relevant support, information, and opportunities to connect with one another using technology with which they are often familiar (Zebrack, 2011). Many of these online communities (e.g., Planet Cancer, Stupid Cancer) were started with limited resources by YA survivors, and they also provide places for YAs to indulge in inside jokes (Iannarino, 2013; Skoch, 2009). The I’m Too Young for This Foundation also uses arts and social media to organize YAs, reduce the stigma of cancer as a death sentence, and attempt to make it easier to talk openly with others about cancer (Skoch, 2009).

Although social integration programs both in online and face-to-face settings have the potential to enhance positive outcomes (e.g., reduce social isolation, improve psychosocial functioning, promote successful adjustment; AYAOPRG, 2006), many programs have not been developed, expanded, or assessed empirically (Seitz, Besier, & Goldbeck, 2009). Additionally, few tools currently exist to measure the efficacy of patient/survivor and family support psychosocial interventions delivered in diverse settings (AYAOPRG, 2006). As communication researchers investigate YA cancer survivors as a unique group with distinct social and emotional needs, they need to consider how their findings can be applied to the development and evaluation of age-appropriate psychosocial interventions, informational resources, and educational programs that can improve the maintenance and initiation of YA survivors' social relationships following a cancer diagnosis.

Psychosocial Needs of Close Social Network Members

In the well-documented need for more effective, age-appropriate, and visible psychosocial and support interventions for YA cancer patients and survivors, members of the YA's social network (i.e., family members, friends, romantic partners) with whom the YA shares a salient relationship are being overlooked as potentially needing unique services and intervention. Not only might targeting these individuals provide one of the best opportunities to improve psychosocial and ultimately health outcomes for YA survivors (i.e., by incidentally improving the instrumental and emotional support perceived by the survivor), but YAs' close social network members (SNMs) likely experience unique psychosocial and support needs of their own.

First, similar to YAs who are diagnosed with cancer, close SNMs are often faced with a unique and unforeseen life disruption in response to their loved one's cancer diagnosis. For example, parents must come to terms with their YA child's surprising illness and either reassume or relinquish their role as primary caregiver as their child moves toward, or has already established, familial independence. Additionally, YA siblings, friends, and romantic partners must work to support and maintain their relationship with the YA patient/survivor on top of their own attempts to foster a fledgling family or career, solidify social relationships, achieve financial independence, and manage communication about their loved one's illness with other supporters. Unlike their loved one, most SNMs' lives are forced to continue despite their experience with severe or chronic illness. In other words, close SNMs are unable to adopt the "sick role" afforded to patients, which encourages those who are physically ill to take time away from their obligations in order to become well again (Parsons, 1951). SNMs may also paradoxically be forced to ask for or accept necessary support from others when they are still striving for independence in their lives. Therefore, attention should be spent on supporting SNMs in particular with their unique needs associated with managing the burden and potential isolation of care while balancing their own attempts to achieve normative life plans and social processes.

Second, the unique and unforeseen life disruption associated with their loved one's illness may cause SNMs to negotiate new and unexpected roles with both the survivor and other members of the survivor's network who are either interested or uninterested in being involved in various support efforts. In fact, because the experience of a YA cancer diagnosis is rare and often unexpected, SNMs and survivors may lack

existing scripts that would be helpful in providing effective support to one another. For example, close SNMs may be so uncertain about how and when to provide support to the YA patient or survivor that they may accidentally make the person with cancer feel worse, perhaps by offering too much support or by emotionally or physically withdrawing themselves from the patient or survivor. Additionally, they may not feel equipped to help the YA patient or survivor make medical and personal decisions related to their cancer (e.g., about treatment options, genetic testing, potentially disfiguring surgeries) that may require them to discuss possibly uncomfortable or upsetting topics (e.g., sexual function, fertility, death). Close SNMs may also have to negotiate their support role or “domain” within the survivor’s network to claim the privilege of or solicit help in fulfilling certain tasks and making various decisions. SNMs could receive more effective information about how to recognize and avoid offering negative or unwanted forms of support that could complicate YA survivors’ and other close SNMs’ challenges or attempts to adjust.

Thus, for many of the same reasons that YA cancer patients and survivors are a group that has unique psychosocial needs due to the disruption of normative developmental, identity, and interpersonal communication processes, YAs’ close SNMs may have distinct psychosocial concerns and coping strategies that should be explored, particularly through their interaction with their YA loved one. Without the development of appropriate psychosocial resources and interventions, close SNMs may struggle to effectively seek social support that is perceived to be effective and provide it to others.

Need for Continued Research

Although the identification of previously overlooked aspects of YAs' unique cancer experiences has recently led psychosocial researchers to emphasize the study of these individuals as a separate age-defined population, more empirical studies are still necessary to further distinguish specific psychosocial outcomes and needs in YAs (AYAOPRG, 2006; Zebrack et al., 2011). Part of the problem is that YAs are still frequently underrepresented as a unique population in psychosocial studies (Zebrack et al., 2010). Before oncology progress review groups began issuing calls for more YA-specific patient and survivorship research in 2004, less than one percent of cancer-related citations in the PubMed database focused solely on YA survivorship issues (NCI, 2004). Not only do older adults far outnumber YAs in terms of incidence (Zebrack et al., 2010), but survivorship studies that claim to examine YA populations still recruit survivors of pediatric cancers (Canada, Schover, & Li, 2007; Rabin, Dunsinger, Ness, & Marcus, 2011; Wakefield et al., 2011), which prevents researchers from gaining a clear understanding of the unique outcomes associated with the experience of cancer at the YA life stage (AYAOPRG, 2006). Learning about YA survivors' post-treatment needs is becoming more important because technological advancements have improved cancer screening and treatment procedures, causing cancer to become less ubiquitous as a terminal illness and more common as a chronic disease for all age groups.

When the psychosocial literature has featured YA survivors who were diagnosed as YAs, unique concerns related to navigating interpersonal relationships or (re)establishing social networks are often lumped together with other psychosocial and biomedical concerns such as managing distress (e.g., anxiety, depression) and assisting

with other disease and treatment effects (e.g., symptom management, pain control, sexual dysfunction, fertility preservation); in other words, social support and other interpersonal communication issues have rarely been studied in their own right (e.g., Zebrack et al., 2006, 2010). In addition, researchers have frequently recruited YAs through survivor networks, retreats, and other age-relevant psychosocial services. This practice may cause researchers to underestimate average survivors' perceptions of social isolation, awareness of YAs as a "brand" or social identity, and knowledge of the unique needs of and support services available to this population (Kent et al., 2012; Zebrack et al., 2010).

Additionally, there is a significantly heavier emphasis placed on the needs of the YA population than on how and why they are able to cope with their cancer experience. With health communication research in particular, there are few published empirical investigations of how YAs use communication to integrate their cancer diagnosis, treatment, and survivorship into their lives in order to reach a "new normal." Instead, communication research to this point has tended to focus more on cancer prevention, risk reduction, and early detection among YAs as a population at risk for enacting behaviors that could lead to cancer (e.g., Greene & Brinn, 2003; Head & Cohen, 2012; Wanzer, Foster, LaBelle, & Servoss, 2011).

To date, little published YA survivor research has been driven by theory, aside from the integration of developmental stage and identity frameworks (Zebrack, 2000) and Folkman and Lazarus's (1980, 1988) coping theory (Miedema et al., 2007). Because this literature is largely non-programmatic and scattered across psychosocial, medical, and social work journals, it is important to start grounding YA survivorship issues in interpersonal communication theory, which is needed to inform the development of

communication interventions and provide useful advice to YA cancer survivors and their close SNMs (Donovan-Kicken, Tollison, & Goins, 2012; Miller & Hefner, 2012).

Further, no communication research has examined the specific social experiences of both YA cancer survivors and their close SNMs as individuals and as dyadic partners to identify their unique interpersonal communication and support dynamics while addressing other concerns following a diagnosis. Regardless of whether a social relationship is platonic, familial, or romantic, both partners' sense of shared identity can be changed in different ways due to cancer. Even though each partner may view themselves as a unified couple, their individual identities can vary meaningfully (Miller & Caughlin, 2013). Researchers must continue to examine how YA survivors experience altered social relationships following a diagnosis, but little research exists on how SNMs use interpersonal communication to manage their new and unexpected role in supporting the YA survivor, negotiate their role or "domain" with others in the YA survivor's network, and perceive or seek support for both themselves and the YA survivor.

YA cancer survivors and their close SNMs experience distinct concerns related to initiating and managing social relationships with family, friends, peers (e.g., coworkers and classmates), and romantic partners following a diagnosis. These unique interpersonal communication challenges are compounded by a lack of existing effective and appropriate support resources. As a result of cancer diagnosis, treatment, and issues related to survivorship, YA survivors and close SNMs experience a unique interruption and redefinition of social relationships with one another, family, friends, romantic partners, and peers.

In an attempt to gain insight into the unique social needs inherent in both partners' individual cancer experience and to represent a joint picture that constitutes a dyadic perspective of a common experience, this dissertation examines both YA survivors' and their close SNMs' accounts of the cancer experience on both an individual and dyadic level (Eisikovits & Koren, 2010). Dyadic analysis assists in deriving themes related to the nature of individuals' relationships, which could otherwise not have been reached by interviewing only one member of a dyad. This process is also useful when the topic of study is a shared experience by members of a dyad, such as adjustment to illness. When examining YA survivors and close SNMs who experienced cancer as a dyad, researchers can examine each participant's subjective version of their experience on both an individual and dyadic level (Eisikovits & Koren, 2010).

The Present Study

In this dissertation, I use interpersonal communication concepts to examine how YA cancer survivors and their close SNMs (i.e., familial, platonic, or romantic relational partners with whom the survivor had a salient relationship at diagnosis) engage in important (and often difficult) conversations to manage their relationships and to seek, perceive, and offer social support across the experience of diagnosis, treatment, and survivorship. Particularly when considering the many unique struggles experienced by YAs following a cancer diagnosis, it is important to examine how support can hinder or facilitate YA survivors' and their close SNMs' adjustment to the illness experience. While other scholars have examined various aspects of the who, what, when, and where YA cancer patients employ to manage their illness, taking an interpersonal communication perspective allows researchers to focus on *how* and *why* YA survivors

and close SNMs talk about their illness experience with one another, family, friends, romantic partners, and peers and how that communication affects their psychosocial and physical health.

Conceptualizing Cancer in YA Relationships

A cancer diagnosis causes a disruption in the lives and relationships of YA survivors and their close SNMs. In order to reconstruct their biography to normatively regain or create balance and equilibrium in their lives, YA survivors and their close SNMs must engage in communication as a responsibility or form of labor and communication to receive, offer, and solicit social support. However, changes in YAs' interpersonal relationships with family, friends, and intimate partners may serve as barriers to the interpersonal communication processes that enable biographical reconstruction.

Biographical Disruption

According to Corbin and Strauss (1987), chronic and severe illness “separates the person of the present from the person of the past, and affects or even shatters any images of self held for the future” (p. 249). Cancer often represents a major disruptive experience to YA patients' and survivors' concepts of self; perceptions of the past, present, and future; possession of a functional body capable of action; and communication within their relationships (Corbin & Strauss, 1987). In other words, when YA cancer survivors and their close SNMs experience diagnosis, treatment, and survivorship, their *biography*, or expected life course and structures of everyday life, is disrupted (Bury, 1982).

When a person comes to the understanding that they have a life-threatening illness, they often begin to reappraise their existing relationships, particularly with those

closest to them (Miedema et al., 2007). Likewise, YAs' experience of biographical disruption entails a unique alteration and redefinition of relationships with SNMs such as romantic partners, family, friends, peers (e.g., coworkers and classmates), and medical practitioners (Kent et al., 2012; Zebrack, 2000; Zebrack et al., 2012), which can create major challenges for YAs in these relational contexts such as feelings of isolation, alienation, discomfort, and frustration (AYAOPRG, 2006).

For example, the biographical disruption of cancer is often described by YAs as a frustrating but necessary tension or "paradox" because it disrupts their unique process of moving toward independence—particularly through the formation and maintenance of new relationships, achievement of important social milestones, and development of normative life plans—with a necessary state of dependence on others (Kent et al., 2012). Additionally, changes in or challenges to the ways that YA cancer survivors see themselves in relation to the world, including their ability to carry out the social roles and responsibilities they held before a diagnosis, may affect their sense of wellbeing (Zebrack, 2000).

Biographical disruption may be particularly problematic for YAs because members of this population are simultaneously undergoing a normative state of psychosocial and biographical transition (AYAOPRG, 2006). Even before the biographical disruption of a cancer diagnosis, many YAs work to maintain family, friend, romantic, and peer support systems that are already less established than at other stages of life, particularly during childhood and older adulthood (Rosenthal, 2009; Soliman & Agresta, 2008; Zebrack & Isaacson, 2012). Following adolescence, family members and longtime friends may move across the country for education or employment

opportunities, or they may begin spending time with new social networks established at school or work. Social identity is also especially important to YAs, who are often at a developmental stage in which peer-group approval and self-image are challenged by diagnosis, treatment, and issues pertaining to survivorship (Bleyer, 2007). For example, YAs may feel uncertain about whether or how they will be accepted among healthy friends and peers; some feel that their prior identity has been threatened by or replaced with their new primary identity as “cancer patient” or “cancer survivor” (Carpentier et al., 2011). Because they are already in a state of transition, the biographical disruption of cancer often alters YAs’ social relationships in a manner that is distinct from those at different stages of life.

Similarly, YA survivors’ close SNMs also may experience a unique biographical disruption following their loved one’s cancer diagnosis. Not only do these individuals often assume additional cancer-related responsibilities on top of their pre-existing obligations that may delay, derail, or redirect their existing career paths, personal goals, and family lives and cause them to reconceptualize perceptions of their capabilities and limitations, but they are also often forced to cope with altered social relationships of their own. For example, following a biographical disruption, close SNMs may struggle to manage their relationship with the survivor. Additionally, close SNMs may find themselves negotiating with one another about the support roles or “domains” (e.g., what type of support, how much support to provide to the survivor) that are best and that they plan to fulfill.

In response to the biographical disruption associated with their illness experience, most YA cancer survivors and close SNMs strive to achieve *biographical reconstruction*,

or a return to a sense of “normalcy,” by regaining or creating a new balance and equilibrium following the completion of primary treatment (Miedema et al., 2007). Sometimes this “normal” entails a return to an experience of life similar to that of pre-diagnosis. However, YA cancer survivors often continue to view themselves and their relationships differently than they did before they learned they had cancer (Miedema et al., 2007).

YA survivors and close SNMs attempt to integrate illness into their lives and achieve biographical reconstruction by countering the disruption of cancer through the cognitive process of *biographical work* (Bury, 1982; Corbin & Strauss, 1987) and the tangible process of *communication work* (Donovan-Kicken et al., 2012). According to the theory of illness trajectories, in order to become oriented to, cope with, and treat their chronic illness, cancer survivors and close SNMs must manage numerous complicated tasks, conceptualized as *work*, that go beyond ordinary daily responsibilities and the newfound duties resulting from their illness (Corbin & Strauss, 1987).

In addition to these lines of labor, the biographical disruption of cancer requires survivors and close SNMs to engage in an imaginative process of cognitive reorganization called *biographical work* (Corbin & Strauss, 1987) where meaning-making (Williams, 1984) and the reacquisition of control (Bury, 1982) may take place. Biographical work is an inherently intrapersonal process in which an individual attempts to cognitively restore and reconstitute the self in light of the new trajectory their identity and future plans seem to be taking (Bury, 1982; Corbin & Strauss, 1987). YAs must engage in the process of biographical work to integrate their cancer diagnosis, treatment, and survivorship into their pre-existing self-concept, possibly resulting in a new or

renewed sense of self or normalcy (Miedema et al., 2007; Zebrack, 2000). YAs also often draw on their “pre-cancer” social identity, life events, experiences, and activities to influence their altered identity as a cancer patient or survivor (Miedema et al., 2007). For example, YA survivors sometimes create illness-related alter-egos in response to physical changes in body appearance and function that evolve across the illness trajectory and are divergent from their identity before diagnosis (Iannarino, 2013). However, the process of biographical reconstruction in illness sufferers takes on tangible and communicative forms through the interpersonal performance of *communication work*.

Communication work is an additional line of labor added to the theory of illness trajectories that describes the obligations, demands, and preparation devoted to managing talk and information about the cancer experience (Donovan-Kicken et al., 2012).

Communication work involves keeping others informed about the cancer patient/survivor’s diagnosis, treatment, changes in prognoses, health status, and other news (i.e., choosing what, how, and to whom to disclose information about the cancer experience). It also involves soliciting or offering social support, engaging in identity management, and managing social uncertainty by actively designing messages to prepare for cancer-related conversations (Donovan-Kicken et al., 2012). Adult cancer survivors reported that these consequential interactions commonly take place with significant others, family, friends, peers, and healthcare practitioners (Donovan-Kicken et al., 2012). Cancer survivors often view communication work as demanding because it is a time-consuming process that requires effort to cope with others’ questions, comments, and emotions in response to their illness-related disclosures. They also feel that they have a duty or responsibility to communicate effectively with others. As a result, cancer

survivors sometimes recruit close others to share the responsibilities of engaging in communication work (Donovan-Kicken et al., 2012).

Normative Social Support

One tangible interpersonal communication process that is integral to YA survivors' and close SNMs' achievement of biographical reconstruction (but does not always constitute communicative work or labor) is the reception, solicitation, and offering of social support. Following a cancer diagnosis, YA survivors often readily acknowledge and appreciate the instrumental and emotional support they receive from their pre-existing social networks (Kent et al., 2012), particularly social support messages that enable them to make sense of their cancer experience and its influence on their current and future identity and social situations (Zebrack et al., 2010). Like patients and survivors of other ages, YAs appreciate the receipt of positive attention—such as others' ability to simply be present, listen, show personal interest in them, and pledge to care—that made them feel better, cared for, and more like a “normal person” (Zebrack et al., 2010). Additionally, many cancer survivors offer support through identity management by portraying themselves as “strong” or “reassuring” despite being scared or uncomfortable (Donovan-Kicken, 2012). These identities may be enacted to limit the amount of stress and fear their disclosures will cause in others and to solicit specific types of support by encouraging others to treat them normally.

YAs also express appreciation for family and friends' efforts to be emotionally available, engage them, recognize when they wanted to be left alone, encourage them to maintain a sense of normalcy, push them to engage in social activities, and use humor (Zebrack et al., 2010). YA survivors have also stated that they consider humor to be one

of their primary and most valuable coping tools to help them face the effects of cancer in their lives with others (Elad, Yagil, Cohen, & Meller, 2003). Survivors have claimed that they use raunchy and cynical humor to help them speak openly to others about the “absurdity of life with cancer,” and they consider it a better support alternative to the “pink-ribboned, glassy-eyed earnestness” often advanced by older sufferers and the foundations that represent them (Skoch, 2009, para. 7). Humor’s function as a socially acceptable outlet for complaints and expressions of fear and inferiority may be a reason why individuals who use humor in medical settings often perceive increased social support in turn (duPre, 1998).

However, given the difficulties YAs have with managing their pre-existing social relationships, gaining new connections following a cancer diagnosis, and perceiving enacted support as overbearing or detrimental to their coping (e.g., Kent et al., 2012), it is important to continue investigating the communication challenges YAs and close SNMs experience in seeking, receiving, and offering social support from a communication perspective. In other words, *how* and *why* people communicate information, tasks, and feelings to cancer survivors and close SNMs (and not only *what* is communicated) affects how they experience their illness and think about themselves, their relationships, and their current and future social situations (Zebrack et al., 2010).

Thus, employing a normative, message-centered perspective to the study of social support can enable scholars to better understand *how* and *why* enacted support messages elicited in conversation are evaluated by the receiver as successful or unsuccessful, helpful or unhelpful in coping with illness (Goldsmith, 2004; Goldsmith, Lindholm, & Bute, 2006). According to a normative approach to communicating social support, the

perceived effectiveness of enacted social support during conversations in which individuals talk about their problems is contingent upon *what* the receivers and providers of support say, *how* they say it, and the meanings that participants attribute to the message (Goldsmith, 2004; Goldsmith et al., 2006). Receivers' positive or negative evaluations of enacted support may depend upon how support messages are used to (a) define the problem and coping options, (b) affirm or challenge the receiver's identity, and (c) portray the qualities of the participants' relationship (e.g., power, intimacy, closeness, involvement; Goldsmith, 2004; Goldsmith et al., 2006).

The effectiveness of communication is dependent on the *manner* and *content* of communication as well as the *social* and *emotional* context in which the communication occurs (Zebrack et al., 2010), particularly if the intent is to provide positive instrumental or emotional support. In this dissertation, I seek to further understand why and how YAs', close SNMs', and the dyads' communication involving the solicitation, perceived receipt, and offering of social support can be useful or detrimental in improving relational functioning and satisfaction that can assist in the biographical reconstruction of a "new normal."

Because the biographical disruption of a cancer diagnosis, its treatment, and issues pertaining to survivorship cause altered social relationships between YA survivors and their romantic partners, family, friends, and peers, it follows that members of this population may experience barriers in their attempts to engage in productive communication, which may prevent their adjustment to illness (i.e., biographical reconstruction). Thus, it is important for communication researchers to study YA survivors' interactions with others to learn how this altered interpersonal communication

functions to counter or exacerbate their attempts to manage the biographical disruption of cancer. In this section, I review research that examines the nature of the relational interruptions and alterations that YA survivors experience in their interpersonal communication with others following a cancer diagnosis. I focus specifically on how YA survivors' experience of biographical disruption causes altered social relationships with potential close SNMs, including their family members, pre-existing and newly-formed friend and peer groups, and intimate partners, which may impede their attempts to engage in effective communication that enables biographical reconstruction.

Barriers to Support in YA Survivors' Altered Interpersonal Relationships

Interpersonal health communication scholars currently know little about how cancer survivors and their close SNMs manage the challenges of navigating their interactions with others following the biographical disruption initiated by their illness (Donovan-Kicken et al., 2012). This lack of knowledge is particularly true for YAs as a unique age-defined population whose disruption is often associated with feelings of social isolation and unsatisfactory social interactions (Zebrack, 2011). For example, empirical studies have yet to explain whether, why, and how YAs and close SNMs integrate their cancer experience into their altered personal and dyadic biographies, identify and understand the social factors that facilitate or hinder this integration, or consider the social consequences and outcomes of such integration (Zebrack, 2000).

Following the biographical disruption of cancer, YA cancer survivors may experience impediments in their attempts to engage in productive communication and biographical reconstruction with their family members, friends, peers, and romantic partners due to their altered relationships with these individuals. As discussed below, the

social barriers related to YAs' biographical disruption following a cancer diagnosis include hovering behaviors, struggles to reintegrate following treatment, receiving ineffective or no support, and perceiving a lack of opportunities for the management of existing social relationships and the development of new relationships.

Altered relationships with family. While many YA survivors report improved family relationships during their cancer experience (AYAOPRG, 2006), they still struggle to engage in effective supportive communication in this relational context. As a result of the biographical disruption brought about by a cancer diagnosis, many YAs feel frustrated in navigating their altered relationships with family members, on whom YAs often necessarily rely for assistance in navigating the healthcare system and in supporting them financially (AYAOPRG, 2006; Iannarino, 2013; Rosenthal, 2009). Sometimes this requires moving back in with parents or delaying plans to move out (Kent et al., 2012).

As a result, YAs are often disheartened to sacrifice a measure of relational autonomy in return for their parents' support, at a time when achieving independence from family, financial or otherwise, is a primary developmental objective (AYAOPRG, 2006; Bleyer, 2007). Although YAs still express appreciation for their family's role in their cancer care, many also struggle with their parents' "overprotective" tendency to hover or to be overly vigilant in their support (Kent et al., 2012). These "helicopter" behaviors create a stable and supportive presence, but YAs also feel that they restrict their privacy and sometimes contribute to feelings of infantilization (Kent et al., 2012). These behaviors associated with the biographical disruption of cancer may prevent YA survivors from engaging in effective supportive communication with family members and achieving biographical reconstruction.

Altered relationships with peers and friends. YAs also sometimes experience difficulty engaging in supportive communication with friends and peers due to the biographical disruption of cancer because they (a) have fewer opportunities for integration during treatment, (b) struggle to reintegrate into society following primary treatment, (c) perceive ineffective or no social support from established friend networks, and (d) experience difficulty forming new relationships with fellow YA patients and survivors. First, during lengthy periods of treatment and recovery, YA patients and survivors are, in effect, taken away from their normal, preexisting social groups. They often find it difficult to maintain their social lives at school, work, and in the community as a result of this disruption (AYAOPRG, 2006; NCI, 2004), and they struggle to watch their peers enjoy experiences in which they cannot partake (Gorman, 2011; Zebrack, 2011). Many YAs are necessarily isolated at a time when they should be learning social, coping, and negotiation skills that are crucial to social development and successful adult functioning (NCI, 2004). Thus, these individuals do not even have the opportunity to engage in productive communication with existing friend groups and achieve biographical reconstruction.

Second, the sense of isolation brought about by the biographical disruption of cancer also sometimes extends into the period of survivorship following primary treatment, when the process of becoming reintegrated into society as a functional, able-bodied, whole-minded individual presents difficulties for many YA survivors (Iannarino, 2013; Rosenthal, 2009). These individuals often struggle to transition out of the “sick role” they necessarily maintained for months during and immediately after the completion of treatment (Parsons, 1951). Re-entering the school system or work

environment, for example, can lead many members of this population to feel “different” from others (AYAOPRG, 2006), particularly as they struggle to biographically incorporate their pre-cancer identity into their current experience of self (Iannarino, 2013; Rosenthal, 2009; Zebrack, 2000). For example, YAs often notice that their preexisting friendship groups have changed during their extended absence, and they sometimes feel out of touch with issues that they once found important and that continue to remain significant to their friends (e.g., drinking, fashion, sports, entertainment). Compared to what they had experienced during treatment, these interests may be viewed as superficial, immature, and unimportant (McLoone, Wakefield, Butow, Fleming, & Cohn, 2011; Miller & Hefner, 2012; NCI, 2004).

YAs’ struggles to engage in supportive communication upon reintegration may also be exacerbated because, due to poor finances and a lack of insurance, they are sometimes forced to rush their transition back into the workforce before they are mentally, physically, and emotionally ready (Iannarino, 2013; Rosenthal, 2009). As a result, many YA survivors are greeted by employers or school systems that do not recognize, validate, or accommodate the long-term side effects of their treatment (e.g., chronic pain, attending follow-up appointments), which may put YAs in an uncomfortable position of having to justify their illness-related behavior and experiencing increasingly strained peer relationships at school or work (Iannarino, 2013; Rosenthal, 2009).

Third, YAs may also struggle with altered social relationships upon reintegration due to their biographical disruption, especially if they do not perceive positive forms of social support from friends and peers. Although some YAs manage to experience

enhanced intimacy with certain pre-existing friends and peers as they progress through the trajectory of diagnosis, treatment, and survivorship, they often report an increased distance or abandonment from others inherent in the biographical disruption of cancer (Kent et al., 2012). YAs perceive emotional distress or discomfort in some friends and peers who may approach cancer as a death sentence or as an uncomfortable stimulus that reminds them of their own mortality (Kent et al., 2012; Zebrack & Isaacson, 2012). As a result, YAs have stated that their friends, perhaps unintentionally, sometimes ignore, avoid, deny, or dismiss their needs and feelings (Zebrack et al., 2010; Zebrack & Isaacson, 2012). They may demonstrate inappropriate reactions that suggest emotional unavailability or an incapability of dealing with their illness, for example, by refocusing their attention onto themselves or discussing their own problems rather than acknowledging the YA patient or survivor's feelings (Zebrack et al., 2010). YAs have also expressed discomfort with friends' repeated expressions of incredulity in response to their diagnosis disclosure and distressing comments about someone they knew who had previously died from cancer (Iannarino, 2013; Miller & Hefner, 2012).

Negative attention is also heaped upon YAs in the form of inappropriate comments or teasing (Zebrack et al., 2010), which may influence their struggle to decide when, what, how, and how much to disclose about their illness (Zebrack, 2011). For example, YAs with testicular cancer hesitated to disclose their illness to other men because they perceived a lack of seriousness from them (Carpentier et al., 2011). Others were patronized by friends and told that they were incapable of managing their own health (Zebrack et al., 2010).

Another reason YAs experience difficulty in sharing details about their cancer experience to healthy peers is because, like family support, friend support can be overbearing even though it is intended to be positive. YAs have difficulty dealing with the expression of unwanted sympathy and pity (Iannarino, 2013; Rosenthal, 2009). YA survivors in particular struggle to accept, and are often put off by, others' beliefs that they are "strong," "brave," and possess newfound wisdom or a clear purpose in life following the completion of primary treatment. They feel that this perception puts undue pressure on their life, which is already typically shrouded in uncertainty as they attempt to cope with a "new normal" that looks nothing like their pre-cancer experience (Iannarino, 2013; Rosenthal, 2009). YA patients and survivors also express disconcertion with friends' and peers' propensity for telling them to be positive, because they view this sentiment as invalidating their true feelings (Zebrack et al., 2010).

Finally, YAs also experience difficulty in establishing new friend networks, particularly those composed of individuals who have a shared understanding of their illness experience. Because one's identity develops through the context of social interaction, healthy peer relationships are necessary for YA cancer patients and survivors to cope with their illness (Zebrack, 2011). However, many YAs struggle to form and maintain new relationships after diagnosis, often citing their inability to find individuals who share a common experience and mutual understanding of cancer treatment and survivorship, who relate to what they are feeling and experiencing, and who are willing to talk frankly about it (Gorman, 2011; Zebrack et al., 2010). For example, YAs have difficulty approaching strangers in public that they suspect are cancer patients or

survivors based on their physical characteristics, with one survivor likening the awkwardness of the experience to asking a woman if she is pregnant (Iannarino, 2013).

Not surprisingly, when given the chance, YAs report enthusiasm and satisfaction with the establishment of communities comprised of other YA patients and survivors who share common interests and face similar challenges, particularly when that peer support is in person (AYAOPRG, 2006; Kent et al., 2012; Thewes et al., 2004). Building connections with other YA cancer survivors is an important aspect of the healing process for YAs with cancer (Zebrack et al., 2006). In fact, YAs have shown so much interest in meeting other survivors that participants in a recent focus group study admitted that they volunteered to participate in the research with the hope of building new peer connections (Kent et al., 2012). In sum, due to the biographical disruption of cancer, YA survivors experience altered interpersonal communication with existing friend and peer groups and often have few opportunities to build new relationships and engage in effective supportive communication with other YA survivors.

Altered intimate relationships. Barriers to communication inherent in the biographical disruption of cancer also occur in the altered relationships between YA cancer survivors and their romantic partners. Due to the interdependent nature of coping with this disruption, a survivor and his or her romantic partner's relationship may be greatly affected by the illness experience (Miller, 2012). Because YAs are at a life stage in which seeking and forming intimate and long-term relationships and planning and establishing families is the norm, the effects of cancer diagnosis, treatment, and survivorship on communication surrounding dating, marriage, sexuality, and fertility are particularly salient concerns in this population (AYAOPRG, 2006). Compared to older

adults, YAs' romantic relationships are more likely to be volatile and less solidified because they are less established at this stage of life. Thus, the communication in YA romantic relationships is often tested by the strain of the biographical disruption resulting from diagnosis and treatment.

For example, many YAs have difficulty dating or even establishing romantic relationships during and after cancer treatment (Kent et al., 2012; NCI, 2004). It is not only difficult for YA patients and survivors to find the energy to date, but those who do pursue new relationships struggle to know when to tell a possible romantic partner about their illness and how much to disclose (Miller & Hefner, 2012; NCI, 2004). Disabilities related to or adverse treatment effects resulting in alterations to genitalia, bowel function, fertility, and sexual potency, for example, are particularly sensitive areas of disclosure for YAs, who are at a life stage in which they are more self-conscious about body changes and body image (AYAOPRG, 2006; Bleyer, 2007). YAs' struggles to feel comfortable with treatment side effects or physical alterations may prevent them from developing enough confidence and trust to establish relationships that have the potential to become intimate (AYAOPRG, 2006; Kent et al., 2012). For example, testicular cancer survivors often struggle with their self-image following treatment, particularly as it relates to perceptions of diminished masculinity; they claim to feel different from other people, vulnerable, and incomplete (Carpentier et al., 2011). While partnered survivors have said that their cancer experience helped to increase their relational commitment, survivors who were not in an intimate relationship upon diagnosis experienced difficulty disclosing their cancer history to potential romantic or sexual partners. Thus, being unpartnered when diagnosed with testicular cancer may create a disruptive vulnerability that remains

even if the survivor develops a relationship following the completion of treatment (Carpentier et al., 2011).

Additionally, a partner's decision to stay in an established relationship may be disrupted by factors like the ongoing fear of recurrence, long-term side effects, infertility, guilt, sympathy, and uncertainty surrounding whether surgeries or treatment regimens would affect their sexual relationship (Bleyer, 2007; Miller, 2012). Cancer survivors are sometimes unsure of their own or their partner's desire to maintain their relationship following a cancer diagnosis, citing their uncertainty about their own or their partner's commitment to or capability for providing care to one another (Miller, 2012; Kent et al., 2012). Both potential and established romantic partners have told YA survivors that they cannot risk the emotional involvement of being in a relationship due to their poor prognosis (Zebrack et al., 2010). Some survivors find themselves to be more direct and honest about the status of their relationships and are ready to end relationships they felt they could no longer prioritize (Kent et al., 2012).

In married or committed relationships, treatment may force YA patients and survivors to depend heavily on a spouse or partner as a primary caregiver in ways that were unexpected for both partners at their age (Zebrack & Isaacson, 2012). YA survivors have also reported that they find it difficult to grapple with their own emotional response to their cancer experience while attempting to mitigate their partner's stress through identity management by putting on a "brave" or "strong" face (Kent et al., 2012). They sometimes feel the need to use communication to shield their loved one from the reality of the illness, perhaps due to the guilt they feel for knowing their partner is distressed (Zebrack & Isaacson, 2012), which may lead to additional burden on the survivor

(Miedema et al., 2007). YAs and their romantic partners often demonstrate different coping strategies as they begin to deal with and discuss cancer, and conflict sometimes arises over who should be responsible for making medical decisions (AYAOPRG, 2006). For example, partners may want to discuss issues related to the survivor's diagnosis and treatment that the survivor does not want to broach, and vice versa (Zebrack & Isaacson, 2012). Additionally, communication about family planning and fertility issues may be particularly difficult between intimate partners because some survivors do not recall an adequate discussion with a physician regarding the risks of infertility or methods to decrease the risks at the start of treatment (Schover, Brey, Lichtin, Lipshultz, & Jeha 2002).

At any age, a loved one's cancer diagnosis can be a devastating life event. However, for YAs who are actively pursuing degrees, careers, families, and other life events that are normative for this developmental stage, the abrupt disruption and potential loss of future opportunities associated with a romantic partner's cancer diagnosis can be particularly severe. Like YA survivors, YA romantic partners may also struggle with a sense of social isolation, perceive ineffective forms of social support, work to manage uncertainty, come to terms with a new illness-related identity, and face difficulty in disclosing aspects of their experience. Without effective supportive communication with the survivor, family, friends, peers, and medical practitioners, romantic partners of YA survivors may struggle to achieve a "new normal" in the wake of their biographical disruption and experience additional burden.

Research Questions

YA survivors experience altered social relationships following the biographical disruption of cancer diagnosis, treatment, and issues related to survivorship. In an attempt to integrate cancer into their lives, YA survivors and their close SNMs attempt to counter the experience of biographical disruption through the cognitive process of biographical work and the tangible process of communication to manage relationships and provide, solicit, and receive support. However, due to the alteration in social relationships precipitated by the biographical disruption of cancer, YA cancer survivors may struggle to engage in effective supportive communication with family members, friends, peers, and romantic partners. When productive communication does not occur, YA survivors' uncertainty or anxiety about the illness-related social roles they have adopted is exacerbated. Poor communication may also result in YA survivors feeling uninformed, powerless over their ability to make crucial health decisions, alienated, overburdened, and lost (Zebrack et al., 2010). In light of some of the social struggles YA cancer patients and survivors report facing due to the biographical disruption of cancer, there is a need for research to highlight ways in which interpersonal communication can help this population to cope with their illness experience (Donovan-Kicken et al., 2012).

