"IT WAS PART OF THE WATER WE WERE MOVING IN, THE AIR WE WERE BREATHING:" PARENT AND ADULT-CHILD COMMUNICATION ACROSS A MOTHER'S BREAST CANCER TRAJECTORY

BY

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DISSERTATION

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ABSTRACT

A cancer diagnosis is a life altering experience that creates uncertainties and dilemmas. These challenges affect both patients and other members of their families. However, the existing literature focuses almost exclusively on how patients and spouses communicate following a cancer diagnosis, which ignores the perspectives and experiences of other family members. Adult children's involvement in a parent's cancer experience is likely complex. In particular, adult children may find it challenging when their preferences for information management are not congruent with what their diagnosed parent divulges. Further, factors characteristic of the adult child life stage, like geographic separation and changing parent-child relationship dynamics, may complicate interaction following a parent's cancer diagnosis. The current study employed a normative perspective of communication to better understand how adult children negotiate involvement in a parent's breast cancer experience. In-depth qualitative interviews with thirty adult children provided insight into the specific challenges adult children face, and the strategies used to overcome those challenges, during each stage of a mother's breast cancer trajectory. Adult children reported challenges relating to (a) information management, (b) social support, (c) geographic separation, and (d) changes to the parent-child relationship. Potential dilemmas associated with each challenge complicated adult children's involvement in their mother's cancer experience. Findings illuminate strategies that adult children consider to be effective in managing dilemmas of interaction in this context. The major implications of this dissertation extend theoretical and practical knowledge of family communication and cancer. In addition, this dissertation highlights the benefit of building a more complete picture of how various family members communicate following a cancer diagnosis.

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CHAPTER 1: Introduction

Interpersonal communication is a major factor in a family's ability to adjust to cancer. Following a cancer diagnosis, family members often renegotiate relationships and identities (e.g., Goldsmith, 2009), mutually manage uncertainty (e.g., Beach & Good, 2004), and exchange illness-related information (e.g., Donovan-Kicken & Caughlin, 2010). Positive family interaction during this health crisis is critical to the patient's well-being and adjustment because "the way people cope is largely a function of their interactions with others" (Afifi & Nussbaum, 2006, p. 282). Several scholars have attended to the notion that family members differ in their ability to cope with a loved one's cancer diagnosis, which can lead to varying levels of adjustment (Northhouse, Templin, & Mood, 2001). Most of the literature, however, centers on the *patient's* perceptions of family communication (e.g., Donovan-Kicken, Tollison, & Goins, 2011; Yoshida, Otani, Hirai, Ogata, Mera, Okada, & Oshima, 2010) rather than focusing on family members directly. This is problematic because it incorrectly assumes that patients understand and can competently assess each family member's functioning (Lewis & Hammond, 1996). What is more, the vast majority of the extant literature that does directly consider family members' perspectives only spotlights the spouse's experiences (e.g., Miller & Caughlin, 2011; Zhang & Siminoff, 2003). This research, however, may not successfully extrapolate to other family members, like adult children.

There is a vital need to expand research concerning how adult children communicate about a family member's cancer diagnosis, treatment effects, and day-to-day survivorship (Harris, Bowen, Badr, Hannon, Hayt, & Regan Sterba, 2009). In particular, because the median age at diagnosis for most types of cancer hovers around 65 (American Cancer Society, 2015; National Cancer Institute, 2013), scholars must turn their attention to understanding how adult

children communicate following a parent's cancer diagnosis. Examining adult children's communication behavior from the patient's perspective would be incomplete because there does not appear to be a tight fit between what family members experience and what parents think family members do to cope with cancer (Lewis & Hammond, 1996). Thus, additional research that solicits the views of adult children is needed to understand how families communicate following a parent's cancer diagnosis.

Although most of the literature has focused on patients' and spouses' perspectives, substantive inroads have been made to more fully understand how adult children are implicated in a parent's cancer diagnosis. Harzold and Sparks (2006), for example, explored adult children's perceptions of a diagnosed parent's use of cancer-related humor. Similarly, Fisher (2010) and Fisher and her colleagues (2014) explored the ways in which mother-daughter communication about breast cancer impacted how daughters coped with their mother's diagnosis and how mothers adapted to the disease. Yet, current investigations of how parents and adult children communicate in this context only provide a snapshot of the cancer trajectory. Fisher (2010) and Fisher and her colleagues (2014), for example, focused only on the initial cancer disclosure and communication between mothers and adult daughters during cancer treatment. Other scholars (e.g., Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011; Stone, Mikucki-Enyart, Middleton, Caughlin, & Brown, 2012) focused on the other end of the cancer trajectory by exploring how adult children coped with the death of a parent due to lung cancer. Missing from this body of work is an acknowledgement of how the diagnosis, treatment, remission, and recurrence phases of cancer create specific challenges for families.

A normative approach (Goldsmith, 2001, 2004) offers a useful way to conceptualize challenges or problems associated with communication between parents and adult children in

this context. In particular, a normative approach provides a theoretical account for the effectiveness of adult children's communication behaviors by highlighting strategies that may be more adaptive, effective, or functional for adult children at different points in the illness trajectory. This type of research is important because adult children admit to not knowing how to talk about cancer with a parent, and parents report unhelpful family communication, which limits family members' ability to cope in adaptive ways (Fisher, 2010; Reynolds & Perrin, 2004). Family members often have a large repertoire of behaviors to cope flexibly with cancer (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992), but communication behaviors that may have worked well during one stage of the cancer trajectory may no longer be of use when transitioning from one stage to the next (Jacobs, Ostroff, & Steinglass, 1998; Veach, Nichols, & Barton, 2002). Understanding how and when adult children employ these strategies and their perceived effectiveness would allow for a better understanding of how parents and children communicate about cancer.

The purpose of this dissertation is to examine how communication about cancer is meaningful to adult children across a parent's cancer trajectory. To this end, the subsequent chapter provides a brief overview of how one type of cancer, breast cancer, impacts the family system and current approaches to understanding how families communicate about breast cancer across the illness trajectory. In that chapter, Goldsmith's (2001, 2004) normative approach is introduced as a way to account for the specific challenges adult children encounter across a parent's illness trajectory and why some strategies for overcoming those challenges may be more effective than others. Chapter three outlines the methodological procedures, and chapter four presents the results of thirty qualitative interviews with adult children. The final chapter

concludes this dissertation by interpreting the findings, highlighting theoretical and practical

implications, and suggesting avenues for additional research.

CHAPTER 2: Literature Review

Family Communication and Breast Cancer

There has been growing recognition that cancer is a family illness (Kristjanson & Ashcroft, 1994; Northouse & Northouse, 1988; Ostroff, Ross, & Steinglass, 2000). In other words, in addition to cancer affecting the patients themselves, its diagnosis, treatment, and recurrence or remission affect other family members as well. There is a specific need to understand how families communicate following a patient's breast cancer diagnosis. As of January 2010, approximately 2.9 million women and 14,000 men in the United States were living with a history of breast cancer (i.e., currently being treated for cancer or completed treatment; American Cancer Society, 2015). In 2015, an estimated additional 231,840 women and 2,350 men will be diagnosed with breast cancer and 40,290 women and 440 men will die from breast cancer (American Cancer Society, 2015; National Cancer Institute; 2013). Based on this data, the number of family members affected by breast cancer is staggering.

Efforts to investigate family members' reactions to a breast cancer diagnosis have mostly centered on spouses of female breast cancer patients (e.g., Donovan-Kicken & Caughlin, 2010; Weber & Solomon, 2008). However, because breast cancer most commonly affects individuals between the ages of 60-75 (National Cancer Institute, 2013), an increasing number of adult children will be faced with a parent's breast cancer diagnosis. Exploring how children communicate following a parent's breast cancer diagnosis is important because, as a family encounters this transition, children must adopt new "strategies, skills, and patterns of behavior to solve new problems" (Cowan, 1991, p. 17). And, although children of all ages struggle with fear, sorrow, anxiety, anger, and withdrawal when a parent is diagnosed with cancer (Bugge, Helseth, & Bardyshire, 2008), children in different life stages face unique challenges. Adult children, for

example, often struggle to maintain a balance between living their own lives, attending to the needs of the family, and caring for the ill family member (Veach et al., 2002).

Individuals encounter unique communication challenges within the parent-child relationship following a parent's breast cancer diagnosis. For example, mothers who have been diagnosed with breast cancer frequently report that one of their main concerns is when and how much to tell their children about the diagnosis (Fisher, 2010; Fisher et al., 2014; Helseth & Ulfsaet, 2005; McGivern, Everett, Yager, Baumiller, Hafertepen, & Saal, 2004). Many parents report not knowing how to respond to their children's reactions to their diagnosis in appropriate ways (Helseth & Ulfasaet, 2005), and many mothers find it hard to establish the right balance between telling the truth and protecting their children (Fisher et al., 2014). Even after communicating about breast cancer with a child, mothers sometimes continue to doubt their decisions (Stiffler, Haase, Hosei, & Barada, 2008). It is unclear, however, whether adult children experience the same, similar, or different communication challenges as their parents.

To date, much of the research on how children experience a parent's cancer has focused on individuals who were either young children or adolescents at the time of their parent's diagnosis (e.g., Lewis & Hammond, 1996; Spira & Kenemore, 2000). Little is known about how adult children communicate during a parent's cancer trajectory (Fisher, 2010; Harzold & Sparks, 2006). And, because many adult children do not live with their parents (whereas most young children and adolescents reside in the family home), accounts of how young children or adolescents experience a parent's cancer may not apply to adult children. Adult children who do not live at home, for example, often do not face the everyday impact of a parent's cancer and may experience more of a shock upon seeing a parent's worsening condition (Basinger, Wehrman, Delaney, & McAninch, 2015).

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The available research concerning how adult children experience a parent's cancer suggests that parents often have higher expectations for older children's behavior than they do for younger children (Bugge et al., 2008). Parents' strategies for disclosing the diagnosis (Hay, Shuk, Zapolska, Ostroff, Lischewski, Brady, & Berwick, 2009) and parents' expectations for the child's communication following the disclosure (Fisher, 2010) also appear to differ based on the child's life stage. Fisher (2010), for example, found that mothers expect their adult daughters (more so than adolescent daughters) to be willing to talk about their breast cancer experience and be able to give suggestions for how to cope with treatment effects. In addition, although it is common for breast cancer patients to selectively disclose information or avoid communication about cancer with children to prevent worry or upset (Asbury, Lalayiannis, & Walshe, 2014), adult children often report being worried and upset when they are excluded from a parent's cancer experience (Stone et al., 2012). This may lead parents to think critically about how to disclose cancer related-information to adult children and to coordinate disclosure decisions in order to reduce adult children's anxieties (Hay et al., 2009).

One line of research asserts that adult daughters ultimately live with a psychological "chronic risk" due to a fear of future disease reoccurrence for their mother as well as a risk for themselves in developing the disease (Kenen, Arden-Jones, & Eeles, 2004). When daughters are aware of their increased risk of developing cancer, they often display higher emotional distress and elevated levels of stress hormones (Cohen, Klein, Kuten, Fried, Zinder, & Pollack, 2002). Although this research does not take into account sons' perspectives, it does suggest that breast cancer creates unique challenges for both mothers and their adult daughters. Communication may be the key to a family's ability to "adopt new strategies, skills, and patterns of behavior to solve new problems" (Cowan, 1991, p. 17).

In sum, a breast cancer diagnosis is a family condition that affects the patient, spouse, and children in unique ways. Although all children may struggle with similar emotions (Bugge et al., 2008), some research suggests that expectations for older children's communication behaviors may differ from children in other life stages (e.g., Fisher, 2010). Exploring communication behavior between parents and adult children (rather than relying on parents' reports or data based on children in different life stages) would allow for a better understanding of how families communicate following a parent's breast cancer diagnosis. In particular, highlighting the communication between adult children and their parents during each stage of a parent's cancer trajectory is one way to understand how adult children communicate in this context.

Family Cancer Communication Across the Illness Trajectory

The clinical course of breast cancer can be broken down into four phases: diagnosis, treatment, rehabilitation/remission, and recurrence (Corbin & Strauss, 1988; Holland, 1989). Although family members tend to be included in each stage of the illness, most scholars have focused on family communication during the diagnosis and treatment stages (Veach et al., 2002). Leading up to and following the initial diagnosis, individuals may share symptoms with select family members or they may choose to keep symptoms a secret (Veach et al., 2002). If information about cancer is shared with family members, the family moves into the acute phase of hearing the diagnosis, understanding and comprehending the diagnosis, and making treatment decisions. Scholars (e.g., McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; Shields, Travis, & Rousseau, 2000) have identified social support, changes in appraisal, and family reorganization as particularly important for avoiding crisis following the disclosure of a cancer diagnosis. Viewed as a relational event, the initial disclosure of the cancer diagnosis can be defined as a relational transition that changes the way parents and adult children view each other

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and their relationship (Knobloch & Solomon, 1999). Transitions can prompt intrapersonal and interpersonal doubts as partners renegotiate patterns of interdependence to fit their new circumstances (Solomon & Knobloch, 2004).

The treatment of breast cancer may include surgery, chemotherapy, radiation therapy, or some combination of each (American Cancer Society, 2014, 2015). During the treatment stage, family members often want to understand more about how to cope with different treatment regimens and their side effects, how to reassign roles within the family, and how to maintain a balance between living individual lives, attending to the needs of the family, and caring for the ill family member (Veach et al., 2002). Family communication during this stage may vary based on which family member has been diagnosed with cancer. For example, a woman's cancer diagnosis can be particularly difficult for male spouses, who are often suddenly expected to take on a caregiver role (Harris et al., 2009). When a child is diagnosed with cancer, parents may feel that their role as a protector and authority figure is threatened. For instance, Coyne, Wollin, and Creedy (2012) found that mothers often wrestle with guilt over their daughter's breast cancer diagnosis. Following a parent's diagnosis, children sometimes take on more of a 'parent' role by helping with childcare and household tasks (Wong, Ratner, Gladstone, Davtyan, & Koopman, 2010), and extended family members may be called upon for secondary support depending on level of medical knowledge (Beach & Good, 2004; Coyne et al., 2012). Overall, family members appear to struggle with "anxiety about whether medical treatment will be successful, resentment about this unwelcome intrusion, or despair that expectations about family life have been ruptured" (Sherman & Simonton, 2001, p. 194).

Following the initial course of treatment, patients and families enter the rehabilitation or remission phase. For some, this could come just a few weeks after diagnosis, while for others it

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could have been months since diagnosis (American Cancer Society, 2014). In this stage, families must adapt to life with uncertainty of whether the disease will recur (Veach et al., 2002). A major challenge during this stage involves family members' differing preferences for how to communicate about cancer. This phase is sometimes characterized by a disconnect between the patient and the rest of the family, and conflicts may arise between family members who are eager to put the experience in the past and patients who may struggle with increased feelings of vulnerability (Sherman & Simonton, 1999). For example, the entire family may have been mobilized into action during the treatment phase, but once treatment concludes, family members sometimes want to get on with their own personal lives (Miller, 2015). Failure to adapt to the survivor's desire for a new, post cancer identity can result in negative relational consequences if survivors begin to avoid the people who highlight this kind of identity challenge (Miller, 2015). Overall, families report that talking about a family member's potential death following a cancer diagnosis is difficult, even several years after remission (Galvin, Dickson, & Marrow, 2006).

If the cancer recurs, a second round of treatment is often offered (American Cancer Society, 2014, 2015). In this stage, patients and families are frequently faced with the same stressors as in the initial treatment stage (Veach et al., 2002). At the same time, families typically experience heightened levels of shock, disbelief, and despair (Sherman & Simonton, 2001). For example, the family must adapt to renewed tests and a more aggressive cancer treatment. If renewed treatments fail and the disease progresses, families enter the terminal illness and bereavement phase (Veach et al., 2002). Families who adapt better to the bereavement phase take time to review their lives, resolve family conflicts, and communicate important messages (Shearman & Simonton, 2001). Conversely, families who have greater difficulty in this phase regard death as a taboo subject and avoid communicating about death by encouraging more

aggressive treatment options (Shearman & Simonton, 2001). As this research suggests, communication and (mal)adaptation appear to be intimately linked during the recurrence stage.

Importantly, not all individuals diagnosed with cancer will go through every stage, and families spend varying amounts of time in each stage (Holland, 1989; Nicholas & Veach, 2001). All breast cancer trajectories share the common phases of diagnosis and treatment planning. After these initial phases, however, breast cancer trajectories can differ dramatically from family to family. Cancer often follows one of four trajectories: (a) cancer diagnosis, primary treatment, and remission resulting in long-term survival; (b) cancer diagnosis with no primary treatment possible, resulting in terminal illness and death; (c) cancer diagnosis, primary treatment with no response, resulting in terminal illness and death; and (d) cancer diagnosis, primary treatment, remission, disease recurrence resulting in additional treatment or death (Holland, 1989). These common trajectories suggest that families will experience breast cancer diagnoses in a variety of ways, and some families will experience longer cancer trajectories than others.

Corbin and Strauss' (1988, 1991) *theory of illness trajectories* recognizes that chronic diseases, such as breast cancer, have their own phases, turning points, and periods of stability and instability. This model conceives of chronic disease as a multidimensional experience with biomedical, psychosocial, and environmental components that constitute the illness experience (Corbin & Strauss, 1988, 1991). The theory of illness trajectories was originally developed as a conceptual model for chronic and terminal illnesses, but it also been used to study nonterminal chronic illnesses by taking into account a person's disease over time. One key component of the model is the idea that people have to *work* to deal with the twists and turns of a chronic illness (Corbin & Strauss, 1988). Work in this context consists of "tasks that must be carried out consecutively or concurrently, assignment of workers' responsibilities (to oneself or to others);

exertion of effort and demand for resources; coordination and organization of duties and resources; division of labor throughout various projects and phases; the expectation of perceived benefits; and management over time in the context of changing trajectories" (Donovan-Kicken Tollison, & Goins, 2012, p. 642). These tasks can be organized into three distinct lines of work: (a) illness work, which involves managing tasks related to the health condition, (b) biographical work, which means coming to terms with what the illness entails for identities and future plans, and (c) everyday-life work, which refers to ordinary daily tasks aside from the illness (Corbin & Strauss, 1988). Work is considered demanding for both patients and their significant others because it takes place alongside other tasks required in the families' daily lives. Indeed, the theory acknowledges that trajectories differ from day-to-day and person-to-person.

Donovan-Kicken and her colleagues (2012) highlighted the role of communication in managing these three lines of work by proposing the concept of *communication work*. After interviewing individuals diagnosed with a variety of cancers, the authors concluded that communication work includes four major features. First, communication work was found to be *demanding and effortful* because cancer patients described situations where a significant amount of thought was needed to design messages, report to others about diagnosis, treatment, implications, prognosis, and further developments, and coordinate the flow of information with loved ones. Second, communication work was found to be a matter of *duties and obligations* because cancer patients felt a sense of duty to talk to others, especially in terms of informing loved ones about the diagnosis, explaining what was happening, and keeping people updated. Third, communication work entailed *preparing and planning for talk* because cancer patients thought carefully about how to deliver cancer-related information and had to learn how to estimate how others would respond to that information. Part of this work involved researching

information ahead of time and being prepared to answer questions and respond to concerns. The final feature of communication work was *active message design*. The women in Donovan-Kicken and colleagues' sample reported staying positive, practicing what they wanted to say, and using email as ways to deliver cancer-related information effectively. The four defining features of communication work highlight communication challenges that are often experienced by both cancer patients and family members. For example, one strategy patients used to manage these lines of work was asking family or friends to be "spokespersons, secret-keepers, or information filters" (p. 646). Finally, although it was not a focus in this study, the authors noted that communication work recurred in new ways across the cancer trajectory.

     The role of family in a patient's cancer trajectory. As the previous section implied, family members are often called upon to help manage illness, biographical, everyday-life, and communication work following a cancer diagnosis. Managing the division of work is often problematic for families. Indeed, helping with a parent's illness-related work is an unprecedented role shift that seems to be challenging and emotionally distressing for adult children (Ravies & Pretter, 2005). For instance, Fisher (2010) reported that it was common for adult daughters to help with everyday-life work by taking on new roles as acting parent, helping with childcare, and completing housework. Adult children's biographical work may be challenged when they take on everyday-life work that would usually be in the parent's domain (Oktay & Walter, 1991). And, although Donovan-Kicken and her colleagues (2012) focused on the communication work experienced by cancer survivors, the four defining features of communication work suggest that managing cancer-related information and dealing with questions/comments/emotions of others also may be regarded as challenging work for family members. Indeed, Donovan-Kicken et al. noted that children, spouses, and close friends often helped with disseminating information by

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presenting illness-related information in the best possible light or by helping control the flow of information by withholding information from certain individuals. Thus, it appears that adult children are likely implicated in all four lines of work.

Moving from one stage of an illness to another (e.g., moving from treatment to remission, or from remission to recurrence) also creates a corresponding change in the type and nature of patients' and family members' lines of work (Corbin & Strauss, 1988, 1991). For families experiencing a more advanced stage cancer, the clinical course may move directly from diagnosis to palliative care. Illness work may take center stage in this situation as the patient and his or her family manage continual oscillations between illness, treatment, and recovery (Reed & Corner, 2015). This is problematic, however, because a focus on illness work complicates the successful management of biographical, everyday-life, and communication work. For example, adult children may find it hard to maintain a sense of self (biographical work) or carry out tasks related to school or work (everyday-life work) while coping with a parent's rapidly changing health status. Beach and Good (2004) recounted one example of a son who booked a flight home when his mother took a turn for the worse, but then had to suddenly cancel his plan when his mother stabilized. This example highlights how a parent's changing health status can make it difficult for adult children to successfully manage tasks related to their own everyday life work. Communication work is likely also effortful for adult children as they negotiate what information to ask for, how to decide what information to share with others, and when to provide (or ask for) social support. Adult children's communication work may also be characterized by challenges related to attending to their own, their parent's, and their other family members' preferences for communication.

Management of the four lines of work also appears to differ depending on the parent's unique illness trajectory. As compared to trajectories characterized by a gradual decline, family interactions during trajectories characterized by a sudden decline are more intense, rushed, and have less information flow between family members (Matocchio, as cited in Kristjanson & Ascroft, 1994). When a family's expectations of the illness trajectory are similar to the actual illness trajectory, families are less exhausted and have less conflict and guilt than families who report incongruence between their expectations and the actual illness trajectory members (Matocchio, as cited in Kristjanson & Ascroft, 1994). In addition, patients and their family members may experience elevated levels of communication work due to differing needs for information across the illness trajectory (Donovan-Kicken et al., 2012).

Taken together, this research suggests that unique cancer trajectories may impact how adult children and their family members experience biographical, illness, everyday-life, and communication work. For example, adult children may spend a tremendous amount of time preparing and planning for talk about the cancer diagnosis and treatment for an aggressive cancer, whereas less effort may be needed if the cancer was diagnosed in an early stage. Similarly, keeping each other updated may be less effortful or demanding if the cancer goes into remission after one round of treatment. More work would be required, however, if the cancer does not react positively to treatment and a new regimen is recommended. Thus, although all families likely experience the same types of work during the cancer progression, the content and timing of stages may impact adult children's experience of communication work. Thus, rather than expecting uniform communication across the illness trajectory, research must account for different experiences of cancer (e.g., stage of cancer), different relational histories and interaction patterns (e.g., relational roles), and individual preferences (e.g., information seeking

orientations) across the illness trajectory (Goldsmith & Miller, 2015). Additional research that examines the work undertaken by adult children, and how that work may change across the illness trajectory, would be a significant contribution to this body of research. As such, I propose the following research question:

RQ1: What is the nature of adult children's work across a parent's breast cancer trajectory?

A Normative Approach to Adult Children's Communication Work

Because one goal of this study is to examine how communication about cancer is meaningful to adult children across the illness trajectory, it is important to document how adult children evaluate the purposes and effectiveness of those interactions. Families often find talking about health topics to be challenging and complex (e.g., Goldsmith, Miller, & Caughlin, 2008). Cancer patients, for example, often consider the benefits and drawbacks of disclosing their health concerns to family members (Donovan-Kicken & Caughlin, 2010). Similarly, although family caregivers consider communication about cancer to be among their most urgent needs, they talk less and hold back more than the patient. Thus, it appears that health concerns often create communication dilemmas for both patients and family members, and coordinating each family member's preferences for communication can be difficult.

For these reasons, employing Goldsmith's (2001, 2004) normative perspective on communication is a useful way to understand communication in this context. The normative approach is a particular variation of multiple goals theories that focuses on the multiple and potentially conflicting meanings of talk within particular contexts (Goldsmith, 2001). At the heart of this perspective is the idea that scholars can make normative claims about competent communication by looking at which goals are salient in a given situation and how people attend

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to those goals. Three types of goals are relevant to communication: instrumental goals, which define the purpose of an interaction (e.g., gaining more information about a parent's cancer treatment); identity goals, which focus on the mutual presentation and reinforcement of communicators' selves (e.g., trying to be a 'good child' by respecting the parent's autonomy); and relational goals, which address the development and negotiation of relationships (e.g., dealing with concerns about how conversations about the parent's breast cancer might change the nature of a parent-child bond; Clark & Delia, 1979). Sometimes, the pursuit of one goal may interfere with the successful accomplishment of another goal, thereby creating a communication dilemma (Goldsmith, 2001, 2004).

In the context of cancer, patients and family members often feel that conversations with close others are packed with multiple purposes. For example, breast cancer patients report feeling obligated to inform family members about treatment decisions or their prognosis while also worrying that telling family members may disrupt that person's life or cause too much anxiety (Donovan-Kicken et al., 2012). Similarly, family members find it challenging to attend to the multiple, and sometimes competing, demands during conversations about cancer (Goldsmith, 2004; Miller, 2015). In the context of communication between adult children and their diagnosed parent, dilemmas may arise if geographically separated children receive a different amount or type of information as compared to family members who still live at home, if the diagnosed parent asks an adult child to withhold cancer-related information from other family members, or if an adult child feels that his or her identity is threatened due to taking on a caregiving role during treatment or recurrence. In these examples, dilemmas arise when actions to accomplish one objective (e.g., information exchange) conflict with actions to accomplish another objective (e.g., impression management).

In addition to identifying context-specific communication dilemmas, a normative approach illuminates reasons that some conversational strategies may be more successful or effective than others (Goldsmith, 2001; Goldsmith, Lindholm, & Bute, 2006). A normative perspective determines the relative success of a conversational strategy by considering the relevant communication challenges within a given context and then evaluating whether an individual's communication and behavior successfully managed those specific challenges (Goldsmith, 2001; Goldsmith & Fitch, 1997). In other words, each communication context has a particular set of challenges, and the strategies an individual employs while working to meet those challenges emerge from factors related to the specific context and individual relationships. This suggests that gaining a better understanding of the communication challenges and dilemmas that an individual may encounter in a given situation (and the various strategies that can be utilized to overcome those challenges) is one way to determine what counts as more or less successful communication.

Caughlin and his colleagues (2011) provide a relevant example of how the normative approach can be used to understand how adult children communicate following a parent's death due to lung cancer. Adult children reported unique challenges related to avoiding information and avoiding their own and their parent's emotions. In order to overcome these communication dilemmas, adult children employed the strategies of *segmentation* (enacting avoidance of certain topics while engaging in open communication about other topics), *denial* (choosing avoidance over openness), and *being open while avoiding* (clearly stating that communication was open but also admitting that there were salient issues that they never talked about; Caughlin et al., 2011). This suggests that as adult children communicate about a parent's cancer, they experience unique communication challenges and employ unique strategies for managing those challenges. Some

strategies were more successful than others in balancing multiple meanings of openness and avoidance.

Past investigations of parent and adult child communication in this context have focused on interactions that occurred during one or more specific stages of a parent's cancer rather than exploring how communication may differ across the cancer trajectory (e.g., Caughlin et al., 2011; Fisher, 2010; Fisher et al., 2014; Stone et al., 2012). This is problematic because the challenges related to communicating about cancer change across the illness trajectory (Beach & Good, 2004; Donovan-Kicken et al., 2012; Miller, 2015; Reed & Corner, 2015). For example, cancer survivors sometimes initially feel a sense of duty to help family members understand the prognosis and plans for treatment, but withhold more information from certain individuals over time to avoid additional worry and anxiety (Donovan-Kicken et al., 2012). Similarly, preparation and planning for communication takes place in distinctive ways during each stage within the cancer trajectory (Donovan-Kicken et al., 2012; Fisher, 2010; Miller, 2015). Taken together, it appears that communication challenge manifest in unique ways depending on the cancer trajectory, and adult children are likely required to adapt their strategies accordingly. Effective communication in this context can be assessed by investigating how adult children respond to the demands imposed by each stage of a parent's cancer trajectory (Goldsmith, 2001, 2004). To explore this idea, the following sections highlight how information management, geographic separation, and relationship changes may create unique challenges or dilemmas for adult children.

Information management. Family members' decisions to either reveal or conceal cancer-related information hinge on a variety of motivations (Goldsmith et al., 2008). Because maintaining control over information appears to be particularly relevant to individuals who feel

that they are losing control of their health (Donovan-Kicken et al., 2011), challenges and dilemmas for parents and adult children likely revolve around competing desires to conceal or reveal cancer-related information. One avenue for regaining control over the cancer experience is by regulating the exchange of cancer-related information. For example, cancer patients often think critically about the timing, wording, amount, and content of information shared with family members and close friends (Donovan-Kicken et al., 2011). Low communication efficacy (Semple & McCaughan, 2012), the desire to maintain a hierarchical role and identity as a parent (Caughlin et al., 2011), and the desire to avoid worrying or burdening the child (Weber & Solomon, 2008) have also been cited as reasons for avoidance of cancer-talk between parents and children. In addition, a main theme guiding how women with breast cancer talk to their children is a goal to protect children from distress; mothers prefer to share information when there is something definite or factual to tell, but withhold more when information is uncertain or unclear (Asbury et al., 2014). Across studies, parents who report not knowing what information to share with the child or how the child will cope with that information appear to be less likely to disclose cancer-related information. Thus, although some parents may want to disclose the news soon after a diagnosis so that they can be the primary source of information about their illness (Semple & McCaughan, 2012), there are a variety of factors that influence the decision to withhold information.

Because cancer is considered a family disease (Kristjanson & Ashcroft, 1994; Northouse & Northouse, 1988; Ostroff et al., 2000), communication scholars must consider how other family members are implicated in the successful management of cancer-related information. One way that family members negotiate co-ownership (Petronio, 2002) of private information is by creating individual and content specific rules about sharing and withholding information. In the

context of infertility, for example, spouses sometimes create mutually agreed rules that allow each of them different parameters for disclosure (Steuber & Solomon, 2011). Creating unique rules enhances satisfaction for partners who disclose different amounts of information, or who are differentially comfortable with disclosure. Interestingly, decisions about sharing and withholding health information can evolve over time, even within the same relationship and the same topic of conversation. For example, individuals who never used to talk about sex become more comfortable with that topic of conversation after experiencing infertility issues (Steuber & Solomon, 2012). Conversely, some individuals withhold more infertility-related information over time due to the risk of being asked to share additional information. Taken together, these examples demonstrate how a family's privacy rules (Petronio, 2002) may be adjusted to meet new situational demands and preferences for talk following a health crisis.

Issues relevant to each stage of a parent's cancer experience suggest that information management will be challenging for adult children. Some of these challenges likely persist across all stages of a parent's illness trajectory. If parents withhold cancer-related information, adult children may experience ongoing challenges related to fulfilling their own needs for support, determining standards of appropriateness (e.g., differing views on what counted as supportive and unsupportive communication), and establishing how much talk about cancer is acceptable (Petronio, Jones, & Morr, 2003; Stone et al., 2012). Similarly, talk about feelings may be complicated during every stage of the illness trajectory. For some individuals, talking about feelings may lead to a greater understanding of the illness experience, whereas talk about feelings may exacerbate fears (Goldsmith & Miller, 2015). Some adult children may talk about feelings only if it becomes too overwhelming to continue to avoid talking. In this case, talk about feelings may resemble an outburst of negative affect (Goldsmith & Miller, 2015).

Other communication challenges may be specific to, or particularly relevant during, one stage of a parent's cancer. The typical cancer trajectory may prompt parents and adult children to start with talk about facts and medicine and discuss emotion only after they have attended to the facts (Goldsmith & Miller, 2015). Indeed, a cancer diagnosis often immediately leads to an intensive search for facts and medical information relevant to decision-making, followed by decision-making relative to treatments and adjustments to everyday life work. And, although it may be common for adult children to help their parent make treatment decisions, adult children may feel that being left out of family decision-making relative to their parent's cancer is functional if it was done for protective purposes (Caughlin et al., 2011; Wolf, 2014).

A cancer recurrence likely poses additional information-management challenges. For example, one mother in Veach and colleagues' (2002) study about family communication and cancer said, "I just couldn't bother my daughter with my fears of cancer recurrence any longer. She was finishing school and getting ready to go to Europe. She had so much to do and so many things on her mind. Every time I talked to her, I felt like I upset her. I tried to keep our conversations light, but then it just got easier to stay away from her too." Although this quote is from a diagnosed parent (rather than an adult child), it illustrates how the recurrence stage may give rise to unique communication challenges for parents and adult children. In particular, parents and adult children who keep worries and feelings about cancer recurrence hidden may experience additional emotional and relational turmoil.

The previous review highlights some of the challenges adult children may face and some of the communication strategies adult children may employ in this context. Explicating challenges or dilemmas related to information-management in each stage of the cancer trajectory is important given that managing information appears to be central to adult children's

experiences surrounding a parent's cancer. The available literature tells us little, however, about how adult children manage these dilemmas during each stage of a parent's cancer trajectory. Donovan-Kicken and her colleagues' (2012) research concerning patients' strategies for addressing communication dilemmas suggest that management of these dilemmas will require adult children to strategically choose the people with whom to discuss their parent's cancer and make deliberate decisions about the timing, wording, and channel of communication. The following research questions were posed to explore adult children's dilemmas, and strategies used to overcome those dilemmas, related to information management:

RQ2: What are adult children's communication challenges in managing cancer-related information?

RQ3: How do adult children manage communicative dilemmas pertaining to managing cancer-related information?

Geographic separation. Unique structural stressors may create a complex coping context for adult children. Adult children are often geographically separated from parents and other family members during some (or all) of the cancer experience (e.g., Basinger et al., 2015; Beach & Good, 2004; Harzold & Sparks, 2006; Stone et al., 2011). Geographic distance places additional stressors on family relationships, which in turn influences communication processes. For example, adult children who live away from a parent experience difficulties balancing their own everyday-life work while remaining involved with their parent's treatment regimen (Beach & Good, 2004). This may in turn lead to feelings of guilt for not being readily available to the patient, a sense of longing to care for the patient, and feelings of shock concerning a family member's change in physical appearance once reunited face-to-face (Basinger et al., 2015).

Special efforts to share cancer-related information with geographically separated individuals may help to decrease feelings of isolation for both the patient and his or her family members (Veach et al., 2002). Ironically, however, information exchange appears to be especially challenging for geographically separated family members. Even when family members promise to supply information, there may be a delay in the transmission of details, or information the geographically separated family member perceives to be relevant may be left out (Basinger et al., 2015). Geographic separation may also make caregiving especially difficult for adult children, both in terms of providing care and communicating support to proximal caregivers (Stone et al., 2011).

Interestingly, some research suggests that geographic separation may actually help adult children cope with a parent's cancer diagnosis. For example, being away at school can give young adult children something to focus on other than worry and fear for the ill family member (Basinger et al., 2015). Similarly, some adult children feel that involvement in their mother's breast cancer experience is made easier by geographic separation because being away from home reduces the possibility of being included in difficult decision-making processes (Wolf, 2014). Thus, it appears that some adult children may not conceptualize geographic separation as a challenge during a parent's cancer experience.

Although the previous review provides some understanding of the ways in which geographic separation may present unique challenges for adult children, there is a lack of research about strategies adult children may employ to manage this particular challenge. One study (i.e., Basinger et al., 2015) provides initial insight into strategies adult children may employ. The authors suggested that adult children used three strategies: a) psychologically disconnecting from their everyday activities due to a preoccupation with their family member's

illness, b) throwing themselves into work and avoiding thoughts about the ill family member, and c) engaging in frequent phone and email conversations in order to stay in the loop. These strategies suggest that balancing illness work and everyday-life work may be particularly challenging for adult children. Similarly, they stress how distance may create additional communication work for adult children. The following research questions are proposed in an effort to explore the unique challenges experienced by geographically separated adult children, and the strategies that may help adult children manage those challenges:

RQ4: What are adult children's communication challenges when geographically separated during a parent's cancer experience?

RQ5: How do adult children manage communicative dilemmas pertaining to geographic separation?

Changes to the parent-child relationship. A parent's cancer diagnosis and the ensuing treatment regimens often cause dramatic changes in family relationships and roles, and those changes affect cancer patients and their close family members (Fisher et al., 2014; Harzold & Sparks, 2006; Kristjanson & Ascroft, 1994; Northouse & Northouse, 1988). Because the parent-child bond is intergenerational, adult children and parents experience unique relational stressors across the stages of a parent's cancer. For example, adult children who take on different roles following a parent's cancer diagnosis experience elevated ambiguity within the parent-child relationship (Stone et al., 2012). Similarly, some adult daughters feel that taking on a caregiving or 'mothering' role following a mother's breast cancer diagnosis is problematic due to unique relational expectations within the mother-daughter relationship (Fisher, 2010; Given, Qyatt, Given, Sherwood, Gift, DeVoss, & Rahbar, 2004). More generally, the negotiation of new roles

takes time and transitioning roles following a family member's cancer diagnosis is often awkward (Kristjanson & Ascroft, 1994).

Although several scholars have focused on the impact a parent's cancer diagnosis has on young children (Semple & McCaughan, 2012), we currently know very little about how adult children manage relational changes during a parent's breast cancer experience. What we do know about adulthood as a life stage suggests that adult children will struggle with unique role changes following a parent's breast cancer diagnosis. Adulthood is a life stage that already includes several major life transitions and responsibilities; adults often have work-related responsibilities, such as income generation and stressors arising from work (Cattan & Tilford, 2006). In addition, adults have a range of relational responsibilities, especially as parents of young children (Cattan & Tilford, 2006). Previous work in this context (e.g., Kristjanson & Ascroft, 1994) has focused on how a parent's cancer diagnosis requires a reassignment of everyday-life work, which may in turn create difficulties in family relationships. In particular, Kristjanson and Ascroft (1994) suggested that redistribution of housework, childcare, and other duties often result in adult children assuming roles beyond their abilities. Adult children may, for example, be drawn back to their family of origin to help care for the sick parent or for their younger siblings following a parent's cancer diagnosis (Rolland, 2005). This would require that adult children make several adjustments to their own daily routines and existing family roles.

Role changes are likely especially problematic when communicating about emotional topics. Some adult children report avoiding emotional topics altogether due to their own emotional overload (Stone et al., 2011). Adult children also question what should be communicated given the possible relational outcomes following a parent's cancer diagnosis (Stone et al., 2011). This challenge may arise in unique ways depending on the parent's current

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stage within the illness trajectory. For instance, if a parent's cancer goes into remission, adult children may struggle with whether to move on from the disease or remain focused on continued prevention (Rolland, 2005). Family members who move on from the cancer experience may grow distant from the patient, whereas individuals who remain focused on the illness often experience more role conflict, more role strain, and more overall disruption to the family system (Miller, 2015). Clearly, communication is impacted when adult children experience complex and conflicting roles as both caregivers and children. Gaining a better understanding of how changes to the parent-child relationship are coordinated would provide additional insight into what makes family communication functional or dysfunctional in this context.

The following research questions are proposed in order to illuminate the relational challenges adult children experience across a parent's breast cancer trajectory as well as the strategies adult children may employ when faced with relational changes:

RQ6: What are adult children's communication challenges in managing changes to the parent-child relationship?

RQ7: How do adult children manage communicative dilemmas pertaining to changes to the parent-child relationship?

Effectiveness of adult children's communication strategies. Because not all communication strategies are perceived to be equally effective, simply identifying adult children's communication challenges and strategies in this context is not enough to help families communicate more effectively. The normative model proposes that communicators assess the skillfulness of communication by examining the extent to which the various goals in a communicative scenario are attained without undermining other pertinent goals (Goldsmith, 2001, 2004). Thus, rather than presuming that behavior can be quantified in "degrees of positive,

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bilateral, direct, or supportive" (Goldsmith, Bute, & Lindholm, 2012, p. 68), a normative approach conceptualizes communication as strategic and proposes that meaning arises in particular contexts. One implication of this perspective is that not all families will manage dilemmas in the same way, and "the same" strategy may look quite different depending on the context. Thus, when making judgments about more or less effective communication, scholars must recognize that "strategies and dilemmas are situated in individual and relational history, in social networks, and in everyday life" (Goldsmith et al., 2012, p. 83).

One way to judge effectiveness is by considering the extent to which an individual can express multiple and potentially divergent meanings (Goldsmith & Domann-Scholz, 2013). For example, couples coping with heart problems sometimes use strategic ambiguity to address conflicting task, identity, and relational concerns. This strategy can manifest in several ways. Some couples are strategically ambiguous by having one "big talk" following a health crisis, but then avoiding additional talk so as not to dwell. Other couples are strategically ambiguous by communicating openly about medical facts, but not talking about feelings. Although these strategies are slightly different, both tactics can be considered effective because they allow interactants to address the potentially contradictory behaviors of being "open" and communicating cautiously. In a similar vein, "rationing talk" (e.g., being selective about topics, saying something once, letting the patient initiate discussions, going along with occasional violations, or monitoring a threshold of unhealthy behavior before commenting) and "saying it nicely" (e.g., using conversational indirectness, inquiries and suggestions, routine exchanges, joking, and nonverbal cues) can also be considered effective strategies in this context because they allow interactants to demonstrate caring and respect for both individuals' identities while also recognizing the limits on one person's control over the other (Goldsmith et al., 2012). In

each example, conversational strategies that allow interactants to balance multiple meanings are evaluated as being the most effective.

Although every conversational strategy has both advantages and disadvantages, effective strategies across contexts appear to capitalize on desirable identity and relational meanings (rather than ascribing undesired identity and relational meanings). For example, adult children were more satisfied with end-of-life conversations when they could talk about the topic while achieving the secondary identity and relational goals of minimizing dissatisfaction, hurt feelings, and relational distancing (Scott & Caughlin, 2014). Some researchers suggest that parents and adult children can capitalize on desirable identity and relational meanings by having an open conversation about the initial diagnosis, the parent's emotions, and treatment procedures (Harzold & Sparks, 2006). By contrast, adult children seem to attribute negative relational and identity meanings when their parent withholds cancer-relevant information or is unwilling to discuss feelings (Harzold & Sparks, 2006). A normative approach would add depth to this analysis by indicating situations in which openness and avoidance are more or less effective for parents and adult children. For example, in the context of lung cancer, avoiding upsetting topics may actually be considered an effective strategy when it insulates adult children from emotional upset (Caughlin et al., 2011). However, adult children's awareness of their use of this strategy may be dissatisfying when it conflicts with their perception that their family is "open."