In this dissertation, I examine the barriers to and facilitators of the effective receipt, solicitation, and offering of social support among YA cancer survivors and their close SNMs in response to the biographical disruption of cancer diagnosis, treatment, and survivorship. In particular, I focus on YA cancer survivors' and close SNMs' interactions with one another, along with family, romantic partners, friends, and peers (e.g., classmates, coworkers).

Examining how YA survivors and close SNMs talk about the experience of disrupted biography can shed light on their attempts to cope with their suddenly altered reality through communication work and social support, and it can call attention to their unique problems and needs in managing relationships with members of their social networks (Donovan-Kicken et al., 2012; Sharf & Vanderford, 2003). This dissertation begins with the assumption that the experience of cancer disrupts survivors' and SNMs' conceptualization of a past, present, and future self. A cancer diagnosis initiates a new life path and social role as a patient, survivor, or primary supporter that extends over the remainder of one's life (Zebrack, 2000), which often requires these individuals to potentially amend or completely reconstitute the biography they maintained pre-diagnosis (Corbin & Strauss, 1987). Following the disruption of illness, YA cancer survivors often report feelings of isolation and sometimes struggle to engage in productive, meaningful interactions with others. The same may be true for SNMs, particularly those who are also YAs. In fact, because the experience of a YA cancer diagnosis is rare and often unexpected, both parties may lack the existing scripts necessary to provide effective support to one another.

Thus, I examine the potentially unique experience of YA cancer survivors', SNMs', and the dyad's suddenly altered communication practices resulting from cancer diagnosis, treatment, and survivorship. Gaining insight into how this population perceives their cancer experience and how they talk about it with others at different stages, in different contexts, and across time can help future researchers build more effective and age-appropriate interventions and education programs and create and disseminate more effective targeted information to YAs and their close SNMs (Zebrack, 2000).

Eliciting and analyzing YA cancer survivors' and their SNMs' illness accounts may help shed light on cancer's social effects in a manner that illustrates the lived experience of the illness (Sharf, Harter, Yamasaki, & Haidet, 2011). Although anecdotal accounts of the YA cancer experience have been published through the popular press (e.g., Katan, 2005; Rosenthal, 2009) and portrayed in fictionalized films like *50/50* (Goldberg, Karlin, Rogen, & Levine, 2011) and young adult novels like *The Fault in Our Stars* (Green, 2012), little empirical research exists in the health communication literature that captures the experience of cancer as a biographical disruption in YA cancer survivors and close SNMs as distinct individuals and as dyadic members that provides insight into their attempts to navigate relationships with members of their social networks.

Thus, research to examine communication work and social support with romantic partners, family, friends, and peers is necessary to structure and make sense of YA survivors', SNMs' and the dyad's response to the biographical disruption of cancer diagnosis, treatment, and survivorship. Examining the nature of social support throughout the cancer trajectory from participant accounts can enable researchers to better understand how YAs make, or struggle to make, communication choices in order to integrate cancer into their lives (Donovan-Kicken et al., 2012). Social support is one mechanism through which YAs and SNMs reconstruct a disrupted biography, adjust to a "new normal," and achieve a richer social quality of life within an altered—or altogether new—social reality. This process of communication work and social support may be hindered or facilitated by salient interactions with romantic partners, family, friends, and peers. In short, how and why do YA cancer survivors and their close SNMs communicate social support with romantic partners, family, friends, and peers?

CHAPTER TWO: METHOD

In this chapter, I provide a review of the methods guiding this dissertation. First, I describe the characteristics of the individuals who participated in this study and how I recruited them. Second, I explain the procedures used in this study. Third, I detail the measures (including the participant demographics questionnaire and narrative interview protocol) I used to collect the data. Finally, I describe how I analyzed the data to draw conclusions.

Participants

Participants in this study consist of dyads composed of two types of individuals: (a) YA cancer survivors (i.e., men and women currently between the ages of 18 to 39 years old who were diagnosed with cancer and have completed primary treatment within this same age range) and (b) an individual who the YA survivor considered a close SNM at the time of their diagnosis or during primary treatment (e.g., romantic partner, parent, sibling, friend). Being specific about participant survivors' age at the time of major cancer-related events helps to gain insight into the unique biographical disruption, interpersonal communication processes, and biographical restoration processes inherent in YA survivors as a distinct age-defined population.

Additionally, although there are conflicting views as to when a person with cancer becomes a "survivor" (e.g., from the moment of diagnosis, after the completion of primary/initial treatment, living five years beyond diagnosis, having a genetic risk of cancer without being diagnosed; NCI, 2004), I adhered to the Macmillan Cancer Support (2008) definition, which regards an individual as a survivor after they have completed primary treatment. Therefore, survivor participants may not have been disease free at the

time of recruitment (i.e., he or she may have had a cancer recurrence, secondary malignancy, or ongoing late/side effects) and may currently be enrolled in additional rounds of cancer treatment. I selected the Macmillan Cancer Support (2008) definition because YA “survivors” and their close SNMs would likely have greater perspective, deeper insight, and more coherent and detailed accounts about the initial biographical disruption of cancer with the time afforded to them by primary treatment. Conversely, if I would have recruited participants who were only a few weeks out from initial diagnosis and still mired in the early stages of primary treatment, they would likely have been without the benefit of the retrospective sense-making needed to fully consider and articulate their experience and address concerns about reintegration moving forward. Therefore, participants’ narratives may have been more fractured and less detailed with limited insight into how their experience has changed across the trajectory of initial diagnosis and the later stages of primary treatment.

Following approval from the institutional review board, I engaged in purposive sampling techniques to recruit participant dyads. Fliers were posted on public bulletin boards on the campus and in the community surrounding a large southeastern university. Online notices were posted on my personal social media pages (i.e., Facebook, Twitter, Instagram) and on the regional (i.e., Midwestern, Middle-Atlantic, Southeastern) social media pages (i.e., Facebook, Twitter, LinkedIn) of cancer survivor support group organizations and websites (i.e., Cancer is Stupid, Stupid Cancer, Kentucky Cancer Program, Cancer Support Community, American Cancer Society, Light the Night, Susan G. Komen, Pelatonia, Fuck Cancer, First Descents). I also engaged in email messages, phone calls, and face-to-face conversations with patient services managers, registered

dietitians, social workers, and cancer navigators at a large southeastern university hospital, a large southern university hospital, two regional chapters of the Leukemia and Lymphoma Society, and three non-profit organizations that provide psychosocial services in cancer hospitals to spread word about the study and ask if they would solicit potential participants.

I also recruited participants face-to-face through my involvement as a volunteer with a newly-formed YA cancer survivor support group in Ohio by making announcements at the beginning of YA cancer support group meetings at the southeastern university hospital and by networking at a YA cancer survivor fundraising event in Indiana. In addition, I made several announcements to students before undergraduate classes in the communication department of the large southeastern university. Snowball network sampling was also used to contact additional recruits by asking participants who had completed the study to extend the opportunity to participate with eligible YA survivors and close SNMs they knew who might be interested. All disseminated recruitment materials contained my contact information (i.e., email address, phone number). Individuals interested in participating in the study were encouraged to contact me to learn more about the research.

When participants contacted me, I described the purpose of the research (i.e., to learn about how YA cancer survivors and their close SNMs talk with one another and others about the experience of cancer), the activities entailed in participation (i.e., engaging in a one-on-one, in-depth, face-to-face interview lasting approximately 60 minutes), and the remuneration for participation (i.e., one \$15 gift card per participant;

\$30 per dyad). I screened the potential participants for eligibility based on the YA survivor's current age, age at diagnosis, location, and completion of primary treatment.

The final sample ($N = 51$) was composed of 20 survivor-close SNM dyads and one survivor-close SNM triad (in this case, the additional SNM member was recruited due to interesting data that emerged from an interview with the initially-selected SNM). The remaining YA participants ($n = 10$) were interviewed separately because the individuals who were close to them at diagnosis or during treatment were not available during the recruitment period (e.g., the SNM's schedule or location did not allow for a face-to-face interview). I included one YA survivor who was initially diagnosed several months shy of his 18th birthday and another YA survivor who was one week shy of completing her initial round of chemotherapy treatments. Additionally, one interview was completed by an IRB-approved and trained communication researcher and university faculty member because the participant was located in an area that was not within drivable distance from me as the primary investigator.

Participants were 20 YA survivor-close SNM dyads, 1 survivor-close SNM triad, and 10 single YA survivors ($n = 30$ survivors, $n = 21$ close SNMs) from Ohio ($n = 29$), Kentucky ($n = 18$), Indiana ($n = 2$), Minnesota ($n = 1$), and Alabama ($n = 1$). Close SNMs included the survivor's wife ($n = 6$), mother ($n = 5$), husband ($n = 2$), older sister ($n = 2$), younger sister ($n = 2$), older brother ($n = 1$), boyfriend ($n = 1$), girlfriend ($n = 1$), or daughter ($n = 1$). Survivors included 16 females (53%), and their initial diagnoses included leukemia (i.e., acute promyelocytic, acute myeloid, acute lymphoblastic, chronic myelogenous; $n = 7$), head and neck (i.e., thyroid, parotid, tongue; $n = 6$), testicular ($n = 5$), breast ($n = 4$), lymphoma (i.e., Hodgkin's, primary mediastinal; $n = 4$), liver ($n = 1$),

cervical ($n = 1$), mediastinal germ cell ($n = 1$), and ovarian/uterine ($n = 1$). Most of the survivors ($n = 22$, 73%) had not experienced a recurrence of secondary malignancy following the completion of primary treatment.

YA survivors' average age at initial diagnosis was 24.80 years old ($SD = 4.51$, $range = 17-36$) while SNMs were 31.86 years old ($SD = 13.59$, $range = 17-59$). Most of the survivors were between the ages of 17 and 24 ($n = 18$) or between 25 and 31 ($n = 10$) years old, with considerably fewer survivors ($n = 2$) between the ages of 32 and 39 at initial diagnosis. SNMs were between the ages of 17 and 24 ($n = 7$), 25 and 31 ($n = 7$), and 50 and 59 ($n = 5$) at the time of the survivors' initial diagnosis. At the time of the interview, survivors on average were 4 years ($SD = 3.69$, $range = 0-13$) from the completion of primary treatment. Most survivors did not have children at the time of the interview ($n = 23$), but 6 participants had one child and 1 participant had 2 children. Participants identified as European American ($n = 43$), mixed race ($n = 3$), Hispanic ($n = 2$), African American ($n = 2$), and Asian ($n = 1$). Participants' religious affiliations included none/other ($n = 18$), non-denominational Christian/Protestant ($n = 13$), Catholic ($n = 10$), Baptist ($n = 6$), and Methodist ($n = 4$). Most participants had received a Bachelor's degree ($n = 22$), but others' education varied among Master's degree ($n = 10$), high school diploma ($n = 10$), Associate's degree ($n = 6$), doctoral degree ($n = 4$), and some high school ($n = 1$).

Procedure

I asked participants to choose a convenient date and time to meet, and I requested that they select a relatively private location (e.g., their home, my campus office) where they felt comfortable having the interview. First, before beginning any interview, each

participant was given a detailed explanation of the project and taken through the informed consent process, which was obtained using a document that provides participants with a description of the study, the benefits and risks of participation, and a clear description of the voluntary and confidential nature of participation. Participants were reminded of the purpose of the project, what types of questions would be asked, and that their interview would be audio-recorded.

Participation consisted of three tasks. First, participants individually completed a short questionnaire used to collect demographic information. The questionnaire did not contain any directly-identifying information. However, given that the proposed research was designed to study dyadic processes, it was necessary to link each participant's responses to their partner's responses (if applicable). For this reason, a list containing a record of individuals' names and an identification number (e.g., Dyad 01-A, 01-B, 02-A, 02-B) was created in order to link the partners and kept in a locked location. Questionnaires were marked with the participant's individual identification number, and they later selected or were assigned a pseudonym for use in data analysis and written reports of the study's findings.

Second, in an attempt to thoroughly understand and engage with YA survivors' and SNMs' unique experience of cancer, I encouraged respondents to share their accounts through the dynamic and open-ended process of narrative elicitation (Lindlof & Taylor, 2011). Talking about cancer creates, shapes, and gives structure to the meaning of a survivor or close SNMs' experience of illness (Sharf et al., 2011). In many cases, this illness-related interaction comprises the co-construction and sharing of narrative stories (Harter, 2009), which enables researchers to comprehensively witness the worldview of

others (Fisher, 1984, 1987). In other words, eliciting and analyzing YA cancer survivors' and their SNMs' narratives helped shed light on cancer's social effects in a manner that illustrates the lived experience of the illness (Sharf et al., 2011). Each member of the dyad engaged in a private one-on-one, in-depth, face-to-face interview that followed an open-ended narrative interview protocol. These interviews lasted an average of 72 minutes each (ranging from 25 to 120 minutes), and they were audio recorded with the participant's permission for verbatim transcription.

Both partners were interviewed separately in an attempt to (a) gain insight into the unique social needs inherent in their own cancer experience; (b) to supplement, contradict, and potentially deepen their partner's narrative responses; and (c) to represent a joint picture and shared narrative that constitutes a third perspective of a common experience (Eisikovits & Koren, 2010). In an investigation of how dyadic partners manage heart disease, Goldsmith et al. (2006, p. 2082) interviewed dyadic partners separately to "facilitate forthright expression of positive and negative reactions to what their partner said or did." In this dissertation, holding separate dyadic interviews afforded the opportunity for participants to discuss sensitive information that they have not felt comfortable disclosing to their partner or to explore conflicts and criticisms that may upset their partner if they were discussed in front of him or her (Eisikovits & Koren, 2010). In other words, interviewing the members of the dyad individually may result in narrative data that is not adulterated by social desirability or impression management effects that may be inherent when speaking with both partners together (Eisikovits & Koren, 2010).

Although separate interviews enabled each partner to tell the story of the experience of cancer from their own perspective, transcripts for dyads were examined together to reflect a dyadic view that provides insight into the overlaps and contrasts between the individual narratives (Eisikovits & Koren, 2010). This practice bolsters the trustworthiness of the data (Lincoln & Guba, 1985) because the multiple sources of information could be considered a form of data triangulation (Eisikovits & Koren, 2010). The partner who was not being interviewed was asked to not be present in the interview space. Members of the dyads could choose different days, times, and locations to be interviewed, based on their availability and convenience. However, participants who had completed the study were asked to keep the protocol questions and their responses private until their partner was also interviewed. Every effort was made to interview each member of the dyad as closely together as logistically possible to prevent participants from discussing the research with one another before both members of the dyad were interviewed.

Finally, upon completion of the interview, participants were given a \$15 gift card to iTunes, Starbucks, or Amazon (\$30 per dyad) and asked to complete a form on which they indicated their willingness to answer follow-up questions in the future. If they granted permission to be contacted, they were asked to provide a phone number or email address that I could use to reach out at a later date. I also asked participants on this form if they were aware of other dyads that might be interested in participating in this study. In any case, I provided participants with my contact information and printed descriptions of the study that may be passed along to potentially interested dyads.

Measures and Instruments

Because narrative interviews often depend on the development of close, long-term relationships with participants (Lindlof & Taylor, 2011), it was important for me to demonstrate narrative competence, or skill at eliciting narrative data effectively (Charon, 2004). For example, my narrative interviews needed to strike a precarious balance between providing structure to the participant's narrative and providing open-endedness. Avoiding the use of subtle directional nudges or follow-up questions can result in an elicited narrative that provides little to no insight into the substantive and theoretical foci of my investigation. Thus, as a narrative interviewer, I was prepared to give up considerable control over the interview in order to provide opportunities for the storyteller to share detailed accounts of his or her experience rather than provide brief answers or general statements (Riessman, 2008). Additionally, eliciting rich and detailed accounts of lived experience is highly dependent on establishing trusting relationships between me as the interviewer and my participants (Butler-Kisber, 2010). I encouraged the respondent to select a setting that they found comfortable; worked to foster a sense of rapport, sensitivity, and empathetic listening; attempted to inspire interest and excitement in participants about the research; and demonstrated that I was credible as an investigator (Butler-Kisber, 2010; Riessman, 2008).

Interpretive methods were chosen to derive insight into YA romantic couples' social experience of cancer through participants' own words. Because talking about the cancer experience through narration helps to create, shape, and give structure to the meaning of illness (Harter, 2009), data collection was achieved through one-on-one, in-depth, face-to-face narrative interviews, which allowed me to gather important details

and clarify participant responses through the use of probing and follow-up questions. Interviews followed a semi-structured protocol (see Appendix A), which was developed to provide a comprehensive view of YAs', SNMs', and the dyad's interpersonal communication processes. As such, the protocol was based on interpersonal communication concepts that emerged in the existing psychosocial literature on the YA cancer experience (i.e., biographical disruption, normative approach to social support).

Participants were asked to recall their cancer experience and conversations they had as a YA cancer survivor or a close SNM. The interview questions were designed to elicit specific examples from participants (e.g., "Can you tell me about a time when...") about their attempts to navigate altered social relationships and engage in supportive communication following the biographical disruption of cancer diagnosis, treatment, and survivorship. Specific topics covered within the interviews included participants' stories of how they were or their loved one was diagnosed with cancer; experienced interruption in their life; attempted to (re)claim agency through the management of social and personal uncertainty; felt like they had a different identity; solicited, received, and offered social support; made treatment decisions with others; and made sense of illness through the use and receipt of humorous messages. The order of these specific topics was varied among the interviews so that the same questions were not consistently asked first or last. I also asked for verification, validation, and elaboration on information through the use of probing or follow-up questions while still allowing the participant to generate their own narratives (Riessman, 2008). Consistent with emergent design that is often inherent in qualitative research, interview questions were revised after initial interviews to account for salient topics introduced by participants (Butler-Kisber, 2010).

Participants were also asked to complete a demographics questionnaire (see Appendix B), which was composed of nominal-level checkboxes and blank spaces for open-ended responses. Different versions of the questionnaire were developed for the YA survivor and for the caregiver. I collected information about both dyadic participants' gender, current age, highest level of education completed, current job and education status, religious affiliation, relational status with their dyadic partner, number of children, ethnicity or race, current state and county of residence, and current status of the survivor's cancer. Survivors were asked additional questions about the length of time since initial diagnosis and the completion of primary treatment, the type and stage of their primary malignancy(ies), instances of recurrence or secondary malignancy(ies), enrollment in additional rounds of treatment, and their health insurance status.

Data Analysis

I first analyzed the narrative interview texts by "flattening out" the talk from digital audio recordings onto the page through a process of word-for-word speech-to-text transcription. The goal was to provide an accurate representation of what was said by transforming the spoken word into narrative text that summarizes or reconstructs the process of narration (Riessman, 2008). However, an important portion of the narrative's social dynamics and organization (e.g., the movement of words and gestures, visual qualities, speech cadence) was likely lost during this process (Gubrium & Holstein, 2008). However, I did the best I could to replicate emphasis, gestures, laughter, pauses, rising voice, increased pace, sarcasm, and so on in the text. Thus, transcripts are necessarily incomplete, partial, and selective (Riessman, 2008). To ensure completion in a timely manner, 21 interviews were transcribed by a contracted transcription service.

However, I maintained my analytical control over the data by listening to each audio recording and tweaking the transcript to account for subtle vocal interpretive insights and nonverbal context cues that I recalled from facilitating the interview.

I also attempted to account for this loss of richness by writing brief analytic memos after each interview to chart immediate interpretive insights and note nonverbal context cues (Saldaña, 2009). I also kept detailed memos throughout the transcription process to comment on how I related to the participants and the phenomenon, I noted the factors influencing early interpretations of the data, and I explored possible links between emergent themes and *a priori* concepts, and charted how my presence as an investigator influenced narrative co-construction with the participants (Saldaña, 2009). This process of reflexivity is important in qualitative data analysis because it enables researchers to interrogate their own perspectives; better understand the populations under study; and develop interpretations that are more rigorous, sensible, sensitive, and meaningful to readers (Markham, 2009).

Once the “transcript *becomes* the interview,” (Lindlof & Taylor, 2011, p. 211), I continued to interpret the textual data through the use of narrative analysis, which can be accomplished in a number of ways, depending on the objectives of the investigation (Riessman, 2008). The aim in narrative analysis as a whole is not to evaluate whether the narratives themselves are inherently “truthful,” but to understand the relayed experience of the narrator (Orgad, 2009). In this study, I employed thematic narrative analysis (Williams, 1984), which is used when primary attention is paid to “the told,” or *what* the narrator reported in regard to marker events and experiences, rather than aspects of “the telling” (Riessman, 2008, p. 54). Narrative analysis is particularly appropriate in

exploring interpersonal experiences, better understanding the human condition through story, and documenting the life course across the cancer trajectory (Saldaña, 2009).

Thematic analysis allows researchers to emphasize the content a narrative communicates, with *minimal* focus on “how” it was constructed, “to whom” it was intended, and “for what purposes” (Riessman, 2008, pp. 53-54). In other words, because the focus should be placed on interpreting the meaning that participants attributed to their experience, I did not deeply consider the conditions under which the narrative discourse was shaped and how the narrative unfolded in a conversational exchange (Riessman, 2008). My role as an investigator in the narrative’s co-construction remained mostly obscure in the development of thematic categories; it was not directly discussed as a salient theme by participants and I do not believe that my presence was a consistent limitation that kept participants from narrating deeply. Because the cancer experience has long been conceptualized primarily from the perspective of older adults (AYAOPRG, 2006), it was important to note the broader social forces and contexts that likely shaped participants’ accounts (Gubrium & Holstein, 2008).

Narrative researchers must also consider the boundaries of what they constitute as a narrative unit; however, an investigator does not always know what will be considered a narrative unit until he or she begins reading over the text several times (Riessman, 2008). Because each interview was comprised of a number of individual narratives based on my open-ended questions, I did not consider the interview as a whole to be a narrative unit. Rather I focused on the individual narratives within each interview. Once the boundaries of the narratives were established, however, I kept that narrative intact in the analysis process by preserving its sequences (Riessman, 2008).

One approach to thematic narrative analysis involves the use of *a priori* theoretical concepts to generate thematic categories across individual narratives while also attempting to derive new insights by theorizing from a case-centered approach (Williams, 1984). This is accomplished while preserving and grouping the narrative sequences according to their representation of preexisting or newly emergent categories (Riessman, 2008). In this study, I generated thematic categories based on *a priori* theoretical concepts based on a normative approach to social support (Goldsmith, 2004; Goldsmith et al., 2006).

I also collated demographic information to provide context to participants' narratives and enable me to draw inferences throughout the interpretation process across participants' smaller age groups within the 18-39 range; life responsibilities (e.g., children, career or educational pursuits); cancer type and stage; length and status of a romantic relationship (e.g., dating, engaged, married, estranged); experience of recurrence, development of secondary malignancies, enrollment in additional treatment; and stage of survivorship (i.e., length of time following completion of primary treatment).

The procedure and process of individual interviewing coupled with dyadic data analysis were based in part on a methodological essay by Eisikovits and Koren (2010), which argues that the dynamics of couple relationships is well-suited to being examined through dyadic analysis. Particularly in the case of studying experiences that are shared by members of a dyad, this form of analysis enables researchers to examine each participant's account on both an individual and dyadic level. In other words, rather than simply receiving "one side" of the story, researchers can learn about a relationship or a series of events from three different angles, including one from each dyadic member and

from the dyad itself (Eisikovits & Koren, 2010). However, because there is still no existing guide for how to perform dyadic thematic narrative analysis based on individual narrative interviews, my analytic procedure took place through a process of trial and error. First, I selected and trained two coders to assist with the interpretation process. They were briefed about the normative approach to social support that was used to generate thematic categories. I instructed them to consider how each narrative relates to or works against existing theory and research on offering, receiving, and soliciting support. In particular, we began making note of narratives that provided insight into the barriers and facilitators YA cancer survivors, their close SNMs, and the dyad experienced when attempting to effectively send, receive, and solicit social support.

Individually, the coders and I read through each interview in its entirety, marking the boundaries and existence of narrative units; making note of the coherence and fidelity of the narratives (i.e., do they hang together and ring true?); highlighting words, phrases, and marker events that struck us as memorable; and paying attention to general patterns related to the narratives' assumptions and morals. We also began to compare what was said by one partner in relation to the other member of the dyad. Because I sought individual perspectives based on the one-on-one interviews and dyadic interpretations gleaned from focusing on the joint experience of the romantic couple, we began to make note of the thematic contrasts and overlaps between the partners' narrative accounts (Eisikovits & Koren, 2010). Each coder kept an individual list of emergent thematic categories that represented how and why participants received, sent, and solicited social support that they perceived to be effective and ineffective. We then met in person to assess initial interpretations and discrepancies and to compare, collapse, and contrast the

individual categories that emerged individually. A fourth member of the research team also attended this meeting to provide an external assessment of the validity of the categories as the focus of further analysis. Through intense and detailed conversation, we reached consensus regarding the consistency of the emergent themes and generated one joint list of themes that each coder would use to classify narratives during the second round of coding.

We then read through the narratives independently a second time, labeling sequences according to our emergent list of thematic categories and identifying any emergent themes if they arose. We also examined each narrative more fully in the context of the narrator's collated demographic information, and we made additional note of any thematic overlaps and contrasts across individuals based on this information. We searched for additional thematic overlaps and contrasts between each dyad's individual experiences, which further enhanced our understanding of the nature of their relationship (Eisikovits & Koren, 2010). The coders then reconvened to assess additional discrepancies and to further clarify the classification of marker events according to the *a priori* categories and descriptions of the normative communication processes related to social support.

When reporting the results of my analysis, I integrated the individual narratives into one stand-alone narrative as a research representation that depicts "how and why a particular outcome came about" (Polkinghorne, 1995, p. 19). The larger narrative weaves together the themes across individual cases and dyads to thickly describe the common experience of how YA cancer survivors and their close SNMs navigate social relationships following a cancer diagnosis. Unlike most qualitative psychosocial research

on YA cancer populations to this point, my write-up contains rich descriptive detail and a multidimensional examination of individual participants' and dyads' lives (Saldaña, 2009).

Reflexivity in Analysis

In keeping with the interpretive tradition, my findings evolved as I continually engaged in reflexivity from the beginning of data collection to the completion of this dissertation. Following a brief review of the narratives I elicited and analytic memos I scribed based on my interviews with YA survivors and close SNMs, I instructed my coding team about how we should conduct our first round of thematic narrative analysis to determine how and why YA cancer survivors and their close SNMs communicate social support. Based upon an understanding of YA concerns from the broader psychosocial literature, an *a priori* use of Goldsmith's (2004) normative approach to social support, and initial interpretations of the most salient themes that emerged from this data, I maintained that YA survivors and their close SNMs were experiencing barriers in their attempts to reconstruct their biographies in part because they were struggling to effectively send, receive, and solicit social support with one another and with other members of their social network. Therefore, I suggested that we enter coding with three themes in mind: the forms of received social support attempts that were perceived as effective/ineffective, the forms of sent social support attempts were perceived as effective/ineffective, the forms of solicited social support attempts that were perceived as effective/ineffective. However, upon further attempts to engage in personal reflexivity and in intensive discussions with my two additional coders, we began to notice that our emergent codes were being unsuccessfully retrofitted into the regimented themes

on which I had instructed us to focus. As a result, we began to discover a broader, more complex and nuanced portrait of support that evolved beyond simple typology and more thoroughly reflected the unique process of social support communication within this context.

CHAPTER THREE: FINDINGS

A cancer diagnosis often causes biographical disruption in the lives of young adult (i.e., 18-39; YA) survivors and their close social network members (i.e., familial, platonic, or romantic relational partners with whom the survivor has a salient relationship; SNM). In order to integrate their illness into their lives, normatively regain balance and equilibrium, and achieve a “new normal” following a cancer diagnosis, YA survivors and their close SNMs must work to reconstruct their biographies by engaging in tangible interpersonal communication processes often used to initiate and maintain relationships. However, YA cancer survivors report facing social struggles due to the biographical disruption of their illness across the trajectory of diagnosis, treatment, and survivorship. This disruption often causes altered relationships with family, friends, romantic partners, and peers (e.g., classmates and coworkers).

By examining the narratives of YA survivors, their close SNMs, and the dyad itself, I explore the interpersonal communication processes used to initiate and maintain relationships across the illness trajectory. In this chapter, I specifically focus on how and why YA survivors, the close SNMs the YA survivors selected to participate in this dissertation, and the dyad itself communicate social support with romantic partners, family, friends, and peers. Findings include YA survivors reporting the receipt of unique types of social support from family, friends, romantic partners, and peers that they perceive to be effective and ineffective and that they appreciate and do not appreciate. YA survivors report that commonly good forms of support involve being treated “normally,” while ineffective forms of support are largely a result of others not knowing how to provide appreciated support to YAs. Several forms of support, including the

degree to which SNMs fulfill instrumental tasks and spend quality time, acknowledge the survivor's strength and wisdom, and use humor were normatively perceived by YAs as both positive and negative.

The emergent categories of normative support also demands a closer look at who is providing the support to YA survivors and how by examining the illness experience from the close SNM's perspective. The SNM population faces a different kind of life disruption and social alteration that also requires them to restore their biography through social support. This restoration specifically involves adjusting to their role as "top supporter," negotiating their perceived domain within the survivor's support system hierarchy, and having license to comment on and manage others' support of the survivor. The YA cancer experience can also be viewed from a dyadic perspective when examining the communicative function of guarding potentially distressing information and managing perceived negative emotions as a form of support within the relationship between survivors and their close SNMs. However, the enactment of putative protection can paradoxically contribute to additional burden for both the YA survivor and the close SNM. Three emergent thematic findings are described below.

Theme One: YA Survivors' Perceptions of Normative Social Support

Consistent with prior research (Goldsmith, 2004; Goldsmith et al., 2006), YA survivors' narratives reviewed the perceived normative types of social support received by the survivor. Because YA survivors are a distinct population that has not been studied from a normative social support perspective, a focus on aspects of support that appear to be unique to a YA population is more appropriate to include in this dissertation. Normative forms of support that are commonly perceived among general adult cancer

populations are reported elsewhere. However, upon studying YA cancer survivors' accounts of their illness experience, the aspects of normative support that are unique to this context can be broken down into support that is perceived by this population to be helpful/appreciated and unhelpful/unappreciated. While commonly good forms of support perceived by YA survivors included anything that encouraged them to maintain a sense of normalcy, support types that were consistently interpreted as negative appeared to be a product of potential supporters' lack of experience with and confidence in providing effective support to this population. As a result, YA survivors often perceived negative support in the form of pity, negative stories, rude questions and comments, excessive self-monitoring, uneducated advice, insincerity, withdrawal, and self-absorption. YAs also reported the receipt of several additional forms of support that were circumstantially perceived as *both* positive and negative. These included instrumental tasks, spending quality time, acknowledging the survivor's strength and newfound wisdom, and using humor.

“I Wanted to be Treated Just Like Any Other Person Walking on the Street”:

Commonly Good Forms of Support

Consistent with previous research on general adult cancer survivors, emergent normative support that was commonly appreciated by YAs, but not unique to this population, included others' displays of genuine interest, attentive listening, and offers to distract the survivor from the day-to-day discomfort and isolation of treatment (e.g., vacations, magazines, games). However, YA survivors consistently stated that being treated “normally” or “the same” despite having cancer, and not as a fragile, weak, incapable, or severely ill person, was a commonly positive form of support that they

received from others. In other words, YAs generally perceived support to be helpful when it aligned with their own perceptions of their normality and capability: that they were the same person as before their diagnosis or that whatever physical or emotional alterations they have experienced were not abnormal, negative, or shameful.

For example, YA survivors appreciated when others engaged in “normal” conversational topics that did not deal solely with their cancer. Graham, who was diagnosed with Stage III testicular cancer at age 24, liked that he and his fiancée Lauren discussed events related to her new job and their mutual friends rather than focusing solely on his dreary experience spent alone at home as he recovered from treatment. Gunther, who was also diagnosed with testicular cancer at 25, explained that he and his wife Kiki maintained normalcy in their conversations during survivorship by not dwelling on the experience once he had recovered physically from treatment:

Kiki and I both kind of lightheartedly look at a lot of it like, “We’re done. It was cancer, big deal.” We don’t dwell on it a whole lot and we don’t make it out to be a big thing. We don’t see it in our lives or in our relationship as this big thing, even though, I guess, in some cases it was. YA survivors also found support to be commonly positive when others

encouraged and enabled them to maintain normal, regular activities. Several YAs had friends who agreed to meet them for weekly lunch dates or golf outings. These activities helped John, diagnosed with Stage IV testicular cancer at 24, feel normal and keep his mind off of having to return the next week for five straight days of chemotherapy. Charlotte, a 24-year-old acute myeloid leukemia (AML) survivor, appreciated the normalcy of being asked by friends to do things “just like [she] always had” rather than having to respond to inquiries about her illness:

I think when people just treat me like I’m a normal healthy person and say, “Hey, do you wanna go get dinner,” or “Do you wanna go to a

movie?” that’s the most helpful. I don’t really like being asked like every single day like, “How are you feeling? How are you doing today?” I think people who are willing to treat me like I’m a healthy person and not like I’m fragile or really sick is helpful.

Ann, diagnosed with Hodgkin’s lymphoma at 24, said that going to bars with friends during treatment was her attempt to maintain a sense of normalcy, even if it was potentially detrimental to her overall health: “And then if I went into chemo hung over, they would just give me fluids, and I’d be fine anyway [*laughs*]. Probably not how you’re supposed to do that. [...] But I don’t wanna be different.”

YA survivors also expressed appreciation for others who reinforced the normalcy of, and did not express discomfort regarding, the physical and functional alterations that were caused by their treatment. Ellie was diagnosed with acute promyelocytic leukemia (APL) at age 20, and she described her desire for others to treat her normally in spite of her physical appearance:

When you look sick, people treat you differently. So I think it was more the people that I wasn’t really close to that just look at you and treat you differently, and so I didn’t want that. I wanted to be treated just like any other person walking on the street. If you’re gonna be mean to that person, be mean to me, so don’t treat me differently just because I have cancer.

Kelly, who was diagnosed with breast cancer at 25, appreciated her boyfriend’s compliments, which helped her to feel more comfortable with the visible effects of chemotherapy:

It’s so weird, [my boyfriend is] always like, “You need to buzz your hair. I liked when your hair was buzzed.” He took this picture of me when we were in Florida for a wedding. Peach fuzz was coming in and so he convinced me to not go out with anything on my head. Then he took my picture of me at this bar and he still has it on his phone, and he’ll pull it up and be like, “You need to do your hair like this again.” And I’m like, “But that’s like when I didn’t even have any hair!” [*laughs*]. So yeah, he liked it.

John also felt that he could discuss sensitive topics and express a sense of vulnerability with his older brother Aaron. John knew that Aaron would not judge him or treat him differently like he believed his other male friends would:

With my brother, I would be like, “Yeah, I feel like shit.” Yeah, like that’s the only guy I can be completely honest with. [...] I can be more real with my brother than some of my guy friends and that I ever would with my parents. Especially about the fertility stuff. Like my brother’s one of the first ones I went to. And like straight locker room talk. Like, “Hey, dude...they say I’m gonna be shootin’ blanks [*laughs*], you know? Like, “What the hell do I do?” And that’s somebody I can say anything to and I didn’t have to worry about anything from it. And it’s just way more real conversation than anybody else could have at the time.