Evaluating effectiveness of strategies in this context is complicated for several reasons. First, effectiveness may depend on existing family communication patterns. Not all parents and children will start on a level playing field; some families may be better equipped in managing communication dilemmas than others (Goldsmith et al., 2012). Families who stress open communication prior to the cancer diagnosis, for example, may find it easier to share decision-

making and care decisions (Wittenberg-Lyles, Goldsmith, Demiris, Oliver, & Stone, 2012). Conversely, families who value conformity may struggle to maintain preexisting family roles during a complete role-reversal of child taking care of a parent (Wittenberg-Lyles et al., 2012). Second, effectiveness of strategies may shift across the illness trajectory. For instance, adult children may feel that it is effective to avoid thoughts about the ill family member before treatment, but they may feel that the same strategy is less effective once treatment begins. Later in the trajectory, such as when a parent is in remission, adult children may again feel that it is functional to avoid intrusive thoughts about their parent's cancer.

Currently, we know very little about how adult children more or less effectively manage the challenges of interaction following a parent's cancer diagnosis, or how effortful this management might be. The following research question focuses on identifying communication strategies that are normatively effective for parents and adult children:

RQ8: Which communication strategies are perceived to be more or less effective in the context of a parent's breast cancer trajectory?

Chapter 3: Method

Participants

Participants for the current study included thirty adult children (aged 28-55) who had a parent who was diagnosed with cancer within the past ten years. The mean age of participants was 38.90 years (*SD* = 8.67). Six participants were male, and twenty-four participants were female. A majority (26) of respondents identified as Caucasian, two identified as African American, one identified as Pacific Islander, and one identified as Hispanic. Two respondents were only children, six had one sibling, twelve had two siblings, three had three siblings, one had four siblings, three had five siblings, and three had six siblings. Of the respondents that had at least one sibling, six were the first-born child, seven were somewhere in the middle, and fifteen were the youngest child. Most (22) respondents were raised in two-parent households with birth parents, five respondents were raised in a single-parent household with their birth mother, two respondents were raised in a step family with their birth mother and stepfather, and one respondent was raised in a single parent family with their birth mother and grandmother.

Although participants were not specifically asked to report on a mother who was diagnosed with breast cancer, no participants chose to report on a father who had experienced a breast cancer diagnosis. Six mothers had passed away due to breast cancer or related treatments and complications. The average age of surviving mothers was 69 (*SD* = 13.04). Two respondents did not know what stage their mother's cancer was upon diagnosis, and nine of respondents only knew that their mother's cancer was in an "early" stage upon diagnosis. Of the participants who did know what stage their mother's breast cancer was in upon diagnosis, two reported their mother was diagnosed with stage 0 cancer, four reported their mother was diagnosed with stage 1 cancer, five reported their mother was diagnosed with stage 2 cancer, five reported their mother

was diagnosed with stage 3 cancer, and three reported their mother was diagnosed with stage 4 cancer. Three mothers were reported to be currently undergoing their first round of primary treatment, four mothers' breast cancer had recurred at least once, and twenty-three mothers had completed primary treatment and were currently cancer-free or in remission. No mothers were reported to be diagnosed but not yet in primary treatment.

Inclusion/exclusion criteria. In order to participate, adult children had to be between the ages of 28 and 55 and have a biological parent who was diagnosed with breast cancer within the past ten years. Age was limited to include only older adult children because some research (e.g., Arnett, 2000; Fisher, 2010; Williams & Nussbaum, 2001) suggests that older and younger adult children may experience different communication challenges and use different strategies for overcoming those challenges. For example, responding effectively to the multiple meanings present during conversations about a parent's cancer diagnosis may be more problematic for young adult children (as compared to older adult children) because the major developmental task during that life stage is to actively seek independence and a separate self from their parent (Arnett, 2000). Fisher (2010) illustrates this point. She found that mothers diagnosed with breast cancer were especially concerned with their young adult daughters' inability to cope, and young adult daughters were aware that they often withdrew as a result of their emotional suffering. Conversely, older adult children may be expected to exhibit more competent and successful communication (e.g., providing advice). For these reasons, participation was restricted to sample only older adult children.

Second, cancer type was restricted to breast cancer because family communication processes appear to vary based on type of cancer (Williams & Nussbaum, 2001). For example, although breast cancer is still quite dangerous, many patients who are able to detect the disease

in the early stages live full lives for many years. In addition, parents and children appear to share a breast cancer diagnosis psychologically, physically, and socially (Fisher, 2010; Fisher et al., 2014). These communication patterns can be contrasted with family communication following a lung cancer diagnosis, which is often characterized by higher levels of guilt, shame, anxiety, and depression (Caughlin et al., 2011; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). Because the way a family experiences cancer appears to vary depending on cancer type, participation was restricted to only children who had a parent diagnosed with breast cancer.

Third, because some types of breast cancer have a genetic component (American Cancer Society, 2014), adult children may communicate about breast cancer with a biological parent differently than with a stepparent or adoptive parent. Indeed, a woman's risk of breast cancer approximately doubles if she has a first-degree relative (mother, sister, daughter) who has been diagnosed with breast cancer (American Cancer Society, 2014). Hereditary cancer predispositions appear to be managed in ways that are unique from other types of cancer. For example, daughters of women with breast cancer may experience a 'chronic risk' wherein they fear disease recurrence for their mothers and fear developing the disease themselves (Kenen et al., 2003). As a result, parents may wait to disclose certain cancer-related information until the child is older, regardless of norms of open parent-child communication (Segal, Esplen, Toner, Baedorf, Narod, & Butler, 2004). Because parent-child communication appears to vary depending on a child's risk of developing cancer, participation was restricted to only children who had a biological parent diagnosed with breast cancer.

Finally, biological parents must have been diagnosed with breast cancer within the past ten years. This time frame was selected because adult children were asked to recount conversations across the illness trajectory, and participants may have a difficult time

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remembering conversations that occurred more than ten years ago (Bolger, Davis, & Rafaeli, 2003). In addition, although breast cancer can recur at any time, most breast cancer recurrences happen within the first five years after breast cancer treatment (American Cancer Society, 2014). Thus, a ten-year timeframe best positioned participants to accurately recall conversations across the illness trajectory while also including trajectories where a parent's cancer recurred.

Recruitment. After obtaining IRB approval, participants were recruited in a variety of ways. First, recruitment flyers were posted in university buildings, local businesses, and shopping centers. Second, electronic recruitment flyers were sent through University newsletters, listservs, and social network sites. Third, an advertisement was posted on Craigslist. Fourth, college students were offered extra credit for trying to recruit someone they knew to participate in the study. Finally, a snowball sampling technique was used with adult children who participated in the study. More specifically, at the end of each interview, participants were asked whether they would be willing to forward study information to someone they knew who also met the inclusion criteria. Participants were assured that none of their responses would be shared with their social network or family members should they choose to participate.

Procedure

Potential participants contacted me by email or phone to express interest in the study. If the individual met all inclusion criteria, an interview was scheduled to occur at a private, university research lab or via telephone. The research lab space was quiet and had minimal distractions or potential for interruption. In addition, the lab space was private, which ensured that other individuals would not be able to easily hear respondents' answers. If the participant did not live within a reasonable driving distance of the University, the interview was conducted over the phone. Sixty percent of interviews were conducted face-to-face in the lab space, and 40% of

interviews were conducted over the phone.

Before beginning the interview, the informed consent document was fully explained. Participants were told that their information would remain confidential. Then, we engaged in a semi-structured, qualitative interview. Interview questions were not expected to elicit significant psychological distress. However, talking about a parent's cancer can be challenging for some individuals due to the distressing nature of the disease and the parent's possible death (Northouse & Northouse, 1988; Zhang & Siminoff, 2003). Therefore, respondents were informed that they could skip any questions that they did not wish to answer. In addition, optional breaks were built into the interview schedule in case some participants became upset or wished to briefly pause the interview. Finally, all participants were provided with information regarding local counseling and mental health services (see Appendix A for resources). After the interview concluded, participants completed measures assessing demographic information. Taken together, participation took 60 to 120 minutes. Respondents were compensated with a $25 gift card to either Target or Walmart. Undergraduate students who attempted to recruit someone to participate in this study received course credit (no more than 2% of their course grade).

Interview schedule. The interview schedule was semi-structured interview and focused on participants' perceptions of communication with their diagnosed parent. Questions focused on changes in communication and the parent-child relationship during the different stages of the parent's illness trajectory. Demographic questions asked about age, sex, cultural/racial heritage, and family characteristics. Appendix B contains the complete interview schedule and demographic questionnaire.

All interviews were digitally recorded. Immediately following each interview, I completed a detailed research memo that highlighted my general impressions of, and any themes

that emerged from, the interview (Charmaz, 2006; Rubin & Rubin, 2005). In addition to recording my initial impressions, memos helped to ensure the trustworthiness of the study results. In particular, because memory can be flawed and selective, memos help a researcher to denote conceptual ideas derived from each interview (Charmaz, 2006; Rubin & Rubin, 2005).

Analysis

Data was analyzed using a modified grounded theory approach that has been described by Tracy (2013) as *iterative analysis*. Rather than grounding meaning solely in the emergent data, an iterative approach encourages the use of sensitizing concepts from current literature and various theories. Specifically, Tracy (2013) outlines a way to analyze qualitative data by moving between "emic, or emergent, readings of the data and an etic use of existing models, explanations, and theories" (p. 184). In this study, I began with the normative perspective (Goldsmith 2001, 2004) as a frame for identifying constructs of interest. Iterative analysis enhanced this framework by allowing me to use participant data to generate inductive categories suggested by the normative approach (e.g., communication challenges and strategies, effectiveness of those strategies) while also grounding these categories in participants' own voices and experiences. The constant comparative technique (Charmaz, 2006) allowed me to systematically assess each category. Through this process, the normative perspective was shaped and changed by participants' data. This inductive and iterative approach proved useful as unique constructs that were not identified by the normative approach also were identified from the data. The analytical process described in the paragraphs that follow highlight this iterative analytical process, which was accompanied by memo-writing throughout the interview, transcribing, and coding process.

A research memo was completed following each interview, which allowed me to capture initial ideas and begin to make comparisons between participants' accounts (Charmaz, 2006; Tracy, 2013). Consistent with Charmaz's approach to memo-writing, memos were unstructured and free flowing based on immediate observations and reflections. Memos served the function of establishing an audit trail of my initial impressions of what the data meant, how the data related to each other, and how my ideas evolved as I collected additional data (Charmaz, 2006; Starks & Trinidad, 2007). Following memo writing, I transcribed each interview in its entirety. While transcribing, any identifying information (e.g., names of the respondent and any family members mentioned, places of employment, and any locations that may reveal respondents' identities) was replaced with pseudonyms or was de-identified. All transcripts were accuracy checked by the primary researcher or a trained undergraduate research assistant to help ensure validity of conclusions (Maxwell, 2005).

Following transcription, I began to formally analyze the data. First, I read each transcript in its entirety in order to identify concepts related to the complex communication situations faced by adult children during their parent's cancer experience (Charmaz, 2006). This allowed me to get a general sense of the data and sensitized me to the respondents' experiences. While reading each transcript, I identified first-level codes (Tracy, 2013). These codes were mainly comments describing any communication behaviors that participants mentioned (e.g., tell her to stay positive, talk about treatment, text instead of calling). Guided by the normative approach, I also took note of adult children's communicative dilemmas and strategies for overcoming those dilemmas. Given that respondents could discuss issues unrelated to research questions, I was sensitive to other concepts that emerged from the data (e.g., determining how much talk was appropriate, asking about privacy rules). Following this, I systematically examined each

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interview transcript to clarify what was meant by each dilemma and strategy. After locating and refining these concepts, I generated a brief code and definition to designate each dilemma or strategy (Charmaz, 2006).

An iterative approach was especially useful for attending to the unique ways in which participants described their experiences because scholars who use an established theoretical lens might miss original insights in their own data (Charmaz, 2006; Tracy, 2013). In other words, an iterative approach allowed me to stay open rather than analyzing the data based on an established theoretical perspective. I acknowledged participants' voices by using in-vivo codes (i.e., wording that participants used in the interview) and actions using gerunds (i.e., -ing words that capture participants' actions or behaviors) as codes (Charmaz, 2006). When I created a new code (Rather than applying a sensitizing code from existing frameworks), I worked to choose a label that did not distort the idea introduced by the interviewee. I did this by reading and re-reading the passage in question and identifying a label that best captured what was said. During this process, I constructed a codebook, which contained general definitions for each code so that I could then apply the code effectively as I continued to code each interview. This coding process helped me to see salient codes and identify gaps in the data (Charmaz, 2006).

Next, I engaged in more focused or second-level (Tracy, 2013) coding of each interview transcript. The purpose of focused coding is to begin synthesizing larger segments of the data using the initial codes that were most salient in the data, as well as the codes most relevant to the research questions (Charmaz, 2006). The focused coding process enhanced my analysis in two ways. First, focused coding allowed me to check the adequacy of codes and their significance in the data. Second, focused coding assisted in condensing related codes into larger categories. Following Charmaz (2006), I wrote conceptual memos about the focused codes I developed.

These memos assisted in recording my thinking about the meaning of codes and categories, as well as how and when these processes occurred in the illness trajectory. As I worked to construct new categories, first-level codes were either integrated into existing categories or included as new categories. Whenever possible, interviews were coded before the next interview was conducted so that new information could be incorporated into subsequent coding schemes (Charmaz, 2006).

Throughout the analysis process, I engaged in constant comparative methods (Charmaz, 2006) by checking my concepts and categories carefully against my notes, memos, and the interview transcripts for any evidence that my conceptualizations were incorrect or incomplete. This was accomplished in several ways during the data collection process. For example, I brought together all of the data units given the same code name into a single file and then wrote a summary of the content of that file (Charmaz, 2006). In summarizing that information, I listed main points associated with the content of that code. This file was then updated as new data was collected and coded. This process allowed me to identify similarities and differences both within the same interview and between different interviews. For example, some participants reported similar challenges and strategies for managing those challenges, whereas other participants mentioned new or unique challenges or strategies. Constant comparative methods allowed me to explore dimensions of each communication challenge (e.g., to what extent the challenges were dilemmatic, during which stages the challenges were relevant to the participant), communication strategies (e.g., ways that strategies were used to manage one or multiple communication challenges, during which stages the strategies each strategy was employed), and perceptions of effectiveness (e.g., when and for whom strategies were more or less effective). In keeping with

Charmaz's (2006) definition of theoretical saturation, focused coding continued until I had fully elaborated the properties and dimensions of each category.

Finally, I engaged in theoretical coding in order to determine how categories were related to one another (Charmaz, 2006). During this stage, I brought my analysis to a higher level of abstraction by connecting codes that were theoretically related. During this process, I worked to answer questions such as: Does one category cause or influence one or more of the other categories? Do several categories influence each other? Are some categories consequences of other categories? (Charmaz, 2006). During this process, I experimented with placing different codes at the center of the emerging theory in order to theorize about the central process occurring in the data. For example, I positioned the concept of "negotiating co-ownership" at the center of one model and examined the ways that respondents discussed the antecedents and consequences of being a co-owner of their parent's breast cancer experience. As with first and second level coding, the theoretical coding process was iterative. More specifically, I kept analytic memos that highlighted how codes might be related to each other and constructed several theoretical models in order to determine the fundamental story in the data (Charmaz, 2006; Tracy, 2013).

Trustworthiness of my conclusions, or the degree to which the findings are supported by evidence and can be trusted as accurate reflections of participants' beliefs and experiences (Lincoln & Guba, 1985), was achieved in five ways. First, I thoroughly documented the data collection and analysis process through the use of memo-writing. Second, I systematically compared observations within and across study participants (Charmaz, 2006). Third, an advanced undergraduate student, who was a communication major, accuracy checked and coded five of the transcripts based on the first and second level codes I had previously constructed. More specifically, I provided the undergraduate student with my research questions in order to

give her a framework for interpreting the data. After she read through the data independently and

accuracy checked the transcripts against the interview recordings, I provided her with the

codebook I had previously constructed. We then met to discuss her impressions of the data. In

that meeting, we compared our assessment of each transcript. Fifth, I met with my dissertation

advisor regularly in order to check my conceptualizations of the data. Finally, in the chapter that

follows I provide direct quotes from the participants as evidence of the results and conclusions of

this study.

Chapter 4: Results

Overview of Results and Findings

Adult children characterized their experience with a mother's breast cancer as transitional. Adult children served as their mother's confidant, advisor, friend, and caregiver. Parents and children often became closer and more emotionally connected during the breast cancer experience. The typical trajectory of cancer seemed to prompt an increase in communication; for many participants, a mother's diagnosis led immediately to an intensive search for relevant facts and medical information in order to understand the diagnosis and provide input, followed by turning attention to helping her cope with treatment, followed by adjusting communication to acknowledge how the diagnosis will continue to impact their lives. For some adult children, this experience constituted an unexpected relational shift as they took on additional roles and responsibilities. In particular, many adult children struggled to navigate new power dynamics after taking on caregiving responsibilities.

Cancer appeared to be meaningful to adult children in that it meant becoming uniquely involved in their mother's illness trajectory through taking on unique lines of work (Corbin & Strauss, 1988). A mother's breast cancer experience often catapulted adult children into the role of "insider" in their parent's life. For example, respondents referred to their parent's cancer as something "*we* needed to be ready for" or "*we* fought." This was complicated because adult children often felt obligated to treat cancer-related information according to the needs and desires of their parent. As one participant, Nicole, put it: "It's kinda a private thing – it's *her* thing." Thus, although respondents articulated a personal involvement in their mother's cancer experience, they acknowledged that only the parent "had" cancer.

Involvement in the parent's breast cancer experience also gave rise to context-specific and intertwined communication challenges and dilemmas related to information management, social support, geographic separation, and relationship changes. These responsibilities shifted during the diagnosis, treatment, survivorship, and recurrence stages. For example, information management was an important element of providing and receiving support and managing illness-related uncertainty. Yet, informational avoidance was also a common strategy for providing support to a parent and managing relationship changes. Geographic separation often problematized adult children's involvement, but could also make it easier for adult children to cope with their mother's breast cancer experience. Coordinating multiple goals and expectations was necessary to negotiate involvement effectively.

In the sections that follow, I first outline adult children's lines of work across their mother's breast cancer trajectory (see Table 1 for an outline of the types of work over the course of the illness). Then, I highlight adult children's challenges related to information management, social support, geographic separation, and relationship changes. For each of these factors, I discuss both communication challenges and the relevant strategies for managing such challenges (see Table 2 for an overview).

Adult Children's Lines of Work Across a Parent's Breast Cancer Trajectory

As a whole, the adult children in this sample articulated their involvement in the illness experience through the use of communal language. For example, Amanda said the general idea was "what are *we* going to find out now – or what do *we* need to find out – what do *we* need to do now – what do *we* need to ask the doctor now? It was always what do *we* gotta do?" Through the use of communal language, adult children catalogued the range of responsibilities related to being part of their mother's cancer experience. Although adult children consistently used

communal language, they did not articulate a strict communal orientation towards their mother's cancer. Rather, respondents largely conceptualized their involvement as being on the sidelines of the experience. Thus, rather than defining the cancer experience as truly communal (our problem / our responsibility; Lyons et al., 1998), adult children described their involvement as "our responsibility" but only the "parent's problem." This orientation towards coping, which was labeled "help/support seeking" by Lyons and her colleagues, highlights how helping a mother deal with cancer during the diagnosis, treatment, survivorship, and recurrence stages created unique and intertwined lines of work for adult children.

In this dissertation, the term *communication work* refers to instances where communication constituted an additional and unique form of work beyond responsibilities related to illness, biographical, or everyday life work. Foregrounding communication work in this context highlights how the process of achieving meaning and negotiating successful achievement of other lines of work was demanding and effortful for adult children. By contrast, the general term *work* encompasses intertwined responsibilities related to illness, biographical, everyday life, and communication work. Using the more broad conceptualization of work was useful in situations where it was unclear which specific line of work adult children were referring to or when adult children described situations where a combination of more than one line of work was apparent. As the following sections illuminate, adult children's conceptualizations of involvement meant that some responsibilities were more challenging to communicatively manage than others.

Adult children's work during diagnosis. Adult children experienced unique illness, biographical, everyday life, and communication work during the diagnosis stage. In this stage, adult children had to determine how to enact their new identity as a co-owner of a parent's

private health information. They often struggled to manage personal reactions to their mothers' diagnosis-related disclosures. These responsibilities were challenging because the amount of information that could be co-owned and the timing of disclosures were determined solely by the diagnosed parent. For many respondents, the most pressing lines of work revolved around being a good listener, providing reassurances, and helping their mother make treatment decisions.

Work is determined by mother's disclosure decisions. As Petronio (2002) argued, many different criteria interact to shape specific decisions about whether to reveal private information, which individuals will receive some (or all) of the information, when information should be divulged, and how to frame information in order to manage impressions. In the current study, adult children felt that their mothers carefully picked a particular set of circumstances before disclosing their diagnosis. Sometimes this meant that news of the breast cancer diagnosis was not conveyed immediately; respondents recalled their mother waiting for days, weeks, or months before disclosing the diagnosis. For example, Elise expressed that she did not know that her mother was going in for tests and was only made aware of the situation once her mother received a positive diagnosis. For many respondents, becoming involved later than they would have liked was frustrating. When talking about how her mother was already completely done with treatment before she disclosed the diagnosis, Heather said, "I was disappointed that she kept it from me! 'Oh Mom!' I felt lied to." Similarly, Leigh expressed her mother's decision to hide the diagnosis as "more upsetting than the actual diagnosis."

In these examples, adult children had to do biographical work in order to frame their mother's disclosure decisions. Indeed, although adult children were dissatisfied when they became a co-owner later than they would have liked, they often attributed the timing of the

disclosure to the parent's desire to protect her children. For example, Scott felt his mother simply wanted to disclose the diagnosis once she had more definite information to share:

> The diagnosis was between my mother and father for some time until they knew something definite to talk to us about. I don't think they wanted to scare us or say it in a way that would have had us worried. So they knew there was a cancer cell and that it was something that could either be treated or not be treated. I don't know the exact timeframe of it in the sense of how long they knew. I just knew that my mother started going to the doctor a little bit more frequently than normal.

Because Scott perceived that his parents waited to disclose because they did not want to scare him unnecessarily, he was not particularly upset about the late timing of the disclosure. Similarly, Lauren felt that her mother made a strategic choice to disclose the diagnosis the night before her lumpectomy surgery was to take place. Thus, although she was not particularly happy with the decision, she felt her mother waited to disclose the diagnosis "until it was too late to travel" so she would not feel pressured to uproot her vacation plans to be present for the procedure.

As these examples demonstrate, adult children often expected to be involved in their mother's cancer experience from the very beginning and were dissatisfied when a parent attempted to leave them out of the privacy boundary. Adult children who recognized that their mother was in control of the information felt that there was not much they could do to overcome this challenge. Indeed, most respondents seemed to understand that their mother's disclosure decisions were made in the spirit of protection. Once a parent did disclose, adult children were thrust into the role of co-owner. For this reason, work in this stage usually involved a readiness to be involved when the parent was ready to involve the child.

Work involves prioritizing the parent. Respondents felt that they needed to react in an appropriate way when learning of their mother's diagnosis. In general, adult children felt that the appropriate way to react to the news was to prioritize their mother's feelings and reactions by not letting their mother witness their own emotional reaction. Prioritizing the parent could manifest by "vibing" on how the parent was acting (Anna) or waiting to hang up and only then freaking out and crying (McKenzie). Nicole put it this way, "I had a freak out moment - but I didn't act like I was freaked out. You want to be cool because she's being cool. So I tried to just take her lead since she seemed okay with it." Similarly, Shannon discussed how, because her mother immediately expressed feelings of gratitude about how quickly the cancer was caught and that it had not spread, she felt that the appropriate reaction was to deemphasize fear and instead "follow Mom's lead" by also expressing gratitude for the early diagnosis.

Some respondents described problematic enactment of this type of communication work when their own emotions got in the way of focusing on the parent. Lauren, for example, bemoaned that she did not provide any assurance to her mother during the disclosure conversation. She put it this way: "My reaction was very self-centred. I had no reassurance for her. My reaction was tears and I'm scared. There was – the reassurance was very one sided, no question. And that's not how it should have been." Lauren felt that her reaction was inappropriate because it was "one sided" and focused on her own emotions rather than her mother's. Similarly, Matthew recalled being so emotionally overwhelmed when his mother disclosed over the phone that he immediately ended the phone call. Then, after "taking time to collect my thoughts and everything" he called back and went into "counselor mode" by saying things like "don't worry, everything is going to be fine." Thus, although Matthew did not think

his initial reaction prioritized his mother, taking time to have a private emotional reaction allowed him to do so.

Adult children's communication work in this context involved having the wherewithal to simply listen to whatever their mother felt comfortable sharing instead of asking questions or responding emotionally. For example, respondents described how the best thing to do was "just listen" (Scott), "let Mom talk it out" (Sandra), or allow their mother to "vent" while they "listened a lot" (Jade). Frank, for example, noted that he simply "gave a lot of responses in the affirmative… 'Okay, okay, okay'" when learning about his mother's diagnosis. It was important to him that he remained unemotional and neutral during the disclosure conversation in order to appear supportive and calm.

The importance of listening seemed to be connected to the general feeling that the diagnosed parent would want her children to be patient, understanding, and composed. Megan explained how she just "let her have her moment to cry" and did not say anything because no words could "help her get through this painful moment." Similarly, Amanda described her role in the initial disclosure conversation as "just being an able-bodied person who was there to listen." She expressed that listening helped her mother "sort out ideas and things." In general, adult children seemed to have strong convictions about what reactions or responses were and were not appropriate when learning about their mother's diagnosis. This particular type of work involved being a good listener and reacting in a way that prioritized the diagnosed parent.

Work involves helping with treatment decisions. After the initial disclosure conversation, a major responsibility during the diagnosis stage was jumping into action to determine what next steps should be taken. Respondents described conversations as quickly moving from "What are we dealing with here?" to "What's the next steps? What are the things

we do then?" (Elise). Matthew also recalled how conversations rapidly evolved into "planning out when's her next appointment, what does she have to do, did they give her any prerequisites leading up to the appointment? That kind of thing." Matthew felt that his responsibility had shifted from "just being there for her" to a focus on "what had to be done to get through it." Adult children like Shannon seemed to appreciate this conversational shift:

> I think talking about treatments helped us be more practical – like 'What course of treatment should she choose? What's she going to do? Is she going to do the tamoxifen?' So there was less discussion of anxieties and more 'What are you going to do?' That was easier to talk about.

> Although helping make treatment decisions made adult children feel helpful and involved, this type of work was also stress-inducing. In particular, adult children often felt torn between expressing personal opinions and simply agreeing with the parent's plan of action. Peggy, for example, recounted being unsure about whether to express the concerns she had about her mother's treatment decisions:

> I told her that I was worried about her options with the radiation or not to have it. You have to take these drugs for the rest of your life after you have it. But I didn't tell her. I didn't want to be that person that makes a mountain out of something that may not even exist. I just wanted to know if there were other options.

Several respondents explicitly acknowledged that they were ultimately expected to support whatever decision their mother made. Megan, for example, felt that children should be "supportive no matter what" and thus did not feel it was her place to say anything other than "I'm fine with whatever you do" when talking about treatment decisions. As these examples

suggest, this particular type of communication work involved actively designing messages that balanced personal opinions and the parent's decisions.

This type of work was particularly effortful when adult children had to decide whether and how to suggest alternate treatment ideas. For example, Elise recounted how she was expected to support her mother's decision to not receive chemotherapy treatment. She recalled saying, "Mom are you sure?" but did not feel it was her place to push beyond that. Similarly, Ashley struggled with helping her mother make a decision about whether to start on a second round of chemotherapy after having a bad reaction to her first round of treatment. Ashley said:

> The chemo just destroyed her and suggesting that she stop was in the back of my head – but her saying 'I don't want to die.' – I don't know, we just listened to what the doctors were telling us so I wasn't going to say, 'Hey maybe you shouldn't do any more treatments,' especially because a lot of people associate that with giving up or not trying. But for her – it would have been better (crying). And I feel like doctors don't really tell you that.

Ashley blamed chemotherapy (not cancer) for her mother's death and said at several points that her biggest regret was not suggesting "no treatment" as an option.

Disagreeing with a mother's treatment decisions sometime created conflicts for parents and children. For example, when Brooke suggested that her mother should consider getting a mastectomy, her mother quickly snapped, "I never said that!" Brooke recounted quickly responding with, "Well you did at one point." Clearly frustrated, her mother said, "Well now I don't know if I want that." Brooke felt the best thing to do at that point was back off and just say, "Okay I'm sorry. You can do whatever you want. I just remember at the beginning you said you wanted to [get a mastectomy] so I thought maybe you were still thinking that." Brooke went on

to explain that she "really wasn't trying to offend" her mother by bringing up a mastectomy, and she hoped her mother was not too upset that she brought it up.

In these examples, being involved in the decision-making process was challenging because, although adult children had personal opinions about their mother's treatment plan, they did not necessarily know whether it was the best idea to share those opinions. The communication work involved in navigating this challenge necessitated active message design. Yet, respondents struggled to design messages that both expressed their own opinions and acknowledged that their mother would make the final decision.

Adult children's work during treatment. Although adult children's work shifted as primary treatment began, the responsibilities from the diagnosis stage did not completely go away during this new stage. Instead, respondents noted additional responsibilities due to their involvement in this stage. For example, adult children who were not very involved during the diagnosis stage often found the treatment stage to be confusing and bewildering. Kevin recalled not understanding why his mother was "so tired" all the time and was surprised that it took her six months to "get back to normal." Similarly, Matthew recalled wondering during this stage why his mother "wasn't as talkative" as she usually was during this stage. Overall, adult children's communication work in this stage was demanding and effortful because they had to cope with the reality of their mother's treatment plan, help their mother navigate the health care system, and try to understand and follow their mother's desires for cancer-related information dissemination.

Work involves helping the diagnosed parent cope with the realities of treatment. Adult children commonly described the work involved in helping their parent cope with the physical and emotional effects of primary treatment. Feelings of fear and worry were amplified during

this stage. McKenzie noted that, once her mother actually started treatment, it finally "started sinking in that something *could* go terribly wrong […] That's when I started to freak out like, 'Chemo is going to kill my Mom.'" Conversations during primary treatment often focused on how hard treatments were and how they impacted the parent both physically and emotionally. As Ashley put it:

> We were focused on how shitty she was feeling and what we could do to make her feel better. We focused on how to get through the current – that day or whatever – that week. Whatever situation we were in, we just focused on that moment.

> Adult children described the effort involved in coping with, and helping their mother cope with, physical changes and pain. Witnessing a mother's painful treatments often made adult children feel helpless. Accordingly, several respondents suggested that their parent should get additional medical help for pain management. Sandra, for example, suggested that her mother "talk to somebody" for help with pain management:

> I called her to check in around the middle of her first round of chemo and it was the first time she ever cried since she got the diagnosis. And I was just shocked because she had been handling it so well – but she told me she just couldn't stand the pain. I think I mainly cried like, telling her 'I understand' and 'Let's get an appointment' and 'Let's talk to somebody and see if we can do something.'

Lisa also dealt with the difficulty of seeing her mother in pain by suggesting she talk to a doctor:

> It was six weeks of radiation and they just burned her skin, and burned over it, and burned over it. And she had huge blisters. It was extremely painful and, as a loved one, when you see someone that you love going through so much pain – I mean, it was frustrating! Like, 'Why don't they stop burning you all the time?!' So then I started

asking her doctor a lot of questions like, 'Can't you do anything about this? Are there

other options? What can she put on the burns?'

Similar to Lisa, Lauren and her mother also had many conversations surrounding pain

management and not knowing what could be done to soothe radiation burns:

I would constantly ask her, 'What are they doing to help you with the burning? Can they

give you something, are you putting something on it?' So I was really questioning how

they were or were not making her feel better.

As these examples illustrate, respondents often struggled to figure out what they could say or do

to help their mothers cope with pain during primary treatment. Suggesting that their mother

could seek additional medical attention appeared to make respondents feel useful to their parent

during a moment that not much could actually be done to help.

Adult children also provided their mother with verbal reassurances to help her cope with

the emotionally painful side effects of breast cancer treatments. For example, Kaylin reported

reassuring her mother that "hair is not the most important thing, the most important thing is that

you will get better and your hair will grow back. Your hair doesn't define you!" Similarly, Anna

talked about how her mother would look in the mirror and say, "Oh my God I'm gross – I feel

like a monster – I'm Frankenstein.'" Anna expressed that it was "really hard to hear" that her

mother was feeling that way about herself. In order to reassure her mother, Anna would tell her

mother that losing her hair was "not a shocking thing, she's not ugly, she's not a monster." Anna

did not feel that this made a big difference in her mother's mental state, however. As this

example demonstrates, adult children recognized situations in which their efforts to communicate

effectively fell short.

Work involves personally coping with the realities of a parent's treatments. Coping with the reality of their mother's treatment plan and seeing how treatments impacted their mother's wellbeing was challenging for adult children. Adult children felt responsible for facilitating a parent's adaptive coping behavior during this stage. At the same time, however, they recognized how being physically present during or immediately after a painful treatment was personally traumatizing and thus created additional work. Bonnie, for example, said that her "lowest point" was watching her mother get a painful biopsy during her third round of treatment:

> You know if you microwave a piece of meat too long and it turns into the hard rubbery thing? Well that's what happened to her breast tissue. So when they needed to do a biopsy – well it was boring in with a drill because her skin was so tough. I remember the surgeon being like, 'Will you be fine to watch this?' and I was like, 'I'll be cool.' And wow, I was *not* cool! Of all the things I had to see her go through, that one was the hardest for me. It may not have been the physically hardest for her, but I really almost passed out that day.

In this case, coping with the reality of treatment was difficult for Bonnie because she felt both personally overwhelmed and unable to help her mother cope with the painful biopsy. Sandra expressed feeling the same way after her mother's mastectomy:

> The first time I saw her incisions and everything was – it was terrifying for me. It was so much trauma to that area and that was very scary for me. I think I even sat down for a second before I could help her clean her incision sites. Which, that's not super gross to me or anything but I was just – well, I was taken aback. I don't know what I expected but – she had lost her hair at that point too so to see my mom with just kinda – emaciated and

with no hair and everything – that was huge. I needed a minute before I would say, 'Okay

I can help you now.'

For both Bonnie and Sandra, a challenging aspect of their mother's primary treatment was

personally coping with seeing their mother in pain.

Several adult children noted that helping a parent during primary treatment often meant

talking about their mother's body in a way that was novel and sometimes uncomfortable. Peggy,

for example, noted that her mother's diagnosis created a "shift" in their relationship because she

saw her mother naked for the first time. For other respondents, just talking about their mother's

female anatomy was awkward. Matthew explained his discomfort this way:

I guess as her son I really didn't want to talk about that part of her body. If it was a close

friend or something it might have been a little more comfortable but yeah – I didn't really

want to know. So it was just like – I don't need to know the details of it!

Matthew recalled that, in order to avoid any reference to his mother's breasts, he would just refer

to the disease as "cancer" rather than "breast cancer." Scott had a similar experience. He felt that

his mother "was a little more reluctant to share certain things about her body" and that "some

things were just off limits" because his family was comprised of his mother, father, and three

male children. Scott felt it was harder for his mother "as a woman to talk to us about a disease

that affects women." Lisa explained her discomfort with talking about her mother's breasts this

way, "Asking about the type is a very personal question… because it's a female organ. So she

would just say, 'Well it's in my reproductive organs.' [Saying *breast* cancer] was almost like a

swear word." As these examples demonstrate, some respondents' work during this stage

involved navigating the discomfort associated with talking about their mother's female anatomy.

This discomfort appeared to make communication surrounding breast cancer treatment especially challenging for some respondents.

Work involves helping a parent navigate the health care system. Adult children noted that they were often expected to help their mother by making appointments with physicians, arranging tests, researching health information, assessing care facilities, and explaining medical information. For example, Kaylin described "changing the wording" so her mother could more easily understand what the doctor was saying. Similarly, Ashley described having to "explain what was going on" after every appointment because her mother "didn't understand a lot of it, what the options were and what she should do." Other adult children noted that simply being present during medical appointments helped their mother more fully understand treatment options and medical updates. For example, McKenzie felt that her mother was "probably hearing 'death, death, death, cancer, cancer, cancer'" and, by attending medical appointments, she could help her mother more fully understand medical information.

Work involves asking about privacy rules. In contrast to coping with the realities of treatment or helping a parent navigate the health care system, respondents noted that they felt obligated to understand and respect their mother's preferences for sharing cancer-related information with other family members, friends, or even neighbors. Adult children appeared to recognize that their mother wanted to enact control over her personal health information. Shannon put it this way, "I think she wanted some control over who knew, which is totally fair. It just meant that I had to be very careful not to talk about it with people she hadn't already talked about it with." Communication work in this context appeared to include the obligation to treat information according to their mother's preferences. Nadine explained the expectation this way: "She always said, 'It's nobody's business what goes on in this house – this is what *I'm*

going through.'"

Respecting a parent's preference for disseminating information sometimes meant that adult children were not able to share information until their mother decided to disclose. Megan, for example, explained that talking to other family members about her mother's cancer was complicated because "not everyone had the entire information. At first she didn't tell them everything, and Mom really didn't want other family members to find out through somebody else." Taken together, this meant that Megan had to be careful about who she talked to about her mother's cancer and what information she shared with family members who may have been told differing amounts of information.

Communication work during this stage meant checking who was already in the privacy boundary and how much information should be shared with individuals outside of the boundary. For instance, Shannon wanted to ensure that her mother got to decide "who she was going to tell" so she "checked in" with her mom before telling her mother-in-law and sister-in-law. Lisa also described explicitly asking her mother, "What do you want me to tell people?" Similarly, Kaylin checked in with her mother before disclosing information about the diagnosis, "I had to ask, 'Is it okay tell this person or this person?'" Checking in with a parent was useful because it allowed adult children to ensure that they were not overstepping the boundaries of co-ownership.

Rather than having to "check in," some respondents noted that their mother expressed explicit rules about who was and was not going to be told cancer-related information. Matthew's mother explicitly said that her own mother was not to be told about the diagnosis. Matthew explained his mother's logic this way: "She didn't want Grandma to feel like she couldn't call and talk to my mom about things that she needed." Leigh's mother also said that her grandmother should not be told about the breast cancer diagnosis. Leigh explained that, because

her grandma was "in her early 90s and worried about everything" her mother decided that it would be best to avoid worrying her and then asked other family member to "not say anything to Grandma." And, although Leigh and her sisters "agreed that it was okay" to not tell their grandmother, she noted that the whole family continues to be very cautious about what is said in front of their grandma for fear of "spilling the beans." As these examples demonstrate, respondents seemed to feel obligated to adhere to a parent's rules for sharing information, even when those rules required extra effort and prevented them from being able to talk to, or receive support from, certain family members.

Adult children's work during survivorship. As a parent completed primary treatment, adult children felt that their responsibilities shifted once more. Rather than focusing on making it through painful, confusing, and stressful treatments, adult children talked about the positive conversations surrounding being done with primary treatment. Indeed, several respondents noted that the most positive interaction that occurred during the cancer experience was the "I'm done" conversation. For some, this conversation occurred when treatment ended. Anna said:

> Our most meaningful conversation was after she finished her chemo in early November. I went over after work to celebrate and we ordered pizza and had a cake and that kind of thing. She showed me the video of her ringing the bell to show she was finished – she was definitely on the positive end then.

For other respondents, this happy conversation happened once their mother finished with the five years of tamoxifen treatment. Katie remembered her mother calling and saying, "I'm done with the tamoxifen! I don't have to take it anymore – I'm *done*! We don't have to deal with it anymore!" Leigh's mother also called her when her five years of tamoxifen were up:

She called after that last appointment where she got a clean bill of health and didn't have to take the tamoxifen anymore. She was like, 'I'm so happy that is done – I don't have to worry anymore.' I think it had been a reminder for her that she will still under that cloud, and when she was done she was so relieved.

At the same time, the excitement of "being done" could sometimes stigmatize any further discussion of a parent's breast cancer. Indeed, some respondents seemed shocked by the notion that some families may continue to talk about cancer after treatment. When asked about this topic, Darla laughed and said, "No, of course we don't talk about it now. I mean, it's done now!" Megan explained it this way, "It's not something we need to talk about anymore – that experience is in the past for her." Feeling that talk about cancer was less appropriate following primary treatment left some respondents wondering when and how it was appropriate to bring up lingering fears for their mother's risk of breast cancer, their own risk of breast cancer, and breast cancer prevention. Consistent with work during previous stages, adult children sought to communicate in ways that prioritized their parent's reactions and emotions.

   Work involves managing lingering fears. Cancer-related fear did not seem to dissipate after a parent completed primary treatment and moved into day-to-day survivorship of cancer. Oftentimes, adult children continued to worry about the chance of their mother's cancer recurring. Yet, respondents were unsure when and how to talk about the possibility of recurrence. Bonnie explained:

It's scary – very scary. And it just – you can't ignore it. As much as you want to, it's in the back of your mind somehow. Sometimes more or less present, but I certainty haven't found a way to turn it off. I mean, even right after you're like 'Yay!' and there's a few months of not worrying about anything. But when a check-up appointment is on your

calendar, you're thinking, 'Is something happening? Is something happening in her body that I'm not really aware of?' I think definitely, it was just part of the water we were moving in, the air we were breathing.

Sandra expressed a very similar concern about breast cancer recurrence, "She downplays the risk that the cancer can still be there. And I'm, like, very worried." Lisa also had lingering concerns for her mother. She said, "You know, this could come back when she is 55, this could come back when she's 85. So I don't think my worry ever went away."

Respondents catalogued several reasons for holding back in expressing these concerns. Lisa, for example, felt that the topic of conversation just did not come up anymore and so it would have been odd to talk about her lingering fears:

I didn't want to bring it up as much once the crisis was over. You know, you stop asking as much 'How are you feeling?' Once treatment was over I would think of my mom when I saw a breast cancer ribbon or a fundraiser or a walk or something - but I don't really talk to her about it much anymore.