However, some YAs were so desperate to receive support that helped them to feel normal that they pursued dissatisfying relationships with people who were comfortable with their cancer history. Despite being treated normally by his brother, John still acknowledged that he married the wrong person because he did not think that any other future partners would accept him for the potential loss of his fertility:

My brother asked, “Was [your wife] cool with [your infertility]?” And I was like, “The one thing I can say about her is she never had any issues with that, and she appreciated that I was upfront about it from the very beginning.” And I think that was one thing that kept me hangin’ onto her, probably for the wrong reasons [...] We didn’t have anything in common, but once I knew that she was cool with [my infertility], I found myself not wanting to be without her. [...] I just stayed close to her, which ended up bein’ a huge mistake. And we both acknowledged it. We were very amicable. We both looked at each other in the face this last fall and we were like, “We’re not meant for each other. And we found this out the hard way.” And that’s embarrassing, but we both acknowledged it. And I told her, I said, “You’re an awesome person, but we do not [*laughs*] agree on a lotta stuff.” And I was like, “I think I’ve been with you this whole time because of that sensitivity. You were cool with that. If we had to adopt, you were awesome with that.”

Accounts like these are indicative of YAs’ common appreciation of support that helped them to feel as normal as possible, whether it involved maintaining normal conversations

or activities or encouraging them to feel normal despite experiencing altered appearances or bodily functions.

“They Didn’t Know How to React at All”: Commonly Bad Forms of Support

One of the barriers to YA survivors being treated normally, however, is that SNMs are typically so unfamiliar with providing support to YAs with cancer that they lack an existing framework or template necessary for understanding how to handle the situation in a way that genuinely benefits the survivor. Many YA survivors expressed that the illness experience was isolating because others, including their closest SNMs, could not understand what a cancer patient physically and emotionally experiences without living through it themselves. Ann expressed her inability to accurately describe some of the physical barriers to social interaction that she encountered with others:

I'm a really social person. I just don't think that I had the energy to interact much. I mean, there were things that I tried to go out and do, but I was just so tired. It's been the only thing that I really haven't been able to explain to people. Like until you know that fatigue, you will never know it. I don't care how tired [*laughs*], you will never know that fatigue.

YAs also felt that others’ general lack of education and misconceptions about cancer as a disease state caused them to feel uncertainty in knowing how best to support them. Perhaps as a result, YAs like Brad, who was diagnosed with Stage II testicular cancer at 22, experienced a wide variety of reactions and support attempts from members of their social network:

It’s almost kind of a bizarre conversation to tell friends and acquaintances or co-workers, because some people take it very differently than others. Some people are very, very, accommodating and helpful and, you know, go out of their way. And others I think are a little bit more—they just kind of, they’re not that comfortable, you know?

Ofelia, who was diagnosed with liver cancer at 23, also perceived that her friends were all over the map with their support attempts, which she attributed to their different predispositions toward cancer: “I have a huge group of friends, and just like so many different people say different things. I just kinda took it as some people thought I was gonna die, and some people thought I was gonna make it.” While many YAs reported that intended supporters believed their cancer diagnosis was a “death sentence,” Amber, who was diagnosed with Stage II breast cancer at 36, said that her sisters adhered to a similarly common belief that breast cancer is easily curable: “[They think] it’s just gonna be you get a pink t-shirt, you’re gonna be fine. The reality is it doesn’t work quite like that.” Michael, who was diagnosed with Stage II testicular cancer at 19, felt that he needed to educate others about his disease in order to receive effective support, which became burdensome:

With your average person, whenever I’m talking to them about cancer, I feel like I’m educating someone. I have to stop all the time to explain like what chemotherapy is, what the [retroperitoneal lymph node dissection; RPLND] is, and what testicular cancer is, how there’s multiple subtypes of testicular cancer. And so it’s just this long process where if I wanna actually explain to them what I went through, I have to do a lot of educating.

The disparate support tactics of YAs’ SNMs may indicate the lack of an existing script that has been proven to be helpful in providing support to YAs with cancer. Not only are YA cancer patients and survivors comparatively rarer than those initially diagnosed at older and younger ages, but the support templates or frameworks that do exist are generally geared toward assisting the considerably more ubiquitous pediatric or older adult population, who experience different needs and coping strategies following a cancer diagnosis. Stella, who was diagnosed with Stage I breast cancer at 31, knew that

her supporters meant well, but she did not feel that they were prepared to deal with her unique situation: “Nobody is ever not trying to be supportive. It’s just that they don’t know how to handle it.”

An additional problem is that many of YA survivors’ most influential supporters are also YAs themselves, and they often lack the wisdom and life experience afforded to the closest supporters of older and younger survivors. Similar to other YA survivors interviewed, Ann did not take it personally that her friends struggled to support her, but she acknowledged that their uncertainty was a product of their lack of experience with cancer:

I think my friends being younger, they didn’t know how to react at all. And some people acted really kinda almost immature about it, and I think it’s just because they were just not sure what to do. Like I was the only one of my friends that I know who was diagnosed with cancer.

Perhaps due to the lack of an existing support category for this population, YA survivors often reported that potential supporters within their social network experienced hesitancy, fear, discomfort, shock, denial, self-absorption, and ineptitude when faced with opportunities to provide support to YAs with cancer. The eight forms of social support listed below were commonly identified by YA survivors as being negative, and their prevalence was largely a product of SNMs generally not knowing, or attempting to learn, how to support YAs during the cancer experience. These negative forms of support include pity, negative stories, awkward remarks, uneducated advice, excessive self-monitoring, physical and emotional withdrawal, getting in on the drama, and self-absorption.

“Oh my God, look at him now”: Pity and exaggerated sympathy. YA survivors consistently reported the receipt of negative support in the form of pity,

somberness, and exaggerated sympathy, which caused the survivor to feel uncomfortable. Stella believed that potential supporters' inherently overwrought emotions prevented them from providing effective support: "They're trying to help, but in their sympathy they say dumb things or they being sad makes me sadder [*laughs*]." Gunther said that he was more likely to put himself in a position to receive support from people who did not elicit overly sympathetic responses (e.g., "Ohhh, I'm *so* sorry for you," "Ohhh, let me help you) and instead reacted in a manner that was more neutral (e.g., "Ahh, that blows"). However, Gunther reported that his mother Angie, one of his closest supporters, struggled to cope with his cancer without expressing her pity:

Just typical mother [*laughs*]. Just crying all, you know—[*crying voice*] "I feel so—why—I, I, I wish I could take this from you! I wish I was the one! Ughhhh!" You know, I don't wanna hear it. Not that she was never helpful, but with the "don't feel bad for me" stuff, she was heavy on that [*laughs*].

Gunther also perceived different levels of sympathy at various points along his cancer trajectory, which he attributed to others' perceptions of the physical and cognitive toll that his chemotherapy took on him following a recurrence compared to their more benign attitudes toward his orchiectomy:

Now it's not like, "Oh you have cancer. That's horrible, what can we do?" Now it's like, "You look like absolute shit" [*laughs*] [...] With the [orchiectomy], it's like, "Yeah, you got cancer, but you're still kind of *there* [mentally]," and then chemo, with how *not* there I was anymore, I'm just not even close to the same person, just a shell of who I am, you know? That was, I guess, just a whole other, I don't know, like, "Oh my God, now look at him."

YAs also perceived exaggerated sympathy and somberness from others nonverbally, specifically in the form of "big pity eyes" and a "pity face," which Josie, who was diagnosed with Hodgkin's lymphoma at 18, experienced when she told others

she had cancer: “They’ll be like, ‘Ohhh, you *doooooo*.’ [...] I just hate that face.” Many YAs, like John, felt that they received overwrought support because their friends and loved ones believed that they were issued a death sentence upon their diagnosis:

And everybody—it was weird. The more people there were—it was almost like watchin’ your own funeral, because they mourned around you and they talked about it—cuz I was like, “Look, [my doctor] told me to take the weekend [before treatment starts], so it’s Friday. Let’s meet downtown. Let’s have a good time. I wanna enjoy this weekend.” And that was a really good thing, but it was really weird watchin’ everybody around me, because there were those whispers, “Is he okay? Is he this or that?”

YAs also reported that older supporters who had previously been diagnosed with cancer or whose peers or older relatives had passed away from the disease tended to infantilize them. YAs believed many of them felt overly sorry that they had to endure, and would likely die from, cancer at such a young age. Perhaps in an attempt to empathize with them, some supporters provided ineffective support to YAs in the form of telling negative stories.

“My dad died of cancer”: **Negative stories.** Another commonly unappreciated form of support perceived by YA survivors that likely resulted from the lack of available scripts for providing effective assistance to this population involved others’ sharing of negative stories and information about the cancer experience. Frequently these stories were about people the potential supporter had known who had passed away from cancer. Tim, who was diagnosed with AML at 28, bemoaned the lack of positive stories about long-term survivorship following cancer treatment, possibly because the sources of these stories were often older adults.

A lotta times, even just people my parents’ age or my grandparents’ age or whatever, whenever discussions come up about cancer, it’s “Oh, I knew somebody who had that cancer and they died.” You know, that’s all it is.

It's never, "Oh, I know so and so who had that cancer five, 10, 15, 20 years ago and they're still my friend." They don't talk about those types of things. It's always, "I knew somebody and they died." I'm like, "Oh, that's nice."

Survivors also pointed out that the intended supporter was often trying to be helpful in sharing these stories. Amber attributed this unhelpful form of support to others' uncertainty about how to support her effectively:

Everybody knows someone who's had cancer, right? And I just think that people's stories are not needed, because usually those people have died in those stories. I do not want to hear anything like negative. Nothing negative. And it's, you know, people will *say* those things to make you feel better, but really all it does is just make you feel like crap [*laughs*]. So that kind of support is terrible.

Stella not only had to cope with frightening information from others' stories, but she also took it upon herself to make others comfortable with her own cancer so that she could potentially receive more positive support from them in the future:

When I had to tell my boss, he just listened, you know, and he didn't try to interject about, "My dad died of cancer," you know, or that—because people do that too. Like, "My mom died of cancer." It's like, "Don't tell me that" [*laughs*], you know? It's like, "Thanks, fucker!" [*laughs*] [...] They don't know what to say, like it creeps them out or something. It's like, "Hey, it's no big deal! [*laughs*] I'm cool with it, you can be cool with it too, you know?"

Josie struggled with the receipt of others' negative accounts not because they led her to question whether she would survive her Hodgkin's lymphoma, but because she believed that the side effects of her treatment would be considerably worse than they actually were:

When I first got my biopsy, this girl was like, "Oh my God, you'll feel sick, you're gonna puke, you're gonna lose your hair." They'll like tell me all the negative things, and I was like, "I don't really wanna hear that right now." It's not that it's not bad, but I think people think it's like so awful. I mean, it's still hard, but it's not as bad as everyone thinks, I felt like.

Ellie reported that others told her stories about older relatives with cancer in an invalidating attempt to empathize with her:

It was like, “Oh, my like great uncle had leukemia, so I know what you’re going through,” and it’s like, “You don’t though. You don’t know what I’m going through,” you know what I mean? And so I know they were trying to be nice, and trying to offer support, but it was like, “But really you don’t know.” So I think that sometimes kinda irked me a little bit.

Although potential supporters often shared stories in an attempt to empathize with the survivor and normalize the experience, this form of ineffective support was often perceived by the survivor as an attempt to stagehog the conversation because their accounts often invalidated the YA’s experience. Negative stories were also sometimes perceived as misguided assistance from the intended supporter because they caused them to contemplate the worst possible outcomes of their cancer and its treatment.

“Are you still gonna be, like, a guy?”: Rude remarks. YA survivors also described the receipt of rude, insensitive, and awkward comments or questions that were commonly perceived as unsupportive. For example, several married survivors who were at the age in which they were normatively “supposed to conceive” (and were also surrounded by peers who were doing so) reported receiving awkward questions about their family planning, despite likely having lost their fertility following cancer treatment. Graham commented that he thought others’ questions about plans for future children were rude to begin with, but he felt the need to protect others from the reality of his infertility: “I just try to brush off that question and just like, ‘Oh, we’re not ready yet,’ or something like that. I don’t wanna make them feel bad. I don’t think it’s fair, but I don’t like people asking about it.” Despite receiving a full hysterectomy at 36 after being diagnosed with ovarian and uterine cancer, Molly was surprised that she needed to

answer questions related to her fertility from people who should have known better. She also experienced burden in, unlike Graham, feeling the need to explain the situation to those who did not know her well.

You'll get the person who doesn't really realize what's going on and ask me, "So when are you gonna have another one?" You know, like, "Okay, I just told you I had ovarian cancer. Can you not plug two and two together?" But there are a lot of people that can't, and so then I have to go through it even more with people I don't really even know or care to share that much information with.

YA survivors were also faced with addressing perceptions about their altered sexual function. These inquiries were typically made from peers and acquaintances rather than closer supporters. Michael received a question from a classmate after his instructor in an undergraduate social work class, which was filled primarily with females, invited him to talk about his testicular cancer experience:

This guy, he asked this really awkward question like, you know, "How was sex after the [RPLND] surgery?" And I was like, "What do you mean, really? Like, do you mean did like things work? Or like did it hurt or like was I able to? Like what are you talkin' about?" And like the whole class just got really quiet. It was just awkward. Like it was a relevant question, but just the way he put it and just kinda threw it out there, it was really awkward.

Gunther also received questions from "not that close of friends" about the effects of his testicular cancer procedure, but he perceived the inquiries to be more insulting and ignorant than awkward in their execution:

Since I lost a nut, uh, "Are you gonna, like, have testosterone or are you still gonna be, like, a guy?" [*laughs*]. And I'm like, "Yeah, okay, shut up." [...] I'm just kind of like, "Really? Really? Yes, I'm still completely fine." I'm an open book, but, to me, that was just like, "That's just a dumb thing to say."

YAs also described receiving insensitive comments from others about the status of their romantic relationships. Following her diagnosis, Kelly was aware that one of her

boyfriend's friends had commented on her boyfriend's relational commitment ("You're a better man than I am, because I would have left"), which reinforced Kelly's uncertainty about her partner's willingness to stay with her: "I didn't think very highly of that friend for awhile. But I was like, 'See! That just goes to prove—like I told you that that's what some "men" would do' [*laughs*]." In Brad's case, unsupportive comments regarding his relational status came from older adult family members who had previously suffered the loss of a loved one from cancer:

I remember one of [my wife] Carrie's cousins or someone—she has a really big family—told her and her mom that she shouldn't marry me because I'll cause nothing but pain and suffering or heartbreak or something like that. And I think it was really because her husband died like within the last year or two of cancer. So that kind of sticks out in my head in terms of—and yeah, I understand where she was coming from. She probably had a lot of pain and suffering, you know? That's her way to try to rationalize those things.

Some YA survivors who did not bear obvious physical indicators of their cancer treatment reported dealing with insensitive questions and comments from others that called into question the legitimacy of their illness. For example, Ofelia explained that an acquaintance from high school asked her if she was speaking to friends about the removal of her malignant liver tumor "for attention." Megan, who had trouble managing long-term side effects following her primary treatment for non-invasive breast cancer at 24, said that a formerly close coworker questioning her work ethic after she was forced to miss several days of work was "so heartbreaking." However, YA survivors who did experience physical alterations as a result of their treatment described receiving rude comments from acquaintances and strangers. Like Eva, who was diagnosed with AML at 24, many of these comments were directed toward young female survivors' wigs, head wraps, or temporary hair styles during and after chemotherapy:

[A friend-of-a friend and I] were talking about my hair. I was saying that I might do something funky with it, maybe even like, you know, shave part of the sides again or something, just cuz like I might as well since I have short hair now. And he sorta said something like, “You’d look like a dyke.” And it was kinda like one of those moments where it’s like, “Are you joking or are you serious?” And I am not sure if he was or not. And then he kinda like walked away, and so it was like I didn’t even respond because I was so surprised by what he said.

“Just be normal!”: Excessive self-monitoring. While YA survivors reported the receipt of comments or questions that were rude, insulting, and awkward, many also felt that intended supporters were not helpful when they perceived them to be overly wary of saying something that could be potentially upsetting. Following her hysterectomy, Molly explained that her conversations with others felt different:

At my age a lot of my friends are having kids now and so they’re worried about talking to me about being pregnant or having little ones because they know that that’s been eliminated for me. So that’s been an adjustment to be able to deal with my friends about that, and family members. And I’m excited for other people to be able to have kids [*laughs*]! I’m not gonna take away their excitement! But there’s a lot of people who wouldn’t feel that way. And so they’re being considerate of that.

In their attempts to be considerate and avoid saying something negative, supporters tended to monitor their communication to the point that the survivor sensed their conversations no longer felt normal. Michael found it frustrating that others often asked his permission to talk about cancer whenever the topic came up organically: “They’ll sometimes look at me like, ‘Is this okay? [*Laughs*] Like we’re talking about cancer, you know?”

Eva believed that her frail appearance caused others to be overly nice to her after she was released from a lengthy hospital stay. She described feeling burden when potential supporters asked her to repeatedly recount her cancer experience rather than

addressing topics that she perceived to be “natural for someone I’ve known my entire life”:

I think a lot of people kind of tip-toed around me a little bit. Like because I looked frail, they kind of treated me like I was frail. So it sometimes became a little weird, because I feel like a lot of my friends didn’t wanna talk to me about things that were going on in their life too, because they were like, “What you’re dealing with is so much worse than anything I have to tell you. And I feel silly telling you about some weird thing that happened to me on Saturday night when your Saturday night was spent at home or at the hospital, or something.” Everyone just wanted to talk about me and how I was feeling and what I was doing. Even if they had heard the story about everything that happened, they would still wanna hear it from me and like what I had to say. They would tell me kind of general things about themselves, but it definitely was like people didn’t wanna like tell me a lot, I think, because they just felt bad saying anything to me. I guess we talked about me a lot, which was really boring since I wasn’t really doing anything but treatment. [...] Everyone was being so nice, I almost felt bad saying anything mean or kind of like lashing out at things. But I mean I wanted to scream at some people like, “Just be normal! Like I know I’m sick, but you can be a normal person around me still. Like you can tell me what’s going on.” It was frustrating and I think I was a little angry about it, because it was like, “I mean, I’m already sick and I’ve had to kinda pause my life and now I feel like everyone around me is acting different.” And I think it was just like one more change that I didn’t wanna have to deal with.

Eva’s account sheds insight into how the biographical disruption of caused by a cancer diagnosis and its treatment can extend to a YA patient’s support network. It also demonstrates how intended supporters’ uncertainty about how to best provide support can manifest itself as being overly wary of saying the wrong thing around the YA survivor. This commonly-perceived negative form of support encouraged YA survivors to feel “different,” which complicated their attempts to reconstruct an already disrupted biography.

“You’re not a doctor”: Bad or uneducated advice. YAs also perceived unhelpful support from others who they felt provided presumptive advice or unqualified

information about their disease state and treatment. Stella said, “People are always saying what they *know*, and it’s *so wrong* [laughs], you know? It’s like people try to give you advice and you’re like, ‘Thanks for that. Okay.’ But they don’t really know. They’re not doctors.” Eva described a frustrating experience with a peer who attempted to convince her that she had a particular stage of APL because his aunt had a similar diagnosis:

I tried to explain that leukemia doesn’t have stages. And he kind of tried to tell me that I was wrong. And I think that was really frustrating, cuz I was like, “Don’t tell me that I don’t know about my own illness,” or “You’re not a doctor, like you don’t know anything. Just because your aunt had cancer doesn’t mean that you know anything about it.”

In these cases, potential supporters’ limited experience with cancer did not appear to stop them from attempting to presumptively provide support to YAs.

“Where was this before?”: Emerging from estrangement. Some YAs appreciated that individuals with whom they were never or no longer close came out of the woodwork to offer support upon hearing about their diagnosis (e.g., through word of mouth, alumni networks, social media posts). However, other YA survivors were frustrated when they believed that people who were not constants in their lives were suddenly attempting to provide support. YAs often believed that they did so not out of genuine care and interest, but to relieve a sense of guilt, to draw attention to themselves, to “get in on the drama,” or to satisfy their own curiosity about the YA’s experience. Charlotte was wary of a friend who had withdrawn from her life before her diagnosis and had attempted to re-emerge to provide support:

I don’t want someone to come back into my life or be my friend just because they feel bad for me that I’m sick. You either wanna be my friend when I’m sick and when I’m healthy, or you don’t wanna be my friend.

Eva also found it frustrating to manage others' attempts to offer her support when she had never had a close relationship with them:

My best friend from high school would get text messages from people asking her about me. And she was like, "I haven't spoken to you in five years and suddenly, because you heard something's going on with Eva, now you wanna talk about it?" [...] And I would have people suddenly Facebook friend me, and I was like, "Obviously, you're trying to like—we weren't even friends when we were in high school together." [...] Now after I've been diagnosed it's kind of, "Oh, now you want to be." So I definitely ignored those [laughs]. But yeah, there's that kind of like morbid curiosity I think that people have, which it's understandable, but I don't really need to deal with it.

Josie was diagnosed with Hodgkin's lymphoma as an 18-year-old high school senior, and she described her feelings of invalidation when she suddenly received compliments and attention from classmates who were not previously close friends. For example, a classmate who was consistently mean to Josie because of her friendship with the classmate's boyfriend suddenly sent her a text that said, "You're a beautiful girl with a big heart," which prompted an exasperated "Come on!" from Josie. Josie also described her experience at an all-school dance, which was the first time she attended a large gathering of people after buzzing her hair:

I was really nervous, cuz it felt like when I walked in, everyone just kinda gave you that look, like that first time they see you after they hear you've had cancer, you know? It's very weird, and like people who you're friends with but you're not really that close with that you don't really hug that often or ever, they come up to you and hug you and stuff. Like it's weird, you know? Like, "You never did that before [laughs], you know? What's different now?" [...] Everyone was like, "Oh my God, you look beautiful!" like told me the whole night, which is nice and it's flattering, but I look the exact same, but with no hair, you know what I mean? Like my face didn't change. Nothing else changed.

Once again, YAs found it difficult when they felt they were being treated differently as a result of their illness, including when they believed that newly emergent supporters had not sincerely supported them in the past.

“He wouldn’t even look at me”: **Physical and emotional withdrawal.** While some YA survivors felt that they received too much interest from people with whom they were no longer close, others perceived too little attention from people they expected to play a larger role in their support. YAs often attributed potential supporters’ physical and emotional withdrawal to their inability to emotionally handle or “deal with” the survivor’s illness. For example, Ofelia said that her father, with whom she was close, withdrew from her following her liver cancer diagnosis:

My dad, he wouldn’t even look at me. And it was so hard. It was like the guy that I look up to and talk to all the time just wouldn’t even look at me. [...] Then after the denial period, he just wouldn’t really interact with me because he was so scared.

Ann felt a potential romantic partner slip away immediately following her Hodgkin’s lymphoma diagnosis, which she attributed to his inability to talk about severe illness in any capacity:

He has a strong family history of cancer and totally bailed like right when I found out. Like right at the beginning. Right at the beginning. Pretty much didn't talk to him the whole time. Never said anything to me about it. I had known him for like three years, probably seeing him in that light a couple of months. [...] So that was a big surprise, that just like he totally disappeared. He was scared. He was scared.

Jermaine, who was diagnosed with acute lymphoblastic leukemia (ALL) at 28, did not feel much support from his family, who lived six hours away. Jermaine grew up in a low-income neighborhood, and he was the only member of his family to move away and graduate from college. As a result, he believed that his family did not know how to react

to his cancer diagnosis because he had “always been the one that they’ve looked up to, to go out and do this and do that.” Jermaine later came to the conclusion that one reason he did not see his family until “six or seven months” after his diagnosis was because they believed he would get through it on his own:

There was some resentment toward that for awhile for my family. I think they didn’t know how to handle it though. But also at the same time, I found out they was like, “Well it’s J. I mean, it’s J. He’ll get through it [*laughs*]. Oh, it’s J. He’ll be straight.”

Several other YAs perceived support at the start of their treatment, particularly if they were treated as inpatients at the hospital, only to notice people begin to drop off as they became homebound and their treatment wore on. Tim said, “When I was in the hospital, [getting support] was very easy. It was a very tangible thing that people could rally around and could do things to help.” However, his attempts to prod friends to come visit him at his house several months into treatment were often unsuccessful, which his friends attributed to their chaotic graduate student schedule. Michael also felt his close friend support networks begin to dwindle (and not return), but he believed their withdrawal was a result of their inability to face his poor physical condition:

[My friends] definitely dropped off. Definitely. When I was in the hospital, I felt like three friends came once, but they came like the second day I was there. And so I didn’t really even talk to them that much. I had a tube in my nose. I had like multiple IVs. I was on the epidural. Had the urinal catheter, all that. I just [*laughs*], you know, I was out of it. I basically said, “Hi,” and that was it. And I think that was when they actually realized like, “This is real.” Like until then, they hadn’t really seen any indication that I wasn’t healthy until I walked in there [*laughs*] and I looked really awful, basically like an ICU patient kinda thing. So I think that was kind of a shock for them. And they didn’t really know what to do. They stuck around for a few minutes and left. [...] After chemo I felt like I didn’t really have any [friends] anymore, and so I felt like I basically had to start over at that point.

In several cases where potential supporters physically or emotionally withdrew, YAs reported that these individuals apologized for their disappearance after the survivor appeared to be regaining their physical health. Ann said that it “took a lot” for the man she was loosely dating to admit to her after treatment that he could not handle the situation and “wouldn’t have been helpful.” Eva also accepted apologies from friends who reached out to her when they felt it was safe to do so:

A lot of people, I think, when they heard that I was in remission, then I feel like they felt like they could say something to me. I had a few people who text messaged me, or called me, or whatever to say like “Congratulations, and sorry by the way that I haven’t been great these past couple months.” [...] It was weird cuz I feel like part of it was I let them do it, cuz I obviously could tell that they were very uncomfortable with the whole topic.

Looking back on the situation, YAs seemed to understand why the people they expected to support them withdrew. Megan said she did not blame her friends because “some people just take news like that really, really hard” and “they don’t know what to do and how to act.” However, survivors like Ellie still often took their expected supporters’ disappearances personally, and they used the experience to gain a better understanding of who would be there for them in the future:

In a way, you see who your friends like truly are and the people that really care about you. And I think it really hurt me to know some of the people I thought were close to me didn’t really seem to be there as much as other people who you would have never thought, you know, were good friends to you.

“You don’t want somebody to drag you down”: **Self-absorption.** YA survivors also reported that some of their potential supporters, particularly those who were YAs themselves, sometimes prioritized their own normative life goals or interests over

offering them effective support. For example, Ellie's off-and-on dating relationship was permanently halted shortly after she was hospitalized for her APL treatment:

I was confined to a hospital bed for months. How do you really have a relationship with somebody? And I was in college. I didn't expect for a boyfriend to, you know, stick around and stuff. I mean, he did and that's fine, but it wasn't really anything super serious. [...] But it made me realize I don't wanna be with him [*laughs*]. He was just more concerned about, you know, like, going out and stuff on weekends, which again he was in college, like "I don't blame you, you don't want somebody to drag you down, like whatever." That was like how he acted about it. And you can tell from me since I'm hard headed, I was like, "Okay, see ya later."

Eva said that her cancer experience "sped up the process" of becoming distant from a friend when she began to notice her lack of empathy:

She was one of my closest friends in college and I just wouldn't hear from her very much, even when I was sick. Even afterwards she didn't really ask me that much about it. She didn't really acknowledge it that much. And then a little bit after I went into remission, she got engaged. And then everything just became her engagement and, you know, she like wanted me in her wedding and didn't really realize like how hard that would be for me, especially because the wedding was like three months later after her engagement. So I just kind of like saw her, I guess, in a different light, and kind of saw how very self-absorbed she was and like how much she really just—it almost felt like she just didn't really care about me. It just felt like she cared about her own life exclusively and getting married and everything. And that's a big deal, and I was really happy for her, but I also kind of, I guess, felt like, "Why should I be here for you when you weren't here for me during a difficult time?"

Although YA survivors did not want to receive support that communicated pity or a wholesale deviation from what they believed made them normal, their close relationships became strained when they sensed that these individuals began prioritizing their own goals or interests over acknowledging what the survivor has gone through.

In summary, YAs perceived several types of support that they considered to be commonly negative. These forms included pity, negative stories, insensitive remarks, excessive tip-toeing, uneducated advice, insincerity, withdrawal, and self-absorption. In

many of these cases, SNMs' failed attempts to provide support were largely a product of their lack of understanding about how to support a YA with cancer. Many of these supporters were YAs themselves, who are undergoing their own normative transitions and are often inexperienced in dealing with severe illness themselves, particularly when it involves people of a similar age.

Forms of Support Perceived as Positive and Negative

YAs also reported the receipt of several forms of support that some survivors perceived to be positive and others considered to be negative. In some cases, the frequency with which the support attempts were offered and the relationship the YA had with the intended supporter dictated whether the support was evaluated as positive or negative. Consistent with previous research on general adult cancer survivors, emergent normative support that was perceived as helpful/appreciated and unhelpful/unappreciated by YAs, but was not unique to this population, included SNMs' unfulfilled offers to provide support that relied on a survivor's follow up (e.g., "I'm here if you need me. Let me know what I can do"); the preference of words of encouragement over instrumental actions or emotional gestures (and vice versa); gestures (e.g., offering to shave head, participating in cancer support runs or benefits, wearing cancer awareness bracelets or getting tattoos, hosting hair cutting parties, decorating hospital rooms) and gifts (e.g., survivors appreciated cards, scrapbooks, and practical items like hats and gift cards for gas and food, but they felt that receiving an excessive amount of blankets, stuffed animals, and ribbons was wasteful); respecting the survivor's wishes for self-imposed isolation due to physical barriers (e.g., "chemo brain") and social uncertainty (e.g., looking frail might invite pity or distress in others); accommodation and flexibility from

coworkers, employers, instructors, and classmates; and a sense of reassurance, positivity, optimism, and spiritual encouragement from others. However, forms of support that were perceived as uniquely positive and negative among a YA survivor population included attempts to fulfill instrumental tasks and spend relational time, acknowledging the survivor's strength and wisdom, and using humor as support.

Fulfilling instrumental tasks. YA survivors expressed similar patterns in their positive and negative assessments of others' instrumental support (i.e., offers to complete or actually fulfilling helpful tasks) and relational time spent (i.e., "hanging out"). Their evaluations typically depended on the perceived amount and availability of the support and the existing relationship they had with the supporter. For example, when survivors perceived that their supporters were babying (i.e., hovering or "overdoing" instrumental tasks) or smothering them (i.e., constantly around), the task and relational support was considered to be overly burdensome. However, even when both forms of support were perceived as frustrating or awkward, YA survivors often acknowledged the paradoxical necessity of others' completion of tasks and immediate social presence.

"Let's research it together": Effective instrumental support. When assistance with tasks was offered and completed at an optimal level and performed by appropriate parties, YA survivors often perceived the instrumental support to be effective. Perhaps most apparent was YAs' appreciation of their close SNMs' assistance in navigating the healthcare system. These tasks included accompanying the survivor at appointments and treatments, taking notes, filling out paperwork, asking the providers questions, and resolving insurance frustrations. Both of Ellie's parents worked in the medical field, and they assisted her with interpreting and researching information related to her disease state

and treatment options. Ellie attributed her lack of ability to effectively navigate the healthcare system alone to her relatively low health literacy as a YA and the physical and emotional barriers to interpreting complex information while undergoing treatment:

Since my mom's a nurse and my dad's a doctor, they were, at the time, more experienced in the medical field. So when the doctor told [my mom] that I had 193,000 white blood cells and the average is 4,000 to 10,000, they knew what that meant and I didn't really necessarily know [...] If I didn't understand something, you know, that the doctors were gonna do, my mom was always the first one to be like, "You know, this is what I think. Let's research it together. Let's figure out exactly what this arsenic trioxide treatment—" because I think it's overwhelming when doctors are—and now that I'm in the medical field it's different. But for me at the time I was just starting in that, so I didn't really understand stuff. So they give you just this plethora of information. And you are already on chemo and your brain is smooosh, and you don't really have a clue what they're talking about. So I think for my mom to take that initiative and know, "She doesn't have a clue what you just said. Let's go research it, explain it in more layman's terms," I think I needed that. Because I didn't even know where to start with some of this stuff, you know? Like when I had EPS, extrapyramidal symptoms, like that's not a very common thing. And so they took that time to explain to me what it is, and they were actually the ones who realized I was having it.

Supporters also assisted YAs in finding ways to cope with the side effects of their treatment. While Amber's husband researched ways to help her keep her hair and fingernails as intact as possible during chemotherapy, John turned to his older brother after discovering an alternative method of managing his nausea:

One of my nurses said, "I'm a Christian lady, but start smokin' pot." And I was like, "No shit?" [*laughs*]. She goes, "Half the people in here are smokin' pot." Because I would take Phenergan—that's another anti-nausea, anti-chemo drug—and all it did would knock me out for eight hours and I didn't have a life. I would wake up feelin' like shit again. So that's something I could go to my brother and say, "Hey, we're gonna call up—" my brother was in my fraternity house, and I was like, "Let's call the biggest pothead in our fraternity house." And he left his job, came and picked me up, we drove over to the guy's house, and we sat there and smoked pot with him all afternoon. Afterwards we had a big pizza and I hadn't eaten like that in months. The nausea was gone, and I wasn't falling asleep. And I actually had a great freakin' day.

Other emergent forms of effective instrumental support included tasks related to managing the survivor's daily medical care. Many survivors noted that these duties were often unpleasant, such as cleaning up vomit and wiping out surgical drains and chemotherapy ports. Tim appreciated his wife's ritualistic performance of tasks that may have been uncomfortable for other YAs, because he felt their completion gave the couple a chance to bond and achieve a state of consistency:

I had Sydney pretty much giving me baths up until I got my port out [laughs]. I didn't really tell her so much at the time, but with the port and the whole cover thing that I had to put on it, bathing myself was possible, but it was an uncomfortable pain in the ass, because I could not raise my left arm. If I raised my left arm, it would rip all the tape off and then I would get water and soap and everything on my bandage and that was—I just didn't wanna wrestle with it. Especially right after I got it. It was a pain. And so as much out of convenience as anything else, I had her helping with that. And I told her after awhile that "I can bathe myself, but I like it just the way—" it was a bonding thing for us too. And we had our routine with the port itself and the maintenance of that, the cleaning of it and the replacement of the dressings and so that, along with the bathing routine, it was a routine that we just kept the same the whole time, and we didn't forget anything or mess anything up or any of that. So that worked out well. But it was something that was nice for me.

YAs also appreciated when supporters provided rides to treatment, financial assistance, food, clothing, logistical assistance (e.g., dropping the survivor's college courses, contacting instructors), and child/pet/house care. Like Jess, who was diagnosed with salivary gland cancer at 23, YAs often acknowledged the demand placed on their SNMs by the necessary completion of tasks: "I was *probably* pretty needy [laughs] just as far as, 'Can you get this for me? Or can you do this for me?' And [my mom] took it all in stride and did everything." Jermaine also considered the instrumental tasks provided to him by his girlfriend Delia as "essential," because he had met other YA survivors who lacked similar types of support: "I've talked to people whose girlfriend or boyfriend left them,

like right when they got sick. Or left right when they got through it a little bit, because it's a long process."

"Am I six years old or 25?": *Hovering and babying.* Despite expressing their appreciation for most of the instrumental forms of support completed for them, YA survivors often reported that these tasks were appropriate only until the assistance crossed over into a perception of "over-helping" or "overdoing" it. Typically these less helpful forms of instrumental support involved an overbearing sense of hovering or babying from members of their support network that infringed upon the independence the survivors had normatively achieved and were continuing to pursue as YAs before their diagnosis. For example, several survivors reported feeling frustrated when close SNMs who completed daily instrumental tasks began hovering, or monitoring them to an infantilizing degree at home. Many YAs, like Eva, said that the experience of living with a supporter who began offering too much task-related support felt like reverting back to their childhood:

My dad slept in my room every night just in case. I'm also the youngest in my family, so I think everyone already treats me kinda like the baby and they definitely babied me a little bit during the whole thing. And there were definitely times where I was like, "Am I six years old or 25?"
[laughs].