Kaylin also felt that talk about her mother's breast cancer was no longer commonplace or expected during this stage. In particular, she felt that talking about her lingering fears would keep her mother from moving forward:

I mean, we talk about it here or there but it's not something that we bring up often anymore. Now that she's done, I don't want to bring stuff up unless she brings up the topic. I want to let her rebuild her life and let things get back to normal. I mean, I think we've been through it so much that I don't feel like she even wants to talk about it anymore.

As Kaylin explained, starting a conversation about cancer-related fear was challenging when cancer was conceptualized as something that the diagnosed parent may not want to discuss. Waiting for a parent to start a conversation seemed to be a common way to determine when talk about their mother's breast cancer risk was appropriate during this stage.

Once the immediate fear for a parent had dissipated or treatment ended, adult children's fears and concerns sometimes shifted to what the diagnosis may mean for their own (or other family members') health and wellbeing. For example, Lisa explained how her mother's breast cancer diagnosis impacted the larger family system:

> You know, we talk about things like the BRCA gene now. We didn't think about those things before. But now it's like – are the girls going to get it someday? Is this something that can be passed on? What caused it? That's something we talk about all the time, something that I think about all the time.

Similar to the worry surrounding bringing up a parent's possible cancer recurrence, adult children were also unsure about when it would be appropriate to talk about their own fear about being diagnosed with breast cancer. Peggy put it this way:

> I don't want her to - I think I'll wait until maybe a year. I just don't want her to think I'm not concerned with *her*. I would like to know what the chances are that is gets passed down to myself or my daughter, but I want to make sure the focus is on *her* right now before I think about anything like that. So I haven't asked her yet – maybe I mentioned it once – but I'm waiting to have that actual conversation.

Rather than sparking conversation, lingering fears for personal cancer risk were often managed internally or pushed to a later date. Overall, it seems that adult children's fears and desire to talk about breast cancer did not conclude once a parent's primary treatment ended.

Work involves coordinating talk about prevention. Some adult children felt that talking about cancer prevention was the most demanding type of communication work in this stage. For example, Katie noted that conversations about prevention started immediately after her mother was deemed cancer-free: "She called to say she didn't have cancer anymore and I was like, 'Awesome – great!' and she was immediately like, 'Go get a mammogram now!'" Talk in this context concerned such measures as mammograms, genetic tests, and exploring the family's medical history of cancer. Almost all female respondents reported that their mother had made it a point to talk about getting mammograms, doing self-exams, and generally becoming more health conscious. Some respondents were interested in prevention and communicated about this topic easily. Other respondents did not appreciate the repeated attempts to talk about prevention. The latter group admitted actively avoiding certain topics of conversation during this stage.

Once the fear of surviving primary treatment had passed, several adult children mentioned a personal desire to get an early mammogram. Early testing was frequently seen as the logical thing to do. Jade, for example, went to the doctor to get a mammogram as soon as she turned 35 and was eligible for the procedure. Similarly, Megan said that, even though her doctor did not think an early mammogram was necessary, she insisted she wanted it "just to be cautious." Other respondents noted that their mother emphasized the benefit of getting an early mammogram. Bonnie, for example, recalled her mother saying, "It doesn't matter what your doctor says – you get a mammogram!" Meredith described her mother lecturing her to "stay on top of your mammograms – go when you're supposed to!" Heather described these conversations as a warning, "She would say, 'You girls make sure you get checked. You have to make sure you're doing mammograms. This is something you need to take serious." Whether the

adult child initiated the conversation or their mother brought it up, getting a mammogram was a common topic of talk for mothers and daughters once a parent finished primary treatment.

Beyond getting a mammogram, talk about prevention also surrounded genetic testing for the BRCA gene. Heather had recently talked to her mother about getting tested for the BRCA gene because she has two daughters and she felt a need to "be thinking of them as well." Similarly, Ashley explained that, because her mother's type of cancer qualified for a free BRCA test, she got it done for her "own benefit and peace of mind." In contrast to talk about mammograms, which occurred exclusively between mothers and daughters, sons also described being included in discussions about genetic testing. For sons, this conversation often manifested as a "if you ever have a daughter…" warning. Matthew explained it this way:

> Once Mom was in remission there was a consultation with the doctor and she told me one of the things they discussed was whether this was something that could be passed down to children. And that's when they told her that it is the type of cancer that could be linked genetically, but there's really no definitive way of telling. So she said, 'Just keep in mind that if you were ever to have a daughter they said that – if in the slim chance it is genetic it's a good idea that you make sure your daughter knows to start testing for symptoms early on.'

Talk about genetic testing was infused with more fear than conversations about mammograms. Frank, for example, noted that the fear surrounding the BRCA test was "palpable" in his family due to his mother's fear for her grandchildren. Fears about genetic risk of breast cancer, or talk about whether or not to get tested for the BRCA gene, appeared to be common in many families during this stage.

Although talk about prevention was common once a parent completed primary treatment, many daughters in this sample seemed to be uncomfortable with conversations about their own risk for breast cancer. Brooke, for example, recalled her father saying, "There's a gene and you need to get tested for it." Unsure of how to respond, Brooke told her father, "I will ask the doctor about it when I see him. I do perform breast self-exams and whatever." Brooke explained that, because she was not particularly concerned about her own risk for cancer, she was not interested in having conversations about prevention. Other respondents found talk about their own risk to be intrusive. Michelle described acute displeasure when her mother used her own experience as "an advertisement to get a mammogram":

> She brings it up *continuously*. You know, 'You should get a mammogram, you should get a mammogram.' I'm like, 'It's on my list! Thanks Mom!' She's like, 'I can come with you if you want.' And I'm like, 'No thanks.' It's pretty intrusive. I think because I'm her only daughter she's like, 'You're the one who would most likely be affected.' But honestly I just don't want to be involved in it.

In thinking back to conversations across her mother's breast cancer experience, Jade noted that the most distressing conversation she had with her mother about breast cancer surrounded her own risk:

> My mom told me, 'You know, you can get a genetic test to see if you have the gene.' And my response was, 'Well, if I do have the gene, what am I going to do about it?' And that's when she said, 'Well you know, maybe you should just go ahead and have it done.' And I was like, 'Have what done?' And she said, 'The procedure – a double mastectomy.' And I was like, 'You want me to have a double mastectomy right now? Are you kidding me? You're crazy!' I thought it was totally absurd. I did *not* want to have a

conversation about having *my* breasts removed. And I think I made that clear – I said, 'We're not talking about this. We're not going to – no.' I mean, I understand that she's worried about me - but wow!

Once a parent finished primary treatment, talk about lingering fears and prevention was a demanding and effortful form of communication work. These conversations occurred with both sons and daughters, but daughters expressed more frequent and more distressing conversations in this context. Conversations about personal risk for breast cancer seemed to be more difficult for daughters when they were not open to the conversation. In particular, adult children did not appreciate conversations in which parents made unwelcome suggestions about how to manage their own risk.

Adult children's work during recurrence. Four respondents had a mother who had a breast cancer recurrence. All four women described recurrent breast cancer as an overwhelming emotional rollercoaster where they thought they were done after the initial treatment ended and felt unprepared to go through the experience again. Recurrence created a variety of emotional responses, including anger, fear, stress, and depression. Communication work during this stage involved having hard conversations with a parent about treatments and mortality.

Conversations that reflected back on treatment decisions that may have prevented recurrence were particularly difficult. Following her third recurrent diagnosis, Bonnie recalled talking to her mother about her past decisions to have lumpectomies rather than a mastectomy. Despite the belief that her mother should have gotten a mastectomy after the cancer recurred for the second time, Bonnie recalled trying to "protect" her mother by saying "there's no wrong choice when it comes to your own heath." Bonnie went on to describe conversations about

mortality as being "Hollywood" in the sense that the conversation was avoided in order to maintain a sense to hope about her mother's prognosis:

> It was like, 'If it hasn't spread then here's the standard of care with chemo and blah blah blah. And if it has spread…' and I don't even remember the end of that sentence! Like… I actually don't even think there was exactly an end of the sentence. And that's one thing that I found fascinating that I always reflect on now through her whole care the last time: nobody ever said the whole time, 'You have blah blah blah amount of time.' And that's so – I'm going to say so *Hollywood* for a lack of a better term. You just know that's what happens. When someone says you have cancer you immediately think 'How long do I have!?' and she never asked 'How long do I have?' but nobody actually said that either.

Several respondents, including Bonnie, seemed to think that talk about the parent's prognosis was inappropriate when the patient did not seem to want to know that information. This complicated talk during the recurrence stage.

Another form of work in this stage surrounded helping a parent make decisions about whether or not to receive treatment when the cancer recurred. There are many treatment options for advanced breast cancer, and respondents were aware that new medicines were being tested every day. At the same time, respondents were aware that their mother's recurrent breast cancer would likely not go away completely. Meredith expressed feelings of helplessness when her mother's cancer recurred:

> I started calling Cancer Centers of America because – well I felt helpless. I couldn't help my mother knock the cancer out of her. I even got natural supplements for her to take, and the only thing she would eat was candy. That was the only thing that would stay down.

As compared to conversations during a mother's initial diagnosis, respondents seemed to feel more helpless when trying to help a parent make treatment decisions during recurrence. Amanda noted that her mother's "try whatever we can" mindset made talk particularly complicated when the cancer recurred:

> She got the diagnosis that it had spread to her liver and they – she took the option to do chemo again. And I had doubts, but we weren't really talking about them, you know? I just pushed those doubts way down because I was like – well she wants to do this.

For Amanda, preparing for conversations about her mother's recurrence was difficult because she did not feel comfortable expressing doubts about her mother's treatment plan. Amanda thought the best strategy was to avoid communication about her mother's prognosis in order to go along with the "try everything" mindset.

At the same time, adult children who had experienced a mother's cancer recurrence felt that their mother's first cancer experience provided some insight into how they could communicate more effectively during the recurrence. Sometimes a desire to change communication patterns sparked a more difficult conversation. For example, Meredith said that she "knew what the outcome would be" if she left communication patterns up to her mother the second time around:

> The first time around she didn't tell me anything. I didn't know what to do, I didn't know what to think, I didn't know if I needed to prepare. And she wouldn't give me the information so I didn't know what to ask her doctors. So the second time I told her right away, 'I want you to be straightforward with me this time!'

Meredith seemed to recognize that her mother would likely continue to "hide things" if she did not clearly express a desire to be involved when the cancer recurred. In this way, Meredith used

her mother's first cancer experience to improve their communication patterns during recurrence. Heather also described how, following her mother's lack of unsolicited disclosure during the initial diagnosis, she made a point to proactively start conversations about breast cancer. Heather went on to say that she "didn't care" if her mother got "tired of hearing from me so often" when the breast cancer recurred because she "was *not* going to be left in the dark this time." Although communication during a cancer recurrence appeared to be problematic for respondents, some adult children noted that they were able to remedy problematic communication patterns during the first diagnosis by talking to their mother in a way that was more personally satisfying.

Challenges and Strategies when Managing Information

Adult children's communication work during each stage of a mother's breast cancer experience gave rise to communication challenges related to managing a mother's cancer-related information. As the previous section highlighted, coordinating privacy boundaries in this context depended on the parent's desired level of boundary permeability (i.e., how much is revealed to and concealed from family members; Petronio, 2002). When family members did not agree about their preferences for permeability, managing a mother's cancer-related information further complicated parent-child communication.

Respondents often recognized that their mother was the central source of information about cancer, and their mother's wishes regarding what should be discussed greatly influenced communication within the family. For example, if the diagnosed parent did not want to talk about her cancer, the family may not have had access to information the patient had gained from medical appointments or other sources. Lack of information regarding the patient's cancer was often a source of emotional distress and frustration for respondents. In particular, adult children discussed the identity and relational challenges involved in both obtaining and avoiding a

mother's cancer-related information. Respondents also noted that uncertainty about their mother's illness trajectory could be both an antecedent to wanting more information and an outcome of not having sufficient information.

Negotiating differences in information management preferences. Information management was particularly difficult when the amount of information desired by the adult child differed from the amount of information their mother was willing to provide. Some respondents noted that their orientation towards information management simply differed from their mother's. Lisa articulated this challenge clearly when she said, "It always struck me that, just because *I* want to know something doesn't mean *she* wants to know. It's important to be there to support them and stuff, but to not let your own preferences get in the way." Lisa went on to say she would "butt heads" with her mom because she was an "information seeker" whereas her mom was an "I don't want to know, I will just do whatever the doctor says" type of person. This was a dilemma because, although Lisa wanted more information, she felt bad "pressuring" her mother for details or putting "undue" stress on her mother by telling her to ask the doctor about something that was beyond her mother's personal information needs. Lisa said she "settled for the brief updates" but "always wanted to know more." Similar to Lisa, Matthew felt bad about "prying" information out of his mother when he wanted more details than she was willing to provide. He explained:

> She's not one to want to talk openly about what's going on in her life. She will talk about it – but she won't go into detail unless you really pull it out of her. Like, when she called initially and told me that she was diagnosed that was all she said: 'I just want to let you know, I went to the doctor today and found out that I have breast cancer.' And so it was

up to me to figure out what to ask her because I knew she wouldn't offer more - it was up

to me to prod about it.

As these examples demonstrate, information management was difficult when parents and

children had different permeability orientations (Petronio, 1994).

In other cases, respondents felt that differing preferences for sharing information

stemmed from altruistic reasons rather than general orientations towards information

management. For example, Jade justified her mother's decision to keep information private by

saying, "I think that's how parents are – they try to shelter their children from the worst things in

life. And this was one of those worst things." Other adult children, like Peggy, felt that their

mother withheld information because she was did not want to "intrude" in their busy lives:

I think she feels like I'm too busy with stuff. Like, she's always saying, 'Parenting is so

hard and time consuming and work.' I think she felt like if I had the time to do something

I wouldn't want to spend it in a hospital and talking about cancer. Or that I wouldn't be

able to take the time off. I think she just thinks that way because, you know, when people

hear you have kids it's, 'Oh you're so incredibly busy.' And yeah, I'm busy – but I was

always going to be there for her.

Although Jade and Peggy each expressed frustration at not being able to easily obtain

information about their mothers' breast cancer, they also seemed to feel that their mothers

withheld certain information for altruistic reasons.

Strategies. Respondents who recognized the limitations of obtaining information directly

from their diagnosed parent often *talked to other family members* in order to obtain additional

information. Frank recalled that the only information he would get from his mom was, "Well

today I'm having a lot of trouble with – I feel really nauseous or the chemo is really knocking me

down." By asking his father additional questions, he was able to "get the physical but also the 'Well she's having a very hard time today' or 'She seems really tired and it seems like it's really got her down.'" Frank highlighted the benefits of gathering "contextual information" and hearing about other family members' "viewpoints." In particular, the additional information helped Frank "piece it all together and get an idea of the bigger picture." Similar to Frank, Lauren also described going to her father for additional information about how her mother was "mentally coping" because she "figured he would tell me more honest information than she would." As these examples demonstrate, some adult children who became frustrated with the lack of clarity in some conversations with the diagnosed parent were able to relieve that frustration by talking to other family members.

Respondents sometimes described being very strategic when obtaining information from other family members. Michelle, for example, recalled calling her father at a time when she knew her mother "would be out doing something" so that she could ask her father some pointed questions like, "How serious is this exactly?" Michelle explained:

> She didn't need to have *another* conversation with me after having a conversation when she was diagnosed, and a conversation with her doctor who does the mammogram, and a conversation when they send you to another doctor. I mean, I wanted the information but it didn't need to be from her.

Michelle perceived that this strategy was useful both to herself and to her mother.

Rather than going to other family members to obtain more information, some respondents described *gathering firsthand information* about their mother's breast cancer by attending medical appointments, chemotherapy treatments, and radiation therapy treatments. Attending appointments was seen as an important source of information because it provided firsthand

knowledge regarding treatment and care. For example, Shannon talked about how she went with her mother to a radiation therapy appointment because she was "really curious about what it was like and what the process was like and stuff." She explained:

It helped me understand more concretely what the process was like. It was such a big part of her day-to-day life at that point that I wanted to know what it looked like. So yeah, it helped me have a more complete picture. Otherwise, they get this diagnosis and then they go see a doctor and then they do more tests and you just get these update messages. It helped to see the machines and screens and the nurses who were really nice.

Similar to Shannon, Brooke said that attending medical appointments meant that she could ask questions and "gather information firsthand" that her mother might not necessarily have.

It is important to note that attending medical appointments was not always an effective strategy for gathering additional information. Indeed, this strategy was sometimes a source of conflict for parents and adult children, especially when adult children provided clinicians with information in their parent's absence. Connor, for example, explained how attending medical appointments with his mother created additional conversational dilemmas:

It got to the point that she wouldn't want me to go to the doctor's appointments because when she would go to the doctor I would tell him 'Hey her stomach was swollen, what's going on with this?' and she told me 'Be quiet, the doctor will handle it.' I think she didn't want the doctor to know some things because then she started going to dozens of doctor's appointments without me. And then she started telling me afterwards 'Hey I had a doctor's appointment today.' and I'm like 'Well why didn't you tell me so I could go?' 'Well you didn't need to go.' 'Mom, I need to know what's going on!' 'Well I took care of it!' So I – yeah I wasn't able to really go anymore.

In contrast to Connor, Lisa had more success in gathering information directly from doctors because she worked with her mother to *develop a code* for when she was going to ask the doctor a question that her mother did not want to know the answer to:

If I wanted to know, like, the statistical likelihood of getting another type of cancer, I looked at my mom and said, 'Why don't you go get a cup of coffee?' and that was all she needed for like, 'Okay you're about to ask something I don't want to know about.'

This code allowed Lisa to attend medical appointments and gather information without damaging the parent-child relationship.

Respondents often described *researching breast cancer on the Internet* in order to gather additional information. Lisa, for example, described "researching it on my own" in order to get additional information about the details of her mother's treatments. Similarly, when Leigh did not want to upset her mother by talking about mortality, she went to Google to "look up the difference between stage 1, 2, 3, and 4." She explained:

I wanted to know what exactly do those – does that mean for her chances? Because I really didn't know at that time – even though I had heard people talk about having cancer – until it happens to someone you really know like – what *is* stage 1? And looking that up helped a lot because when I read that I thought, 'Oh that sounds so – that's doable. I'm okay with that.'

For Leigh, looking up information online helped to reduce her fears without upsetting her mother with questions about her prognosis. Internet searches could also help adult children provide a parent with useful supplementary information. Lisa said, "I think doing some online investigating on my own helped me come up with some useful suggestions about how to manage the radiation burns."

Similar to attending medical appointments, doing research on the Internet was not a universally effective strategy. Indeed, sometimes doing research online created conflicts for parents and adult children. For example, Matthew felt that gathering information on the Internet was necessary because he did not want to overwhelm his mom with questions. However, Internet searches sometimes resulted in more questions than answers:

I didn't know anything about it so I had to do my own research on what she might be experiencing, what she could be feeling – everything! And so I would ask her, but a lot of the time she would say, 'What are you talking about!?' and I would say, 'Well I read online that this could be occurring.' and she's like 'No – it's not!'

Thus, although Matthew was using the Internet in an effort to avoid overwhelming his mother, he ended up overwhelming her more when Internet searches created new questions.

Respondents also talked about *getting official access to health records* by becoming their mother's medical power of attorney or being granted official access to their mother's medical records. Peggy, for example, described how getting access to her mother's medical information relieved a lot of strain in their relationship:

I was always asking, 'Well why didn't you ask if there were other options? How necessary is this? What would happen if you didn't have it?' and she was like, 'Well I didn't even think to ask that.' So I finally asked her to add me to the list so I could have access to her medical information.

Peggy explained that, after she was "added to the list" of people who could view official medical records, she was "able to see everything – the test results, the screenings, everything." Similarly, Amanda noted that being her mother's medical power of attorney provided an opportunity to have hard conversations about her mother's "end of life wishes" before it was too late. Thus,

although this strategy required a parent to give up control over her medical information, adult children seemed to perceive it as a successful strategy for sharing cancer-related information.

Determining how much cancer-related talk is appropriate. Sometimes adult children did not seek additional information simply because they did not feel that the parent wanted to talk about cancer. In this case, the diagnosed parent did not explicitly designate a cancer as a taboo topic. Rather, adult children were unsure about whether it was okay to bring up the topic due to the mother's reactions to past conversations. As Shannon put it, "one challenging thing was just figuring out how much she wanted to talk about it!" Shannon went on to talk about a specific time that made her unsure how much talk was appropriate: "Well, I asked her, 'How are you?' and she just said, 'Well I have cancer!' And I was just like, oh crap, are we not – are we not attending to this in a way that she's happy with?" This interaction made Shannon feel like it was not okay for her to bring up her mother's cancer and, instead, she had to wait for her mother to bring up the topic. This was problematic for Shannon because she did not want her mother to think that she was "avoiding it by not asking." Similar to Shannon, Nicole noted that her "only fear" was that she would bring up a topic that her mother did not want to discuss. Bonnie also recalled trying to decide whether it was acceptable to talk about her mother's prognosis. She felt it was a "betrayal" to want more information about this topic because her mother was not asking about her prognosis. She expressed wondering, "Is it okay for me to ask?"

Strategies. Some adult children, like Nicole, *had* an *explicit conversation about appropriateness* with their parent in order to determine how much talk was appropriate:

> I wouldn't push her to talk about something if she didn't want to. I would say, 'If you don't want to talk about this…' I don't know. I would just say, 'If you don't want to talk about it it's okay, but what do you think about this? Should we do this?'

More commonly, adult children tried to *pick up on the parent's subtle clues* that indicated times when talking about cancer would (or would not) be appropriate. Amanda recalled that she could easily tell that her mother did not want to talk when her mother would "snap a little – give a snappy little 'ugh' and I would be like 'okay.' Or she would say 'I just need to go lay down' and she would walk away. She just needed a break from talking."

Using *humor* was a common strategy for determining whether talk about cancer would be an acceptable topic of conversation. For example, Meredith noted that her mother would "laugh about things like losing her hair and her wig." Her mother's "humorous remarks" made Meredith feel like it was okay to talk about those topics. As she put it, "Hearing her laugh about it would make me feel so much better." Similarly, Tom recalled his mother making jokes about, "Oh finally losing some weight, finally managing to get the weight off" during her chemotherapy treatments. This helped Tom feel more comfortable talking about the physical toll treatment was taking on his mother's body.

Adult children would also make subtle jokes in order to "test the waters" about whether their mother was open to talking about breast cancer. Lisa recalled having an easier time talking about her mother's hair loss when she could joke about how easy it must be to "just put your hair on in the morning and not have to style it." Similarly, Katie found it easier to broach the topic of her mother's treatments by joking about the "cool new tattoo" her mother had to get for radiation treatments. Some respondents referred to reconstructed breasts with humorous nicknames. For example, Peggy recalled focusing on getting new "Perky-boobs" in order to bring up the topic of reconstruction with her mother. Similarly, Jade recalled using the term "Franken-Boob" in order to bring up her mother's upcoming reconstruction surgery in a "less scary" way. In these

examples, humor appeared to help adult children talk about cancer in a less serious way, release emotion, and validate a relational bond with their mother.

Navigating shifting boundaries towards openness. Some adult children described how their parent became more open to certain topics of talk across the illness trajectory. For example, Sandra described how conversations during the first weeks of her mother's chemotherapy were focused on "the physical pain" but over time her mother would "actually talk about how she felt mentally." Similarly, Bonnie explicitly described how both she and her mother became more open about the possibility of cancer recurrence over time:

> There was just no point in avoiding it anymore because we knew everyone was thinking
> it anyways. I mean, sometimes it was just expressing the uncertainty like, 'I don't really
> know what to say' or 'I'm really worried, Mom. I'm worried that they are going to find
> something.' Finally owning it, saying it, helped in some weird way. Not keeping it in,
> you know? And then you have to imagine what that other person is feeling like, 'Me too!'
> I think so much of the avoidance in the beginning was protecting each other, when really
> we could be helping each other by allowing each other to be real. Like, of course we are
> both terrified!

For many adult children, there appeared to be a point in the illness trajectory at which openness was prioritized over relational or identity goals. For example, Anna explained how her mother became more open when she could no longer hide the physical effects of treatment. She said:

> When she was first diagnosed she didn't come out and say 'Don't tell anyone' but it was
> an unspoken thing. We started to tell people when it was necessary – when she had her

chemo and her hair started to fall out she was like 'Well everyone's going to be asking

me or they're going to notice.'

In a similar vein, Maci noted that, once her family "realized it was going to be a long-term

treatment," they started to talk about cancer in more detail. As these quotes demonstrate, there

seemed to be a turning point at which avoiding talk about cancer was no longer functional and

thus boundaries shifted towards openness.

Strategies. Some respondents noted that they were able have more open conversations by

highlighting pragmatic reasons for openness. For example, when adult children acted as a

parent's primary caretaker, they often stressed that the parent had to become more open for the

sake of effective medical care. Kaylin, for example, explained how she always told her mother to

be open "no matter what, even if you think it's something small and stupid, because I can't help

you – I have to call somebody to tell me what to do because I'm not a doctor." Kaylin attributed

her ability to be open in talking about her mother's treatments and general well-being to her role

as her mother's primary caretaker. Similarly, many female participants explicitly stated that their

mothers started to share more information about their diagnosis when they learned about the

ramifications her disease might have for future generations. Meredith, for example, explained

that her mother was a "very private woman and didn't really want to tell us anything" but that,

because Meredith was the only daughter and her mother was very worried about her "future with

breast cancer," her mother shared information that she was not necessarily comfortable talking

about. Meredith said, "She only told me because she knew it was something I could possibly face

in the future." Similarly, Michelle felt that her mother shared more information with her than she

did with her male siblings because the information was more relevant to her than her brothers.

For instance, Michelle recalled many information-based exchanges with her mother being

prefaced with "you should know this because…" In general, female respondents seemed to appreciate that their mothers became more open in order to help them understand personal risk for breast cancer.

Navigating shifting boundaries towards closedness. In contrast to the previous examples, some adult children noted that their mother became less open about certain topics over time. For example, McKenzie recalled that as her mother began treatment, she became less willing to talk about breast cancer because she "didn't want to be about cancer – she didn't want to identify with it – so she tried to play it off like nothing was happening." In McKenzie's case, although her mother had initially shared her diagnosis with the larger family network, it was understood that once she started treatment, cancer was no longer an open topic of conversation.

One specific topic that seemed to become more difficult to talk about over time was mortality, and some adult children even reported being in complete denial of their mother's possible death. Maci provided the most detailed example of this challenge when she talked about how having a "truthful and honest" conversation about her mother's breast cancer being diagnosed at Stage 4 became increasingly difficult to discuss as time went on. Maci initially described avoidance of both thoughts and conversations about her mother's possible death. For example, Maci recalled having "moments" of wondering, "What if it's not going to be okay – What if you're not going to walk away from this?" but then immediately shifting her mindset to "No, don't think about that – don't think about that. If you don't think about it, it's not going to happen." Maci also recalled explicitly avoiding this topic when her mother tried to talk about her prognosis:

She said 'This is the beginning of the end' and was playing with the skin on her knee and she said 'This is it – this is what your skin starts to do before you die – I've seen this a

million times – your skin starts to do this.' All of us were like, 'You're not dying! It's okay!' Like, we were immediately like, 'That's not what's happening here – don't say that Mom! You're going to fight this, you're going to be okay!' Which I kind of regret now because we never – we never approached that actual reality. I wish I would have been more capable of having the conversation with her about whether to not she was really – what could really happen.

Later in the illness trajectory, Maci *almost* had a conversation with her mother about mortality:

At some point I just said 'We need to have that conversation - even though that's *not* going to happen, we should probably still talk about it.' But, like I said, neither of us knew how to have the actual conversation so we just talked about having the conversation and it never really went further than that.

As her mother's breast cancer progressed, mortality became increasingly difficult to discuss. This was extremely dissatisfying for Maci:

If I would have been less in denial about it, I could have been a better daughter for her. I could have provided her maybe more of the comfort and the strength that she'd provided to so many people in her career. So yeah, that gets to me. If I hadn't been so in denial maybe it would have gone better for her at the end.

Similar to Maci, Heather noted that the "difficult conversations" happened when her mother wanted to talk about what would happen if the treatment did not work or the cancer came back. She said:

Mom wanted to go over paperwork and wills and 'if something happens' and all of that. But – ugh – I avoided those conversations completely. I just said, 'Mom I don't want to hear about this stuff!' So that was very challenging for me.

Inability to talk about death was particularly dissatisfying when adult children perceived that they "missed the window" for "actual conversations" with their mother. For example, Ashley described how her mother was on such high doses of hydrocodone that she "wasn't herself anymore" and so they never got to have a final conversation. She said:

> I hate that I never acknowledged that she was going to die. I regret not having that conversation. It would have been a hard conversation to have but I do regret not talking about it.

Bonnie expressed a similar sentiment: "I remember thinking at some point that I missed my window – like, at some point because of the medication she was so out of it that we couldn't really talk anymore." Discussing death or mortality appeared to be particularly challenging as time went on, which represented a shift towards her permeable boundaries. Even though death and mortality were considered important topics to discuss with the diagnosed parent, many adult children reported an inability to have what many respondents referred to as "actual conversations" about death and dying.

Strategies. Adult children reported two strategies for overcoming this challenge. First, avoidance of talk about mortality was considered functional when adult children *cognitively reframed avoidance as maintaining hope.* For example, Amanda explained that her family did not talk about death until "very close to the end – until two weeks before she died." Amanda saw her family's denial as an effective strategy because it meant that they did not focus on her mother's probable death. Amanda went on to say that her family did not talk about the "imminence of death" because they "wanted to have hope that the treatments were going to work and that she was going to pull through and that it wasn't the end." Adult children who reframed

the shift towards increased closeness as maintaining hope did not seem to experience the shift as a challenge.

By contrast, respondents who were dissatisfied with the shift towards increased closeness suggested *acknowledging needing help having difficult conversations*. Maci suggested "having a chaplain come in to be like, 'Hey this isn't 100%, you should talk about the worst case scenario' could have helped us navigate it a little better." Similarly, Ashley suggested "taking advantage of the social worker assigned to your case" because social workers are "a good resource for families who need someone to talk to." Although respondents suggested getting a third party involved, no adult children actually reported using this strategy.

Contextualizing previous family experience with cancer. As suggested by Foster and her colleagues (2015), previous family experience with cancer also shapes family communication about cancer. Previous experience with cancer sometimes results in more open communication, whereas other family members may note how previous experience with cancer hinders communication due to fear and worry. Elise, for example, noticed that there was very little talk about her mom's diagnosis being stage 4 because the family was still coping with the loss of their father due to stage 2 cancer:

> We were all devastated. We just lost our dad in September and it's like, just a few months later that we found out our mom was stage 4. […] We didn't talk about it much because we were all scared we were going to lose our mom too.

Similarly, Amanda recalled going to the "same doctor we had for my dad" when her mother's breast cancer spread to her liver. She described sitting in "this same very office with the same doctor who told my dad that there was nothing more they could do for him." She went on to depict the doctor telling her mother "I think cancer is going to take your life," which was the

exact same phrase the doctor had used with her father. For Amanda, repeating the events of her father's cancer amplified the fear surrounding her mother's breast cancer. Clearly, previous experience with cancer could hinder the flow of information, particularly due to a reluctance to discuss mortality.

Conversely, previous experiences could also open lines of communication. For example, McKenzie explained how her aunt's recent passing led her uncle to push the family to talk more openly about breast cancer. Similarly, Frank's aunt's recent passing due to breast cancer "broke down a lot of the walls, a lot of the barriers that would have been there otherwise." Frank noted that his aunt's experience led to explicit conversations about how scary breast cancer was and made the family "more supportive through the whole thing." Frank concluded that his family's recent experience with his aunt's breast cancer "completely changed the way we talked about it and the way we felt about it" when his mother was diagnosed.

Strategies. Respondents were able to leverage previous family experience with cancer by *cognitively reframing their mother's cancer as being unique or different* from other family members' experiences. For example, Kaylin explained how, in conversations with her mother, she would intentionally point out how cancer-related treatments had advanced in order to highlight how her mother's experience was different than her grandmother's experience. She said:

> My mom's mom died from brain cancer when I was a baby so I think her – I think talking about how times were different then and how medicine has just come such a long was helped. I would tell her 'I'm not going to have to live without my mom.' It was important that I told her that.

McKenzie also recalled talking to her mother about how medical advances would make her cancer experience different from past diagnoses:

> Generally speaking in my family, cancer is usually like – the person dies of it… when my mom had it, it was sort of a surprise… she had chemo and radiation and surgery, a lumpectomy, and then she was and continues to be fine. So she's the rough draft. So I think the cancer narrative in our family is less tragic now that medicine is improving.

In this way, some adult children framed their mother's experience as unique by highlighting ways that her cancer experience was "better" than other family members' experiences. In general, previous family experience with breast cancer appeared to shape the ways in which adult child respondents talked about, and coped with, their mothers' breast cancer experience.

Managing uncertainty in illness. Respondents often saw communication as a source of uncertainty about their mother's cancer experience and, in turn, an uncertain illness trajectory created problems for family interaction. Consistent with prior research on the pervasiveness of uncertainty in illness (Brashers et al., 2003; Mishel, 1988), participants noted that interaction often generated or exacerbated doubts about their mother's symptoms and prognosis. Elise, for example, described being "extremely distraught" because there were "so may 'what if's' – what if Mom doesn't survive? What if the cancer spreads?"

For many respondents, not knowing "how bad" the cancer was created uncertainties. Indeed, Peggy recalled how initial conversations with doctors elevated her uncertainty about how the cancer trajectory might progress:

> The first conversation with her doctor wasn't really helpful. They say, 'We see something so you will have to come back for another, a more thorough exam or screening.' And so

we were hopeful that it wasn't anything – but then on the other hand we had to think

about just being strong and working through it together. It was depressing.

The drawn-out diagnosis process left Peggy with heightened uncertainties. She explained the

process as being "very grey" because "you know something's not good but is it *really* bad? Or is

it, you know, a *little* bad? Or is it… you know, *incredibly* bad?" Bonnie also felt that the drawn-

out diagnosis process elevated uncertainties. In particular, she remembered waiting for her

mother's scan to come back following the third breast cancer diagnosis and wondering whether

the cancer had spread to other parts of her mother's body:

> There was this big question mark around whether it had spread, but no one was really
>
> talking into that space. It was like 'dun dun dun!' And then you just wait – and it was so
>
> stressful.

Shannon also experienced heightened uncertainty while waiting for her mother to "call with the

results of the biopsy and *knowing* they were going to call this one day and just *waiting*." As these

examples demonstrate, several aspects of the diagnosis process created and exacerbated

uncertainties for adult children.

For other participants, uncertainties were heightened during primary treatment. In

particular, some respondents perceived that their mother was not forthcoming when asked about

disease progression, which gave rise to illness related uncertainties. Matthew, for example,

described never getting a "full understanding" of his mother's treatment:

> I just know that there was the chemo, I know that there was radiation, I know that she had
>
> reconstructive surgery. But I don't know the details surrounding those treatments. Still to
>
> this day I don't really know what they are. Like, I know that cancer goes with
>
> chemotherapy – that's common. But I don't know what all is involved in it. I know that

people go through it, I know that it's very unpleasant, I know that there are a couple

different types of treatment. But that's really – I would have liked to know more detail

about it rather than her just saying, 'Okay I found out I have breast cancer.' It's like –

okay well, I don't know, I know what that *is* but I don't know what is *involved*.

In a similar vein, adult children sometimes did not know whether to attribute behavioral changes

to their mother's cancer treatments. Scott, for example, was unsure what treatments his mother

was having or how they might be affecting her:

It wasn't something we probed about – I would see them leave on the weekend or at

night, going to her appointments. And when she would come home – I don't know what

kind of treatment was going on or her emotional state, but I do know she would tend to

try to sleep it off. She would get back from an appointment and sleep all weekend. I think

she said that some of the medications she was taking to balance her out would tend to

change her emotions – but she didn't really tell us that for *years*. Like *many* years. We

would have arguments in the sense of, 'Why do you stay up here by yourself and shut

yourself off?' She finally said she just needed time away to handle the medications and

what they were doing to her body – she didn't want to basically go off on us. So, I saw

the effects all along, but I didn't know it was because of the medicine she was taking. I

didn't know that for *years!* I would always think she was just upset with one of the boys

or whatever was going on in her life. I just wasn't aware of it. After she told me, after

that, I think it was more of a – I understood why she was doing what she was doing all

weekend when she finally told me. She just didn't want us to be worried for her.

In this example, Scott clearly articulated how a lack of information about his mother's disease

and treatments meant that he (a) did not know whether to attribute behaviors to his mother's

cancer treatments or to "changes in emotions" and (b) was uncertain about the severity of his mother's diagnosis. Although Scott was frustrated that his mother's lack of disclosure heightened his anxiety and uncertainty, he also seemed to understand that his mother chose to conceal certain information in order to protect the rest of the family.

An additional source of uncertainty for respondents was whether their mother's cancer would recur. Sandra described the uncertainty this way:

> You just don't know, right? Like, there still could be something, even though they removed both breasts. But in my mind, I'm like, you just don't know! Especially since she was almost stage 4 – you just don't know. There are a lot of instances where people have surgery and then it still comes back.

As Sandra clearly articulated, being diagnosed with a later stage breast cancer could heighten uncertainties about recurrence.

Strategies. In situations where uncertainty was exacerbated due to lack of information, some respondents *asked for updates about the disease progression.* For example McKenzie recalled that her mother's updates helped reduce her speculation about what might happen:

> She was always saying, 'Dr. K says this, and Dr. K says that.' So she was basically relaying all the information from her doctor. Both she and my dad basically echoed what the doctor said and that helped me a lot in terms of having news to fill to void of information so I wasn't speculating and worrying all the time.

Matthew also discussed how his uncertainty was reduced by his mother's regular updates:

> The best conversations were when she would tell me exactly what was going on so there wasn't any – I didn't feel like there was information being held back. I mean, there are undertones and nuances to a conversation and I'm no idiot. If she was holding something

back, I knew. She did that from the beginning – told me what the doctor said and what

stage it was and where it was. All the details. Once she put all of that information out

there I was like 'Oh, okay.'

For McKenzie and Matthew, feeling that they were receiving all of the relevant information

greatly reduced feelings of uncertainty.

As a conversational strategy, *minimization* could both increase and soothe respondents'

uncertainty. Many adult children felt that their mother was "nonchalant" or "casual" when

talking about the diagnosis. For some respondents, this behavior made them feel more confident

about their mother's chance of survival. Leigh explained that her mother "downplaying" the

diagnosis helped her realize that the cancer was caught as early as possible:

When I talked to my mom about it she really downplayed it. You know, that some people

have stage 4 or 2 or 3 or whatever. But she explained it was very little and she was like,

'It's going to be fine, this is what the doctor said, he's recommending that I *only* do

radiation which is the least you can do. And the lumpectomy. I'm not worried about it.'

She seemed really fine with it and not too upset about it… and I think because she made

it sound so minimal, I really didn't feel worried about it.

For Leigh, her mother's framing of the cancer seemed to help her believe that everything was

going to turn out okay in the end. Similarly, Lauren's concerns were relieved when her mother

described the treatment plan as being "the least invasive way to deal with it" because it was "*just*

a lumpectomy." As Nicole put it, her mother's "low-key demeanor" helped her think about the

experience as, "Okay she says it's going to be alright, so it's going to be already! She's Mom,

she knows!"

When minimization was viewed as an effective conversational strategy, adult children felt their mother minimized in order to facilitate coping. Framed this way, minimization could deemphasize, and in some cases reduce, uncertainty. Sandra put it this way: "I think she downplayed it for my sake, my sister's sake, and for her own self, you know?" Heather also felt that her mother minimized in order to "reassure us to we didn't worry." Minimization sometimes helped respondents focus on "next steps" rather than getting bogged down in their own fears and uncertainties. For example, Amanda recalled her mother saying, "Okay well we're just going to figure out what this is and go forward." This was useful to Amanda because she was able to then "follow Mom's lead" in order to be "supportive and optimistic and positive" about the diagnosis. Similarly, Katie said that, because her mother talked about treatments during "kind of a casual conversation," her family quickly moved on from terror to "alright we have to deal with this – what do we need to do?" Shannon also felt that minimizing the severity of her mother's diagnosis helped the family be more "action-oriented:"

> So she was like 'It's malignant - it's cancerous – and we caught it early, it's Stage 1' so diffusing anxiety around it, 'It looks really good and they want to do this and we're going to do this' So it was very statement of fact, but defray emotion around it, and then the course of action.

In these examples, minimization was effective in that it helped adult children process information about the diagnosis in a straightforward manner and focus on the treatment plan rather than fear and uncertainty.

Minimization was not always considered to be an effective strategy, however. Indeed, some respondents noted that minimization of the diagnosis or extent of the illness complicated

interactions. In this case, minimizations made respondents feel unable to express their own fear or receive support. For example, Michelle said:

> Because she was kind of blowing it off – she was very causal about it – so I was very casual about it. But I wish I would have pressed more. I can't come up with the exact words but something like – just expressing my concern more. Because they were kind of backing away from it so I kind of backed away from it. But I wish I had said, 'Hey I'm really concerned about this!' Maybe asking questions or just being more expressive in terms of that I was concerned and that I'm willing to help – do a bone marrow transplant, give a kidney, whatever.

In this case, her mother's minimization of the diagnosis made Michelle feel that it was inappropriate to express her fears, concerns, and willingness to help. Thus, although minimization often effectively reduced respondents' cancer-related uncertainties, it could also complicate information exchange.

Summary. In sum, adult children experienced an array of communication challenges related to information management while negotiating involvement in a parent's breast cancer experience. Differing preferences for sharing information and shifting boundaries across the illness trajectory complicated adult children's involvement in their mother's breast cancer experience. Often, this exacerbated illness related uncertainty for adult children. In particular, adult children struggled to determine how much cancer-related talk was appropriate. Talking to other family members, gathering firsthand information, having explicit conversations about preferences, and cognitive reframing were chief strategies for overcoming challenges of interaction in this context.

Challenges and Strategies when Communicating Social Support

Adult children's work during the diagnosis, treatment, survivorship, and recurrence phases of a parent's breast cancer experience also gave rise to communication dilemmas related to providing and obtaining social support. Adult children conceptualized social support as "being there" for the parent and providing reassurances. At the same time, however, they thought it was best to conceal their own fears. In other words, social support was seen as particularly important to the parent's functioning, but respondents often deemphasized their own support needs.