Meanwhile, Molly's aunt temporarily moved in to provide instrumental support to her, her husband, and their one-year-old son, but she felt that her aunt's presence sometimes "just became too much" because "[she's] not my mom, and therefore I'm not used to [her] being here all the time. Plus, I haven't *lived* with my mom [laughs] in a very long time." Jermaine felt that his girlfriend Delia's constant surveillance, specifically when checking in to make sure that he was okay, prevented him from maintaining as much agency as he would have liked:

If I dropped something in the bathroom, I could hear [*mocks footsteps coming up stairs*] “You okay? You okay? You okay?” “Geez, I’m straight, man.” But I understand it, though. I mean, she was just scared. [...] But I always called her “Thirsty” cuz when I dropped something she’d be like, “You okay?” “Yeah, Thirsty, I’m alright. Relax.”

Not only did YAs grow tired of supporters’ repeated attempts to make sure they took their pills and ate enough food (which YAs often attributed to supporters’ inability to understand the intensity of their nausea), survivors also became frustrated when close SNMs’ attempts to monitor their health and provide instrumental support impinged upon their decision-making autonomy. This may be attributed to close SNMs’ struggles to accept that YAs survivors are often mature enough to make their own health decisions. Michael had to consistently remind his parents that “it’s not their body that’s gettin’ cut open” when they pushed him to proactively schedule a major surgery (his RPLND) instead of respecting his decision to first monitor for cancer progression. Similarly, Charlotte felt the need to be assertive when her mother’s fiancé attempted to make medical decisions for her without reading the hospital’s orders for her discharge:

The other night when I was running a fever my mom’s fiancé was like, “I think you need to go to the hospital, blah, blah, blah.” And I was like, “That’s not what the discharge instructions say. I’m not going to the hospital until I absolutely need to, because I’m spending enough time in the hospital as it is. I’ll go when it’s necessary, but I’m not gonna go just as an alarm.” He didn’t really push back too much, but I just kind of like had to be firm. You know, “It says 100.5. My fever’s 100.4 [*laughs*] right now. If it get to 100.5, then I will go.”

YA survivors also experienced hovering and babying from intended instrumental supporters beyond their home throughout and following the completion of primary treatment. These offers often occurred as YAs attempted to maintain or reacclimate back into their work lives and normal social activities when they felt well enough to do so. Many YAs reported that their coworkers offered them support by being overly cautious

of their physical and mental exertion. Graham said that his coworkers were “too scared to have me do anything,” which was a “weird experience.” Ofelia said that her coworkers at a bridal shop would not even let her move 20-pound boxes, which frustrated her: “They started treating me like I was weak. I hate when people think I’m weak. I’m not weak.” YAs also said that their friends constantly asked if they were feeling okay upon their return to their normal social activities. Jermaine’s first attempts to play pickup basketball brought upon repeated questions of, “J, you alright? You good, J? You good? J, you okay?” which invalidated his attempts to return to normalcy:

I think that’s the stigma though with cancer survivors just thinking we’re half dead already [*laughs*]. It’s like, “Nah, dude, I’m good.” So it’s weird. I understand it cuz they’re just trying to—you know, they love me. They’re just trying to make sure I’m okay.

YAs like Ellie were also frustrated by unnecessary offers of assistance from strangers in public:

I think that people tend to feel sorry for you, and you just get those looks. Like if you’re walking on campus or at the grocery store or whatever, you have no hair, you’re super thin, you know, I had to wear a mask because I couldn’t get sick, so I think people look at you and they’re like, “Ohh, can I get that for you?” like, “Can I do this?” And that’s nice, and don’t get me wrong, like I appreciate people wanting to help, but I think some people just take it overboard and they just feel so sorry for you and at that time in your life, you want so much—because everything else around you is different and everything else around you kinda sucks, and you just want some normalcy in your life. And so I feel like people just baby you almost and you don’t want that.

In many of these cases, supporters’ attempts to fulfill tasks were met with resistance by YAs when they were perceived as “going overboard” because survivors found them to invalidate their attempts to maintain a normative sense of independence and agency.

“I don’t want to be cared for, but I needed it”: Frustrating but necessary

paradox. In several cases, YA survivors looked back on their experience and realized that

although the receipt of overbearing, babying, or hovering instrumental support was frustrating or awkward at times, it was necessary for their ability to function. Gunther, who struggled with his inability to maintain a sense of autonomy during treatment, acknowledged that his girlfriend Kiki's tendency to hover was necessary: "I don't want to be cared for, but I needed it. So pretty much the whole time, I didn't want it, but I acknowledge that, yeah, it wasn't going to happen by myself too much." Graham appreciated his fiancé Lauren's necessary instrumental support, even though it was sometimes frustrating for him. However, he experienced additional burden when she would not allow him to repay her:

She was working and taking care of me, and taking care of the household chores, so I was very thankful for that, but it's frustrating to be told you shouldn't be doing something, even if it's something as silly as lifting laundry baskets from upstairs to downstairs. And she says, "I can do that." Well, I know it's a pain in the ass for her to have to be doing that all the time.

Sometimes this instrumental support paradox occurred as YAs like Charlotte, who was attending graduate school in Washington D.C. until she was diagnosed with AML, became frustrated about losing their independence upon necessarily moving back in with and receiving financial assistance from their parents. However, like Michael, survivors often acknowledged that they could not have gotten through treatment without the help of close supporters:

It was weird. It was like reverting, cuz I just turned 20 before chemo. I was kinda tryin' to be more independent and everything, and then here I was. I was on [my mom's] insurance, she was paying all this, so that kinda takes your independence completely away there. I lived with her, so she was really the only one around constantly. Then a lot of times I would get up and not make it to the bathroom in time to puke and I'd get it on the floor and stuff and she'd end up cleaning it up like I was a little kid again basically. And anything I wanted to do, she would—if I wanted to go somewhere, she had to take me. She had to take me to chemo. I probably

couldn't drive. Just anything that I needed done, she pretty much had to do it. And that just definitely felt like I was her little kid again. And it was awkward.

Although YA survivors often appreciated the receipt of instrumental support, it sometimes became overbearing when supporters began to hover or baby them. Despite their frustration, however, survivors often retrospectively acknowledged that the receipt of aggravating or awkward instrumental support was paradoxically necessary. Similar patterns also occurred with relational support.

“I’ll just stay here”: **Providing relational support.** YA survivors appreciated when supporters spent quality time with them at home and in the hospital, particularly when their “hanging out” promoted normalcy and provided a respite or distraction from their physical discomfort and isolation. YAs like John were particularly grateful when SNMs went out of their way to visit them and were comfortable just sitting, talking, and “being there” for them.

My friend was a ski instructor out in Colorado. And freakin', you know, he didn't have to come home. And I told him that. He would call me, and I'm like, “Dude, don't come home. Like I appreciate you calling.” He just showed up. He came home and sat with me every day during a five day session. I was like, “That's cool.” I mean, it's really—and I warned him, I was like, “It's really boring. I just sit here and watch TV all day.” And he was like, “Nah, man. I'll just stay here.”

Eva appreciated her boyfriend's and sisters' hospital visits because she would ask them to lie in bed with her to promote a sense of comfort and normalcy: “It's weird, you don't realize when you're in the hospital how little physical contact you have, or the only time you're being touched is by nurses pushing a needle in you.”

Many supporters were also effective when they played games and watched movies with the survivor, especially when YAs did not feel pressure to talk about their cancer. John enjoyed hanging out with his friends like he did before he was diagnosed:

And when they left, I was like, “Thank you, you know? It wasn’t people over there just kinda starin’ at ya or wonderin’ “What’s next?” [...] That’s the things I appreciated the most was just hanging out. And the fact that they were there. But, yeah, just hanging out just like old times was my favorite thing. Cuz there wasn’t any normalcy.

“Ehh, please go away”: *Suffocating and smothering.* Although YAs often wanted someone to be around, normative relational support sometimes got to the point of becoming suffocating. Eva said that she liked having her dad and sister in her hospital room, but she felt like she needed to entertain other family members when they came to visit:

Everyone in my family wanted to be part of it or have some amount of control or something. And so they would wanna come down to my hospital room all the time and I would feel obligated to stay awake, even when they said, “Oh, you don’t have to stay awake. We can just be in here.” And I’d be like, “But if you’re in my room, I feel like I need to stay up and talk to you.” And that’s kinda hard. And I have a big family. I have five siblings and a large extended family as well. So there just came a point where it was like too many bodies, too many people, and it’s the last thing I wanted when I wasn’t feeling well. And so I think sometimes people trying to be there physically all the time to be supportive was frustrating. I think there was a smothering a little bit from certain people. And then they would get angry if they couldn’t visit and I would end up feeling guilty if I told people, “No, I just am not feeling well today,” or something. And then they would get mad. You know it all comes from a good place, but there’s something about when you don’t ask for the support, there’s a reason you’re not asking for it [*laughs*]. And sometimes when they would ask me—that’s perfectly fine—but then respect my wishes and don’t come when I’m not feeling well. Otherwise, why are you asking me?

John also struggled to keep supporters from hanging around and wanting to talk during his chemotherapy sessions:

Imagine your most hungover day ever. That's a bad day of chemo [*laughs*] like times 10, where you just wanna lay there and you don't want anything. And that's when [people] would show up. And I would just be like, "Ehhh, please go away."

While some YAs reported feeling smothered by having too many people around them too often, other survivors experienced suffocation from one person's constant presence. Josie's said that her mother, with whom she still lived before she was diagnosed, became too much of a physical presence:

My mom will just be like, "Do you wanna cuddle? Do you wanna lay in bed together? Like what do you wanna do?" I'm just like, "Mom, sometimes I just wanna be left alone." [...] Like she'll touch me and kiss me and touch my hair, and I'm just like, "Don't touch me today." And I feel bad bein' like that. I just don't wanna be touched sometimes.

Several YAs, like Michael, also began feeling uncomfortable when their romantic partners never left their side, particularly when their relationship was not well established:

[My girlfriend and I] broke up once right at the end of chemotherapy, because she had just been around constantly and when someone's around that constantly when you're goin' through something pretty bad, you kind of associate them with it [...] She stuck around really close [*laughs*] basically. Too close. And we didn't even have a chance to get to know each other all that well before. You probably don't want, you know, within the first few months for your girlfriend to see you with a urinary catheter [*laughs*] and to like be in the room when you're having it removed. And to be there when you're getting chemotherapy and when you're going into a major surgery. People always get really concerned when you're going into the operating room and all of that. I mean, it was just too soon [*laughs*] for a new relationship basically.

Although YAs often wanted relational support from others in order to experience normalcy and a distraction from their physical discomfort, they sometimes wanted to be allowed to feel sick without having to worry about other people's presence.

***“Life’s too short for all that stuff”*: Premature maturation.** YAs also reported withdrawing from the receipt of relational support from existing friend groups because they felt that they had matured beyond them or that their interests had changed following their cancer experience. Some survivors chose not to hang around certain friends as often because they were heavy drinkers and smokers, and they knew that partaking would make them feel worse. Eva said that she sometimes felt like “a 50 year old” because she believed that her priorities and her mentality caused her to “think about things a lot differently” than she noticed her friends did. Tim also made it a point to remove himself from people who he felt were constantly hung up on insignificant matters:

I care less about stupid drama. Just the piddly day-to-day stuff that people deal with. I don’t really care about those things anymore. If I am spending too much time around somebody who has all that petty drama surrounding them, I make the point just to get away. Life’s too short for all that stuff. I don’t have time for that.

These examples indicate that YAs sometimes chose not to receive relational support because they believed that their cancer experience caused them to mature faster than their friends.

***“And now it’s quiet”*: Missed the relational time when it was gone.** Despite YAs’ occasional feelings of suffocation from SNMs, survivors acknowledged that they often missed their relational support if it was not being provided. YAs reported that their time spent with others was often in flux because their established support networks were typically geographically scattered at their age. Michael was critical of his parents’ smothering relational support during his hospital recovery from the RPLND procedure, but he found himself feeling hurt after they went out of state to visit his sister at her college:

My sister's graduation happened to be at the end of the week I was in the hospital from the surgery. And so my parents had actually left that Friday to attend her graduation and to help her pack her stuff up and whatnot. And while I didn't want them to be there all the time, it felt kinda like, "Okay, you're just goin' out of state while I'm here in the hospital bed?" I mean, my girlfriend was there and everything and some other friends were around. But yeah, my dad, my mom, and stepmom all went there, and it was just like, "Okay."

Although Tim was sometimes frustrated by his parents' and parents-in-laws' constant presence during his treatment in Texas, he admitted struggling when they moved back to their homes in the Midwest: "That was when the boredom really started to hit, because everybody had left the house. I had had several people around me all the time for months and now it's quiet." Brad had just moved to a new city a few months before his diagnosis. With his family and established friends several hours away, he did not have much of an opportunity to build a relational support network within a more reasonable proximity.

In summary, when survivors perceived that the instrumental tasks that were offered or fulfilled and the relational time that was spent were at a normal or optimal amount from people with whom they shared a positive relationship, they perceived the support to be helpful or normal. However, when survivors found their supporters to be babying (i.e., hovering, "overdoing" it) or smothering them (i.e., constantly around), the task and relational support was considered to be overly burdensome. Yet YA survivors sometimes paradoxically acknowledged the necessity of excessive instrumental support, and they often missed the relational time when it was gone.

"You must have such courage and willpower": Acknowledging the survivor's strength and wisdom. Another form of support that was perceived by YAs to be both affirming and invalidating were compliments about the strength and wisdom displayed or presumptively developed by the survivor during and following their cancer experience.

Stella reported appreciating acknowledgements of her strength like “You handled that with a lot of grace” and “Stella can do anything” from friends following her treatment. She believed that these comments indicated that “people have some respect” for what she went through. Megan also interpreted messages from people with whom she was no longer close as similarly affirming:

Random people from high school sent me messages just saying like them watching my trial, like my journey on Facebook, like that I’m the strongest woman that they’ve ever met. And I’ve never been told so many times that I’m an inspiration to people. And I get told that a lot, that like I’m an inspiration and stuff like that.

However, many other YA survivors stated that they found comments similar to those that Megan received to be naïve, overblown, invalidating, and used to selfishly place the survivor on an unwanted pedestal. Charlotte said that compliments about her strength were merely others’ romantic projections upon her and that getting through treatment was “not really a choice” but “what I *have* to do.” Jermaine believed that comments about his resilience meant that people were using his suffering to essentially canonize him and derive inspiration for themselves:

No disrespect to anyone, but it’s like, “Man, you’re so strong for going through this. You’re doin’ this, man.” Fuck that, man. And that’s just how I felt. Like “Fuck that.” Like “I gotta be sick to make you feel inspired? Like at the expense of me throwing up all over the place? At the expense of me not eating? I’ve gotta go through this so you can feel inspired?” Nuh uh. I didn’t like that at all. That was a frustrating period, especially when I relapsed.

Michael also struggled to accept several currently ubiquitous and well-intended cancer-related labels and phrases to be meaningless because the people who used them did not truly understand what he was still enduring even in survivorship:

I had some friends who would occasionally try to talk to me about it like, “Man, I’m just so impressed at the way you’re handin’ this and

everything. You know, it's an inspiration." It's just like, "Okay [*laughs*], you don't really know what I'm goin' through here, you know?" And it's weirder even post-treatment, cuz now people see me and I look healthy. You can't look at me and know I had cancer unless I showed you my scar basically. And so it's easier for people to look at me and say, "Wow, you're a survivor. You battled cancer. You've won your fight with cancer. You must have such willpower and courage and everything." Like "*You weren't there* when I was, you know, sleeping 16 hours a day, puking all the time, and would occasionally lash out at people around me because I was so angry. You don't really know. It wasn't a battle, I don't feel like. I feel like I just barely made it through."

In addition to comments about their strength, YA survivors found others' assumptions that they had gained wisdom and clarity during their experience to be frustrating, particularly because survivors' newly-disrupted biography often ensured that their future was now more uncertain than ever. Jermaine found statements like "Oh man, you're here for a greater purpose. You lived for this," to be particularly unhelpful: "I'm like, 'Man, I just beat this. Now what? What am I supposed to do now?' There's like no answers necessarily. No immediate answers." Eva said that her intended supporters looked to her for answers about their own lives, as if her cancer experience turned her into a spiritual guru:

One of my friends said something like, "Well, what have you learned?" I'm like, "Do I have to learn something? Do I have to like give you wisdom now?" I feel like they [think I'm more enlightened now because of this] and I'm like, "I'm not sure that I am. Maybe I just have a different perspective than you guys do. But I am not here to like give out advice based on my experience." I think that is a little frustrating. People automatically think that I'm wiser or something now [*laughs*].

While some YA survivors felt that comments about their strength and wisdom were respectful and gave them helpful encouragement, others thought that they glossed over the survivor's experience for their own benefit rather than attempting to truly understand what they went through.

“We named my brainstem lesion Harold”: Humor as support. YA survivors also expressed largely positive perceptions of others’ supportive uses of humor. When humor was considered as an appreciated and helpful form of support, YA survivors said it “lightened the mood” and lessened the stress related to their cancer experience. Stella said that her husband Dave’s use of humor helped her not to dwell about her chances of a secondary malignancy:

Dave sometimes is almost like defiant about it. It’s like a joke where I’ll be like, “Oh, I have a headache,” and he’s like, “You don’t have brain cancer.” And he’s almost like, “Oh stop it.” That’s kinda like his reaction. I’m like, “Hey, this is serious. I actually had cancer. We know I’m prone [*laughs*] to it.” And it’s like he tries to like force it out of me [*laughs*] or something.

In addition to alleviating stress, YAs felt that helpful forms of supportive humor provided them with a sense of normalcy and control over their cancer experience. Tim said that he and his wife Sydney experienced a great deal of uncertainty after doctors discovered a mysterious lesion on his brainstem. In an attempt to exert their control over the experience and to reduce stress, they used personification:

We named my brainstem lesion Harold. It was something to focus on, to think about getting better, making it go away, because really what it was—we just didn’t know what it was. They first identified it after that first MRI after I fell and hit my head. But it was still there, all through the treatment. It was something my doctors just wanted to monitor the whole time. And I had at least a dozen MRIs over the course of treatment to keep up on it, see what was going on, and it just was there, never changed. [...] There for awhile they didn’t know what to think of it: “Is it scarring from whatever you dealt with? Is it fluid buildup? Is it cancer? Is it an infection?” That’s one of the reasons they had all those infectious disease doctors and everything coming in. And so there was this big uncertainty about “What is it? Is it gonna be harmful? Is it gonna create problems? What’s going on?” [...] But making light of it kinda helped to take some of the stress away from the situation. There were times where we were very worried about what was going on, whether that actually was anything to be concerned with or not. So being able to make jokes about it that way helped take away some of the gravity of the situation.

The receipt of humorous support also provided YA survivors and others with an open outlet for easier conversation about and acknowledgement of their cancer. For Michael and his friends, humor helped to reduce pity and face threats related to his testicular cancer experience, and the use of a joke or slogan related to his loss of a testicle created something tangible for supporters to connect and rally:

When I was like high on anesthesia, when I first came out of that surgery and found out they had removed the testicle or whatever, I said somethin' weird like, "Well I guess you only need one ball to play the game, right?" [*laughs*]. And my friend heard that and he ended up makin' little bracelets that said that. And so we all went around wearin' those for awhile. And it was kinda funny. And then after the treatment was done, people would every now and then make a little joke about it. Like, "The Uniballer," you know. And, uh, I always thought that was pretty funny. It's just acknowledging it. Like, you know, people remembering that [*laughs*] that happened, basically. It's kind of an acknowledgement that, "Okay, we remember what you went through." And at the same time, you know, "You got through it, basically. And now we're tryin' to make things normal," I guess.

Supporters also threw humorous parties for the survivor to commemorate important events like cutting their hair, attending cancer events, and "cancerversaries" of their treatment completion. While Kelly's family and friends threw her bra and hat parties, where supporters brought hats with floppy dog ears and Viking hats with blonde braids, Brad's wife Carrie hosted a humorous testicular cancer-themed celebration:

So you hit five years, it's like a big milestone, you know, you're five years post-treatment. We had a big party here, a whole bunch of people over and family. And we made pink piñatas, and, I don't know if Carrie thought of it, and, and, and—testicle piñatas [*laughs*] filled full of candy, hit 'em with sticks on the back porch. We made a bunch of 'em and got everyone sticks and we hit them with, you know, sticks and busted candy. Everyone hit the balls. [...] It felt like [*laughs*], I think a ridiculous way to celebrate something that people often don't...have humor about. It just felt like a fun way to have a party and kind of blow off some steam. I remember I had a great time and everyone came over.

In fewer cases, however, YAs reported that intended supporters' use of humor became excessive or that it was insensitive or insulting. For example, Brad found the humorous "one-ball" slogans so appreciated by other testicular cancer survivors like Michael, Graham, John, and Gunther to gloss over the seriousness of the disease and the loss of the testicle. Female YA survivors were also particularly sensitive about their loss of hair, and close SNMs' attempts to use humor about their appearance were perceived as insensitive. While Josie cried after her sister Lucy said she looked like Voldemort, the villain of the *Harry Potter* series, Charlotte's boyfriend Geoff's attempt at humor was similarly unintentionally hurtful:

[My boyfriend] meant it as a joke but it was not funny to me. I had been wearing like headcovers and stuff a lot, and I hadn't been going out without anything on, and so it was like the night before and I was like contemplating just going out with the little bit of hair that I do have on my head, but I wasn't like sure whether or not I wanted to, or how it would look. And he goes, "Oh, you'll just look butch if you go out like that." And he thought it was funny, but it just really like—probably that's one of the most insensitive things.

The lack of sensitivity mentioned by Charlotte reflects the concern expressed by YA survivors of close SNMs' inability or unwillingness to see their cancer experience from their vantage point. It also reflects the difficulty YAs had in managing the manner in which their illness relates to their personal identity as it is communicated within their relationships.

In summary, YAs articulated the normative characteristics of the social support they received across the trajectory of cancer diagnosis, treatment, and survivorship through narrative accounts of their illness experience. Intended supporters' use of communication often precipitated how YAs perceived their support attempts. While YAs appreciated when intended supporters' messages aligned with their own perceptions of

normality and capability, the ubiquity of negative support attempts (e.g., pity, negative stories, insensitive remarks, excessive tip-toeing, uneducated advice, insincerity, withdrawal, self-absorption) suggests that the cognitive scripts necessary to provide helpful support to YAs with cancer are not commonly possessed by members of their social networks or do not currently exist. Several additional forms of support attempts (e.g., instrumental and relational support, acknowledging the YA's strength and wisdom, and the use of humor) were also interpreted as both positive and negative across YA survivors, and their valence was likely determined by the perceived situational and relational features of the message.

Although individuals' cancer experiences are inherently different, discernible similarities in the qualities of normative messages were nevertheless clear across this age-defined sample. Despite speaking with YA survivors who represented nine different types of cancer—many of whom were diagnosed with different subtypes and stages of the diseases at varying ages within the 17-39 age range—salient categories of helpful and unhelpful support emerged consistently within this group. The inclusion of the category that included helpful and unhelpful forms of support also serviced participants' variability by allowing for the emergence of support attempts that uniquely displayed inconsistency in terms of their valence. After considering the normative messages that YA cancer survivors perceived as positive and negative, helpful and unhelpful, appreciated and unappreciated, and validating and invalidating forms of support, it is important to further examine the source of these messages and the relational context from which they were shared.

Theme Two: A Cast of Supporters

A critical feature of the perceived normative supportive and less-than-supportive behaviors in YA survivors' narratives was the relational context in which the support attempts were delivered. Following a cancer diagnosis, a cast of supporters, often composed of parents, siblings, children, extended family, romantic partners, and friends played a role in supporting the YA with cancer. As part of the dyadic interviews for this dissertation, survivors nominated a close SNM who they considered to be a primary supporter at the time of their diagnosis or during their treatment. In most cases, the close SNM who was interviewed was also considered by themselves and by the survivor to be the YA's "top supporter," which afforded various responsibilities and privileges that other supporters within the larger network sometimes did not share. In this theme, YAs and their close SNMs explained the features of the "top supporter" role and what separated these individuals from other secondary, but often still important, supporters. YAs and SNMs also described how the competition and jockeying for this role and for access to various support domains or territories was negotiated between the top supporter and other supporters and between the top supporter and the survivor. SNMs also described the communication practices that they used to monitor the support the YA survivor was receiving from others and the gatekeeping functions that they served to invite positive and block negative support for the survivor.

"It's My Job Now, I Guess": Negotiating the "Top Supporter" Role

In their narrative accounts, close SNM and YA survivors often indicated a divergence between the perceived roles and domains assumed by the top supporter and others within the survivor's constellation of support. Close SNMs' descriptions of what it

meant to them to be the top supporter provided insight into how their identities were uniquely affected by assuming the duties inherent in becoming the top supporter. Several close SNMs, particularly those that were YAs themselves, described the biographical disruption that was caused by their loved one's cancer diagnosis and their acceptance of the top supporter role. Amber's 17-year-old daughter Jayden said that accepting this new role was a distinct transition for her:

I went from being such a normal kid to having to like take care of my mom. And like my mom had always taken care of me and I was like, "Well I guess this is my turn to like kinda take care of her and like be there for her."

Lauren said that she was "really not good" at performing medical tasks at home, such as changing her fiancé (now husband) Graham's IVs: "We had medical stuff everywhere.

[...] It was just not normal." Gunther's girlfriend (now wife) Kiki also decided to permanently accept new support responsibilities that had previously felt foreign to her as a YA:

I wouldn't say I had an identity crisis or anything like that. Mostly I identified with, "It's my job to take care of [Gunther]." So primary caretaker was my new role, which I've never had before as far as like in a relationship, and he's always taken care of me, my parents took care of me, like I've never had anyone that I had to take care of on my own that wasn't an animal [*laughs*], you know? So I guess that was my new transition and I guess that has kept. I feel like because of that, now I am the primary caretaker. I do all the stuff that I did then, but it's my job now, I guess.

In several cases, top supporters also described a bifurcation between themselves and other supporters because they felt that others could not truly understand or relate to their experience as top supporter. Brad's fiancé (now wife) Carrie said that as top supporter she felt like she was in her "own little bubble, and people just didn't understand, and so you kind of push some people away." Kelly's mother Kathy also

stated that as top supporters, her and her husband felt more isolation and burden than others within Kelly's support network because others could not relate:

I remember when Kelly was first diagnosed. It's almost like when someone dies. The world is going on around you, and you feel like you're stuck in this tunnel or whatever and can't believe what's going on. [...] I felt like my husband and I—we were more homebodies. We didn't feel like going out with our friends. We didn't wanna go on vacation. We didn't wanna socialize, basically. It's almost like you're in mourning. [...] And people don't know what it's like to be at work a half a day, take your daughter to chemo, and sit there for four or five hours. It's not a pleasant experience. Until you're in those shoes, you just have no idea. You just don't know. You don't really know what it's like.

Jermaine's girlfriend (now wife) Delia also experienced social burden and felt different from secondary supporters because they sometimes offered praise and expressed surprise that she did not back down from the role of top supporter:

My friends always say we were so young in the dating stage, like "You didn't have to stay. Why did you?" And people are like, "It's really nice of you to stay." And I'm like, "The only thing I can say is when I think about it, [Jermaine] didn't cheat on me. He didn't do anything wrong. He was a 27-year-old healthy man, educated. Like it could happen to any of us. Would I want somebody to just leave because that happened? No. It's just life. Life comes at you fast, right [*laughs*]? And so you just do the best that you can. And I figure as long as our relationship was solid, I'm gonna go through this with him, because next year, tomorrow, it could be me. It could be anyone. You just don't know."

Despite the fact that top supporters felt that their divergent roles and domains caused a unique biographical disruption that other supporters could not understand, they also sometimes reaped benefits from their top support role that other supporters could not. For example, Delia's experience as top supporter enabled her to learn things about herself that she never knew and accomplish things she never thought she could:

I definitely think I'm stronger than I realized that I was. It has given me a lot of strength. I feel a lot more resilient. I feel like I have a big heart. I didn't realize it. I don't think that's changed. I just didn't have this type of

example to really understand it [*laughs*]. I think I understand a lot more of who I am, and what I want, and what's important to me.

Close SNMs' acceptance of the top supporter role affected their identity and relationships with others. However, a better understanding of what the acceptance of this support role entails also requires an investigation into how close members of YA survivors' support networks competed for and negotiated with one another to assume, share, or relinquish top supporter roles and domains.

“I’m the main person in his life, not you”: Dilemmas involving roles and domains. In their narratives, YA survivors and their close SNMs explained how members of the survivor's support network negotiated the roles and domains that distinguished top supporters from secondary supporters. In other words, jockeying occurred in an attempt to determine who got to be “in charge” of the survivor's support. Many of the dilemmas involving support roles and domains took place between the survivor's parents, who struggled to relinquish their existing top supporter role, and the survivor's YA romantic partner, who felt the need to assume the top supporter role as their relationship with the survivor became more and more committed. Kiki believed that her boyfriend Gunther's cancer experience accelerated the shift in support dynamics that would have normatively occurred between her and Gunther's mother, Angie, as their relationship moved toward marriage:

I wanted to be in charge but his mom wanted to be in charge and it was kind of also at that point where “I’m the main person in his life, not you” [*laughs*]. So it was the transition of our relationship, but at a time that was during all of this trauma and stress that it just kinda amplified it.

At 23, Carrie struggled to assert herself within her fiancé Brad's family as primary supporter, particularly as it involved her ability to gain first access to information from providers.

I stayed at the Hope Lodge with Brad's family when he was in the hospital for 10 days. So there was his family who has supported him his whole life and then there's me who...I'm his future, I'm the person who's been taking care of him. So it was hard, especially in the hospital when [medical providers] were giving updates. Who do you go to first? Do you go to his parents? Do you go to his fiancé? Who do you talk to? Who's the primary caregiver?

While Carrie acknowledged that her protectiveness "probably pissed some people off," she believed that her attempts to take charge were ultimately important in proving her commitment to Brad's family and signaling that "we didn't just get engaged because he was sick":

There were a couple times when—even though I'm like, "This is your baby boy and I understand that," I was like, "This is like everything in my future. I've put all my eggs in this basket" [*laughs*]. [...] And so I'm sure that was not [*laughs*] taken the best way. But I was very aggressive with the fact that I wasn't going to just sit by idly and have everybody talk to [medical providers], and then have to get all of the information from them. I said, "That's just absolutely ridiculous." So I think that I pushed and pushed a little bit that way. [...] It's a hard time in your life when you're feeling like you're so connected with your own family and dependent on them, but you're also striving to be your own person and be an adult and make it on your own. And as a support person you feel very much like a guard dog a little bit [*laughs*]. And that can put you on edge, you know, with [your partner's] family. But I feel like it's important to assert yourself because it's also showing them you're not going anywhere, like you could just step away and let them take care of them and say, "Oh, it's too much for me and I'm just going to walk away." [...] So I think that [Brad's parents] saw me as somebody who was very strong-willed. I was asking the questions, was always wanting to see the doctor, I was there for all of it, and I wouldn't leave. So I think that they really gained a lot of respect for me and saw a lot of strength in me during that process that I could be a good caregiver. I think they had a new respect for the strength I was able to provide for him.

Not only did top supporter role and domain dilemmas involve negotiations related to who was able to have first access to information from providers, conflicts also occurred regarding who was better positioned to make decisions with and know what was best for the survivor. Dave had been married to Stella for several years at the time of her diagnosis, but he still experienced some pushback from his mother-in-law:

There was almost a competition. It was one of those times where in my heart I knew what was best for Stella at that time, because I asked Stella. And her mom had an opinion of what was best for Stella at that time and had not asked Stella. And at our age, our early 30s, there's a greatly independent, "I've been out in the real world for a *long* time. I've been paying my own bills there, lady." So there was certainly a tradeoff of respect there. And I had to be stern with her mom a couple of times and she understood that. And so our dynamic changed. Our relationship changed. And it wasn't necessarily a bad thing at all. It just changed itself.

Part of the reason why some YA close SNMs struggled to negotiate their position as top supporter was because they did not know where they fit in with their relational partner's family. YAs face a unique support negotiation in this context because, similar to Kiki's experience, their romantic relationships are typically not as established at the time of diagnosis as older adults': "[Gunther and I] were living together, and, *yeah*, I was the main contact for everything. But we weren't married or even engaged. So technically...I wasn't really his person. So that was kind of complicated to handle." When Gunther's family wanted him to receive his final round of chemotherapy in Key West following a family wedding at Disney World, Kiki realized that she did not possess the decision making power that she felt she deserved as Gunther's top supporter:

That was a *huge* issue, because they were like, "Well, he can just get chemo in Key West!" I...had such a meltdown. I actually was at work and I had to—I ran outside and I was crying. I was running around the building crying and calling my mom, so upset that they would even think that that was an option and didn't even think about how it would affect me, because I couldn't go. I wasn't gonna go to Key West. They were all

gonna go. And I was gonna have to fly back home by myself. And that they got his hopes up about it. He was so excited at the idea of, “Oh, I’ll go to Disney and I’ll have the wedding and then I’ll be in Key West with my family. And it’ll be fun. And even though I’m gonna be laying in bed, I might as well be laying in bed by the sunshine.” So he was so hyped up about it, and they never said one word to me about it. I heard about it from him. Like they told him, “Oh, we’ll find you a doctor and you can come to Key West.” Like I said, I was the primary caretaker [*laughs*]: “You can’t just change that! You can’t find a new doctor. Yeah, it’s chemo, but they know what you’ve been on. They know how you’ve reacted. They know what kinda time period it takes to get this through you. *Why on earth* would you think that you can move a *five day week* cycle? No. No.” I was just *so* upset over that [...] But I never said a word. I called my mom, and I mean I was *so, so* upset. And she’s like, “It’s not your choice.” And at that point it wasn’t. It was not my choice. If they were able to find [a doctor] and he wanted to go...So I just had to let it go and I mean I had a *terrible* journal entry that night. I was *so* angry and you could just see it in my writing. Like I just remember being *so, so* mad when I was writing, because I couldn’t talk to him about it. I said, “I don’t think it’s a good idea. These doctors know what you’ve gone through.” And that’s where it came up, like, “Well it’s the same treatment and they can give me that there.” And I was done. I’m like, “I’m not arguing about this. This is a bad idea. This is a very bad idea. That’s my opinion of it. Nobody’s asked me about it. Nobody cares how I feel about it. Done.” [...] And I was just mad that they even picked him up for that. That he got so excited about something and then *so, so* crushed by it. And it’s like, “Thanks, because now *I* have to deal with him. I live with him. He’s upset and it’s on *me*. And he’s mad at me because I didn’t want him to do it in the first place, even though it wasn’t my decision. But I’m the one who thought it was a bad idea, and ‘Now I can’t do it, and so now it’s your fault,’” which was his logic back then [*laughs*].

Top supporters also expressed their need to maintain boundaries from other supporters. For example, Kiki felt uncomfortable when Gunther’s mother Angie accompanied them at an early doctor’s appointment and the topic of avoiding pregnancy during chemotherapy was discussed: “Well, the fun part was that me, and Gunther, *and his mom* met with one of his nurses. And birth control came up, which was a super fun topic to talk about in front of his mother.” Eva lived with her sister Marie, and their father’s constant presence as an additional supporter infringed on Marie’s boundaries:

When Eva was sick, my dad ended up coming down and living with us for six months, probably like three to four days out of the week. And I was living in the tiniest, little office. I slept on an air mattress. It was just too small a space. And like I know I'm not easy to live with to begin with. So having him there was not fun. I mean I love my dad and all that stuff, but it was like, I'm 28. I'm used to living on my own. I don't want my parents living with me. So that was definitely a *huge* adjustment. And he does things a certain way and I do things a certain way. So there was a lot of head butting with that.