Enacting support by "being there." Similar to Fisher's (2010) study of mother and adult daughter communication about breast cancer, respondents in this sample frequently stated that the most helpful enacted support they could provide was "just being there" (Brooke) or letting a parent "know I was there" (Amanda). Respondents enacted this type of emotional support by being with their mother for appointments, shopping for wigs, and being available to talk. For example, Lisa said it was important that her mother not feel like she was "going through the experience alone." She explained:

> I never said 'I'm here to take care of you' or 'I'm here to comfort you like a child.' It was more a - I'm here, which is good because she shouldn't be alone. It was more of just being there for her.

As this quote suggests, being there was often more behavioral than communicative. Leigh felt that "Just calling her once and while - just kind of being there for her like, 'How's it going? How are you feeling?'" was helpful because she "didn't really know anything specific – any advice - to help her." Frank expressed a similar sentiment:

> I think just affirming that I was there and I was hearing what she was saying helped. Just kind of 'Well keep me up to date as far as that goes' and a lot of 'Yeah' and 'Okay' and 'I understand that.' I let her do the talking; I was just there for her.

Respondents emphasized how much their mothers appreciated "being there" as a support strategy. Peggy said:

> She expressed to me how thankful and appreciative she was that I was there for her. You know, to explain things, emotionally, for her surgeries, after her surgeries. And I was just glad that I could be there for her. She never said, 'I really, *really* want you to be there.' I just told her 'I *will* be there.' And she was like, 'Okay good I want you there.' So I feel like – just the fact that I was there for her even though she wasn't expressing as much that she *really* wanted me to be there – that was important to me.

Other adult children suggested being open to whatever direction that conversation moved could improve their mother's functioning. Lisa put it this way,

> I wanted her to know that I was there if she wanted to talk about it, but I didn't expect her to come to me to talk all the time. I didn't ever push or anything because I didn't really want to talk about it unless she wanted to. And if she wanted to, I was going to be there 100%.

As these examples demonstrate, adult children especially emphasized the value of "being there" for their mother if and when she wanted to talk.

Strategies. Adult children reported using two strategies to successfully "be there" for the diagnosed parent. First, being there often manifested as advice to *be available and open for discussion if and when their mother wanted to talk*. Darla suggested that adult children "stay open and allow the parent who is going through this to express their feelings about it, listen to them, try to be there for them. Just be there for them." Brooke expressed a similar sentiment: "I let her say whatever she wanted and just say what she felt. That was the most meaningful part to me." This strategy emphasized the importance of demonstrating willingness to talk about their

mother's condition and a readiness to engage in difficult conversations. Second, *communicating with the parent more often*, particularly during treatment, was another strategy that helped respondents successfully "be there" for their mothers. For example, Nicole remembered calling her mother "every day, at least once a day, to check in on her. I wanted her to know I was thinking about her." This strategy emphasized demonstrating "being there" by checking in with the parent on a more regular basis and physically attending medical appointments. Overall, respondents felt that "being there," especially during their mother's treatment, was an important form of social support.

Enacting support by providing reassurances. In addition to "being there," adult children enacted support by reassuring their parent that everything was going to turn out okay in the end. For example, Kaylin recalled telling her mother, "Everything is going to be fine, we will have a treatment plan, we will go to the doctor. And once we have a plan we will go through with everything and everything will be okay." Matthew used reassurances as a way to help his mother get through the hard times, "I would say, 'You're going to feel this way now, but it's not going to be an everyday thing. You just have to keep that in mind." Anna reassured her mother by looking forward to when she would be done with treatments:

> She was really struggling with losing her hair – she was fixated on that. Which I understand […] I would try to just reassure her and listen like, 'Well you have to do it. Chemo gives you a better chance of it not coming back and it's only four treatments.' That was a big thing, I would say 'It's only four!'

Similar to Anna, Kaylin recalled providing her mother with the reassurance that she was "beautiful no matter what" when she lost her hair during chemotherapy treatment. Reassuring her

mother that she "looked good" when she wore a scarf, hat, or wig seemed to strengthen Kaylin's bond with her mother.

Strategies. Adult children's strategies for providing their mother with reassurance included *using distraction tactics* and *focusing conversations on the future*. Some adult children felt that the best way to reassure their mother was to simply not talk about the cancer at all and instead distract their parent, even if it was only for a few minutes. Matthew, for example, mentioned sending his mother "cute little videos" that he would find online. He did this for the sole purpose of cheering his mom up:

> I knew there was no way she was going to watch it and not be happy. I just knew if she would sit there thinking about [the cancer] the whole time she would never have a moment in her day when she would be happy or upbeat. So I tried to take her mind off of it and just help her be happy.

Megan also talked about sending her mother "funny stories or funny jokes" to try to put a smile on her mother's face. She described doing Internet searches in hopes of finding something that would make her mother "smile or laugh a bit." Other adult children provided reassurance by focusing conversations on the future. Connor, for example, talked to his mother about "the future down the road – about different things and what we want to do and what she wants to go see and do this and this" as a way to reassure his mother that everything would turn out okay in the end. Similarly, Brooke would tell her mother 'When this is all over we should do this – when this is done you will feel better and we can do this or that!" Providing reassurance with distractions and focusing conversation on the future seemed to be common support strategies.

Maintaining positivity in conversations with the diagnosed parent. Some adult children described times when they were expected to "go along" with their mother's positive

energy or say things to help their mother stay positive. Staying positive involved adult children mitigating their mothers' cancer-related distresses, encouraging them to keep fighting the disease, and making sure that everyone in the family had an upbeat outlook during difficult times. Staying positive was seen as very important for making the diagnosed parent feel better, particularly on down days, and in motivating the parent to stay strong and beat cancer. Darla put it this way:

> It was never, 'I'm worried she's not going to make it.' – I *never* said anything like that to anybody. I don't have those types of conversations because I don't think they are effective – it hurts the situation. Not dwelling on that and just staying positive was better for all of us.

Darla went on to explain that staying positive helped because it was easier for the rest of the family to stay positive when her mother was in good spirits:

> More important than our communication was our outlook. Our attitude. The energy we gave the situation. Because I think attitude and energy will flow into everything else; if you have a positive attitude, those things will come out in your communication and the things that you say and the things that you do.

> In order to help the parent maintain an optimistic attitude, adult children often took on the role of advocate for their mother's positive mental state. This manifested when adult children referred to times when they used positive communication to prevent their mother from speaking negatively. Matthew, for example, described how he would not allow his mother to talk negatively about her cancer:

> She would say, 'Oh I'm feeling really sore today.' or 'Emotionally, I'm just drained.' And I would try to take that and say, 'Well tell me about something that is good today.

What did you do today? … Oh that sounds good!' And I would get a sense that she was

being a little more positive.

Although Matthew noted that his mother probably "went right back to being negative" when she

hung up the phone, he felt good that his conversations always had a positive slant.

Adult children felt that staying positive was dilemmatic when they recognized how

expectations of positivity discouraged the expression of personal doubts and fears. Elise

provided an example of this dilemma when she described her mental state as "completely

negative" but, in conversations with her mother, feeling obligated to "send positive messages."

Some participants even recalled their mother explicitly telling them that they were expected to

stay positive. For example, Megan said that, because her mother framed the experience as

something she was "going to get rid of quickly," everyone was "expected to just stay very

positive through the whole thing." Megan later noted how 'staying positive' made

communication more difficult: "I was much more cautious with what I was saying to her since I

knew she wanted us to stay as positive as we could." In these examples, staying positive when

talking about cancer constrained communication about some topics.

Strategies. Adult children managed this dilemma by *talking to social network members*

outside the family about negative emotions or feelings and *expressing fears and doubts to*

siblings and the healthy parent. These strategies were considered useful when adult children

perceived that these outlets would allow them to be more positive in conversations with their

mother. For example, some respondents found it easier to confide in social network members

who were less emotionally involved in the cancer experience. Work colleagues and managers

could be a useful source of support and information, especially if they could provide the

respondent with flexible working hours or allow the respondent to take time off. Sandra

described feeling "lucky, very lucky" to have a manager that was "so cool and would allow me to leave for every treatment. Like you know, even if I didn't have the leave-time. She would make sure I could make that up somewhere else. That meant a lot to me."

In addition, adult children who struggled to "stay positive" in front of their mother often found an outlet in talking to other family members. Elise explained that she would have many conversations with family members "away from Mom" so that "we wouldn't upset her to see us upset." Elise explained that this was important because it allowed the family to "put up a front in front of her – she knew we were upset, but we tried to be positive in front of her." Similarly, when it was hard to stay positive with her mother, Anna would go to her dad or grandma instead of talking to her mom. This allowed her to voice her fears but not complicate her mother's coping behaviors. Brooke also recalled the benefits of talking to her mother-in-law, rather than her diagnosed mother, because "talking about it with people that I care about but were a little removed from the situation helped me kind of accept it a little more – like, helped me accept it for how it was."

Although respondents recalled the value of talking to various family members, the most common alternative outlet for support was a sibling. Siblings were a useful source of support because respondents felt that they could be more honest or open with a sibling than they could with their parents. In turn, being more honest and open with a sibling seemed to allow adult children to be more positive in conversations with their diagnosed parent. For example, Frank explained how he wanted to be empathetic about his mother's desire to go back to work, but he was also exasperated because she really needed to stay home and recuperate. By talking to his sister about his feelings of exasperation, he was able to be more supportive when talking to his mother:

My sister and I talked about this a couple of times just being like, 'No Mom, stop. You

have cancer, you're undergoing treatment, you need to not add stress to the difficulties

you're having by feeling stressed out that you can't be at work. You need to calm down

about that and focus on recovery.' *Interviewer: You would say that to your mom?* Oh no.

To my mom I would be like, 'Yeah that sucks, you will be back at work soon!' but to my

sister it was like, 'Yeah she needs to not go to work, she needs to stop trying to do that.'

So I think we were a bit more honest with each other about that. I had to be more cautious

with my mom.

Similar to Frank, Leigh felt that "expressing frustration" to her sister was better than sharing

those feelings with her mother. In particular, this strategy meant that she wasn't putting any

"additional strain" on her mother. Shannon also turned to her siblings for support in order to stay

positive in conversation with her mother:

It was really helpful to thrash out some of the more emotional stuff with someone other

than my mother. I didn't feel like it was going to help her at all for me to be like,

contributing to the complexity of what she was feeling. So my sister and I talked about a

lot of the things I didn't want to talk to my mom about.

Like Shannon, Lauren remembered having conversations about her mother's prognosis with her

dad and sister in order to avoid dampening her mother's spirits, "It's not that I was

uncomfortable talking to her but… I would just ask my dad or my sister like, 'What's the

prognosis?' I didn't want her to think about that." As these examples illustrate, the healthy parent

and siblings often provided an outlet for conversations adult children wanted to have but did not

feel were appropriate to talk to a parent about. In turn, expressing annoyances to other family

members allowed these respondents to be more positive in conversation with their mothers.

Turning to a sibling or the healthy parent for support was not universally effective, however. Indeed, some respondents emphasized how a family member's maladaptive coping problematized their own coping behaviors. For example, Lisa said, "I love my Dad but he was just not helpful. He kept working all the time and just didn't know how to provide her any emotional or moral support. That bothered me – I couldn't really talk to him about it." Similarly, Elise described how her sister was "so distraught" that it was hard to have a conversation with her. When Elise would go to her sister for support, she would end up having to reassure her sister that, "Mom is going to survive this, let's not think the worst." As these examples illustrate, not all respondents were able "stay positive" by talking to other members of their family network.

Providing support while managing personal emotions. Considerable discussion focused on the emotional nature of providing support to parents and other family members. As Milligan (2005) stated, there is an "embodied emotional experience" in providing informal care to a family member (p. 2107). For adult children, emotions like sadness, anger, gratitude, disappointment, and a general sense of being overwhelmed were embedded into a parent's breast cancer experience. Interestingly, adult children framed effective provision of social support as hiding their own emotional reaction in order to focus completely on their mother' reactions. Megan put it this way:

> Of course you're going to go through your own stages of feeling low, feeling upset, but at the same time you should try to – I wouldn't say *don't* show it to your parent, but maybe present it in a way that's like, 'This is how I'm feeling but I'm going to be okay.' Let them know you'll get through it and they don't have to worry.

Thus, although Megan did not advocate for completely hiding emotions, she clearly thought that her mother's emotions should be given priority over her own emotions. Kaylin took a more

definitive stance on the appropriateness of emotional displays when she explained that, although she had her own moments of feeling depressed, she would, "never, *never* let my mom see that I was stressed out." This was perceived as a dilemma for adult children: provide support in a way that prioritized relational and identity goals by hiding their own emotions or show their emotions and deal with negative relational and identity implications of support (e.g., possibly upsetting their mother or making a difficult situation even worse).

This dilemma manifested across a parent's cancer experience. For example, Leigh and Amanda experienced this dilemma during the diagnosis stage. Leigh recalled trying to hide her emotional reaction when her mother called to disclose the diagnosis:

> I started crying immediately – but I remember trying to not let her know I was crying because I didn't want to upset her and I didn't want – I didn't feel like it was fair for me to be upset when she's the one handling it and, if she wasn't crying and scared and upset, it's not really fair for me to be. You know what I mean? It's her body, and her – *she's* the one that has to go through it. So I tried to sound strong on the phone and to not let her know I was upset. I mean, she knew I was upset but I didn't break down until we hung up.

Amanda described a similar experience during the diagnosis stage:

> When she told me I had my little breakdown moment. Not in front of her – I didn't want to have that on the phone with her. So that conversation I held the fear at bay so we could focus on just 'Okay well what do we need to do?' but after we hung up I was like, 'Oh God.'

Other adult children talked about trying to hide their own emotional reactions in order to provide effective support when their mother entered primary treatment. Shannon put it this way,

"It feels a little self-indulgent to really express your anxieties unless they invite you to. I just don't think somebody dealing with a diagnosis also needs to deal with someone else's reaction to the diagnosis at the same time." In a similar vein, Shannon felt bad that her mother had to "spend a lot of emotional energy reassuring her kids" during a time when she should have been the one receiving support.

Meredith struggled most with feelings of lack of entitlement to support when her mother's cancer recurred for the second time:

> I remember one time we were in the ER and I started crying and she said, 'Will you stop crying?!' And like, she yelled at me! And I had to leave the room so I wouldn't cry in front of her because it was making her angry. It's hard when you are trying to reach out and be there for somebody and they just – I mean, I was at a loss at that point. I understand that she didn't want to see me upset – she didn't want to feel like she was upsetting me. She had enough problems of her own to not have to worry about me being upset and crying over her condition. But I couldn't hide it so there was nothing I could do.

Meredith appeared to believe that the ideal way to provide emotional support was by hiding her own emotions. When she was unable to "hide" her emotional reaction, she felt that the interaction might have negatively impacted her mother's coping behaviors.

As these exemplars demonstrate, providing emotional support in a way that prioritized the parent's emotional reaction often gave rise to the dilemma of choosing between reacting 'inappropriately' by showing their emotions or reacting in a way that they thought would be most satisfying to the diagnosed parent. This challenge was compounded when respondents articulated feelings of lack of entitlement to support or the belief that voicing their need for help

would detract attention from their mother. When Megan's mother was breaking down, for example, she felt that she "had to be the strong one" in the situation. And, although it was "very hard not to cry too," Megan felt that it was her duty to be strong so her mom "wouldn't get even more upset." Similarly, Lisa described sitting with her mother and "trying to be strong and not cry" when they were in the hospital right before her mother's mastectomy. Staying strong was important to Lisa because she did not want to make her mother sadder than she already was:

> When she would say, 'I feel really sick, I feel nauseous' instead of getting upset like, 'Oh my mom is going through this, this is so terrible!' I would just feel that on the inside but not voice it to her. I think she would rather it just be – like – not brought up.

In these examples, adult children were faced with the dilemma of trying to seem stoic in order to uphold identity and relational goals while managing internal turmoil or distress.

In contrast to the adult children who thought they should minimize emotional expression, several respondents perceived hiding emotions as problematic. Hiding emotions was especially dissatisfying when it precluded adult children from expressing how much they actually worried about and cared about their mother. Anna explained it this way: "I think I tried to keep my emotions in check as much as possible because I didn't want her to start to feel bad – but now I kind of wonder if being stoic may have come off as not very supportive." Nicole also expressed how her mother might not have known how worried she actually was about her cancer:

> I'm not good at the very serious conversations so I think I downplayed it a lot – like it wasn't important to me. I hope she didn't think that I didn't care – I wouldn't want her to think that it wasn't some big deal because it *was* a big deal! So I suppose if I could go back I would make that more clear – that it was a big deal and I was there if she wanted to talk about things. I try to avoid the serious-seriousness and take a lighter side of things

so we probably never talked about it because I avoided those kinds of conversations. But

I would go back and try to do that – I don't know how I would do it, but I would try

harder.

Michelle said that not knowing *how* to talk about more difficult topics kept her from bringing up

more emotional or hard topics:

I know at one point she was depressed and I didn't really know what to do, what to say. I

mean, she talked and I listened but I did *not* know what to say. So it was challenging and

I didn't know how to bring it up after that conversation.

As these examples suggest, some respondents were keenly aware of the multiple meanings

inherent in communication about emotions.

Strategies. Adult children managed the dilemma of providing support while managing

their own emotions by *talking about facts rather than emotions*. This strategy allowed adult

children to have conversations about cancer while minimizing the chance of an inappropriate

emotional reaction. During primary treatment, this strategy manifested as focusing talking on

facts about treatments. McKenzie put it this way: "I would ask about how her nausea was or how

her appetite was or whatever – but that was the extent of it. So we would talk about the medicine

but not so much the disease." McKenzie went on to describe her family as trying to be "very

pragmatic about it" rather than "taking about feelings." Lauren also noted that one of her

"defense mechanisms" was to turn the cancer into "something pretty clinical." Adult children

sometimes reported that they deliberately guided conversations away from emotions. For

example, Matthew recalled that he made sure his "check in" phone calls with his mother were

"just focused on the physical things that the doctor had said" because emotional conversations

"weren't going to help the situation." From this perspective, talking about facts rather than

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emotions seem to be a strategy that respondents employed to protect their mother, and to protect themselves, from emotionally upsetting conversations.

Interestingly, adult children noted dissatisfaction when their mother was the one who wanted to keep conversations clinical rather than emotional. For instance, Lisa said it was her mother's decision to "not delve into the emotional side of things" and instead just "stick to the details." When Lisa would encourage her mother to talk about the more emotional aspects by saying, "*How are you* – are you *really* doing okay?," her mother would usually just go back to talking about her prognosis or treatments. Lisa felt that kept them from having a "real conversation" about it. Thus, although focusing on facts rather than emotions was often seen as a way to provide more effective support, adult children also recognized situations where this strategy had negative relational or identity implications.

Summary. Adult children discussed an array of challenges and strategies for being supportive while negotiating involvement in their mother's breast cancer experience. In particular, respondents emphasized being there for their mother, providing reassurances, helping the parent remain positive, and managing their own emotional reactions. Respondents managed these challenges by showing willingness to talk, talking about the future, talking to family members or other social network members about complaints or worries about their mother, and focusing conversations on facts rather than emotions.

Challenges and Strategies of Geographic Separation

Similar to the conversational challenges involved in giving and receiving social support and managing cancer-related information, many respondents acknowledged the challenging nature of being geographically separated from their family during their mother's breast cancer experience. In particular, respondents experienced difficulties gathering information while being

unable to actually see what their mother was going through, not being able to drop in on their mother, and being unable to attend medical appointments. Interestingly, some geographically separated respondents did not experience dilemmas related to geographic separation and instead felt that distance made it *easier* to communicate about, and cope with, their mothers' diagnosis. Proximal respondents also experienced challenges related to geographic separation when they were expected to keep long-distance siblings involved and up-to-date on their parent's progress. Respondents managed these challenges by strategically employing communication technologies for different purposes, taking time off work to visit their mother, and creating an "information chain" to obtain or disseminate information.

Difficulties gathering and trusting information. Geographically separated adult children commonly discussed the challenges involved in gathering credible information. Elise explained the general sentiment clearly:

> If you live away from home you have to rely on other people to give information – I'm not sure you could really get the bigger picture, you know? It's kinda like playing the telephone game where it's impossible to get the best information.

Lisa expressed the very same idea:

> I think [if I would have lived in town] I would have had a lot more information and I would have known more about what she was *actually* going through. I think it was easier for her to hide stuff from me. She just doesn't call when she doesn't feel well - she calls when she feels good. Or if I call and she doesn't feel well she just doesn't answer the phone and she will call me back later when she does feel fine so she can be like, 'I'm fine!' So I feel like if I would have been in town I would have had more information about what was going on just because I could actually see more.

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Several respondents noted that being geographically separated meant that they had to "pry" or "ask a ton of questions" in order to gather relevant information. Gathering credible information was especially challenging and frustrating when parents provided only perfunctory responses (Caughlin & Scott, 2010), such as "I'm fine," when asked about personal wellbeing. Nicole explained it this way:

> I don't know if it's just an older person thing, but I had to pry a lot of information out of her. A lot of times if she's not feeling good and I call, I really have to listen to her voice to see how she's feeling – because she will usually just tell you she's feeling okay. So you kind of listen to the voice to hear whether she is really feeling okay or whether she's not feeling okay. Sometimes she will say 'I just don't feel good.' But a lot of the time she will say 'Oh I'm doing okay.' So you have to really listen to the voice.