However, in many cases, top supporters who were frustrated by role and domain power struggles with other supporters still reported a paradox when they described their need for supporters' assistance. While Marie was frustrated by her father's constant presence, she acknowledged that she needed his help with Eva, particularly because she was so uncertain about how to translate medical information and provide other support effectively: "It was a good thing my parents were there, cuz the way everything happened, it was—I had no idea. I mean, I knew some of it, but I was just like, 'Oh my gosh.'" Kiki could not make sense of her conflicting feelings of wanting control over the support that was offered to Gunther and needing assistance:

I had a lot of anger and...I wouldn't say disappointment, but just like, "Why do I have to handle all this? Where is everybody else?" But at the same time I *refused* to ask for help, because that's part of my own personality is that I'm gonna handle this myself and I don't need anybody else's help. [...] I had all these people that knew about it and were willing to talk about it, but I never asked for anyone to lend a hand or make a meal or anything like that or to drive him. I actually hated when people offered to drive him, because I was like, "That's not your job." Which is stupid, right? Right? [*laughs*]. It's dumb because I was like mad that I was the primary caretaker but I was mad if other people wanted to be it.

As protective as Kiki was of Gunther when it came to his mother's support attempts, Kiki was also frustrated when Angie was not available to provide support:

It was kind of a butting heads with his mom, because obviously she wanted to take care of him. But she was gone [on vacation for two of the most intense weeks of his treatment]. And so I was mad that she was gone,

but at the same time, like, “Well, this is my place. I should be taking care of him anyway.” So even when she was here, I was kind of mad that she was doing stuff, even though...it *is* her son.

Top supporters also acknowledged the importance of their role and domain negotiations with other supporters because it enabled the survivor to experience complementary forms of support from others. While Carrie competed with Brad’s family to become his top supporter, she still acknowledged the important role their support played for Brad’s adjustment to his testicular cancer:

There are certain things that [Brad’s parents] could address with him that I couldn’t and vice versa. You’re not gonna talk to your parents about the fact that you feel unattractive because you’ve gained a bunch of weight and lost all your hair on your body. But at the same time, you can’t necessarily talk to your fiancé about the fact that you just kind of wish that you could go back to living at your parents’ house and be carefree and let somebody else take care of you indefinitely, because there are all these competing emotions going through him at the time. So it was good that he had support on both sides.

As top supporter, Aaron acknowledged that his younger brother John needed his parents for emotional support and comfort. However, Aaron also felt that he was better positioned than his parents to assist and empower John in making his own cancer-related decisions because he was able to do so without being overly burdensome:

I think he takes [advice] more seriously from me than he does from Mom and Dad. [...] I give him the freedom to determine how serious [his symptoms are] and stuff. [...] So he was having a cough and Mom and Dad were being a little overbearing like, “Hey, you need to go get a scan,” and all that stuff. And my brother’s like, “Are you shttin’ me? Do you know how much radiation you go through? You can’t just go get a scan every time.” [...] So from that standpoint, you know, I think he would listen—if I told him, “You need to get this checked out,” I think he would act a little bit quicker on that than he would a few other people.

Consistent with the literature on social support, top supporters often maintained roles in competition with other members of the YA survivor’s support network. At the

same time, these supporters acknowledged the difficulty in a single individual providing all of the support resources (i.e., logistical, financial, medical) necessary in a stressful situation. SNMs' narratives established that divergent support from multiple supporters was offered to YAs. Supporters also acknowledged consistent concerns with others in the network regarding jockeying for role position, authority, and responsibility. The nature and quality of this role jockeying took place over time.

“We’ve just figured out how to make it work for us”: **Role negotiated over time.** In most cases, SNMs' negotiations related to claiming and navigating support roles and domains occurred over time. YA survivors and their top supporter often reported experiencing a feeling out process that was necessary in determining and adjusting to their new roles. Infrequently, top supporters' roles were solidified by the filing of legal documentation. SNMs also received explicit statements from the survivor and other supporters that validated their place as top supporter.

“It was my job to make him feel better”: *Adjustments with survivor.* Following a YA's cancer diagnosis, top supporters often engaged in a gradual role adjustment with the survivor as they implicitly negotiated the ways that support should be offered within the relationship over time. At times, these adjustments took the form of role reversals, where the top supporter assumed the characteristics of the YA with cancer as they went through treatment. Kiki said that her attempts to fill in the gaps in their relationship that opened as Gunther progressed further into treatment led to feelings of burden:

I had to put my charm on to make him laugh [...] He's always the one who makes me laugh and who makes sure that I'm having a good time and that I'm having fun and that I'm happy. And because he was feeling so bad, it was my job to make him feel better, which I've never—I mean, that's not my job in our relationship. That's his job. So in addition to all

this other stuff—I'm not just physically taking care of him, taking him to stuff, but taking care of his psyche and making him feel better.

Not only did Kiki struggle with the loss of benefits that she received in her relationship with Gunther, but as top supporter she felt that she had to compensate for their absence. Gunther said that “things got strained” with Kiki, and that their dynamic changed “big time,” because he was usually “the one taking care of everything and now I can't do crap. So now she's in charge of *everything*, plus taking care of me.” Similarly, Charlotte's boyfriend and top supporter Geoff absorbed Charlotte's role of “being the planner” after she was diagnosed, which sometimes led to feelings of guilt and burden when he struggled to fulfill the role effectively:

A week and a half ago, it was Charlotte's birthday, and I planned all these things for her. She was neutropenic. I was an idiot and took her out to dinner in a public place. She spiked a fever that night, and then the next night she got admitted to the hospital. And actually, my roommate from D.C. and one of her friends from D.C. had come in town that weekend to visit for her birthday, and she had to go to the hospital, so that kinda sucked.

As top supporter, Delia assumed most of the financial responsibilities for her fiancé Jermaine during and following his treatment, which she believed led Jermaine to assume other duties:

I think that the other thing important to know is us figuring out our roles. His perceived role is, “Okay, I'm the man. I'm gonna provide.” And now that can't happen. And without us even really talking about it, he kinda stepped up in other ways. So he does most of the cleaning and the cooking [*laughs*]. And thank goodness, cuz I hate it all [*laughs*]. So we found out that we just had to make our life our own. And so he does a lot of the house stuff. He actually takes care of the budget. I pay the bills, but he made the budget. So we've just figured out how to make it work for us.

Despite Delia's support and Jermaine's belief that gender roles regarding “breadwinning” are an outdated sociocultural construct, Jermaine's upbringing and perception that he had

already served a similar role around the house before being diagnosed led him to find little fulfillment in his current situation:

As a man in this society you're taught to be the provider, you know? So even though we're part of the millennial age, we know that women have stronger roles now, like Delia's definitely the breadwinner. But at the same time—and I have no problem, like she made more money than me when I *was* workin', but that's not it though. And I tried to explain that to her. It's like, "The way I was brought up, from a man's perspective, like I need to be bringing *some*thin' to the table." And she's like, "Well, you help out at home." I'm like, "Shit, I was doin' that without you." So it's trying to figure that out, being that provider and being a manly man and whatnot.

In each of these examples, it is worth noting that role reversals led to relational strain between YAs with cancer and their YA romantic partner who had assumed top supporter responsibilities.

YA survivors and their top supporters also assumed roles that were less permanent during the cancer experience. In some cases, both parties took turns alternating support roles, which Molly's husband Clint described as a "mutual pick-each-other-up":

There were times when I felt overwhelmed just trying to manage everything, especially when Molly was struggling with the effects of the chemo. And then she would give me support then and kinda give me the "coach at halftime" speech. And I kinda did the same for her. Like I said, with the chemo, when you look at it, four months really isn't that long, but when you're going through it, especially early on, it seems like a long time. So I tried to do the same thing: "It's not that long. You're gonna be okay. We're gonna get through this. We're gonna go and we're gonna find a new normal and live our lives together."

Top supporters and YAs with cancer were also sometimes put in a position of having to mutually reassure each other that their new roles would not cause their relationship to crumble. Carrie felt that Brad's openness about his vulnerability in being

necessarily dependent upon her, and her own assurances that she would not abandon him, helped their relatively inexperienced relationship:

We were newly engaged. [...] He was shaky all the time. He felt unattractive. He was just always apologetic to me, like, “You shouldn’t have to do this.” It was very difficult for him at first lean on me as much as he was and to ask me to do things like to shave his head or to give him an enema or to clean up his vomit when he was too weak to get up off the bathroom floor or whatever it would be. But I think that our interaction and interplay with it made us closer because he was willing to open up to me about his feelings of being unattractive, or, you know, “Do you still wanna marry me? My body’s all screwed up and there’s no guarantees.” And I’m like, “Yeah, like I’m leaving,” you know, “Pssht, whatever.”

In YA survivor-top supporter relationships of all types, close SNMs reported struggling to implicitly negotiate with the survivor ways to provide support effectively without hovering. Several top supporters described this role adjustment as a “feeling-out process,” “trial and error,” and “walking a tightrope” between being effective in their support and being overbearing until they eventually “picked up a rhythm” with the survivor. Melanie described this negotiation with her YA daughter Jess:

[I had to rein] in the mother protectiveness and [try my] best to not be overprotective, which is somethin' that I have tried all their life to do. It's a balance that you never totally feel like you get. But I've always tried really hard to rein in the overprotectiveness in what I feel and what I do. And havin' her go through that you wanna just totally—and she's very independent, extremely independent. And so it was that fine balance between feelin' like I want to baby, but knowin' that she doesn't do well with that. So that part of it was hard. It was prob'ly a minute-by-minute [*laughs*] kinda balance beam walk... And we really haven't talked about this between us, but I'm not sure how she would see it. But things like when she would try to—she'd go to treatment herself, and I would just hafta back off and say, “Are you sure you feel like it?” “Yeah.” “Okay, then go.” When the mother in me is thinkin' I need to run her all these places. And I mean, I prob'ly said, “Are you sure you feel like that?” more than I prob'ly should of, but if she would say, “Yeah,” I think most of the time I would back off then. And sometimes I struck the right balance and I sometimes I didn't. I mean, because from a mother's standpoint, she's your baby, but yet she's a young adult. So it's hard to see your child go through this. And I think it's one of those things where if she went through it at 18

and younger, it woulda been different. But goin' through at 23, she's still my baby, but she's a young adult. So just learning to just step back, and so forth. So I don't know. I've tried to strike the right balance. Sometimes I felt like I was. Sometimes I didn't feel like I was. You always second-guess as a mother [*laughs*].

The experience of cancer necessarily involves an implicit role adjustment between YA survivors and their top supporters. However, these negotiations sometimes become explicit when documentation is filed that legally designates the top supporter within their role.

***“She didn’t have any rights”*: Legal documentation.** In many cases, unmarried YA survivors designated romantic partners as their top supporters by completing living wills and advance directives. Several YA survivors, like Graham, said that they signed power of attorney over to their romantic partners as a symbol of their trust and commitment above other supporters:

[Getting diagnosed] made me want more to be married because, as Lauren pointed out at the first diagnosis, that not being married, she didn’t have any rights as my spouse; that if something happened to me, they were not calling her, they were calling my mom probably. So we did a will and, um, I don’t know what the other document’s called, but if something were to happen and I am unable to make decisions for myself, she would get to make decisions. So we did do those and that eased some of that.

***“They didn’t realize how much I could do”*: Validating statements from others.**

Top supporter roles were also explicitly negotiated over time through validating statements, which were offered by YA survivors and other supporters to acknowledge and reinforce the abilities of the top supporter. Although many implicit role and domain dilemmas were discussed above, close SNMs and YA survivors did not report many explicit invalidating statements. However, top supporters did explain that validating statements helped them to feel secure in their place at the top of the support hierarchy.

Kiki claimed that Gunther's family told her when they saw the support that she offered to Gunther, "that's when they knew that I was gonna be there." Angie clarified this in her own account:

I didn't know what Kiki was made of. I knew Kiki just bein' his girlfriend from college. And so, I would say she really kinda stood up to the plate. She wanted to be with him through his chemo. She really wanted to take care of him. She was a huge support for him [...] I guess, you know, at that point then I really saw her love for my son.

Carrie was also more confident that her position as top supporter was appropriate when she sensed a less explicit, but validating gesture from her parents during one of her visits with her fiancé Brad:

My parents were super, super understanding and really gave us a lot of space during this. My parents are very, very traditional and the fact that we were not married, but like when we would come and visit and he was sick, he would stay in my room and they would not question that. I mean, obviously he's very, very sick, so it's not like we were having sex. But they just didn't judge or anything like that. They just gave us space to know that more so than anything else it was important that I just be there physically.

Top supporters also said that they received validating statements from the YA survivor and other supporters that helped them to feel more capable in fulfilling their support responsibilities. Sydney received validation from her husband Tim that she had made the correct treatment decisions for him while he was in a medically-induced coma:

I told Tim when he was coherent about all the decisions I had had to make. And wanted to know...[*crying*] if I ever have to make his decisions like that again, did I do what he wanted. And he said "Yes." So I wanted to validate that in case things got worse again and I had to make those decisions again.

Kiki was able to generate confidence through the receipt of validating statements from her parents, who also helped provide support to her boyfriend Gunther:

[My parents said] they didn't know that I had that kind of care and compassion in me [*laughs*], which is kind of awful because they're my parents. But I mean, I've never been in that situation. You have to do what you have to do, so I think they kind of finally realized—like that's the moment where you see your child as, "She's a grown up. She's taking care of this other person. She's dealing with these bills. She's dealing with the medication." It's like, "She's on her own and she gets it." And I think they were very, very proud of me too. So that feels good [...] They didn't realize how much I could do and how much I could take, you know, as far as like the pressure and everything.

In many cases, close SNMs explained that their top supporter roles and domains were negotiated with the YA survivor and other members of their support network over time. However, in fewer cases, close SNMs said that they experienced moments of clarity that helped them accept their new role.

“I didn't look back”: **Crystallizing moments.** Although most of the support dilemmas were negotiated explicitly and implicitly among supporters over time, some supporters reported “defining moments” where they suddenly realized that their existing support roles had been irrevocably altered. Although Kiki reported additional role conflicts later in the cancer trajectory, one of these moments that clarified support roles occurred for both her and Angie immediately following Gunther's orchiectomy:

I know [*laughs*] that it was hard for his mom—the surgery in January. He had gone under and everything and obviously he didn't have any clothes on [*laughs*]. His parents were with me while we were waiting during the surgery, which was about two hours or something. And obviously, we're all just freakin' out. Then the nurse came back and said, “Okay, he's done and he's getting ready to wake up. Do you wanna come back and help him get dressed?” And so I stood up and walked in there. And I guess [*laughs*] his mom had stood up and was like—and his dad like held her back down like, “No, no, no, no, no,” [*laughs*] and I guess she started crying, but I didn't know. I didn't look back. I just was worried about him, so I went in there to help him get dressed and everything and I guess [*laughs*] she's out in the waiting room crying. I never heard that story until more than a few months afterwards. So that was an interesting thing. Not that it's a battle between us, but it was hard, because I really wasn't his fiancé or wife or

anyone yet, but I was there, so it was my job and it was kind of like passing the torch, I guess [*laughs*].

While Kiki used the experience to validate her desire to be Gunther's top supporter, Angie felt that the moment served as a signpost that signaled her need to concede control to Kiki.

I wanted to step in and be mom. And I went to go help him get dressed, but I wasn't the person to help him get dressed. It was Kiki. And that was kind of like my eye-opening moment where, "Oh, there's another woman in his life now" [*laughs*]. I kind of at that point knew, you know, my role was different now. I was still his mom, but I had to take kind of a backseat. And I remember [my husband] even said, "It's time to take a step back," and so I did. I had to take a step back. And after that it was like trial and error. I would say, "Kiki, you want me to take him to chemo?" "No, I'm gonna take him to chemo." So I kinda learned, you know, just by offering to do things. I would say, "How about if I bring you guys dinner for next week?" "Okay. That'd be great." [...] I would have felt like my toes were stepped on if I let my ego hurt. But I think that's just a point we all get to as mothers, whether our child has cancer or not, we need to find that defining moment when we need to let 'em become men and grow up and step back a little. So that was my defining moment.

When supporters like Angie are not able to fulfill the roles, domains, and duties of top supporter, they often find other ways to provide support to the YA survivor.

“I think it really just disturbed him too much”: Secondary supporters find other ways to be supportive. As close SNMs assume the roles and duties of the top supporter, other members of the YA's support constellation must determine how they can contribute. As Graham notes, this process may be particularly difficult for those close SNMs who have ceded their top supporter role:

I think my mom felt kind of helpless because there's nothing that she could do. Even those small things that you can do to help somebody who has cancer, I think [my fiancé] Lauren had kinda filled that role as significant other replacing the mother. Not that she didn't like that, but she just wanted to be helpful and there weren't a lot of opportunities to be helpful.

After Angie's crystallizing moment where she realized that Kiki would be assuming top supporter duties, Angie described how she began to filter tasks that she had previously completed herself through Kiki:

There were a few times when I would go to the doctor with Gunther, but I did not go back. Just Kiki did. Only so there were not so many people back there. But I would send questions back. "Will you ask your doctor this? Will you ask your doctor that?" [...] So I did reach out through Kiki to the doctor to find out what we need to do to keep him safe.

In some cases, secondary supporters found opportunities to contribute when it became clear that the top supporter could not be, or chose not to be, involved in certain roles. Molly said that her husband Clint did a great job absorbing her household and childcare duties, but that "to be a stay-at-home-only dad" was "a little bit beyond his comfort zone." Clint described his feelings of comfort and disappointment after he and Molly asked her mom for reinforcement:

Molly's mom was really great about coming in and helping out over the weekends after Molly had chemo. So it was very daunting at first. Then as we got farther in, I think we were much better about planning around it and organizing and structuring. [...] I was talking with my mother-in-law, trying to get a little bit of help just to manage the household. It's weird to say, but in a way it was humiliating because it seems like I should be able to pitch in even for a week without too much trouble. But it was also reassuring that, you know, she was so close and available to come and help out.

While Jayden was helpful in assisting her mother Amber make a decision about not installing a port for her chemotherapy, she chose to recuse herself from any conversations about topics that she deemed to be more awkward in nature:

I know my dad helped my mom make decisions, but, you know, decisions that I didn't really wanna talk to her about. Like things that woulda been more uncomfortable for me to talk with her about [...] Things like having her breasts removed or just getting the tumor taken out. I mean, it's awkward when your mom's going through like breast cancer and talking about getting her ovaries taken out or talking about going through

menopause. I don't wanna hear about that. I don't wanna know these things necessarily. It's not somethin' that like interests me [*laughs*], I guess. Just things that are like, you know, "I really didn't wanna know that." Or like, "Too much information." Awkward situations like that. Like, "Mom, why are you being so hateful?" "Oh, well, I'm kinda going through menopause right now, so..." "Awesome! Like thanks for—I did not wanna know that." Oh, and my dad's like, "It's called chemopause." Like, "Thank you for that, Dad." So I feel like those are more like personal decisions between like them, because it probably like involves like their sex life, and things that I don't even wanna think about. So things I wouldn't wanna talk to her about, you know, he probably helped her make those decisions.

Stella said that a coworker whose husband was a YA testicular cancer survivor filled in for her husband Dave while he worked and as he was conspicuously absent for most of her chemotherapy treatments:

She went above and beyond and really like took care of me, because it was like she knew what to do [*laughs*], because her husband had been through it and she was there. And she would do everything from like—maybe she's just going to Target to go shopping, but she would stop by and pick me up because she wanted to make sure I got out of the house. Or she actually came to see me and sit with me through my chemo treatment, which even Dave wasn't able to do. I mean, he works a lot and he said at the time he had to work, but I think it really just disturbed him too much, because I am certain that his work would have let him take a few hours off [*laughs*] to go sit with his wife while she was at chemo. And I was starting in the morning and he didn't used to go to work until 4:00, so I'm sure they would have let him, but I think he couldn't do it [*laughs*], you know what I mean? I don't think that he was not trying to be supportive. I just don't think he could handle it. So Stacey kinda took over and she would come on her lunch break from work and sit with me for a little while and stuff. And she was always like, "Well what did you eat today?" you know and make sure I was being healthy and just always—if she was going to a movie she called and would get me to go with her.

Carrie also depended on other supporters to share information about her fiancé Brad when she could no longer do it.

I would count on my mom and his mom and even my friends to disseminate the information to everybody else. Sometimes I would talk to one person and say, "Here, spread the word to this group of people," or whatever it would be, because I'd be like, "I'm done. I don't want to talk

about it anymore.” They understood when I’ve had enough and I didn’t want to.

When close SNMs are not the YA survivor’s top supporter, they often negotiate new ways in which to provide support. In some cases, they filter requests through the top supporter, but they are also often able to assume roles and responsibilities that the top supporter cannot or does not want to fulfill.

“That Honestly Bothers Me More Than Anything Else”: Monitoring Ancillary Support

In keeping with the top supporter’s numerous roles, domains, and responsibilities, one of the key features of the YA survivor’s closest SNM is his or her perceived ability to monitor and comment on support attempts from other members of the YA survivor’s support constellation. Top supporters often felt that they had the right to evaluate others’ support as unhelpful to the survivor (or as threatening to their own primary supporter role) when it violated their expectations of effective support. These expectations included top supporters’ own opinions of what constituted ineffective support and also what they perceived their YA loved one found unhelpful themselves. Top supporters’ monitoring habits elicited criticisms of intended supporters’ presence based on their perceived closeness to the YA survivor, their ability to adhere to the top supporter’s schedule or spend an appropriate amount of time with the survivor, and the tone in which the supporter communicated their messages.

“You start questioning the ulterior motives”: Criticisms related to perceived closeness. Top supporters elicited complaints about support from people they believed were not close enough to the YA to offer appropriate or helpful assistance. In many cases, top supporters felt that individuals who maintained an ancillary relationship with

the YA were opportunistically taking advantage of the situation. Aaron became skeptical about the sincerity of potential supporters who suddenly re-emerged in his younger brother John's life after his diagnosis:

Do you ever notice when like—and this is terrible—but whenever there's a tragedy and specifically like when you're young and you're in high school or something and something tragic happens, like a car accident? But there's always people that kinda gravitate towards it? And it's like, you don't wanna look at 'em and go, "Are you really that hurt by it? Or are you just tryin' to kinda tag along for the attention or something?" I remember there was a couple of chicks that I hung out with at the time and one of John's ex-girlfriends at the time came out of the woodwork, started showin' up like, "Whatever you need." Which was great, everybody all enthused. But it was almost like it was being used as a springboard to kinda get back into his life in a way. And John was like, "No offense, but I'm not tryin' to—" you know what I mean? I don't know if it's like driving past a crash scene and you can't do anything but stare at it kinda thing, that mentality. But there were a few people that were just like—and I'd say it was probably people that we didn't tell, because it never dawned on us that it would affect them or anything. But it was almost always just like, "Really? Okay, well thank you for your concern, but I had no idea that it—" you know? So I kinda feel bad sayin' that about people, but I mean it was kind of that phenomenon, you know, where you just see people affected by it that in a million years you'd never dream. And it was probably, I figure now, because I see things today and they usually affect me, and I have no attachment at all to it. But you still feel for people. So it may be kinda overly harsh, but [*laughs*] at the time I was like, "Well, wait a minute, why are you *really* that concerned?" You start questioning kinda the ulterior motives, which is weird.

Delia also struggled to make sense of the sudden re-appearance of one of her boyfriend Jermaine's ex-girlfriends. Although she wanted Jermaine to be able to receive positive support from others, Delia was uncertain about the ex's intentions:

Jermaine had an ex-girlfriend that found out that he was—now keep in mind, we're not engaged or anything. We're just dating. And I remember she wanted to come visit him. And my logical side says, "You don't know what's gonna happen to this man. Don't be mean." Then, I'm like, "No [*laughs*], no, just no." So I felt really bad about that, but at the same time, I'm like, "Hey, if this is the worst I can do." But I remember she brought like art supplies and stuff for him cuz he was in the hospital for a month. And she sent it through a friend. It was like art supplies and she makes

wine. Who makes wine, anyway [*laughs*]? But she brought him a bottle of wine. And I remember thinking like “Good intentions. She does have good intentions. I don’t think she’s tryin’ to steal my man right now, but I don’t like it.” And then I felt bad. That’s awkward for Jermaine.

Several of Josie’s family members, including her older sister Lucy, were critical about the suffocating and inappropriate involvement of their mother’s co-worker, who had only met Josie twice before she became sick:

As soon as Josie got sick, my mom’s co-worker was all of sudden like so interested, like “Oh, like let me take you out to dinner. Let me take you to get your nails done.” She’s probably bought Josie like *hundreds* of dollars worth of gifts. It’s insane. But I think my family and I all kinda felt smothered by her when she showed up at Josie’s first chemo. We didn’t even have close family friends there. I mean, it’s just kind of really personal. We had too many people in the room—my dad actually went to the waiting room cuz my mom’s co-worker was there. And we really would’ve liked to have our actual family members there, or maybe people that have actually been like supporting Josie for years, not just when she got sick. My mom was like, “Oh, she’s going through a divorce. She just wants something to keep her busy.” And my dad was like, “Well, not my 18-year-old daughter with cancer. Like she needs to find something else.” People that suddenly take an interest cuz she’s sick, that honestly bothers me more than anything else cuz I don’t want people to take advantage of her.

Aaron was surprised that several of John’s acquaintances (“friends of friends or siblings of friends”) attempted to offer support to him and his brother despite lacking several pieces of crucial information:

I mean a couple of ‘em still think John’s sick. I mean, even until this day, when they see him, “Man, how you doin’?” And I mean, they’re concerned and it’s good to notice, but it’s like, “Yeah, hey, it’s gone. You know, and it hasn’t come back and every day it’s not back is awesome.” But there was a couple people that did that. And there was a couple people too who literally thought—they’d get us mixed up. And so I’d see ‘em and they’d be like, “Man, how you doin’?” And I’m like, “Man, I’m fine [*laughs*]. I’m not the one healin’.” So I mean it wasn’t like they treated you different in a bad way. I mean, they were concerned. And at the same time it was like, “At least get your facts straight if you’re gonna be that concerned about it.”

In some situations, top supporters were faced with the sudden re-emergence of people with whom the YA was not only distant, but had a troubled relationship. Geoff mentioned that his girlfriend Charlotte's father, with whom she had not talked in eight years, tried to get back into her life after learning that she was receiving inpatient treatment. Security measures were put in place because he was trying to visit her in the hospital, and Geoff said that it was "a bit much" for Charlotte to deal with as she was going through chemotherapy. In other cases, however, top supporters were critical of individuals that they considered to be close enough to the YA to offer their support.

"I'll see you when I see you": Criticisms related to time spent, presence, and schedule. Top supporters were critical of other close SNMs for the time that they spent, or did not spend, supporting the survivor. First, other SNMs were targeted when top supporters believed they were not sufficiently reaching out to, or spending enough time with, the survivor. Delia was initially confused and angered by the absence of her fiancé Jermaine's family, largely because it contrasted with her relationship with her own family and because she was tasked with finding the means by which to compensate for their lack of support:

Jermaine was not as close to his family as I am. I'm very close to my family. And thank goodness because we were here and my family helped a lot with the balance of everything. But I was angry at that a little bit cuz I'm like, "I'm trying to figure out how to manage this, and I could use their help." But they did not come, not once. His mom never came ever, not once, which was bizarre to me cuz if I have a flu [*laughs*], you know, my mom's gonna come. [...] So if you would've asked me back then, I [*laughs*] wouldn't say they were horrible people, but I probably wouldn't have had the most positive outlook. But honestly, now, and I've gotten to know them a lot more after we're married, I think that they just honestly didn't know how to deal. And Jermaine, he comes from the hood of Chicago, okay? Very low income—his family, both his parents have been on drugs before. And he is the one who made it out of the hood. And he is the one who went to college, and got a degree, and moved away, and has

done all these fantastic things. And to them, he's the hero. To them, he's the person that's larger than life. And so I really believe that when this happened to them, to him, they didn't know how to process that. And I don't think that his mom was prepared to see him like that. And she called all the time to check on him. But to me, having my experience with my family, I'm like, "What do you mean you haven't been here yet? Like this is just bizarre."

Top supporters who were home-bound with their romantic partner during their treatment were also critical when they felt that their YA friends began to "fall off the map." Carrie described the experience of hosting visibly uneasy YA visitors with her fiancé Brad, only to have them not return:

There were people who would kind of come over and eh-h-h-h, you know, they were uncomfortable with it, and they didn't want to stay very long. There would be times where it was very uncomfortable for people. I mean, he would get up and just throw up in the middle of when people were visiting, or he knew you'd have to tell people, like, "It was good to see you, but, you know, you gotta go, because he's just not feeling up for company right now." And some people deal really well with that and other people run away from it, or they'll say, like, "Hey, I made my token visit, and now I'll see you when I see you." So I think some people kind of fell off the face of the face of the earth for us for a little while.

Lauren also became frustrated by the self-serving priorities that she noticed within her and her fiancé Graham's group of friends:

Once Graham got sick and he couldn't go anywhere, and he couldn't do anything, and nobody would come over. And I was just super pissed that nobody wanted to break the ice or whatever and reach out to us, because we were very lonely [...] [At that age] you just wanna go out to your bars or whatever and not be bummed out because Graham has to wear gloves all the time [*laughs*] and doesn't have any hair. This is just me guessing, but if they were people with kids or a little bit older that they would've slowed down their lives already a little bit. But now people are just hustlin' and bustlin' all over the place and involved in a million things.

In some cases, committed supporters became jealous of the time certain SNMs were able to spend with the YA. Eva's parents owned their own business in a different city. Her mom typically stayed home to look after it, and she became frustrated when her

husband, who had been staying with Eva and her older sister Marie, would not give her the chance to play a larger support role:

My mom would get mad that my dad was always down here and she would wanna switch roles, and my dad would be like, “No, I wanna be down here,” because he just really wanted to be here. I think that was probably a bit of a conflict between my parents.

Other top supporters received plenty of assistance from the YA’s other close SNMs. However, Kiki’s insistence on maintaining an element of control in coping with her boyfriend Gunther’s cancer treatment caused her to be critical of Gunther’s family when they did not provide support that was consistent with her schedule:

[Gunther’s family] would decide that they were gonna take him to treatment, or they were gonna pick him up, but they didn’t tell me. And it’s like, “I have a schedule, because I’m also working. So I need to know what’s going on. And no, like, you’re right, I don’t need to micromanage it all, but it would be nice to know like, hey, you’re available, hey, you wanna do this. Like, fine, then let me tell you or you know, mark down when you’re gonna do it.” So they would just like randomly pop in. I’m obviously, as you can tell from this interview, I’m very Type A. I like things that were per my schedule [*laughs*], and they would just...kinda throw stuff in. Or like they would bring dinner and I would be mad. Not because it was dinner, just because I didn’t schedule for it. Like I had already bought food, so now that food is gonna go to waste, because he’s already not eating what he used to eat. So I’m like already buying too much and, you know, just—obviously none of that matters now, and none of it should have mattered at the time, but those were the things—like you only have so much control during that time that you wanna control those things that you *can* control.

While some top supporters were critical of ancillary SNMs’ support attempts that violated their expectations of helpfulness according to timing, others expressed frustration with support that they perceived to be unhelpful or inappropriate according to its tone.

“It’s not a celebration”: Criticisms related to tone of support. Top supporters were also critical of support attempts from other close SNMs that violated their

expectations of the tone that helpful or appropriate forms of support should evoke. A large amount of hostility was reserved for support attempts that the person at the top of the YA's hierarchy deemed to be overly fearful and maudlin. For example, Jayden was frustrated by her grandmother's outdated association of cancer as a "death sentence," which was not consistent with Jayden's mother's prognosis:

Bless her heart. She tries. But she just doesn't understand. Like she just thinks the worst is gonna happen, you know? [...] And she would try to be really supportive, but she just doesn't know anything about this. To her, everyone dies from cancer. She grew up when there wasn't chemo and there wasn't all these things that can help reduce their death rate and...she just did not understand. Like to her, my mom was dying. That's like case closed, my mom was dying. And to this day, she'll call me like once a week and every once in awhile she'll be like, "How's your mom doin'?" I'm like, "Grandma, why don't you call her yourself? Like call her and ask her." And she's like, "Well, she doesn't wanna talk to me," and I'd be like, "No! She probably doesn't! Because you'll probably be like, 'Oh, like [laughs] are you still alive?!'"

Lauren was also peeved by her fiancé Graham's mother's attempts to offer support that were overpowered by her sadness:

Graham's mom cried and cried [...] She was talking about how she had told some people that she'd been crying and whatever. And I was just kinda like, I don't know, it really annoyed me that she was so sad about it, and then just wanted to tell us how sad she was.

As top supporter, Jayden believed that her mother Amber appreciated her use of humor to lighten the mood surrounding Amber's breast cancer, particularly when they decided together that they should name Amber's wig after a Yorkshire terrier that the family had always wanted to adopt. However, Jayden expressed frustration when her father (Amber's husband) did not allow them to approach the situation with a lighter tone:

My dad was not receptive to that at all. He was very like, "We should not be joking around about this." And I'm just dying laughing thinking about naming—my mom was like, "What should we name her?" And I'm like, "Fiona, duh." I guess we dealt with it a lot more by laughing about it and

not being upset. It was easier for me to laugh about it around my mom than cry cuz she was the one that was like going through it and the one that was so upset. And so if we could just laugh once, it would—and my dad was like, “No. You’re not. No. Do not laugh about this.”

However, in some cases, top supporters complained that others’ attempts to reach out to the YA lacked a sense of respect for the situation. For example, Josie’s older sister Lucy said that people came to their family’s house “with all these gifts,” almost as if it was “a birthday party” and not a circumstance in which an 18 year old was going through treatment for Hodgkin’s lymphoma. She also pointed out that the wasteful nature of the gifts purchased for Josie did not help matters:

It’s like, “She has cancer, you know? It’s not like a celebration.” I think actually when Josie first got sick, she accumulated like 20 stuffed animals and blankets in like a week, just like random. And it’s like, “What do we do with all this stuff?” And then my dad said one of his coworkers gave him a gas card and he was like, “I know you guys are gonna be driving to a lot of doctor’s appointments. And he was like, “I really appreciate stuff like that. Not like the 20th teddy bear that’s gonna probably be ripped up by Josie’s dog.

When support attempts were perceived by the top SNM to be inappropriate or unhelpful in terms of the sender’s level of closeness to the YA, the time spent with the YA, and the tone of the message, the top supporter sometimes acted on their monitoring role to perform duties related to gatekeeping.

“I Would be Very Defensive”: Support Gatekeeping

Sometimes when support attempts offered from secondary sources were evaluated by the top supporter as ineffective or unhelpful to the YA survivor (or threatening to the top supporter’s role as the primary contact within the survivor’s network), the top supporter acted to serve as a support gatekeeper. Gatekeeping involved protective buffering, where intended supporters were not granted access to the support network

from the beginning, they were completely “cut out” of the support network by the top supporter, or their support attempts were corrected and reframed to be more consistent with what the top supporter perceived as more helpful to YA survivor. Additionally, when the top supporter viewed the YA survivor’s available positive support to be lacking, they sometimes created opportunities for new or existing supporters to rally around the YA. The amount and type of support that was invited in or kept out may have also been determined by the stage at which the YA was located along the cancer trajectory.

“Don’t tell him anything about it”: Not inviting others’ support. In an attempt to protect the YA from receiving potentially negative support in the first place, top supporters sometimes did not go about inviting the support of other SNMs. In some cases, this involved efforts to keep the YA’s diagnosis a secret. Jayden attempted to keep her grandfather (Amber’s father) out of the loop because she knew that Amber and her father did not have a great relationship and that he would have been overly concerned about what she was going through.

It was like a big deal keeping it from him, just because they came over to our house all the time. My grandmother would have to call to make sure Mom was ready or had her wig on and everything. And they were literally at our house once or twice a week. And then I started going there more so they wouldn’t come to our house as much, so my mom didn’t have to like hide so much. And my grandpa would just be like, “Well like why didn’t your mom come with you?” I’d be like, “Oh, uh, you know, she’s cleaning the house.” Or like, “Oh, like she—her and dad went to the grocery store.” Just different things to try to not let him catch on. And he never did [laughs]. So it’s always like really weird to be like, “Oh, don’t tell him anything about it.” Like all my aunts knew. They like knew not to tell him too.

However, when SNMs were already aware of the YA’s diagnosis, top supporters sometimes chose to go about removing them from the network or correcting and reframing their support as much as possible.

“If you don’t like it, walk away or don’t listen”: Cutting supporters out of the loop. If other supporters violated the top supporter’s perception of what constituted effective or appropriate support for the survivor, the top supporter sometimes exercised their gatekeeping responsibilities by removing the intended supporter from the network to the extent that they could. For example, Aaron said that his younger brother John initially “set the tone” for what he wanted his support to be, and Aaron believed his role as top supporter was to ensure that others adhered to his brother’s preferences. Aaron chose to keep significant information from poor supporters by feeding them with clichéd responses to their inquiries about John’s health:

The only thing John said was, “I don’t wanna hear any negative or bad stories.” And that’s where he would draw the line. And I’m like, “Alright. If this person’s gonna be negative, I don’t want ‘em around. I’ll talk to ‘em when we’re done.” And that was kind of like the demarcation line of like, “Alright, here’s the people that we wanna keep in the loop, keep operating with, some of those people that are positive in their outlook and optimistic.” [...] So this guy was in our fraternity and we played football with him. He was like, “Oh, yeah, a friend of mine had cancer.” And we were like, “Oh! This is good.” And this was early on. He was like, “Yeah, he died.” We’re like, “Oh. Okay [*laughs*]. Alright, well, I’ll go look for other assurances from other people” [*laughs*]. He consciously wasn’t being selfish and not trying to not be supportive. I don’t think he meant to. But I didn’t go to him with anything [*laughs*]. You know, after that it was pretty much the cookie cutter answer: “How’s your brother?” “Oh, he’s doin’ good. He’s hangin’ in there and, you know, he’s doin’ the best he can under the circumstances,” you know, all that bullshit.

Dave and Kiki felt that the status they had earned as Stella and Gunther’s top supporters, respectively, afforded them the right to support their partners however they saw fit. As a result, when Dave used humor to explain Stella’s cancer experience in public, and others were critical of his choices, he felt that he reserved the right to shut down the conversation and at least temporarily remove them from the support network:

Some people are just like, “Oh my God, how can you make such light of it?” It’s like, “Well you weren’t the one who was holding her, or rubbing her bald freaking, sweating head while she was puking her fucking guts out for six hours last night. So if I wanna make fun of her right now, and we wanna make fun of each other, go ahead and share your opinion with somebody else. We’re gonna do that.” So there were times when our approach wasn’t appreciated by other people, but quite frankly other people weren’t the ones who were going through it, so “If you don’t like it, walk away or don’t listen.”

“Okay, let’s keep it positive”: Helping the survivor manage other SNMs.

Another gatekeeping approach taken by top supporters was to redirect or correct others’ support attempts to align them more closely with the YA’s or top supporter’s preferences. Similar to Aaron’s enforcement of John’s support preferences, Kendra was protective of her older sister Bailey’s wish that other supporters be positive. While Aaron refrained from providing support violators with additional information from that point forward, Kendra worked to “nip it in the bud” by correcting or reframing the supporter’s attempts according to her sister’s wishes:

I was in a very selfish time of my life back then, um, young, stupid. But I do remember being an advocate for keeping peoples’ mouths shut. If I heard anyone say anything negative, I’d stop them right then, even if it was something that was meant well. Like, “Oh, Kendra, oh, I’m so worried.” I would say, “Stop. She doesn’t want your worry. Be positive. I want you to speak positive words. Switch that around.” I was kind of her voice outside of wherever she was, telling people, “Nuh uh.” Like they would come up to me and be like, “Oh, I hope Bailey’s, you know, is she okay?” I’m like, “Okay, let’s keep it positive,” you know, I would just redirect the conversation and keep it positive.

Marie was also protective of her younger sister Eva. Although Marie often voiced her appreciation for her parents’ assistance in supporting Eva due to her lack of confidence in doing so by herself, Marie still felt it was within her rights to chastise her parents for their behavior when she felt that they were detracting from Eva’s support:

[My parents] would do certain things and it would always bother me. I would be very defensive of Eva and confrontational with my parents. If I didn't like what they were doing, I told them right away. And my mom didn't like that. She was mad at me most of the time. So when Eva was first sick and the hospital, she would be sleeping all the time. And my mom would be in the room talking on her cell phone. And it used to drive me nuts. Cuz I was like, "Well, she's sleeping. Why are you gonna sit there and talk on the cell phone? Especially when you're not even supposed to talk on your cell phone in the rooms?" Like go to the waiting room and do it. And so like if I would shoosh her or tell her to leave, she would get really upset with me.

As the person closest to her older sister Ann, April felt that her role was to serve as "mediator" between Ann and the rest of her support network. This required April to gauge Ann's emotional and physical needs and use that information to dictate what type of support that Ann could potentially receive from her immediate family and friends:

My dad is more of a doer. Like, "Okay, we need to eat lunch. What do you want for lunch? We need breakfast. What do you want for—?" And my mom is more of the like, "Are you okay? Look I got you magazines," and stuff like that. And I was kind of the one that was trying to judge how Ann was feeling or what she needed and then was like, "Okay family, we're doing this." Tryin' to just keep it all flowing for everybody and keep it simple and happy and stuff like that. [...] And then some of Ann's friends specifically from college wanted to go out and do things. And I'm like, "She doesn't have the energy to do that. She doesn't feel like going out [*laughs*]. Just come over and watch a movie or something." So I was glad that I was there, and some friends did that.

Top supporters did not only remove or reframe others' support when they perceived it to be negative. In some cases, they invited other SNMs into the support network or created opportunities for additional positive forms of support to reach the YA.

"You have to try to put some happiness in it somewhere": Inviting positive support. Top supporters also sought to compensate for a perceived lack of positive support by creating opportunities for others to increase their presence. Kiki attempted to

combat her boyfriend Gunther's self-imposed isolation as he progressed further through treatment by asking their mutual friends to reach out to him:

By the second round of treatment Gunther was really...um...out of it...and sad and I thought that he was lonely. So at that point I told a couple of our really, really close friends, I mean, his best friends, what was going on and that he could use, you know, a pick me up or something like that [...] And then at some point Gunther realized that I was the one who told them. He was like, "Why would you tell them that?" I'm like, "Because you're so sad right now! You are just, you're stuck. You're not talking to anyone, you're not doing anything." So at the time, like, I can see that he was glad that they called, but then he was mad that I told them. So I mean that was a weird thing to deal with.

Top supporters who were also the YA's primary source of income often invited others to provide assistance when they could not get out of work. YA top supporters struggled to balance their work and support duties effectively because they did not yet have an established career. When the rest of the YA's main support network was geographically scattered, the top supporter typically reached out to individuals who likely would have otherwise not been as heavily involved in the YA's support. For example, top supporters like Carrie asked their own family members and corralled some of the YA's friends or acquaintances to help take the YA to appointments and treatments and sit with them at home during the day.

I was in my first job out of college, so I didn't have like years of experience behind me to say, "Hey, I'm going to take all this time off and take care of a loved one." [...] I was really kind of big into trying to stay with him during chemotherapy just because it's so sad and it's not like they had separate rooms for like the elderly and like the young patients or anything. I mean, so you see these like terminally ill, like very old—like they looked dead in their chair as they're getting their chemotherapy and there's Brad trying to be positive and trying all this stuff. So I just didn't like to leave him there. So we asked *anybody* and *everybody* who could help in any way. People from our church, people from his class, neighbors, friends, anybody who's visiting family members, anybody.

YAs also often turned to their closest SNM to disseminate information to other supporters. By keeping others within the YA's support network up to date about how the YA was doing, top supporters simultaneously provided opportunities for the YA to receive positive support in return. In order to keep their communication labor to a minimum (i.e., not having to update each ancillary supporter individually), the top supporter often solicited support by setting up Facebook pages, email chains, and CaringBridge journal accounts. These online outlets sometimes allowed for supportive feedback from others. Lauren set up an email chain and encouraged Graham's ancillary supporters to send him funny pictures or website links that would keep him occupied while he was isolated during treatment. Sydney also invited support by posting on online forums in which her husband Tim had previously participated:

I went on to a couple of those places that I knew he was very active and shared with them that he was in the hospital and that this was going on and here's his Facebook page. And on the mountain biking forum, this thread that I started turned into a...I don't know how many page-long thread that went on, the entire course that he was getting chemo. And when he finally came out of it and was able to get back on the computer and stuff, he read pages, and pages, and pages from people he's never met before in his life saying, "Keep up the good fight. Keep going." And through that route, we started making an online friendship with another couple who are in their 40s or 50s. They might be around our parents' age. This guy is a mountain biker on this forum, and his wife was going through chemo. And she ended up having a bone marrow transplant like a year ago. And so we've talked more and more to them.

Kathy also used online outlets to solicit tangible support for her daughter Kelly:

The wig she wanted was \$1400 [*laughs*]. That's like, "If that's the wig you want, that's the wig you'll get." And of course, insurance doesn't cover all that. They give you like \$200. So I actually put it on CaringBridge. And I told people, "Hey, Kelly got fitted for a \$1400 wig, if anybody wants to make a donation." So I had people at work, you know, "Here's \$20, here's \$100." I mean, I got like \$800 from people I work with for her wig. And I wasn't afraid to say that, cuz it's like, well—people kept saying, "What can I do to help?" "Here's what you can do.

My daughter wants this \$1400 wig. Make a contribution.” And other people, like a girl we used to work with, sent Kelly an iPad. Yeah, “Here you go.” Which was something for her to do and pass the time when you’re sitting at chemo for four hours.

Top supporters also created opportunities for others’ increased involvement that helped to dictate the tone of the support provided to YAs. Lauren shared accessories with humorous cancer slogans as a vehicle by which others could rally around Graham’s testicular cancer:

Last year for Christmas we got everyone “Feel My Balls” bracelets cuz we thought it was pretty funny. And I don’t know, I guess it was like an easy way to acknowledge everything that was happening without making everyone focus on the sad and the bad part. Graham’s family didn’t seem to love it quite so much. But my mom took one and put it on her keychain and stuff [*laughs*]. So I think even though it was kinda silly or whatever they were proud to be supporting Graham [...] It gave people something tangible to prove they were so proud of Graham and supporting him and stuff.

Other top supporters invited additional opportunities for positive support and dictated the tone of the support offered to the YA by throwing lighthearted hat, scarf, and bra parties and commemorating events related to the YA’s final chemotherapy treatment. One common type of gathering organized by the top supporter to invite positive support for the YA survivor was hair cutting parties. Clint said that he invited his wife Molly’s friends over to the house while her hairdresser “cut shapes and Mohawks” in Molly’s hair because he wanted the party to help her realize that their circumstances were temporary: “The hair’s gonna grow back, and here’s a reminder that it was a tough situation, but it’s not something that we can’t overcome.” Kathy said that she hosted a similar event to invite positive support at a time that could have otherwise been more upsetting to her daughter Kelly:

When Kelly had to have her head shaved, my hairdresser, who is also my friend, came here. We're out on the back patio. We were having some wine. And we tried to make that, instead of a gloomy, depressive moment—even though it was, I know it was, Kelly knows it was, it was very upsetting to my husband—we tried to make it an enlightening, fun—have a glass of wine, we're outside, it's a nice summer night, we were laughing. You know, life goes on. You have to try to put some happiness in it somewhere, if you can find a way to do that.

YAs were also the recipients of support from their friends with medical experience after top supporters reached out to them. Lauren contacted a friend from college who was training to become a urologist. She explained why asking him to help her fiancé Graham translate medical information and navigate the healthcare system was a helpful form of solicited support:

I feel like with your doctor there's always a certain standard of composure in the way they hafta act. And they can't tell you what they really think. And even if they tell you what they really think, it still sounds like they're just being really detached or whatever. So having our friends who know us and really care about us as people and whatever, explaining things and giving advice if they could make it a little less clinical or whatever and a little easier to digest.

When top supporters believed that their YA loved one lacked helpful support, they sometimes exercised their gatekeeping role to create opportunities for others to provide positive support. In other cases, top supporters acted on behalf of the YA to manage healthcare providers.

“That doctor came in the room, and I let loose on him”: Managing healthcare providers. Top supporters also employed gatekeeping by managing their YA loved one's medical providers in an attempt to improve the care provided to them. Kiki needed to push back on hospital administrators to secure her boyfriend Gunther's nausea medicine:

The hospital lost all of his insurance information in the middle of a—it was like the *third* day of a five day treatment and you're just supposed to take like the last pill and they like didn't have it. I mean, "Are you kidding me? We've been coming here—you know who we are!" And they're like, "Yeah, you're not in the system." I was like, "GIVE ME SOMETHING!" [laughs]. They actually just gave it to me. They were like [scared], "Okay, here you go! Here's like a sample pack!" And I was like, "Thank you" [laughs].

Sydney explained how she permanently corrected the habits of her husband Tim's intensive care unit (ICU) practitioners after she demanded that they improve their vigilance in providing him care:

Every week in the ICU, the doctors would rotate to a different ICU bed area. And the last ICU doctor he had—this was when they were waking him up from his sedation in the morning. And they would do that every morning. And he would wake up, and he would be very agitated. And he didn't know what was going on. He didn't remember what was happening to him. And I knew that if I was there or his mom was there when they woke him up, he would be okay. But if one of us wasn't there, he would start flipping out. And so I told the nurses and the doctors in the ICU that I didn't want them turning off his sedation until visiting hours had started and we could be in the room with him when he did it. And this doctor didn't follow my request one morning, and he was flipping out. By the time I got in there to see him, he was already awake. His hands were strapped down because they couldn't make him stop trying to tear at his tubes and everything. And he was writhing around in his bed, and he had had diarrhea all over in his bed. And he was messed in it, and they hadn't cleaned him up. It was all because he was so anxious because he didn't know what was going on. He didn't remember what was happening to him. And that doctor came in the room, and I let loose on him. I was so angry that she did that. "I told you guys not to wake him up until we're here!" And she's trying to give me all these excuses about why they did it when they did. And I didn't wanna hear it. And then the nurse comes in and says—you know, he's messed all in his bed and says, "How long has he been like this, with this mess?" And I looked at her and I blew up at her too. Because I was like, "What are you asking me this for? I got here five minutes ago. You people should know how long he's been like this in his bed, and he shouldn't be like this very long." I was angry that morning. It took a lot for me to calm down. And actually, Nate's mom and dad and my mom were the ones that had to calm me down and pull me away and be like, "You need to...just sit back for a minute." But they never woke him up after that again without me or his mom there. I can't imagine what it was like for him. Here he is, all groggy, incoherent, in this drug-induced

coma, and they turn off his drugs, and he slowly wakes up, and he's in unfamiliar surroundings, and he's hallucinating, and he doesn't know the people around him, "Oh my God, what's happened to me? I have tubes everywhere." I don't know what's going through his mind. And he told me he didn't remember. Each of those times they woke him up, he really didn't remember what was happening. So every time you wake up and someone tells you you have leukemia, you live through that again every single time. So I was really mad that day *[laughs]*.

Not only did those who were appointed as the YA's closest SNM feel that their top supporter role included monitoring and commenting on others' support, but they also frequently exercised their perceived gatekeeping responsibilities to limit the amount of negative support and increase the amount of positive support received by the YA.

The ways in which individual supporters worked on behalf of YA cancer survivors to jockey roles, monitor, and blunt or invite others' social support is understandable given the discernible difference YAs expressed between the helpful and unhelpful, effective and ineffective forms of support detailed in Theme 1. While YA survivors appreciated forms of support that encouraged their normality, many intended supporters lacked an understanding of why and how to properly offer that to them. Beyond the normative dimensions of YAs' perceived social support, Theme 2 suggests that YA cancer survivors' top supporters were acutely aware of ancillary supporters' social support attempts that may be more or less valuable to their loved ones with cancer. After negotiating their roles and domains with other members of the YA's support network, top supporters felt that they were in a position to comment on others' support attempts based on their perception of other supporters' level of relational closeness to the YA and the timing and tone of the support messages. To compensate for these perceived support disparities, the YA's closest SNM sometimes blocked out and reframed negative support and invited opportunities for positive support into the YA's network. However,

support within the YA-top supporter relationship itself sometimes featured a unique dimension. In an attempt to protect both parties from experiencing additional burden, YA survivors and their top SNMs often managed their negative emotions and concealed potentially distressing information from their dyadic partner, which had a host of positive and negative ramifications in their relationship. In other words, by further examining the relational communication between YA cancer survivors and their loved ones from a dyadic perspective, which allows for the emergence of three distinct perspectives, YA survivors', their close SNMs', and the dyad's narratives evidenced how support often developed against a backdrop of mutual pretense and putative protection.

Theme Three: Mutual Pretense and Putative Protection

In their narrative accounts of the illness experience, many YA survivors and their close SNMs reported that they remained honest with one another as they progressed through treatment and survivorship. Both parties also believed that their ability to maintain open communication throughout the cancer trajectory functioned as an effective form of support between them. For example, Delia stated that her ability to discuss difficult topics with her fiancé Jermaine helped them to remain close during their cancer experience:

Jermaine and I are very good about talking. We are best friends. We talk about everything. We talk about stuff for hours. So just talking it through and just trying to be—he really tries to think through “What’s the best way I can approach these different conversations with her.” And he puts a lot of thought into it. Difficult things like sex, or I don’t know, having kids. But we just talk about it. That’s the biggest thing. And that’s really the best thing I can say is the communication. Just being as open as we can be, even when things get difficult. And like just trying to be open, talk it through, even if it’s uncomfortable. I think that’s the biggest thing.

In addition, YA survivors and their close SNMs often recommended that others going through similar experiences also discuss their situation openly. Angie believed that keeping communication lines open between supporters and YA survivors facilitates empathy and a mutual understanding among the involved parties:

You gotta talk about it. And even if they don't want to at first, eventually they will open up and talk about it. But I think the best thing to do is talk about it. Don't try to harbor what's goin' on. Don't try to cover it up. I think it's better just to let people know because then that's when you find out other people's experiences. And then it becomes like a community, and their experiences can help you, and maybe your experience can help somebody else.

However, despite claims regarding dyads' tendency to remain open and honest in their communication, a more frequently-mentioned means of support employed both by YA survivors and their close SNMs was mutual pretense. Mutual pretense occurred when both parties, in an effort to support one another and to promote normalcy within the relationship, attempted to hide their negative emotions by adopting a positive, strong, or brave face. In most cases, this form of face management was a way in which SNMs and their YA loved ones remained "open" without actually being open. For example, supporters like Jayden attempted to protect their YA loved ones from experiencing additional negative feelings by masking their own fear and sadness in order to remain positive at all times:

You cannot let them see you upset. Cuz when they see you upset, it makes them more upset. And like a positive outlook is what's gonna like help them get through more than anything. If they think they're gonna die, it hurts their chances of survival even more. Just bein' like depressed and things like that don't help. So I was like, "Okay, well Mom has cancer, so let's put a smile on her face." She never saw me cry about it. Never. I was kinda like the positive reinforcement like, "Mom, don't be sad. You're fine and you're gonna be okay. Like think of all the cool things you can do."

Stella also said that Dave remained convincingly positive during an experience that she later learned was considerably difficult for both of them:

I got this cute short haircut, which I had for a couple weeks before my hair fell out [*laughs*]. It was getting kinda thin and there were bald patches, and then finally I came out of the shower one day and most of the hair had washed out. It was just like little patches and I looked like a freak. So Dave was like, “We’re gonna have to shave it.” I was like, “Nooo.” So he had to shave my head. And I was crying, “This is terrible.” I looked in the mirror and saw this bald thing and I looked like an alien [*laughs*]. I looked up and it was just like tears, you know? And Dave was smiling and was kinda jovial through it. But later he was like, “Ahh,” that was like the hardest thing for him ever, you know, but he tried to just keep a straight face. And then later he was sad about it or whatever, but he always tried to be positive for me, I guess.

In supporters’ attempts to remain positive, they often chose to avoid discussing subjects that could potentially upset their YA loved one. For example, Dave said that he never told his wife Stella that the information they had recently received about Stella’s genetic predisposition to breast cancer has caused him to second guess their decision to proceed with a lumpectomy instead of a double mastectomy:

I think about that all the time, as a matter of fact. I would never let Stella know that I think about that all the time, but sure, I often wonder like, “Pfft, now that we know it’s genetic, would we have gone with the mastectomy?” So I hope that she’s not double guessing or even thinking twice about that, but I’m sure she is, you know. And that’s one of the things you don’t need to bring up things, the “What-ifs” and the “Oh my God” and the worst case scenario. Fuck that. We’ve already been through, “Yeah, if it happens, it happens. We’ll deal with it. Welcome to the rest of your life. And as it stands right now, it’s 100 percent cancer free.” So the things that you avoid are things that can be emotionally upsetting, especially any kind of negativity or any kind of criticism. There’s really no point in having any kind of confrontation whatsoever. It’s like, “Yeah, we’ve got bigger fish to fry than that.”

Another common topic that was frequently avoided by close SNMs in an attempt to remain positive was death. However, Delia indicated that topics related to the end of life might be something she would like to discuss with her husband Jermaine:

I think the biggest thing was avoiding talking about the possible negative outcomes. I did not feel comfortable talking with him about death, honestly. That's one thing I don't think to this day we've talked about, which, on one hand is good, cuz we're focusing on the positive. But I never really talked about "How does he feel about that being a possibility. Is he afraid?"

While close SNMs were focused on using pretense in an effort to maintain as much positivity with their loved one as possible, YAs were also simultaneously managing their own emotions in an effort to mutually protect members of their support network. YAs also said they used pretense as a means of protecting themselves from receiving negative support from others who could not manage their emotions. Ellie kept information about her side effects from her father in an attempt to support him and to protect herself from the reciprocal burden she would feel by watching her father suffer even more:

He was more of a mess than I was. Oh my gosh, my poor dad. I thought he was gonna die of a heart attack, honest to God. He was a mess, because I'm the baby, like I said. Not that you wanna lose any of your children, but I'm the youngest one. Uh, he was a mess with that. I like definitely had to be like, "Today is a great day, Daddy," even if I felt like awful. I would always tell him, "Oh, today's a good day. I'm feeling good," even though I wasn't. I just wanted him to not worry about me, because then I worry about him. Because I don't want him to like have a heart attack or something, so I just tried to be strong for my family.

Nine years after completing primary treatment for testicular cancer, John still defended his decision to wear a brave, positive face for his family to limit the amount of worry they felt and the amount of pity he received in return:

Looking back on it, I think I wanted them to not worry. I always just felt this overwhelming sense to protect them from feeling—I didn't want them to feel sorry for me. I wanted to make them feel like, "Hey, I'm okay with this. I'm cool with this. Whatever happens, happens. I'm okay." I didn't want them to think that, "Man, he's down." And I probably wouldn't have admitted that. But looking back on it, I've asked myself like, "Why did you joke so much?" And I think it was a cover almost to protect them from sometimes how bad it felt. I was never completely honest about how

shitty I felt sometimes from the chemo. Just cuz I didn't want anybody to feel sorry for me. And if I went through it again today, I would not be honest with my parents about that for nothin'. And I don't know what's this idea that says, "Protect them from this," but I flat out just don't want my parents to know about it.

Ofelia also employed pretense to encourage her closest supporters to treat her normally:

I tried really hard not to show my emotions to the people that I care about more than anything. My mindset is that I wanted people to just know, "If I'm being positive about it and I'm not letting it affect daily life, then you shouldn't, because it's not like you that's going through it. I know you're my friends and family, but don't change how you are with me."

In rationalizing their use of mutual pretense, many YAs and close SNMs cited a normative belief that masking emotions and withholding potentially troubling information from others who were already undergoing significant amounts of stress was a positive form of support and the right thing to do. For example, Kendra recalled that her older sister Bailey's doctors cited her positivity as playing a large role in helping her to recover more quickly from procedures to remove her leukoplakia. Bailey also said that she wanted to stay "positive and confident" because she "knew that cancer feeds on stress," and she encouraged her mother to stop worrying "for her own health." Meanwhile, Ofelia recalled her spiritual upbringing and cited others' recommendations on online discussion boards in explaining her decision to "just be positive" following her diagnosis:

So I took that positivity and like every time I spent time with people, I just—I didn't speak about it. I was just super positive about everything. And like if you asked my sister, she would literally tell you that like my positivity is like what helped me through. It helped my mom through cuz I did not show her any like emotional breakdown, because I couldn't. And I was tired of putting that face on. But at the same time, I stayed positive. My parents are Buddhist and they're always like about enlightenment and they always taught me to be positive anyways. But I never really did it

until I got diagnosed [*laughs*]. So I was just like, “Positivity. I’m gonna get through this.”

Additionally, Stella cited advice that she and her husband Dave received from their minister during their premarital counseling before she was diagnosed. She took his words to mean that it was not necessary for them to presently address difficult topics that could potentially arise in end of life situations:

Our minister was great. But he was asking us like, “Well, what are you gonna do when one of you dies?” You know, like those are just the questions they ask [*laughs*] and we’re like, “Well, it’s probably not gonna happen tomorrow, so we don’t need to talk about it” [*laughs*], you know? And he was like, “That’s actually a good way to look at it. You don’t need to worry about something that’s not happening right now,” so he felt like we had a good hold on knowing what’s important, I guess [*laughs*].

In other cases, mutual pretense was employed when the top supporter could not talk to their YA loved one because they were too sick during treatment. Gunther said that he and Kiki “didn’t talk about much because my brain didn’t work through most of treatment. It just blows you out. So I was not much at conversation.” Kiki also provided a rationale for why she could not open up to Gunther during his treatment:

We also like slept separately because he was so sick and he was sweaty and that was just really hard because you don’t have your connection to—I mean, he’s my best friend and I didn’t have anyone to talk to about it. And I couldn’t talk to him. I couldn’t tell him how I was feeling because that’s just—he didn’t get it most of the time, because he really wasn’t there. And then the rest of the time he just, he didn’t have to deal with my stuff in addition to his stuff.

Predictably, many close SNMs and YAs mentioned that they began to grow tired of putting on a face or performance to support their loved one. As a result, they often found a person or a means beyond their dyadic partner to use as a resource to which they could vent.

“I Had to Have Someone Else”: Pressure Valve

Managing the performance of mutual pretense often included the use of a pressure valve or outlet so that the primary SNM or YA survivor would not burden their dyadic partner. Most of the time, YAs and their close SNMs felt the use of a vent was helpful and necessary. For example, Stella chose to talk to some of her friends about her cancer more than her husband Dave “just because I knew he was having a hard time and I didn’t wanna make it harder, because it wouldn’t make it easier on either of us.” Ofelia called her best friend after the burden from employing pretense for her mother woke her up in the middle of the night:

It was like a couple weeks before the surgery. And I just started crying because I was like, “They’re saying it’s cancer. Like I cannot believe this is happening.” I just bawled. Because when you go from not crying for so long to keep a front in front of your mom, it eventually comes out. It has to come out somehow.

April had “venting phone conversations” with her mother, who lived out of town, about how best to provide support to her older sister Ann: “I would say, ‘Well, nothing I say is helping. Ann’s still in a bad mood today. I don’t know what to do.’” Jayden also said that she had “other people” that she could be emotional to if she needed it:

I didn’t have to be emotional in front of my mom. Around my mom I could put on a smile and tell her everything was gonna be okay. And then I could go upstairs and cry if I wanted to, you know, like on my own. Like she never woulda seen that. I could go handle my personal issues later. It was just like so much easier to be happy about it than be sad in front of her, just for her personal wellbeing.

Interestingly, Jayden’s mother Amber also “tried not to put as much of a burden” on her daughter about her cancer as she did on her husband:

I had to have someone else. You can’t burden Jayden, who’s, you know, she’s almost 20 now, but you can’t burden your child with that. So my husband just continued to listen and I’ll go probably every three or four

months, and then I'll have like a major [laughs] breakdown. He'll be like just, you know, "Get it out," whatever.

Kiki used her journal as a pressure outlet, but she chose to write in letters to her boyfriend

Gunther:

But of course I never gave them to him [laughs]. Don't ever tell them that I wrote them, because I don't think he knows. He would fall asleep at like 5:00, 6:00 and I would be sitting there with all of these emotions [laughs].

In rare cases, the use of an outlet caused one dyadic partner to feel a paradoxical sense of guilt. Even though she felt it was necessary to vent to someone in order to provide helpful support to her daughter immediately after her diagnosis, Melanie had felt burdened by her decision to use a pressure outlet before speaking with her daughter:

There was a couple a things that I questioned how I handled for a long time afterwards and even to this day [...] After I found out about Jess's diagnosis, I needed to gather my wits about me. I was afraid I was just gonna break down with Jess, and I didn't want her to just—me totally dissolve. And so I went on and met my brother and sorta just let loose on him before I went back home. And then I kinda had my wits together [...] But that's been one of the couple a times over the years that I've questioned how I handled—cuz I almost feel like I deserted her. But I did it *for* her because I didn't wanna break down in front of her. So it was kinda one of those—I feel like I needed to have my breakdown somewhere else instead of breakin' down in front of her. But then hindsight as a mom it's like, "God, I don't know that I shoulda walked outta the house then or stayed around."

“Still to this Day, He Doesn't Know”: “Successful” Attempts

In only several instances did YA survivors' and close SNMs' use of mutual pretense actually go unnoticed by the dyadic partner they were attempting to support. One rare example of a close SNM “getting away” with pretense without the other party knowing their secret was Carrie's decision to withhold information about a fellow YA cancer patient who was important to her fiancé Brad during his hospital stay:

There was somebody that Brad recovered with that was phenomenal. They were a young family, I wanna say they were from like the Chicago area or something, but they had one young son. The wife and the husband were there at the Hope Lodge and he was recovering at the same time as Brad and we stayed in touch and everything. Brad found him very inspirational for everything he had gone through. He had had the high-dose chemotherapy and multiple different surgeries and all these different things, and the cancer kept coming back and kept coming back. And I stayed in touch with his wife for a very long time. And then I think Brad kind of lost touch with the husband. I mean, still to this day, he doesn't know, but he did pass away, and, um, I mean, they had a young family, it's just heartbreaking. But I just didn't want to take that away from him because that was such an inspiring person for him. To see that it had gotten him in the end, I think would just have had been too detrimental to him, so I didn't ever tell him.

In another rare example where pretense was successful, Amber's husband and daughter Jayden helped her to research and incorporate ways to manage some of the side effects of her treatment. Amber was happy with the results:

There are these things called cold caps that you can wear during chemotherapy, which helps you keep your hair. It was about 75 percent successful with me, so much that literally my last treatment, the next week I had a lot of hair. I was able just to go and have extensions put in and it's been really worth it ever since [*laughs*].

However, Jayden and her father were successful in hiding from Amber their opinion that the cold cap strategy was less than effective:

To keep from losing her hair, she actually tried these things called like cold caps and they were supposed to like help stop like hair loss and all this stuff. And I was like, "That's just a gimmick." Anyway, so [*laughs*] I thought it was stupid and they did not work [...] I felt like it was just a really monumental waste of money [*laughs*]. But my dad was like, "If it makes your mom feel better like..."

Despite many claims that they were open and honest with one another during their cancer experience, YA survivors and their close SNMs reported using mutual pretense as a form of support. In rare instances, the SNM's attempts to withhold information from their YA loved one went successfully unnoticed. However, in most cases the use of

mutual pretense by both parties within the relationship typically evolved into putative protection.

“I Know They Were Worried”: Putative Protection

YA survivors and their close SNMs often mentioned that their efforts to employ mutual pretense as a form of support (i.e., both parties masking negative emotions and withholding information that they believed might upset their loved one) ironically did not go unnoticed. In most cases, both the YA survivor and the close SNM said that they were able to detect their loved one’s performance or knew that they were not saying what they potentially needed to say. However, each member of the dyad sometimes explained that putative protection could be a positive form of support for both parties. As top supporter, Kendra first employed pretense because she looked up to her older sister Bailey and wanted to replicate her emotional approach to the situation:

Because Bailey was so positive, even though she was scared—I mean, she admitted, you know, she didn’t know what was going to happen—but because she was so positive about it, I followed her lead. So it wasn’t something that I let myself talk about like, “I’m so scared.” I had full faith in her. So I never allowed myself to express fear even though I was terrified [*laughs*]. I mean, I just wanted to honor what she was doing as far as being positive.

Even though Bailey was aware that her sister was masking her emotions, she greatly appreciated the positive support that she received from others’ ability to exude potentially false happiness and positivity around her:

I appreciated my friends just laughing, not being worried about me. I know they were, but the fact that they didn’t show it [*crying*]. I know they were worried, but they just stayed happy with me, and they laughed with me, and we would go out for ice cream or coffee, or whatever and just hang out. Or just sit in my room and just laugh with me. Like write in our journals or pray or whatever. So it really helped having them—even if they didn’t want to be that way, they were that way for me.

However, in many other cases, it is not clear how the use of putative protection was beneficial to or appreciated as a form of support by both members of the dyad. For example, both parties may be missing out on opportunities to address concerns that could strengthen their relationship or use the cancer experience as a platform by which they could clarify end of life wishes. Gunther could tell that his girlfriend Kiki was burdened as he was going through treatment. However he knew that she would never admit that to him, particularly because he was not in a physical or emotional place to provide her support:

There were a few nights where I'd barely be awake, but I noticed Kiki wouldn't be laying next to me. And I couldn't get out of bed or anything, but yeah, she was probably upset, and she won't show me that she's upset. So I knew that she was dealing with her stuff without letting me know. But I don't know. At that point too there was like nothing I could do [laughs].

Eva also sensed strain in her older sister and close supporter Marie's response to being smothered by their father, who was also attempting to offer support to Eva:

I think Marie had a hard time sometimes. Like she never would say it to me, but I knew that she was a little upset that my dad was there, and that she kind of blamed me for it. I mean, she did kind of blame me for it, even though she knew logically that it wasn't my fault. [...] I could tell that she was upset based on how she was acting. And in my family no one can keep a secret, so I would always kinda hear it from someone that something was going on. And that's the problem with big Italian families so I would kind of hear it secondhand [laughs].

Charlotte mentioned that her and her boyfriend Geoff rarely talked about the possibility of her dying from her rare genetic subtype of AML:

I think like the only thing we don't talk about, and I've brought it up once, is just like if I don't get better, but he doesn't really wanna—it's not something that I particularly wanna talk about either, but he doesn't really like it when I say that kind of stuff, so I just don't bring that up.

However, despite Charlotte's knowledge of Geoff's desire to avoid the topic, he still wanted to ensure that word would not get back to Charlotte that he was discussing his struggle to cope with the possibility of losing her:

Charlotte wouldn't hear any of this, right? The biggest questions that I've had are like, "What am I gonna do if she doesn't make it?" [...] So I try and not think about those things, but it naturally just comes in. [...] I just try and put it out of my mind cuz I don't know what's gonna happen.

In some cases, the decision to protect one another from being distressed through discussing potentially upsetting information paradoxically reinforced the burden that both parties were trying to avoid.

“We just yelled it out”: Burden boomerang. Although several YA-SNM dyads said that their use of putative protection was helpful to their relationship and a positive strategy for offering support to one other, one of the outcomes or side effects of not openly addressing potentially distressing information is paradoxically reinforcing the burden that they are attempting to avoid. When both parties knew that they were not discussing something that they felt they should discuss, putative protection elicited a “burden boomerang” in the form of reciprocal strain, stress, and emotional meltdowns. For example, Gunther mentioned that he did not “talk about feelings,” but he was starting to become nervous before his chemotherapy regimen was scheduled to begin:

Kiki likes to talk about stuff like that and likes to plan. So I just would retreat to the basement and climb and work out and empty the frustrations and things in my head. And it all peaked one night and she was just pissed because I went down there to get away from talking about it and work out my own frustration and she's pissed and came down and we just yelled it out.

Kiki said that the argument actually started due to their conflicting views on potentially pursuing *in-vitro* fertilization. However, she acknowledged that the conversation was

likely handled poorly because neither of them cleared the air about the fact that Gunther was nervous about starting treatment:

I actually said something like, “I don’t wanna have all those needles and everything that you have to do.” And he completely—this was before chemo had started—*completely* went off on me about how I shouldn’t be such a baby and how he’s gonna have to go through all this stuff and. I realized it was because he was upset about having to go through chemo, but he took it all out on me. And so like that was the very first like, “I’m gonna have to shoulder all of this for him, because he can’t handle it all himself and he’s not gonna share it with his parents, so it’s all gonna be on me.” And so that was kind of the first big like oh my God realization that it’s the two of us in here, um, this is our life now [*laughs*].

However, Gunther believed that the argument serve as a defining moment that helped the couple pursue more open routes of communication in the future:

We hashed it out and kind of came to the same terms with it and like, “Alright, we’re in it together. We’ll get through it.” [...] She didn’t give me a chance to get away anymore [*laughs*]. She didn’t give me the option to deal with it myself. It was like, “Alright, it’s a team and let’s work it out.” [...] That was the start of the support, I guess. It’s probably where it first got rolling, and, uh, she started really stepping up there.

In another reciprocal burden situation that was likely caused by putative protection, Stella had trouble speaking with her husband Dave about his perceived inability to attend her medical appointments:

I think Dave had a hard time in the respect that he couldn’t do anything about it other than be there, but even sometimes then I don’t feel like he felt like he could be there. Sometimes I don’t think he could go to the chemo treatments, and he would say, “Well, I’m sorry, I have to work.” But I’m sure he could have if he wanted to, but I think he was like, “I can’t go,” you know what I mean? And of course then I would try to tell him like, “I don’t feel like you were there for me.” And he was like, “What are you talking about?” [*laughs*]. And I don’t think he wants to talk about that. I don’t think he wants to talk about that it was hard for him. So that was the biggest thing and it was hard on him, he didn’t know what to do, he didn’t feel like he could help, he felt helpless.

In Dave's narrative account of his cancer experience, he maintained that he did not attend Stella's chemotherapy treatments when he "had to be at some mandatory meeting."

However, Stella and Dave's inability to discuss Dave's anxiety reinforced the burden he felt at medical appointments, and it likely rendered him helpless in supporting Stella by helping her translate medical information. Dave's nervousness and erratic behavior during Stella's appointments also reinforced her own burden:

He couldn't really be around the treatment. He would go to the doctor's with me and I swear—they tell you to bring somebody because they tell *you*, "You're gonna be emotional, you're gonna hear everything the right way. You're gonna not get all the information," so Dave would come with me, but I think he was worse [*laughs*]. Later on I'd be like, "That is *not* what the doctor said" [*laughs*]. And then I would ask the doctor and I was right about what the doctor had said. I think Dave just heard it all wrong, like he was more freaked out than I was. I just think it was really hard on him honestly, but maybe even harder on him than it was on me [*laughs*], which is weird to say. And like I said, he'd try to be positive and keep a great face and he definitely did that as much as he could, you know, but like I just know it was hard [*laughs*]. [...] I also remember him asking the doctor, and it seemed like such a weird question for him to ask, but if you have a mastectomy they like take out all the things in there that like—they take off your nip, all the milk ducts and everything, just gone. Like they scrape out the entire thing, it's just a shell, right? So I understood that that was happening and the doctor was kinda going over this and Dave was like, "But if she did that, would she be able to nurse a baby?" [*laughs*]. And I'm like, "No!" [*laughs*]. "I don't think you're hearing her!" [*laughs*]. It seemed like a weird question, like it kinda scared him or horrified him in some way that like I wouldn't be able to be normal or something, you know? Like it seemed scary to him. [...] So as much of a talker as he is, he doesn't like to talk about certain things, you know? So I'm sure things came up where he kinda steered the conversation away or didn't wanna talk about. And honestly he started drinking a lot [*laughs*] during that time. Both of us probably drank more than we should have, but I think he really, um...had a bad time of it [*laughs*]. And so sometimes I couldn't talk to him because I felt like he was kinda drunk or something. And sometimes I almost didn't wanna burden him with stuff, because I knew he was having a hard time.

Additionally, Michael struggled to talk about some of the emotional burden that he was experiencing with his mother Nancy:

I didn't really talk to my mom much about the depression that came along with it, or the anxiety that much. I just mentioned it to her that it was there and I thought I needed help basically, but I didn't go into details about like what it was about. Because I just felt like living with her and everything, she would become overly concerned. And, uh, you know, would kinda start to treat me differently. And I was already really anxious and stuff and just didn't wanna go revisiting it. And I didn't know if she would either.

Not only did Nancy know about Michael's depression and anger, but she was also experiencing her own emotional burden. However, she became frustrated by Michael's choice to not talk to her about his emotional state, which tended to peak as moments of anger:

I think he got depressed. Of course he's—he has fought that before. I think that really kicked in. I think he got kind of angry, but he wouldn't talk much about it. And I would try to get him to talk, but he didn't really—it was a whole lot of, “I don't know,” “I don't care.” But I think he was pretty angry and pretty depressed. I think he was scared. I mean, he didn't let me see that. We have “upset stomachs” if we're upset rather than tellin' whoever it is that we're upset with them *[laughs]*. So he put the stiff upper lip on for me and I put it on for him. So I would hear from other people maybe that he was severely down. And I'm sure that he knew that I was too, but I didn't tell him. He told his sister that he was bein' strong for me. And I was doing my best to be strong for him. [...] So, from what I remember, I was tryin' to keep it normal. And sometimes it was just really difficult to keep it normal. And sometimes I would be angry, because he wouldn't tell me about what happened at an appointment that he had made. One time he would be wantin' to take total control of his own healthcare and the next he was wantin' me to call the doctors. And so it was kinda hard to know which Michael I was gonna be talking to. And I got so tired of hearing—like I said, “How you feeling today?” “Uhhhh.” I got so tired of hearing that. Sometimes I just could have throttled him. So I felt that there was some anger there. Not that it was with him, but maybe it was at the cancer or maybe it was just that he wouldn't talk to me.

Michael also acknowledged his mother's emotional burden, and he mentioned that they both sought outside outlets to cope with it rather than discuss it openly together:

I remember especially when I was first diagnosed, my mom was kinda more of a nervous wreck than I was. Especially around that time I had to make that decision about the [RPLND] surgery and everything, she was definitely visibly nervous. I mean, I was too, but she definitely was. And

then throughout chemo and everything, I could tell she was pretty stressed by it. I think she would sometimes stay at chemo with me just cuz she didn't wanna have to go to work and worry about other things basically. I think she probably needed more support throughout the whole thing. And she did actually start counseling around the same time I did.

Charlotte described how her hesitance to discuss her physical discomfort and medical uncertainty to protect her loved ones and to respect their perceived unwillingness to talk about such difficult topics led her to experience additional burden:

I just know that like when I'm having a good day, it makes it easier for Geoff and my mom. And that when I'm having a hard day, it's harder for them. So sometimes that makes it hard for *me* to open up to them when I'm having a hard time, because I know it affects them. There's so much uncertainty in it and I think that for them it's hard to think about if something were to go wrong. So sometimes like that's something I wanna talk about that they don't wanna talk about.

However, Charlotte's boyfriend Geoff mentioned that he felt he was doing more harm than good in encouraging Charlotte to tell him how she was feeling.

I think she gets annoyed at how often I ask if she's okay. Just cuz now, anytime she's not smiling and talking to me, I just think, "Well, she's probably not feeling great," so I ask her. And I think sometimes, she just doesn't feel well but is fine with that at this point, so I don't need to ask [*laughs*].

Aaron also explained how he and his younger brother John's athletic background encouraged them to not be open with one another about what they were feeling. While he acknowledged that this practice likely helped his brother endure intense discomfort, he also felt that their choice to not discuss the situation served as an impediment to their relationship:

The only way we knew how to deal with it was kinda how we approached sports. We played football together in college. So I remember telling him at the beginning, he was like, "You know, I don't know how else to do it other than to hit it head on. And as far as I'm concerned every day from here on out is game day, a Saturday." And I was like, "You know, that's about the only way we know how to deal with stuff." [...] But I didn't

know anybody who had dealt with it and had a sibling or anything like that. He and I were not arrogant people, but at that age, we're both in football and baseball through college and all that stuff, and it doesn't foster a mentality of, you know, "Admit that you can't do it." So you kinda teach yourself to say, "Well that just doesn't—I'm not that hurt. I'm not that sick," and battle through it. So that was probably a bigger inhibitor than we thought, in a way, as far as dealin' with it *[laughs]*. But at the same time it was an asset, cuz it was like, "Alright, well, nothin' I can—no sense in complainin' about it. Suck it up and start moving forward."

It is important to note that these narratives of putative support and mutual pretense often coincided with the dyad's progression along the cancer trajectory from diagnosis through treatment. In other words, these implicit face and information management strategies were sometimes perceived as enabling communication strategies designed to help both the YA and the their close SNM cope with and protect one another from difficult experiences. Although some of these moments were mundane (i.e., pretending to have a good day), YAs and their supporters expressed the need for one another to "battle through" the experience. Mutual pretense strategies were often burdensome and unsustainable. Even with the use of a pressure valve, many dyads experienced instances in which their efforts to protect one another caused additional burden. However, in some cases, YAs and close SNMs described moments following the completion of primary treatment when they dropped their use of mutual pretense and retrospectively leveled with one another.

“What just happened?”: Retroactive leveling. In an effort to define their relationship post-treatment in survivorship, YAs and their top supporters sometimes retroactively leveled with one another as both parties coped with what the experience meant to them. For example, Kiki explained how she and Gunther “rediscovered” one another on vacation as “things were starting to get back to normal”:

We didn't really talk much about the treatment during the treatment, mostly because I was trying to keep him occupied [...] He would tell me what was hurting and stuff like that, but not like what it meant to him or anything. We didn't really talk about like the effects of it either until we went to Costa Rica, when we got engaged. He finished in June. So July, August, September we were kinda just almost rediscovering each other and kinda getting back into our groove and figuring out what it meant to our life [*laughs*], you know? I mean, I had thought about it, but I don't think it had really affected him [...] So just being there and being away from home and everything that reminded us of that time and all of that, I mean, we finally just sat down and cleared the air between us. Like, "This is how I felt when you were going through this and it was really, really hard, and I didn't wanna talk to you about it."

Gunther complimented and apologized to Kiki following the experience by saying, "You are awesome. Sorry I didn't maybe say it during the whole thing, but yeah, you killed."

However, some YAs like Michael regretted not taking the opportunity to debrief with their top supporter following the completion of treatment: "My mom and I never really went back and talked about everything that had just happened. I feel like we probably should've." In other cases, close SNMs and their YA loved ones acknowledged that they needed to engage in retroactive leveling, but that they were not quite ready to do so. For Charlotte and Geoff, and Molly and Clint, these discussions were related to the potential loss of their fertility. Because Molly had just recently completed her primary round of treatment, she said that she and Clint had not yet worked through some of the more emotional implications of their cancer experience:

The first round with ovarian cancer, we were okay with it, because they told us we could still have kids. And then we were in the process of trying when this happened again. And with it being taken away, like we were really, really intent on having more than one kid. So, that's probably the *most* emotional part of it that we've really had to work through and have probably not fully worked through at this point.

Clint said that the couple's focus up until that point had largely been on getting through the physical and emotional challenges of chemotherapy, but he acknowledged that they

needed to explore routes by which to retroactively discuss what the experience meant to them, particularly as it related the fertility implications of Molly's hysterectomy:

I think early on—even up until chemo was over, it was really all about overcoming the physical obstacles. We're now starting to have conversations about how to deal with the emotional impact. [...] I really didn't think about the emotional side of this until—and I kept tryin' to put it off and put it off until after we dealt with the physical side. [...] I can't say that we've talked a lot about not being able to have kids again. We were really upset about it early on, especially when we found out in the ER that she had a mass on her ovary, but like I said, we kinda put it off. It was one of those emotional things that needed to take a backseat to the physical recovery. I think it's something that we've really talked about talking with a professional to sort it out. So I can't say that we've talked about it, but we have talked about talking to somebody about it.

For couples coping with the potential loss of their fertility, the decision to drop their façade and commit to speaking with one another or to an outside counsel coincides with the end of their treatment, when concerns about the cancer survivor's immediate health are less threatening. Once the couple enters survivorship, the decision to be open and potentially level with one another about the experience is important for both parties, not only as it presents an opportunity for the couple to retrospectively generate potentially positive meaning about the experience going forward, but to address any additional concerns related to lifestyle changes or long-term side effects that were placed on the backburner as the YA dealt with the physical and emotional effects of treatment and the uncertainty about whether it would get them to remission. In many cases, YA and SNM narratives showed that these concerns cannot adequately or sustainably be dealt with through mutual pretense and putative protection alone.

Summary

As YA cancer survivors moved across the trajectory of diagnosis, treatment, and survivorship, they perceived differing normative evaluations of what constitutes effective

support. Theme 1 from this study suggests that social support is perceived by YA cancer survivors in a manner that is distinct from other populations. YA survivors indicated in their narratives that social support was perceived as positive when it coincided with their desire to be treated as a normal and capable person. However, many forms of support were often interpreted as negative because YAs often have SNMs that do not possess the competence, knowledge, or attentiveness necessary to provide age-appropriate support to them. As a result, YAs reported receiving negative support in the form of pity, negative stories, awkward remarks, uneducated advice, excessive self-monitoring, physical and emotional withdrawal, getting in on the drama, and self-absorption. Additionally, several other forms of support, including the degree to which SNMs fulfill instrumental tasks and spend quality time, acknowledge the survivor's strength and wisdom, and use humor were normatively perceived by YAs as both positive and negative. These perceptions were typically predicated by the abundance of the support and the relationship maintained by the YA survivor and the intended supporter.

Furthermore, as part of the biographical disruption of cancer, the process of providing and receiving social support often predicated an additional disruption to YAs and SNMs as their relationships with family, friends, romantic partners, and peers are sometimes necessarily altered. Theme 2 establishes how YAs' supporters must negotiate and jostle for perceived roles and domains within the YA's support system hierarchy. Individuals who find themselves as the top member of the YA's support constellation often feel that they have license to comment on others' support of the survivor. In some cases, top supporters even buffer negative and invite positive support into the YA's network based on their own perceptions of the YA's needs and support preferences.

Finally, Theme 3 suggests that against the backdrop of an individual's personal cancer experience, with loved ones jockeying for or withdrawing from roles and domains that would facilitate their ability to provide the closest support, YA survivors and their close SNMs adopt distinct strategic communication efforts within their relationship to protect one another from the reality of their individual experiences. Most participants said that they attempted to manage their negative emotions and withhold potentially distressing information from their loved one in an attempt to protect one another's health and their relationship. However, it is clear that supportive communication based on strategies of mutual pretense and putative protection are difficult to sustain, even with each participants' use of a pressure valve. As a result, the relational partners' attempts to protect one another from experiencing additional burden often causes more stress in the relationship because both parties know that they are not discussing things that they need to discuss. Over time, some dyads described how their process of having conversations in which they retroactively level with one another emerges along the cancer trajectory as the YA survivor moves from diagnosis and treatment to embracing a vision for survivorship and establishing new, or restoring traditional, roles within the relationship.

CHAPTER FOUR: DISCUSSION AND CONCLUSIONS

In 2006, the Adolescent and Young Adult Oncology Progress Review Group (AYAOPRG, 2006) argued that one way to potentially address the negligible improvement in young adult (i.e., 18-39; YA) cancer patient and survivor mortality rates was to learn more about their unique psychosocial needs. One of the most salient psychosocial challenges recently identified by YA cancer survivors is the perception that their social relationships with family, friends, romantic partners, and peers were somehow altered following their diagnosis (Kent et al., 2012). In light of some of the social struggles that YA cancer patients and survivors have previously reported facing due to the biographical disruption of cancer, and because of the relative lack of research that exists on those who closely support YAs with cancer both individually and as dyadic members, this dissertation examined how interpersonal communication (i.e., through social support and communication work) functioned to both hinder and assist YAs and their close social network members (i.e., romantic partners, parents, siblings, friends; SNMs) in coping with the cancer experience.

In this dissertation, I elicited narratives from 20 YA survivor-close SNM dyads, 1 YA survivor-SNM close triad, and 10 individual YA survivors. I used thematic narrative analysis to determine how and why YA cancer survivors and their close SNMs communicate social support with romantic partners, family, friends, peers, and one another. The findings in Chapter 3 demonstrate the unique ways that YA survivors and their close SNMs experience altered social relationships following the biographical disruption of cancer diagnosis, treatment, and survivorship. Due to the redefinition of social relationships precipitated by the biographical disruption of cancer, YAs and their

close SNMs sometimes struggled to engage in helpful communication labor and supportive communication, which possibly served as a barrier to both parties' processes of biographical reconstruction (i.e., integrating the cancer experience into their lives in order to reclaim their pre-diagnosis "normalcy" or to achieve a "new normal") across the cancer trajectory (Corbin & Strauss, 1987). Examining how YA survivors and their close SNMs talked about the experience of disrupted biography provided new and specific illustrations of unique problems these populations face in managing their relationships and engaging in supportive communication with other members of their support network. YA survivors reported the receipt of negative forms of social support that illuminated others' inability to rely on existing knowledge to fulfill their unique needs. SNMs described how their attempts to provide or solicit support led to role conflicts and negotiations with other members of the YA's support network. Top SNMs also described their attempts to engage in communication work through their role as support gatekeeper, in which they shielded the YA from perceived negative support and facilitated positive support from the YA's social network. In addition, YAs and their top supporters explained how support functioned differently within the YA-top supporter relationship, and they specifically addressed how the use of mutual pretense and putative protection as a supposedly helpful form of support sometimes functioned to increase burden within the relationship.

These findings can be contextualized more specifically within the communication literature, and they are distinguished from previous psychosocial research on YA patients' and survivors' evaluations of the manner and content of others' informational, practical, or emotional support attempts (e.g., Zebrack et al., 2010). This analysis

considers all support attempts to be symbolic actions that serve an ongoing communicative function. In other words, because this dissertation adopted a message-centered perspective, support attempts were not considered effective or ineffective in-and-of themselves. Rather, these messages were viewed as serving a larger symbolic function, and thus *how* and *why* they were evaluated was more idiosyncratic and determined by a number of different factors. For example, these evaluations depended in part upon the YA's relationship with the intended supporter (and between supporters themselves), each individual's perceptions of their own identity and that of others, the nature and dynamics of the larger support dynamic as a whole, how the message related to previous messages or expectations for future interactions, and how the message influenced the support that was offered later on. Once again, broadening the analysis beyond a more regimented investigation of the effective and ineffective sending, receiving, and solicitation of social support revealed an entire tapestry of support communication that more thoroughly reflected the YA survivor's complex experience of altered social relationships, their close SNMs' attempts to function within the larger support network, and the YA-close SNM dyad's unique and reciprocal support attempts. In Chapter 4, I discuss the theoretical and practical implications of each major finding, and I address the limitations of this dissertation.

Theoretical Implications

By thickly describing YAs' and SNMs' communication practices following a cancer diagnosis, this dissertation sheds light on cancer's unique social effects among YA survivors and their top supporters in a manner that illustrates the lived experience of the illness (Sharf et al., 2011). This insight is significant because little empirical research

currently exists in the interpersonal health communication literature that captures the YA and SNM experience of cancer as a biographical disruption and that also provides extended examples of these groups' distinct problems and needs in navigating relationships with members of their social networks (Donovan-Kicken et al., 2012; Zebrack, 2000). The nature of social support has also not been examined across the YA cancer trajectory from a normative communication perspective and as a function of altered relationships. Through the elicitation and narrative analysis of YA cancer survivors' and SNMs' individual and dyadic illness accounts, this dissertation extends interpersonal health communication theory by addressing how YA cancer survivors and their close SNMs manage the challenges of navigating their interactions with others following the biographical disruption of a cancer diagnosis. It also explains how supportive communication and communication work can both help and hinder these unique populations in coping with their disrupted personal and dyadic biographies and integrating cancer into their lives.

In Theme 1, YA survivors described the normative forms of social support they received upon diagnosis, through treatment, and into survivorship, and several of these forms were unique to them as an age-defined population. These normative forms were identified as support that was commonly perceived by YA survivors to be helpful or appreciated. Consistent with Zebrack et al. (2010), helpful forms of support aligned with YA's perceptions of their normality and capability. In other words, YA survivors consistently valued others' attempts to help them feel like they were the same person as before their diagnosis (e.g., by engaging YAs in conversational topics that they had prior to the cancer experience, involving them in regular activities) and reduce the perceived

abnormality of the physical (e.g., hair and weight loss) and functional (e.g., reproductive issues) alterations caused by treatment. However, YA survivors also reported that potential supporters within their social network generally did not know or attempt to learn how to support them during their cancer experience, precisely because cancer in young adults is not normal, and thus the supporters did not have a well-developed cognitive framework for responding to the illness. As a result, YAs reported the receipt of eight negative normative forms of support, including pity, bad stories, awkward remarks, unsolicited advice, excessive self-monitoring, physical and emotional withdrawal, getting in on the drama, and self-absorption. YAs also expressed the receipt of several forms of support that some survivors perceived to be positive and others considered to be negative. Supporters' attempts to fulfill instrumental tasks and to spend relational time, acknowledge the survivor's strength and wisdom, and use humor were often evaluated as positive or negative depending on the frequency with which the support attempts were offered and the relationship the YA had previously maintained with the intended supporter.

Through the identification of the normative forms of support that emerged in YA cancer survivors' narrative accounts of their cancer experience, the findings reported in Theme 1 extend interpersonal communication theory into a previously unexplored, unique, age-defined context. By employing a normative, message-centered perspective to the study of social support, Theme 1 provided insight into *how* and *why* enacted support messages (and not only *what* was communicated) were uniquely received by YA cancer survivors as successful or unsuccessful, helpful or unhelpful in coping with their illness (Goldsmith, 2004; Goldsmith et al., 2006). Despite the wide variety of cancer types

represented in this sample, theoretical saturation was still reached in terms of the emergent themes that represented YA's perceptions of the normative support types they received. Consistent with a normative approach to communicating social support, YAs often attributed their positive or negative evaluations of support attempts based on what the providers of the support said, how they said it, and the meanings that the receivers attributed to the message. In other words, YA survivors' evaluations depended on how the support messages defined their cancer experience (e.g., as an excuse for pity and sympathy, as a death sentence, as less important than the supporters' own interests, as a barrier to normalcy), affirmed or challenged their identity (e.g., as being stronger, wiser, less capable as a result of their cancer), and portrayed the nature of their relationship with the supporter (e.g., the supporter's previous level of closeness, how power dynamics within the relationship shifted to cause the YA survivor to feel babied and lose independence; Goldsmith, 2004; Goldsmith et al., 2006). As a result, what was found to constitute normative support within Theme 1 may be salient to the YA survivor population in ways that may not be salient to older and younger cancer populations.

For example, normative support perceived by YA survivors as commonly good and commonly bad appeared to be relevant to a YA population for several reasons. First, YAs often perceived the individuals who offered them the support messages that defined their cancer experience to generally not be well-equipped to deal with the circumstances of their cancer. Because cancer is more common in older adults, that population's supporters are often not as shocked by a cancer diagnosis as the people who support YAs, and thus they generally have a better idea about how to respond. However, when dealing with YAs with cancer, older adults (even those who have had previous cancer support

experience) were reportedly often stunned and devastated upon their loved one's diagnosis. They often felt that the YA was too young to be diagnosed and had too much of their life left to live. Additionally, YAs' friends likely did not have first- or secondhand experience with providing support to other YAs with cancer. Generally, primary cancer support was thought of within this age group of SNMs as something for which their parents either have been or soon will be responsible. As a result, YAs with cancer often reported a sense of isolation because others could not or did not attempt to understand their experience. They often felt that others responded to them with pity, self-absorption, insincere pandering, and aloofness, rather than the uniquely positive forms of support that helped them to feel "normal."

Because so many of their SNMs did not know how to effectively react to their cancer experience, YAs often considered it to be particularly relieving when others at least attempted to relate to them or reaffirmed their identity in ways that communicated that cancer had not caused them to be viewed as a completely different person. Two unique features that compounded YAs' normative identity and relational support struggles during their cancer experience were that many participants were already struggling to solidify their identity and social relationships in ways that were not consistent with children and older adults' experiences. As a result, providing support in ways that reaffirmed their identity as a capable and valuable young adult and communicating that their relationship with the supporter was just as appreciated as it had ever been was distinctly important to members of this age group.

Normative support perceived by YA survivors as both good and bad also appeared to be relevant to a YA population for several reasons. First, the precarious line

between providing helpful instrumental support and hovering or babying, and providing effective relational support and smothering was likely a product of YA survivors' normative need to maintain individuality and agency at that age. In many survivors' cases, the sense of independence that they had achieved after normatively striving for several years was necessarily taken away from them. While YAs needed assistance and informal social interaction, they also needed to maintain a sense of their own agency and capability and to have physical and emotional space to themselves at times. Additionally, others' attempts to bolster YA survivors by saying that they were strong or brave for getting through their experience felt invalidating on an identity and relational level because YAs believed that many of their friends and family members could not relate to them and truly did not understand what they were going through. YAs felt that such compliments were attempts by the supporter to fulfill their own expectations and to relieve their own anxiety about the cancer experience that the reality of their circumstances were being obscured. Support messages that were also used to reaffirm the YA survivor's newfound wisdom or clarity that was supposedly imparted to them through their experience were also uniquely invalidating for members of this population. With cancer survivors living longer than ever, YAs have much more of a future life for which to plan than older adults with cancer. Because the remainder of a YA cancer survivor's life often seems so open-ended and uncertain, others' expectations for a sense of clarity in their lives often seem preposterous to them. By employing a normative, message-centered perspective to the study of social support, Theme 1 provided insight into how and why support messages were uniquely received by YA cancer survivors as appreciated or unappreciated in this context.

Theme 1 also uniquely examined how the receipt of normative forms of social support was predicated by the strain of biographical disruption that resulted from diagnosis and treatment and YAs' struggles to manage their pre-existing social relationships. Eva captured this experience when she said: "I'm already sick and I've had to kinda pause my life and now I feel like everyone around me is acting different. And I think it was just one more change that I didn't wanna have to deal with." In many cases, the receipt of unhelpful social support appeared to compound the biographical disruption of the experience itself, and it further altered their relationships with family, friends, romantic partners, and peers. These findings may provide additional insight into previous claims that the receipt of negative forms of support can affect how YAs experience their cancer and view themselves, their relationships, and their current and future social relationships (Zebrack et al., 2010). However, while YA survivors indicated that good support meant that they were treated "normally," they also explained that they often still felt different and that others could not truly understand what they were going through. As a result, future research should examine the role that other YA cancer survivors play in this population's desire to be treated normally despite feeling different.

In Theme 2, close SNMs (with some additional input from YA survivors) explained the larger relational context in which support attempts were delivered to YAs. In most cases, the close SNM who was interviewed in this dissertation also identified as, and was considered by the survivor to be, the YA's "top supporter." These individuals explained the unique responsibilities and privileges that separated top supporters from other supporters within the YA's larger network. They also shed light on the dilemmas that occurred as supporters jockeyed for or withdrew from various roles and duties, and

how these roles were also negotiated with their YA loved one. As part of their positions as top supporter, close SNMs who found themselves at the top of the YA's support hierarchy often felt that they had the privilege to monitor and critique others' support attempts when they perceived it to be unhelpful to the survivor or threatening to their own top supporter role. Top supporters' criticisms often involved intended supporters' perceived closeness to the YA, their ability to spend an appropriate amount of time with the survivor or adhere to the top supporter's schedule, and the tone in which the supporter communicated their messages. When the top supporter believed that the YA survivor lacked available positive support, they sometimes acted on their monitoring duties in serving a gatekeeping role. In these cases, top supporters limited or buffered the negative support that could potentially reach the YA survivor (i.e., by not inviting people into the support network in the first place, by cutting supporters out of the network, by redirecting or correcting others' support attempts to align them more closely with the YA's or top supporter's preferences), and they invited opportunities for positive support (i.e., by asking supporters to reach out to the YA in person, over the phone, or online; to compensate for their own absence; to throw parties that dictated the tone of the support provided to YAs; to solicit lay medical advice).

The findings reported in Theme 2 demonstrate why it is important to also examine YA support from the SNM perspective, because YAs did not always detect details of the relational support environment that often surrounded them, particularly in terms of their supporters' attempts to jockey for position. As such, Theme 2 extends interpersonal health communication theory by providing insight into how the unique and unforeseen life disruption associated with a YA loved one's cancer diagnosis may cause close SNMs

to negotiate and compete for new unexpected roles with both the survivor and other members of the survivor's network. Similar to their YA loved ones, SNMs' altered relationships—precipitated not only by the YA's diagnosis but also by their own normative life transitions as a YA—may cause additional relational strain during these negotiations. These findings also shed additional theoretical insight into previously unexplored features of supporters' communication work (Donovan-Kicken et al., 2012). In addition to keeping others informed about the YA's health status, soliciting or offering them social support, and preparing for cancer-related conversations, YAs' top SNMs sometimes felt it was their duty or responsibility to monitor others' support attempts. When they perceived a lack of positive support for the YA, top supporters fulfilled gatekeeping labor by blocking or reframing others' support attempts. For SNMs who were also YAs themselves, these features of communication work were an additional hurdle that they needed to clear in order to reconstruct their own biography, which had already been normatively disrupted before their loved one's diagnosis. This disruption may also cause uniquely altered relationships that top supporters must manage to successfully fulfill their support role, such as those that occur between YA survivors' romantic partners and their parents.

In Theme 3, YA survivors, their close SNMs, and the dyad itself illuminated a unique support strategy within the YA survivor-close SNM relationship. While both parties often claimed that they maintained open communication throughout their cancer trajectory—and recommended that others going through similar experiences do the same—YA survivors and their close SNMs often employed mutual pretense in an attempt to hide negative emotions and information from one another. However, mutual pretense

was only used successfully in a few instances. In most cases, both YA survivors and their top supporters were aware that the other party was putting on a performance or were not saying what they potentially needed to say. Because the extended use of mutual pretense became burdensome and was not a sustainable means of support enactment for the performer, both parties often employed another supporter as a pressure valve. Although several YA-SNM dyads said that their use of putative protection was a helpful strategy for offering support to one another, one of the common outcomes of not openly addressing potentially distressing information or emotions over time is paradoxically reinforcing the burden they were attempting to avoid in the form of a “burden boomerang.” However, in some cases, YAs and their close SNMs dropped their use of mutual pretense following the completion of primary treatment and retrospectively leveled with one another in an attempt to address what the experience meant to them and explore options for moving forward.

In Theme 3, the elicitation and analysis of dyadic data enabled the discovery of information that likely would not have emerged without the use of a joint perspective. Little previous communication research has examined the specific social experiences of both YA cancer survivors and their close SNMs as individuals and as dyadic partners to identify their unique interpersonal and support dynamics. As a result, the use of dyadic data in Theme 3 furthered interpersonal health communication theory by detecting the emergence of mutual pretense from YAs’ and SNMs’ individual perspectives. This notion of mutual pretense has surfaced in previous research on secret-keeping and disclosure (e.g., Caughlin, Scott, Miller, & Hefner, 2009), but it has yet to be applied in the context of illness and support. Examining dyadic data also captured the use of

putative secrets (i.e., when a relational partner learns a secret but does not tell the secret keeper that the information is known; Caughlin et al., 2009) and the experience of the reciprocal burden boomerang from a joint YA cancer survivor-SNM perspective.

This dissertation also built on Caughlin, Mikucki-Enyart, Middleton, Stone, and Brown's (2011) study of topic avoidance in families with a loved one who was dying of lung cancer. The authors found that families managed to cope effectively despite often choosing to avoid the discussion of informational and emotional issues related to a parent's lung cancer and despite still claiming to maintain open communication with one another (Caughlin et al., 2011). In this dissertation, mutual pretense was another route by which intended supporters claimed that they were open with a loved one with cancer without actually being open. Theme 3 also extended interpersonal health communication theory by augmenting our understanding of the reasons for YA survivors' and SNMs' use of mutual pretense in this context. Several of these reasons were consistent with Caughlin et al.'s findings (2011) and the larger literature on topic avoidance, including adhering to normative influences and family standards, maintaining autonomy, and appearing strong. However, Theme 3 also showed that protecting others from exposure to their potentially distressing information and emotions was also an effort to subsequently protect themselves from the other person's reaction. This often involved shielding themselves from the reciprocal burden they would feel by watching their dyadic partner suffer even more or dictating the type of normative support they would receive back by limiting the amount of worry and pity they could potentially elicit.

The use of mutual pretense as a form of identity, informational, and emotional management can be constituted as a unique type of communication work that is

performed by YA survivors and their close SNMs in this context (Donocan-Kicken et al., 2012). Despite grappling with their own discomfort and fear in response to their cancer experience, YA survivors (consistent with Kent et al., 2012; Miedema et al., 2007; Zebrack & Isaacson, 2012) and SNMs both enacted communication labor by portraying themselves as strong or reassuring. At times, this work was employed in an attempt to limit the amount of anxiety and sadness experienced by others and to implicitly suggest specific types of support in return (i.e., to be treated as normally as possible). Theme 3 also explored putative protection as a natural extension and dyadic consequence of mutual pretense. Instead of acknowledging one another's pretense performances when they were detected, both parties often continued to mutually and implicitly reinforce their tendency to mask their emotions and not discuss distressing information. Thus, the detection of putative protection in a dyadic YA cancer survivor-SNM context extended Caughlin et al.'s (2009) work on the implications of putative secrets in romantic relationships by detecting the phenomenon in the context of illness management and identifying distinct psychosocial outcomes of mutual pretense for those dealing with cancer.

Practical Implications

Because this dissertation was grounded in interpersonal communication theory, these findings may also be used practically to inform the development and evaluation of future age-specific communication interventions, educational programs, and online informational resources that can assist YA survivors and close SNMs to navigate and maintain altered relationships with peers and closer members of their social networks, facilitate higher quality of life, and, ultimately improve health outcomes (AYAOPRG,

2006; Donovan-Kicken et al., 2012; Miller & Hefner, 2012). Specific practical interventions may be offered on three levels to YA patients and survivors, their social network members, and their medical providers.

First, YAs have been shown to struggle to cope with their cancer experience when they perceive their support to be largely negative or nonexistent. In some cases, YA survivors feel higher levels of alienation, uncertainty, anxiety, and burden in relation to their new cancer-related social roles, and they often feel overburdened, uninformed, and unable to make crucial health decisions without the receipt of effective social support (Zebrack et al., 2010). These poor psychosocial outcomes could have further negative consequences related to this population's lack of improvement in mortality rates, perhaps because YAs are less likely to manage their treatment and engage in future surveillance if they feel less connected to their providers and to other support members (e.g., Kent et al., 2012).

Therefore, findings from Theme 1 should be used practically to assist YA survivors' friends, family members, romantic partners, and peers in becoming more sensitive to this population's support preferences. Because cancer diagnoses are rare and often unexpected among their YA loved ones, SNMs are frequently unaware that YAs have unique support preferences across the cancer trajectory, and they are often unsure about how to effectively support them. When primary SNMs are YAs themselves—as was 66% of the SNM sample in this dissertation—they may also lack the skills and experience necessary to support similar-aged loved ones through a difficult experience. The high number of emergent support types that were perceived as negative by YAs may indicate that their support networks were often uncertain about how to support them

effectively. Additionally, the ubiquity of emergent support types that were perceived as both positive and negative within the YA survivor sample may reflect the variability of YAs' support preferences across individual cancer experiences. As a result, one type of support does not appear to help all YA survivors equally.

However, by gaining insight into the unique forms of normative support that were detected by YA survivors, participants' accounts in Theme 1 can be used to provide SNMs of all types with better information about how to recognize and avoid offering negative or unwanted forms of support that could complicate YA survivors' attempts to adjust to their illness. One potentially effective route for practical intervention in this context could be the dissemination of a popular-press book aimed at YA survivors and their close SNMs. Not only could such a book provide narrative accounts from other YA survivors that can serve a normalizing function for those currently going through cancer treatment or entering survivorship, but close supporters could also be given practical information about how to effectively provide support to YAs with cancer without treating their loved one differently. For example, some supporters could be encouraged to continue acting the same way around their loved one following their diagnosis to promote a sense of normalcy (e.g., continue inviting them out on weekend nights). A popular press book could also focus on assisting SNMs with the social experience of necessarily having to provide a YA with instrumental support in a way that is not overly burdensome or threatening to the YA's normative desire for autonomy. This information could also be used to encourage YAs to feel empowered to voice their support preferences to SNMs in an effective manner. When patients simply acknowledge that certain types of support are unhelpful in an attempt to reframe their supporters' intentions, they may successfully

relieve some of the burden associated with receiving bad support (Scott, Martin, Stone, & Brashers, 2011).

Findings from Theme 2 can also serve a practical purpose because close SNMs of YAs are often overlooked as potentially needing unique services, instruction, and intervention themselves. Like YA survivors, YA SNMs may also struggle with a sense of social isolation and an ability to come to terms with a new illness-related identity. Without effective supportive communication with the survivor and the survivor's family, friends, peers, and medical providers, close SNMs of YA survivors may struggle to achieve a "new normal" in the wake of their biographical disruption and experience additional burden in their attempts to fulfill the communication work associated with their role. Not only may they experience a poor quality of life and potentially negative psychosocial and health outcomes, but top supporters may also struggle in their attempts to provide effective emotional and instrumental support to the YA with cancer and successfully manage the rest of the support network.

By detailing the nature of the often implicit role negotiations that occur between YAs' closest supporters and between the closest supporters and the YA survivor him- or herself, medical and psychosocial practitioners may also be better able to converse with YA supporters and to anticipate their needs. While healthcare practitioners generally tend to be poor judges of their patients' emotional states and are often unprepared and not trained to deal specifically with the unique relational challenges associated with the YA cancer experience (Bleyer, 2007; Street et al., 2009), the findings in Theme 2 may be used in medical education programs to train providers to modify their approach in communicating with YAs and their support networks. For example, practitioners may be

more aware of instances in which YAs' close SNMs appear to have little support of their own or are struggling to maintain strenuous relationships within the YAs' network and thus refer them to targeted and age-appropriate psychosocial services that can assist them (Bleyer, 2007). Additionally, accounts like those from SNMs like Kiki, Angie, and Carrie may push practitioners to be more aware of the person they consider to be the YA's top supporter (e.g., the patient's mother or non-spousal romantic partner) and thus with whom they choose to share medical information.

While Caughlin et al. (2011) demonstrated that it may be possible to maintain a relationship that is suitably open while using topic avoidance to skillfully protect others from negative information and to maintain a sense of optimism, the emergence of mutual pretense and putative protection in the findings of Theme 3 appeared to more often than not cause a reciprocal sense of burden for both YA survivors and their close SNMs. Without choosing to eventually quit the non-sustainable support strategies of mutual pretense and putative protection and retrospectively level with one another to define the past and future implications of the cancer experience on their relationship, the YA-close SNM dyad could potentially crumble under the reciprocal stress and strain it experiences within a burden boomerang. Additionally, both YA survivors' and their close SNMs' hesitancy to discuss possibly uncomfortable or upsetting topics with one another (e.g., sexual function, fertility, recurrence, genetic testing, death) may highlight a potential area for intervention. When YA-SNM dyads employ putative protection without eventually leveling with one another, the couple misses out on opportunities to hold potentially important conversations about medical and personal decisions related to their cancer or other future illnesses. Delaying these conversations until the last minute could leave them

feeling ill-equipped to deal with necessary decisions about treatment options or end of life measures when the time comes.

Limitations

Like any research project, the current study was limited in several ways. Despite my best efforts to recruit a representative sample, several of this dissertation's limitations may be a result of the relatively sparse and geographically-dispersed YA cancer survivor population. First, due to the lack of an easily-accessible population, I made the decision to not limit my sample to one specific form of cancer (e.g., breast, testicular). My coders and I reached theoretical saturation and saw enough consistency across the entire data set to feel confident that the results that emerged in this particular study would be insightful across the larger YA cancer survivor population. However, the amount of variability in other conceptual areas, even within the different categories of leukemia (e.g., AML, ALL, CML) and head and neck cancers (e.g., thyroid, parotid) may be interesting to explore further in the future because specific aspects of their diagnosis, treatment, and survivorship experiences were considerably different, and these factors may have a different influence within other communication contexts.

Second, because of my decision to elicit face-to-face interviews, I was largely limited to recruitment in Ohio and Kentucky. While this was not problematic from an experiential perspective because many of the participants were geographically dispersed across the United States before the time of the interview, my constrained recruitment area likely led to a rather homogenous ethnic sample. As a result, normative forms of social support, role negotiations between SNMs, and the use of mutual pretense and putative protection may differ across YAs' and SNMs' broader sociocultural experiences. Third, I

included 10 single YA survivors in this dissertation, because the SNMs who were closest to them at the time of their diagnosis and treatment no longer lived geographically close to them or were not available to participate during the time of recruitment. Narrative accounts from these individuals may have further enriched Themes 2 and 3. Further, only four SNMs (19% of the SNM sample) were male. Despite potentially being reflective of the actual support dynamic within the YA cancer experience, a more developed male perspective may have provided a different perspective within Themes 2 and 3.

Fourth, only two survivors (7% of the YA survivor sample) were between the ages of 32 and 39 at the time of their initial diagnosis. Both of these survivors had more solidified marital relationships and occupations in place during their cancer experience, and one of the two survivors had a child who was in her teens at the time of the interview. These features appeared to distinguish members from this subset of the YA population from the rest of the sample. Thus, including more survivors who were diagnosed at the older end of the 18-39 age range may have provided a richer perspective regarding their experience of biographical disruption and shed additional insight into social support features that were qualitatively different within this subset. Interviewing more survivors with older children may have also revealed a different support dynamic that is still consistent with the YA experience.

Fifth, I recruited 12 YA survivors (40% of the YA survivor sample) by posting recruitment information to YA cancer support services they follow online or by announcing it at face-to-face YA support programs in which they participate. Because these participants have previously been involved in YA social integration programs and other psychosocial services that target same-age cancer survivors, they may account for

less social isolation, a greater awareness of the common unique support needs inherent in this population, and a stronger social identity as a YA cancer survivor than members of the YA survivor community that do not participate in similar programs and services (Kent et al., 2012; Zebrack et al., 2010).

Finally, the use of narrative elicitation through face-to-face interviews may have led to narrative data that was limited in its ability to provide a clear longitudinal and concurrent depiction of the narrator's social processes across the cancer trajectory because participants can only rely on their use of retrospection (Hookway, 2008). Additionally, my presence as a researcher may have created face threats associated with disclosing sensitive information related to their illness experience. The nature of interviewing also does not always enable participants to have the time and opportunity to engage in more deliberative or creative thought processes that enable detailed retellings of the past, which may have been possible in narrative elicitation through written media (Lindlof & Taylor, 2011; Riessman, 2008).

Conclusion

This dissertation helps to extend interpersonal health communication and social support research into a new age-defined context. Practically, these findings indicate a broader need for and can be used in the development of theory-based, age-appropriate communication interventions, educational programs, support groups and social integration programs, and targeted informational materials (e.g., disseminated in infusion units, hospitals, or through psychosocial services) that apply current evidence derived from the unique social experiences of YA survivors and their close SNMs. Future researchers may also consider how these findings can be used to ease important

supportive communication and everyday interactions with romantic partners, family members, friends, and peers in ways that provide for more effective medical and personal decision making and social uncertainty management. It is also important to assist SNMs in particular with their unique needs associated with managing the burden of care while balancing their own attempts to achieve normative life plans and social processes. Future services could also be provided that help YAs transition from the isolation of treatment to the social integration necessary in survivorship. Findings may also inform interventions used to remind social network members that YA survivors' and close SNMs' cancer experiences do not end following the completion of primary treatment.

A cancer diagnosis during young adulthood is a high-stakes experience in which communication can have a profound impact on quality of life. By studying this experience from a dyadic perspective, the present research provides valuable insight into the connection between supportive communication and psychosocial factors in this context. Communication scholars are well-positioned to conceptualize, measure, and apply supportive communication in YA cancer research, and my hope is that communication scholars will seize the valuable opportunity to expand interpersonal health communication theory and substantively improve the challenging experience of cancer in young adulthood.

Appendix A
Survivor Narrative Interview Protocol

First, I'd like to learn a little bit about your experience with cancer and how you talk about your cancer with others. Please try to think as broadly as you can about your experience.

1. Can you start by telling me the story of how you were diagnosed with cancer? (Probe: When did you start to notice symptoms? Who were you with? How did you react?)
2. Can you tell me about the treatment and procedures you received for your cancer? What physical and emotional changes did you undergo?
3. Can you tell me about your experience in the months following the completion of your treatment? (Probe: Did you feel that things were getting back to “normal” or did they stay different? What was it like to “**reacclimate**” back into your old routines and schedule, if you were able to? How does your cancer experience continue to affect you physically?)
4. Sometimes people who have cancer feel like their lives have been interrupted. Can you tell me a story about something that has felt interrupted in your life? (Probe: This might involve your identity, physical changes, future goals, daily schedule, or relationships.)
5. Can you tell me about a time when your life felt disrupted in a way that was different for a young adult than for someone else with cancer? (Probe: How was this disruption unique to a person your age? How do you think cancer affects people your age differently than others?)

(Re)claiming Agency through Managing Social and Personal Uncertainty

Sometimes people who experience a major diagnosis like cancer report that they feel uncertain, or that they have a lot of questions.

1. Can you tell me about a time that your cancer experience has caused you to feel uncertain or to have questions about something? (Probe: Can you think of a time when you felt uncertain or had questions about your diagnosis, treatment, prognosis, or side effects? Can you think of a time when you felt uncertain or had questions about changes in your identity or career? Can you think of a time when you felt uncertain or had questions about how you were going to communicate with others or manage your relationships?)
2. Did this uncertainty feel like a good or bad thing? (Probe: Can you tell me about a time when your uncertainty affected your life in some way?)
3. What do you do when you feel uncertain in these situations? (Probe: Can you tell me about a time when you've really tried to avoid information?)

4. One experience that many people with cancer face is telling other people about their illness. Think about the times that you have told other people about your cancer. What factors have affected your decisions to tell someone about your cancer?
5. Can you tell me about a time when telling someone about your cancer was **easy**? (Probe: What did the person say or do to *encourage* you to talk about your cancer experience?)
6. Can you tell me about a time when telling someone about your cancer was **hard**? (Probe: What did the person say or do to *discourage* you to talk about your cancer experience?)
7. Can you tell me about a time when you purposely didn't tell someone about your cancer when you had the opportunity to do so? (Probe: Why did you do this? Can you tell me about a time when you specifically told a loved one not to tell someone about your cancer? Why did you do this? Did your loved one ever tell you not to tell anyone about your cancer?)
8. Who was primarily responsible for telling other people about your cancer and keeping them up to date about how you were doing? (Probe: Who managed the information? How were people kept in the loop? Who was most likely to reach out to people?)

(Re)shaping Identity

Sometimes people who experience a major diagnosis like cancer report that they feel like a different person in some ways.

1. Are there any ways that you felt like a different person than before you were diagnosed with cancer? (Probe: What parts of you still felt the same after you were diagnosed with cancer? What does the future mean to you right now?)
2. Can you tell me about a time when you knew that your cancer experience affected how others saw you? (Probe: How did your cancer affect your identity at work, school, or in your activities?)
3. Sometimes when people go through life-changing experiences like cancer they keep mementos like scrapbooks, video journals, or blogs so that they can look back on their experience. Did you or your loved ones make or keep anything to help you or them tell your story? (Probe: Why or why not?)

Building Community through Perceived Social Support

Especially among people similar to you in age, a major diagnosis like cancer can influence how you interact with those who are close to you.

1. Can you tell me about a time when your interactions with someone close to you felt different because of your cancer diagnosis and treatment?

2. Can you tell me about a time when you felt support from someone close to you after your cancer diagnosis? (Probe: Can you tell me about a time when someone close to you offered you support and you thought they handled it in an **effective** way? What made this a positive experience? What kinds of support do you find to be the most helpful from those close to you?)
3. Can you tell me about a time when you didn't feel support from someone close to you when you felt like you needed it after your cancer diagnosis? (Probe: Can you tell me about a time when you felt isolated? Can you tell me about a time when someone close to you offered you support and you thought they handled it in **ineffective** way? What made this a negative experience? What kinds of support do you find to be the least helpful from those close to you? Can you pinpoint the **worst** thing that someone said to you?)
4. Can you tell me about a time when you sought or asked for support from someone when you felt like you needed it? (Probe: What did you say? How did you go about asking for it? How did the person respond?)
5. Can you tell me about your loved one's role in helping you with your cancer? (Probe: What topics related to your cancer are **easy** to discuss? What topics are **difficult** to discuss or are things that you **avoid**? Can you tell me about a time when you felt smothered by your loved one or they overstepped their bounds?)
6. Can you tell me about a time when your loved one needed support during your cancer experience? (Probe: Can you tell me about a time **when you offered** your loved one support when you thought he/she needed it? How did you approach him/her? Did he/she seem to appreciate it? Can you tell me about a time **when you didn't offer** your loved one support when you thought he/she needed it and you wish you had? Why didn't you?)
7. How did this experience change your relationship with your loved one? (Probe: How did it change it for the **better**? How did it change your relationship for the **worse**?)
8. Can you tell me about a time when you felt support from one of your medical providers? (Probe: This can be an oncologist, infusion nurse, surgeon, etc. Can you tell me about a time when you **didn't** feel much support from one of your medical providers? What were the **other patients** like that you saw at your appointments or during your treatment? Do you think that your medical providers were equipped for **dealing with young adult patients**?)
9. Can you tell me about a time when you talked with other young adult cancer patients or survivors? (Probe: Who initiated the conversation? What aspects of talking with other young adult cancer patients or survivors are helpful? What aspects of talking with other young adult cancer patients or survivors are not so helpful?)

10. Have you ever participated in any programs, websites, or other services that were designed specifically for young adults (people between the ages of 18-39) with cancer? (Probe: Can you explain what programs, services, or websites these were? What made them helpful? Would you recommend them to others?)
11. What kinds of things do you want to see in future programs, websites, or informational materials that are designed specifically for young adults with cancer (Probe: Can you think of programs, support services, or information that you wished were available to you during your treatment or even now?)

Making Treatment Decisions

I'd like to ask you some questions about how you made decisions related to your cancer treatment. This can involve any decisions related to your cancer experience (e.g., selecting a procedure that was available to you, deciding the best way to manage your side effects, choosing who was going to take you to the doctor's office on a particular day, etc.)

1. Can you tell me about a treatment decision that you've had to make about your cancer that was easy to make? (Probe: What made it easy? How did you **involve other people** in this decision?)
2. Can you tell me about a treatment decision that you've had to make about your cancer that was hard to make? (Probe: What made it difficult? How did you **involve other people** in this decision? Can you tell me about a time when you and your loved one or others **experienced conflict** when you were trying to make a decision related to your cancer experience? How did you manage it?)
3. Did you ever try or think about trying any alternative, complementary, or holistic forms of treatment? Did your medical providers ever discuss anything related to fertility? Did you undergo any reconstructive procedures?
4. To what extent did you talk to your loved one about your treatment decisions? (Probe: How did these conversations affect the decisions you made? What made these conversations **helpful** in making a decision? What made these conversations **unhelpful** in making a decision?)

Making Sense of Illness through Humor

Sometimes when people are facing stressful experiences (like the experience of cancer), they use humor to help make sense of the situation, and sometimes they don't. I'd like to ask you some questions about how humor has or has not played into your conversations about your cancer.

1. Can you tell me about a time when you or others used humor to make sense of your cancer experience? (Probe: Can you remember any specific instances of humor—any specific jokes or specific situations that were played for humor? Who do you **not feel comfortable** using humor with in talking about your cancer?)

2. Do you feel like humor has helped you or other people deal with your cancer experience better? (Probe: If so, do you feel like you use humor more for your own benefit or for the benefit of others?)
3. Can you tell me about a time when you used humor with your loved one specifically? (Probe: How did he/she respond and why? Do you feel like you use humor with your loved one more for your benefit or for his/hers?)
4. Can you tell me about a time when someone used humor and you felt like it wasn't really appropriate for the situation? (Probe: How did you respond and why? Can you tell me about a time when you used humor and other people felt like it wasn't really appropriate for the situation? How did they respond and why?)
5. Can you tell me about a time when you used humor with other young adult cancer patients or survivors? (Probe: How was using humor with these people different than using it with others?)

Final Thoughts

We have just a few questions left.

1. What has surprised you the most about your cancer experience so far?
2. So you were diagnosed with cancer relatively early in life. Many patients and survivors report that this experience really changed them in some important ways. How has it changed the way you take care of your health now? (Probe: How has it changed your attitudes, beliefs, or behaviors about preventative health, such as getting a vaccine, wearing sunscreen, or getting screened for cancer? Do you engage in more preventative health behaviors now? What kinds?)
3. What advice would you give to a person around your age who is undergoing cancer treatment?
4. Is there anything else you'd like to share before we end the interview?

Close Social Network Member Narrative Interview Protocol

First, I'd like to learn about your experience as a close social network member to a young adult cancer survivor and how you talk about your cancer experience with others. Please try to think as broadly as you can about your experience.

1. Can you start by telling me the story of how you learned that your loved one was diagnosed with cancer? (Probe: When did he/she start to notice symptoms? Who were you with? How did you react?)
2. Can you tell me about the treatment and procedures your loved one received for his/her cancer? What physical and emotional changes did he/she undergo? (Probe: How does your loved one's cancer experience continue to affect them physically?)
3. Can you tell me about your experience in the months following the completion of your loved one's treatment? (Probe: Did you feel that things were getting back to "normal" or did they stay different? What was it like to "**reacclimate**" back into your old routines and schedule, if you were able to?)
4. Sometimes people whose loved ones have cancer feel like their lives have been interrupted. Can you tell me a story about something that has felt interrupted in your life? (Probe: This might involve your identity, daily schedule, future goals, or relationships.)
5. Can you tell me about a time when your life felt disrupted in a way that was different for a young adult than for someone else who might be going through this? (Probe: How was this disruption unique to a person your age?)

(Re)claiming Agency through Managing Social and Personal Uncertainty

Sometimes people whose loved ones experience a major diagnosis like cancer report that they feel uncertain, or that they have a lot of questions.

1. Can you tell me about a time that your cancer experience has caused you to feel uncertain or to have questions about something? (Probe: Can you think of a time when you felt uncertain or had questions about your loved one's diagnosis, treatment, prognosis, or side effects? Can you think of a time when you felt uncertain or had questions about changes in your identity, career, or future goals? Can you think of a time when you felt uncertain or had questions about how you were going to communicate with others or manage your relationships?)
2. Did this uncertainty feel like a good or bad thing?
3. What do you do when you feel uncertain in these situations? (Probe: Can you tell me about a time when you've really tried to avoid information?)
4. One experience that many people who have a loved one with cancer face is telling other people about their illness. Think about the times that you have told other people

about your cancer experience. What factors have affected your decision to tell someone about your cancer experience?

5. Can you tell me about a time when telling someone about your cancer experience was **easy**? (Probe: What did the person say or do to *encourage* you to talk about your cancer experience?)
6. Can you tell me about a time when telling someone about your cancer was **hard**? (Probe: What did the person say or do to *discourage* you to talk about your cancer experience?)
7. Can you tell me about a time when you purposely didn't tell someone about your cancer experience when you had the opportunity to do so? (Probe: Why did you do this? Can you tell me about a time when you were specifically told by your loved one not to tell someone about his/her cancer? Why did he/she do this? Did you ever tell your loved one not to tell anyone about his/her cancer?)
8. Who was primarily responsible for telling other people about your loved one's cancer and keeping them up to date about how he/she was doing? (Probe: Who managed the information? How were people kept in the loop? Who was most likely to reach out to people?)

(Re)shaping Identity

Sometimes people whose loved ones experience a major diagnosis like cancer report that they feel like a different person in some ways.

1. Are there any ways that you felt like a different person than before your cancer experience? (Probe: What parts of you still felt the same during your cancer experience? What does the future mean to you right now?)
2. Can you tell me about a time when you knew that your cancer experience affected how others saw you? (Probe: How did your cancer experience affect your identity at work, school, or in your activities?)
3. Sometimes when people go through life-changing experiences like cancer they keep mementos like scrapbooks, video journals, blogs so that they can look back on their experience. Did you or your loved ones make or keep anything to help you or them tell your story? (Probe: Why or why not?)

Building Community through Perceived Social Support

The experience of a loved one being diagnosed with cancer can influence how you interact with those who are close to you.

1. Can you tell me about a time when your interactions with someone close to you felt different because of your cancer experience?

2. Can you tell me about a time when you felt support from someone close to you after your loved one's cancer diagnosis? (Probe: Can you tell me about a time when someone close to you offered you support and you thought they handled it in an **effective** way? What made this a positive experience? What kinds of support do you find to be the most helpful from those close to you?)
3. Can you tell me about a time when you didn't feel support from someone close to you when you felt like you needed it after your loved one's cancer diagnosis? (Probe: Can you tell me about a time when you felt isolated? Can you tell me about a time when someone close to you offered you support and you thought they handled it in **ineffective** way? What made this a negative experience? What kinds of support do you find to be the least helpful from those close to you? Can you pinpoint the **worst** thing that someone said to you? Can you tell me about a time when you felt smothered or someone overstepped their bounds?)
4. Can you tell me about a time when you sought or asked for support from someone when you felt like you needed it? (Probe: What did you say? How did you go about asking for it? How did the person respond?)
5. Can you tell me about your loved one's role in helping you with his/her cancer? (Probe: What topics related to your cancer experience are **easy** to discuss? What topics are **difficult** to discuss or are things that you **avoid**? Can you tell me about a time when you may have overstepped your bounds or smothered your loved one? How did you provide support without feeling like you were being overbearing?)
6. Can you tell me about a time when your loved one needed support during his/her cancer experience? (Probe: Can you tell me about a time **when you offered** your loved one support when you thought he/she needed it? How did you approach him/her? Did he/she seem to appreciate it? Can you tell me about a time **when you didn't offer** your loved one support when you thought he/she needed it and you wish you had? Why didn't you?)
7. Can you tell me about a time when your loved one was able to offer you support when he/she thought you needed it during his/her cancer experience? (Probe: What made this support effective or ineffective at the time?)
8. How did this experience change your relationship with your loved one? (Probe: How did it change it for the **better**? How did it change your relationship for the **worse**?)
9. Can you tell me about a time when you felt support from one of your loved one's medical providers? (Probe: This can be an oncologist, infusion nurse, surgeon, etc. Can you tell me about a time when you **didn't** feel much support from one of your loved one's medical providers? What were the **other people** who accompanied patients like that you saw at your loved one's appointments? Do you think that your loved one's medical providers were equipped for dealing with young adult patients?)

10. Can you tell me about a time when you talked with others whose young adult loved ones were going through cancer? (Probe: Who initiated the conversation? What aspects of talking with others whose young adult loved ones were going through cancer are helpful? What aspects of talking with others whose young adult loved ones were going through cancer are not so helpful?)
11. Have you ever participated in any programs, services, or websites that were designed specifically for people whose young adult loved ones are going through cancer? (Probe: Can you explain what programs, services, or websites these were? What made them helpful? Would you recommend them to others?)
12. What kinds of things do you want to see in future programs, websites, or informational materials that are designed specifically for people whose young adult loved ones are going through cancer? (Probe: Can you think of programs, support services, or information that you wished were available to you during your loved one's treatment or even now?)

Making Treatment Decisions

I'd like to ask you some questions about how you've helped make decisions related to your loved one's cancer treatment. This can involve any decisions related to your cancer experience (e.g., selecting a procedure that was available to you, deciding the best way to manage your loved one's side effects, choosing who was going to take your loved one to the doctor's office on a particular day, etc.)

1. Can you tell me about a treatment decision that you've helped your loved one make about his/her cancer that was easy to make? (Probe: What made it easy? How did you **involve other people** in this decision?)
2. Can you tell me about a treatment decision that you've helped your loved one make about his/her cancer that was hard to make? (Probe: What made it difficult? How did you **involve other people** in this decision? Can you tell me about a time when you and your loved or others **experienced conflict** when you were trying to make a decision related to your cancer experience? How did you manage it?)
3. Did you ever try or think about trying any alternative, complementary, or holistic forms of treatment? Did your loved one's medical providers ever discuss anything related to fertility? Did your loved on undergo any reconstructive procedures?)
4. To what extent did your conversations with your loved one affect the decisions you made? What made these conversations **helpful** in making a decision? What made these conversations **unhelpful** in making a decision?

Making Sense of Illness through Humor

Sometimes when people are facing stressful experiences (like the experience of cancer), they use humor to help make sense of the situation, and sometimes they don't. I'd like to

ask you some questions about how humor has or has not played into your conversations about your loved one's cancer.

1. Can you tell me about a time when you or others used humor to make sense of your cancer experience? (Probe: Can you remember any specific instances of humor—any specific jokes or specific situations that were played for humor? Who do you **not feel comfortable** using humor with in talking about your cancer experience?)
2. Do you feel like humor has helped you or other people deal with your cancer experience better? (Probe: If so, do you feel like you use humor more for your own benefit or for the benefit of others?)
3. Can you tell me about a time when you used humor with your loved one specifically? (Probe: How did he/she respond and why? Do you feel like you use humor with your loved one more for your benefit or for his/hers?)
4. Can you tell me about a time when someone used humor and you felt like it wasn't really appropriate for the situation? (Probe: How did you respond and why? Can you tell me about a time when you used humor and other people felt like it wasn't really appropriate for the situation? How did they respond and why?)
5. Can you tell me about a time when you used humor with others whose loved one was going through cancer? (Probe: How was using humor with these people different than using it with others?)

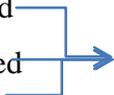
Final Thoughts

We have just a few questions left.

1. What has surprised you the most about your cancer experience so far?
2. So your loved one was diagnosed with cancer relatively early in life. Many people report that watching their loved one go through this experience changed them in some important ways. How has your cancer experience changed the way you take care of your health now? (Probe: How has it changed your attitudes, beliefs, or behaviors about preventative health, such as getting a vaccine, wearing sunscreen, or getting screened for cancer? Do you engage in more preventative health behaviors now? What kinds?)
3. What advice would you give to a person in your situation whose young adult loved one is going through cancer?
4. Is there anything else you'd like to share before we end the interview?

Appendix B
Survivor Questionnaire

First, I'd like to know a little bit about you.

1. What is your gender?
years old
 Male
 Female
2. How old are you? _____
3. What is the highest level of schooling you have completed?
 Grade school
 Middle school
 High school
 Associate's degree
 Bachelor's degree
 Master's degree
 Doctoral degree
4. What is your relationship status with the other person included in this study?
 Married
 Engaged  How many months ago did you first become romantically involved? _____
 Dating
 Parent  Mother Father
 Friend  How many months ago did you first become friends?

 Sibling  Older Younger Twin
 Child  Daughter Son
 Other  Please explain

5. Do you currently live with this person?
 No Yes
6. Do you have any children?
 No Yes  Date(s) of birth _____
7. How would you describe your ethnicity or race? _____
8. In what state do you live right now? _____

9. If you live in Kentucky, in what county do you live right now? _____

10. When were you initially diagnosed with cancer? (month, year) _____

11. How old were you when you were diagnosed with cancer? _____

12. When did you complete your primary round of treatment? (month, year) _____

13. What type(s) of cancer were you diagnosed with? _____

14. What was the highest stage of cancer you were diagnosed with?

I II III IV Unsure

15. Have you experienced a recurrence or secondary malignancy following the completion of primary treatment?

No Yes

16. Have you undergone any additional rounds of treatment following the completion of primary treatment?

No Yes

17. How would you describe the current status of your cancer? _____

18. Do you currently have a job?

No Yes → What type of work do you do?

Are you currently on disability? No Yes

19. Are you currently enrolled as a student?

No Yes → What degree are you working toward? _____

Are you currently taking time off from school? No Yes

20. Do you have health insurance?

No Yes → How did you acquire it? (Employer, parents, purchased it yourself, etc.) _____

What kind of insurance do you have? (e.g., PPO, HMO, Medicaid?) _____

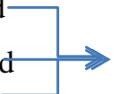
21. Do you have a religious affiliation?

No Yes → What is your affiliation? _____

Would you describe yourself as agnostic? Atheist? Other? _____

Close Social Network Member Questionnaire

First, I'd like to know a little bit about you.

1. What is your gender?
years old
 Male
 Female
2. How old are you? _____
3. What is the highest level of schooling you have completed?
 Grade school
 Middle school
 High school
 Associate's degree
 Bachelor's degree
 Master's degree
 Doctoral degree
4. What is your relationship status with the other person included in this study?
 Married
 Engaged  How many months ago did you first become romantically involved? _____
 Dating
 Parent  Mother Father
 Friend  How many months ago did you first become friends?

 Sibling  Older Younger Twin
 Child  Daughter Son
 Other  Please explain _____
5. Do you currently live with this person?
No Yes
6. Do you have any children?
No Yes  Date(s) of birth _____
7. How would you describe your ethnicity or race? _____
8. In what state do you live right now? _____
9. If you live in Kentucky, in what county do you live right now? _____
10. How would you describe the current status of the survivor's cancer? _____

11. How old were you when your loved one was diagnosed? _____

12. Do you currently have a job?

No Yes → What type of work do you do? _____

↓
→ Are you currently on disability? No Yes

13. Are you currently enrolled as a student?

No Yes → What degree are you working toward?

↓
Are you currently taking time off from school? Yes

14. Do you have health insurance?

No Yes → How did you acquire it? (Employer, parents, purchased it yourself, etc.?) _____

↓
What kind of insurance do you have? (e.g., PPO, HMO, Medicaid?) _____

15. Do you have a religious affiliation?

No Yes → What is your affiliation? _____

↓
Would you describe yourself as agnostic? Atheist? Other? _____

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- Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, *30*, 1221-1226.

Vita

Education

- M.A. **University of Dayton (2010)**
Communication
Thesis: *Laughing at death: The forms and functions of humor in illness trauma narratives*
Advisor: Teresa L. Thompson
Committee: James D. Robinson, Louis P. Cusella, Kathleen B. Watters
- B.A. **University of Dayton (2009)**
Communication: Electronic Media (Minors: English, Film Studies, Writing Certificate)
Summa cum Laude
Communication study abroad in Rome (2009)

Professional Positions Held

- 2014-Pres. **Assistant Professor of Communication**
Department of Language, Culture, and Communication, University of Michigan-Dearborn
- 2010-2014 **Graduate Research Fellow**
Department of Communication, University of Kentucky
- 2010-2014 **Graduate Teaching Assistant**
Department of Communication, University of Kentucky
- 2012 **Editorial Assistant**
Communication Yearbook 37 (Elisia L. Cohen, Ed.)
- 2011 **Research/Editorial Assistant**
Noar, S. M., & Harrington, N. G. (Eds.) (2012). *Interactive health communication applications: Promising strategies for behavior change*. New York: Routledge.
- 2009-2010 **Graduate Teaching Assistant**
Department of Communication, University of Dayton
- 2008-2010 **Foundations of Communication Theories and Research Tutor**
Department of Communication, University of Dayton

Awards and Honors

- 2014 University of Kentucky Department of Communication Graduate Student Dissertation Completion Fund, \$1,900

- 2013 Top Student Paper in Health Communication, National Communication Association Conference, Washington D.C.
- 2013 University of Kentucky College of Communication and Information Carozza Graduate Fund for Excellence in Cancer Communication, \$1,000
- 2013 Top Student Translational Research Paper, D.C. Health Communication Conference, Fairfax, VA
- 2010-13 Graduate Research Fellow, Department of Communication, University of Kentucky
- 2009 Faculty Award for Academic Excellence, Highest Undergraduate G.P.A. in Department of Communication, University of Dayton
- 2009 Ruhlman Library Award in Literary Achievement for Excellence in Writing, University of Dayton
- 2008 National Alumni Association Erma Bombeck Writer's Workshop Scholarship, University of Dayton

Professional Publications

Manuscripts under Review

1. **Iannarino, N.T.**, Veil, S.R., & Cotton III, A.J. *Bringing home the crisis: How U.S. evening news framed the 2011 Japan nuclear crisis*. First revision resubmitted to *Journal of Contingencies and Crisis Management*.
2. **Iannarino, N.T.** *Mike Birbiglia's "Sleepwalk with Me": Analysis of the effectiveness of a humorous narrative*. Under first revision to be resubmitted to *Health Communication*.

Refereed Publications

1. Cotton III, A.J., Veil, S.R., & **Iannarino, N.T.** (in press). Contaminated communication: TEPCO and organizational renewal at the Fukushima Daiichi Nuclear Power Plant. *Communication Studies*.
2. Head, K.J., Noar, S.M., **Iannarino, N.T.**, & Harrington, N.G. (2013). Efficacy of text messaging-based interventions for health promotion: A meta-analysis. *Social Science & Medicine*, 97, 41-48.

Edited Chapters

1. **Iannarino, N.T.** (contracted). Testicular cancer. In G. Colditz (Ed.), *Encyclopedia of cancer and society* (vol. 2). Thousand Oaks, CA: Sage.
2. Scott, A.M., & **Iannarino, N.T.** (2014). Ethical issues in health communication. In N.G. Harrington (Ed.) *Exploring health communication from multiple perspectives*. New York: Routledge.
3. **Iannarino, N.T.** (2012). Neo-Aristotelian analysis: Is this message effective? In S. Kerckmar & R. Kaufmann (Eds.) *Composition and communication workbook* (pp. 168-173). Mason, OH: Cengage Learning.

Manuscripts in Progress

1. **Iannarino, N.T.** (revisions). *Considering testicular cancer campaigns for the next decade*. Manuscript in preparation for submission to *Communication Quarterly*.
2. **Iannarino, N.T.**, & Shaunfield, S. (revisions). “*My insides feel like Keith Richards’ face*”: A narrative analysis of humor and biographical disruption in young adults’ blogs about the cancer experience. Manuscript in preparation for submission to *Health Communication*.
3. **Iannarino, N.T.** (revisions). “*What a loser that guy was*”: Norm Macdonald’s humorous critique of the romantic/warrior narrative. Manuscript in preparation for submission to *Western Journal of Communication*.
4. **Iannarino, N.T.**, Head, K.J., & Iannarino, A.M. (data analysis). *Communicative influences on high school football players’ weight gain behaviors: An application of the message convergence framework*. Manuscript in preparation for submission to *Journal of Communication & Sport*.
5. **Iannarino, N.T.**, Scott, A.M., Shaunfield, S.R., & Steckler, R. (data analysis). *The use of humor in siblings’ negotiations of end-of-life health decisions for aging parents*. Manuscript in preparation for submission to the *Journal of Health Communication*.
6. Goldsmith, J., Wittenberg-Lyles, E.M., Platt, C., **Iannarino, N.T.**, & Reno, J.E. (data analysis). *Family caregiver communication patterns in oncology: Advancing a typology*. Manuscript in preparation for submission to *Psycho-Oncology*.
7. **Iannarino, N.T.**, Thompson, T.L., & Robinson, J.D. (revisions). *Burnt up: A narrative analysis of Richard Pryor and the pipe*. Manuscript in preparation for submission to *Narrative Inquiry*.

8. **Iannarino, N.T.**, Thompson, T.L., & Robinson, J.D. (revisions). *Shangri-Lost in the International House of Cancer: An analysis of Julia Sweeney's humorous illness narrative*. Manuscript in preparation for submission to *Journal of Medical Humanities*.

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