When a parent answered in a brief manner, an adult child's question was not explicitly avoided, but the brevity precluded further discussion of breast cancer. In effect, this meant that adult children had to go to proximal family members to gather information since they were unable to glean any insights from the parent or collect firsthand information while geographically separated. For example, Leigh described checking in with her sister to ask, "Well how's she doing? What does she look like?"

Relying on others for information did not seem to be satisfying for many respondents, particularly if they recognized the limitations of not being able to verify the information they received. As McKenzie put it, "I wasn't around so I was just getting this information secondhand – so who knows." Amanda assumed her brother "softened" information about their mother's condition in order to avoid sounding negative during conversations their mother might overhear, but she could never verify her suspicions:

I think when I would call my brother and my mom was in earshot he was much more careful. I felt like he was being more positive and not really divulging the full reality of things – of how hard it was hitting her. That was frustrating.

Kevin also questioned the veracity of information he received from proximal family members:

I would call my dad and he would just say, 'Well she's doing pretty good today!' and my sister would be the same way like, 'Oh yeah she's feeling pretty good!' But in reality, I'm sure she probably wasn't feeling as well as everybody said. When I would see her, she would look pretty run down – tired. So I didn't know whether I could actually trust what they were saying! Like, were they blind and just didn't want to see how bad she was feeling? Did they just want me to stay positive? I don't know – I never asked.

As Kevin articulated, respondents were often frustrated when their own assessment of a parent's condition differed from the information provided by proximal family members. Indeed, Amanda described irritation when her assessment of her mother's condition varied drastically from the picture her proximal sibling painted:

There were times I would come to visit after my brother had been the only one with her and, you know, because he's there in the moment he didn't see it from an outsider's perspective. So I would come back be like 'Ummmmm what happened?!' Because I could see the difference in her from last time, which he didn't notice because it was a slow progression. Slow changes.

As these examples illustrate, geographically separated respondents had several challenges when trying to gather information about their mother's condition, especially when they could not easily verify the authenticity of the information they received.

Strategies. In order to manage this challenge, respondents noted that they *used communication technologies strategically.* In line with past research (e.g., Perry & Werner-Wilson, 2011), some respondents found it easier to communicate over cue-lean channels because it allowed them to plan out their messages and get emotions under control. Peggy, for example, talked about how she would make sure emotional conversations with her mother only occurred via instant messenger:

> Mostly we talked over the computer because over the phone you can definitely hear the cracking in somebody's voice or just the hard silence. So the computer, I mean it's a very emotionally flat avenue to communicate with a little smiley or sad face emoji.

Brooke recalled using the phone, rather than having a face-to-face conversation, because it helped her get space from the experience:

> Actually seeing her was harder. I would see how pale she was and how she had lost weight and had no hair. It's actually harder to see her than it is on the phone – harder to see how sick she looks in comparison to how she was before. So it was almost easier to talk to her on the phone because I didn't have to see it. It almost wasn't as real.

Similar to Brooke and Peggy, Anna felt that cue-lean channels allowed her to have more emotional conversations without letting her mother know how upset she really was: "Face to face always seems to be a little more intimate and makes things more real. So talking over the phone was easier to just be kind of matter-of-fact about everything."

In contrast to using certain technologies for more emotional conversations, other respondents strategically chose communication technologies that allowed them to gather contextual information despite their lack of proximity. In particular, some respondents talked about how phone conversations allowed them to gather information based on their mother's tone

of voice. Heather explained it this way, "I could tell if she's having a good day or a bad day or if she's weak. I don't know, I just felt better when I could actually hear her voice." Jade expressed a similar sentiment, "I guess too, when we would talk over the phone I would get more reassurance. I could *hear* if she was doing better – I was hearing it from her, in her voice." As Heather and Jade expressed, phone conversations were sometimes preferred because they allowed respondents to gather information via their mothers' nonverbal behaviors that would not have been available over more cue-lean formats.

Strategic use of communication technologies was only effective to a certain extent. Indeed, some geographically separated respondents continued to feel that face-to-face communication would have been more ideal, and that any communication technology was deficient. Leigh, for example, talked about the limits of communication technologies:

> I just kinda wanted to see what her reactions were – you can't see the nonverbal over the phone. It was more reassuring for me to just see her in person. It's comforting to see somebody in person and actually give them a hug. I couldn't do that over the phone or over a text message.

Communication technologies were also considered deficient because they did not always provide adequate information about a parent's physical condition. Some respondents recalled how the "distance" created by communication technologies rendered them unprepared to actually see their mother. Brooke, for example, recalled feeling shocked upon seeing her mother bald for the first time:

> She came over, I think she visited for my son's birthday, and she was wearing a cap. And it was the first time I had seen her since she lost all of her hair. I *knew* that she had lost her hair because she told me over the phone but I hadn't actually *seen* her. So I lifted up

her cap to look at her bald head and she got pretty mad and was like, 'Put that back!' or

something. I think, you know, actually seeing that was hard for both of us.

As Brooke described, talking to her mother over the phone or text messaging was qualitatively

different from seeing her mother in person.

When geographically separated respondents were able to get time off of work or could

afford plane tickets, another strategy for addressing the difficulties of gathering information or

trusting the veracity of information was *visiting the parent* in order to gather information and

reduce uncertainty. In reflecting back on his mother's experience, Frank realized that he made

more trips to see his parents in the 9-10 months between diagnosis and completing treatment

than he had in the previous couple of years. Some adult children, like Heather, visited in order to

attend medical appointments:

I appreciated being able to fly in and actually go to some of those appointments. I wanted

to actually go through the process with her, I guess, rather than just having a

conversation. Then I can relate better when she says, 'It's a sunburn just a little bit

deeper.' I can actually relate to what she's telling me because I actually saw the effects of

the treatments.

Tom also talked about how actually seeing what treatments looked like helped him cope more

effectively from a distance:

On one of the days I was visiting I went with her to her chemotherapy appointments. Just

seeing the facility and having a conversation with her – seeing the medication and having

a doctor come over and say hi – it was so helpful. I got a better understanding of how the

chemotherapy process really worked. Before that I really had no concept whatsoever of

what that looked like. It reminded me of a blood donation – I had envisioned

chemotherapy as lying in the hospital bed in a hospital room or something. But it was

more – people came and went quickly and easily.

Clearly, visiting the parent was one way to address the challenging of gathering and trusting

information while geographically separated. Even when visiting was not an option,

geographically separated respondents felt it was important to express a keen desire to visit the

parent. Lisa recalled telling her mother "Well if you want me to come down from college I will

come down and sit with you while you're having chemo or something – I totally will!" Even

though Lisa's mother said she "didn't need to," Lisa made a point to *offer* to be there. Brooke

expressed a similar sentiment:

I mean, I would offer to go out there and she'll be like, 'Oh don't worry about it – it's so

far.' I think she wanted to make me feel better [about not being there], and I wanted *her*

to know that I wanted to come. But it just wasn't really feasible very often.

Similarly, Michelle recalled telling her mother "I will come out there if you want me to – I can

do that." And, although her mother would respond with "No, no, no, it's fine. I'm fine.

Everything is fine," Michelle felt it was important that she offered to come.

Although travelling to visit was helpful to some adult children, the success of this

strategy was tempered by the ways in which visiting just "wasn't the same" as being there full

time. For example, Michelle talked about how she wished they had been able to "drop in" on her

mother in order to gather "off-the-cuff" information:

If I lived 10 miles away it would have been natural to say, 'Oh I was at the store and

decided to stop in.' Well, you can't show up in another state and say, 'Oh I was just in the

neighborhood.' You know, after a four-hour flight. There just wasn't that option to show

up or check in on her or to drop off a meal so I would have an excuse to see her.

As this example demonstrates, visiting the diagnosed parent was only helpful to a certain extent, and some respondents felt that this strategy was limited in effectiveness.

A final strategy for managing the difficulties inherent in gathering and trusting information while geographically separated was *cognitively reframing geographic separation as a benefit.* Although it was not as commonly mentioned as using communication technologies strategically or visiting the parent, some adult children did acknowledge how being geographically separated from their mother during the cancer experience helped them cope more adaptively. For example, some respondents appreciated (rather than bemoaned) their mother's ability to selectively disclose information over the phone. Bonnie explained it this way:

> When you're not there you don't have the visual – you don't have to deal with as much. They're telling you in their own time. You're not in the moment, in the doctor's office waiting for the news. They have processed it and decided how they want to tell you. It's really just a filter that makes it a lot easier to process.

Frank also felt that not having the "visual" made it easier to talk about his mother's cancer in an appropriate way:

> It was tough, you know, to see the pain my mom was going through in-person. And maybe this is selfish (laughs) but I think being further away made it easier. I had more space to react in the way that I wanted. I felt like I needed to, you know, react in the best way – a way that wouldn't make her feel more scared. And if I was seeing her all the time face-to-face I don't know if I would have been able to keep my reactions in check for her.

Similar to Bonnie and Frank, Jade recognized that living away from her parents created a bit of 'out of sight, out of mind' that meant she could cope more adaptively:

It wasn't ideal but it may have made things easier on me actually. You know, because it's less of your everyday life. So it was easier to go through the day without cancer jumping into my brain and taking things over.

In sum, a few geographically separated adult children felt that getting a little distance from their mother's cancer experience was advantageous. Visiting the diagnosed parent and using communication technologies strategically were more commonly used strategies for managing the challenge of gathering trustworthy information while geographically separated.

Involving and informing geographically separated siblings. Geographically separated respondents often talked about challenges experienced by their proximal sibling(s) due to keeping long-distance relatives in the loop. In particular, geographically separated respondents felt that their proximal sibling likely felt "pressured" to keep other family members informed or to "tell the truth" at times when a parent may be softening information or not giving them the whole truth. Respondents recognized that this extra duty was demanding. Ashley explained it this way:

I'm sure my sister felt a lot of pressure because she would be the one that everyone was getting information from. We wouldn't believe Dad – he would just say, 'Everything is fine.' So I'm sure she felt the pressure of us saying, 'Are they telling us the truth? Is she really going to be okay?' I don't think anyone thought they were blatantly lying to us – but we knew my sister wouldn't try to protect us as much.

Tom noted that his sister, who was the only one living at home during their mother's cancer experience, was the one who updated him on his mother's progress. He recognized that being the only in-town sibling was likely stressful:

My sister called me after Mom's operation to say she was okay. She filled me in on all of those details. Whenever there was something big, my sister would call me and give me the update – or send a text or something depending on the situation […] I know it was hard on her – I tried to reassure her like, 'I'm glad you're there and that you're helping out. It's good that Mom has you.' It gave me some peace of mind knowing that she was there with Mom, but I know it was hard on her personally.

Frank also noted that his sister "bore a lot of the brunt" of being the only sibling at home:

I think because my sister was right there with them, and I was a few hours away, she bore a lot of the brunt of telling my parents like, 'Everything is going to be okay – it will be alright. […] She was the relay of communication between my parents and me and my brother and that had to be a lot. She went with them to appointments, she drove her to chemo a handful of times, and she was talking to us. It had to be a lot.

As these examples demonstrate, geographically separated siblings recognized that their proximal sibling(s) also experienced unique challenges due to geographic location.

Respondents who lived at home during their mother's breast cancer experience also talked about the unique responsibility of informing and involving geographically separated family members. Scott said:

It was difficult being the only brother that saw it on a daily basis. I had such a different experience than my brothers. I didn't know what to tell them about what the medicine was doing to our mother on a daily basis or a weekly basis; all they had to do was hang up the phone at the end of it, but I had to *live* with it at the same time too. They didn't have to live with her being upset or going upstairs and closing the door.

The main challenge of being the only "at home" sibling for Scott was trying to figure out what to tell his geographically separated siblings and how to convey that information in a way that would help his siblings understand their mother's experience. Another proximal sibling, Maci, expressed similar challenges:

No one else was really there seeing what was going on. I was the only one, you know? I was taking her weekly to her appointments, so my sisters didn't know what was going on and I didn't know how to talk about that kind of stuff with my brothers. So I did feel on my own as far as that stuff went. I think they all thought like, 'Oh – Mom is getting chemo.' I mean, I was telling them that the chemo was hard on her but I don't think they really understood what that meant.

Strategies. One way to address the challenges of involving and informing geographically separated siblings was by *creating a system for sharing information*. This strategy manifested in several ways. Frank explained his family's system for sharing information: following medical appointments, his mother and father would call each child with a brief update. Then, all of his siblings would call each other to get more contextual information about what had happened. This was seen as an effective way to get information without having to "bother" their mother with additional questions or worries. Heather's family came up with a slightly different system for sharing information:

My sister and I used the family network to stay involved even though we were 4,000 miles away. We figured out a plan that we could use our dad because he was closer to Mom and he's more in the loop; he knows her appointments and if she's having a good day or a bad day. And I'm – I don't have the flexibility at work to communicate with my dad but my sister did. So I would reach out to my sister on email and my sister would

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reach out to my dad who would then reach out to my mom. So we would just follow this

chain and then Mom would call Dad, he would get back with my sister, and then I would

get a call or an email from my sister. So we all knew what was going on this way.

In addition to establishing a set avenue for obtaining information, creating a system for sharing

relevant updates also allowed adult children to gather information from a distance when the

diagnosed parent did not feel like talking. Matthew explained it this way:

Sometimes I could just tell my mom didn't want to talk about it anymore so I would just

hang up and call my sister right away and be like, 'Look, I know you already talked to

Mom – what did she tell you because she clearly doesn't want to talk about it right now.'

And she would be like, 'Well here's what she told me – what do you know?' It was like,

'If she tells you something, let me know, okay?'

Having a back-up method for gathering information helped Matthew to get additional detail at

times when his mother was not particularly talkative.

Creating a system for sharing information also functioned as a way for proximal family

members to encourage or support geographically separated family members' technology-based

involvement. For example, Frank noted that his father would call or text him to say "Hey maybe

give your mom a call – she's having a hard time today." Similarly, Michelle recalled her father

suggesting "Why don't you call her during the week – she will be home on Wednesday." This

appeared to both reinforce geographically separated family members' involvement in the breast

cancer experience while also providing some direction for when and how to get in contact with

the diagnosed parent.

Geographic distance did seem to place additional stressors on family relationships during

a mother's breast cancer experience, which in turn influenced family communication processes.

Getting information "through the family system" was often labor-intensive and required coordination between several family members. Yet, having a system in place for sharing information appeared to reduce stress for some geographically separated respondents because they knew they had a method for receiving information that they could not gather on their own. Proximal family members appeared to make special efforts to share cancer-related information with geographically separated family members in order to help decrease feelings of isolation for both the patient and their long-distance family members.

Summary. Overall, geographically separated respondents commonly discussed the challenges involved in gathering information and determining the veracity of information they received. Adult children worked to overcome those challenges by using various communication technologies and gathering firsthand information by travelling to visit the diagnosed parent. When a face-to-face visit was not feasible, respondents felt it was important to express a desire and willingness to visit. By contrast, some adult children felt that geographic separation provided much needed distance from the situation and thus made coping easier. Interestingly, proximal respondents also catalogued the challenging nature of keeping geographically separated family members involved in the parent's cancer experience. Creating clear channels for information dissemination minimized this challenge for some respondents.

Change to the Parent-Child Relationship

A minority of respondents felt that a mother's breast cancer diagnosis and ensuing treatment regimens led to changes in the parent-child relationship. Adult children who recognized changes to the parent-child relationship often described how more frequent interactions during their mothers' cancer treatment changed the relationship overall. Spending more quality time with the diagnosed parent in the hospital during treatments was one antecedent

of a stronger parent-child bond. For example, Ashley expressed that "spending time together in the hospital" really forced her and her mother to "spend so much more time together" and that "the whole thing" made them closer. Interestingly, Sandra talked about how she was going to miss her mother's treatments because it was nice to have a reason to spend dedicated time together:

> One of the weirdest things, and this is kind of selfish of me, is that I actually miss going to the chemo treatments with my mom. Not that I want her to go through that ever again, but like – I miss having six hours of time with just me and my mom. I learned so many things about her because the only thing we could do was talk.

These experiences are distinct from the support strategy of "being there" during treatment because these adult children felt that increased interaction impacted the broader parent-child relationship. More specifically, although breast cancer was seen as the catalyst for increased communication, several respondents noticed that they continued to talk to their mothers more frequently even after the cancer experience was "over." Brooke, for example, explained how talking to her mother on a daily basis during treatment became a habit that strengthened the parent-child relationship overall:

> I used to only talk to her maybe once a week and now I talk to her every day or every other day. We're so used to calling each other all the time now. I think that made our relationship more close.

Matthew also noticed that he talked to his mother more often during and since her cancer diagnosis:

> Leading up to her diagnosis I was never one to have daily conversations with my family. I would go, you know, a week and then I would finally hear from my parents like, 'Oh

we haven't heard from you in awhile - are you okay?' And then as soon as she was diagnosed it was like an instinct, 'I need to call, I need to check up, I need to see how she's feeling.' It was immediate. And that hasn't stopped.

Sandra expressed the same feeling:

I definitely will say that the whole experience with my mom really brought us a lot closer. I would call my mom a lot more often, I mean, *a lot* more often. And I would text her too. Now I see her in a different light – I want her to know that I want to talk to her.

Feeling that the increased time spent together and more regular interaction strengthened the parent-child relationship was a common experience for adult children.

When adult children framed the experience as something that strengthened the parent-child relationship, they often felt that they now had a more equal or friend-like relationship. This shift was described in a variety of ways. Kaylin said:

I don't know if it brought us *closer* necessarily because we always were close. But I do think it changed our relationship in the sense that she knows that she can depend on me no matter what. It made our relationship – I don't know, I guess more secure.

Thus, although Kaylin did not think that her relationship became closer, she did sense a qualitative shift in the parent-child dynamic. For other adult children, this shift manifested as communicating more appreciation and love than they had in the past. Peggy put it this way, "We didn't used to really say 'I love you.' But I think I told her that I loved her a lot more then – and more since then too." Showing increased affection after the experience was considered "over" helped adult children adjust to their mother's cancer. In particular, expressing love and affection more frequently represented an effort to provide comfort and express gratitude that the parent had survived.

In contrast to adult children who did not experience dilemmas related to shifting parent-child dynamics, other adult children felt this shift complicated communication during their mother's cancer experience. This group described how they struggled to redefine the parent-child relationship in a way that included caregiving roles. In particular, adult children struggled to respect their mother's autonomy while providing advice. Using siblings as a sounding board and phrasing advice as a suggestion were useful strategies in this context.

Managing role reversals. Adult children described a transformation in their relational connection with their mothers due to reversing roles. For many adult children, their mother's cancer experience was the first time they acted as her caregiver. Similarly, it was sometimes the parent's first experience being taken care of by one of her children. Lisa eloquently explained how a reversal of roles could impact the parent-child relationship more broadly:

> I remember her trying to be strong and not cry because I'm her kid. You know, she probably wasn't really comfortable crying in front of her daughter. It was the first time in our lives when the roles were ever reversed – where she wasn't the caretaker. And I think that made it harder for both of us. I mean, you kind of expect that as you age the roles get a little reversed. But you know, at the time I was still the kid. She sent me food and – I don't know. It made it tough. I was suddenly thrust into this role of comforting my mother, who had always been the comforter.

When mothers and adult children did not have a model for reversing roles, they appeared to struggle more to figure out how to navigate this relational shift.

Adult children who felt their mothers were uncomfortable with being taken care of struggled most with the role reversal. Frank, for example, explained how his mother's breast cancer diagnosis was the first time his mother "went from being the one who would take care of

everything – the mom – to someone that could suffer and needed to be taken care of like everyone else." He went on to say that he is "much more aware" of this role reversal since her diagnosis. Kaylin experienced this challenge acutely while encouraging her mother to "eat certain foods and drink a certain amount of water." Feeling like she was "arguing with a child" was particularly difficult for Kaylin and her mother, and often resulted in one or both of them crying. As these examples demonstrate, caregiving tasks were often a main precursor to feelings of role reversal.

When mothers seemed uncomfortable with this role reversal, adult children were often left wondering how to enact their new caregiver role. Kevin, for example, felt that role reversal involved in providing his mother with care was hard for his family because his mother "didn't want to worry anybody." As a result, Kevin felt uncertain about how to be helpful. Similarly, Maci explained how her mother was "such a mom and just – she didn't like to be taken care of and wanted to be the one taking care of people." Her mother's feelings about the role reversal appeared to make Maci uncertain about how to support her mother in an effective way. Overall, adult children seemed to struggle most with the relational impact of a role reversal when it was the first time that roles were reversed.

Strategies. Adult children nominated two strategies for addressing relational challenges due to reversing roles. First, adult children suggested that *explicitly addressing the role reversal* might be helpful. For example, in reflecting on what she could have done differently, Maci said, "I wish I would have been smart enough to be like, 'You can put that on me, I can take that.'" Maci felt that having a conversation with her mother about how caregiving tasks were impacting the mother-daughter relationship would have "taken a little bit of the burden" off of her mother and thus made it easier for them to navigate these new family roles.

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A second strategy for managing the role reversal was *using siblings as a sounding board.* Adult children often expressed that turning to a sibling for advice and support was helpful in managing changes to the parent-child relationship. For example, siblings were often a source of advice for how to talk to their mother about concerns and treatment decisions in a ways that would not damage the mother-child relationship. Heather and her sister, for example, would frequently "bounce some information off of each other" in order to make sure they were both "up-to-date on relevant information." In turn, Heather felt that increased "trust and understanding" with her sister made it easier to enact her new caregiver role. Megan also said that she would talk to her sister first, before talking to her mother, so she could "bounce things off of her before going to Mom." She went on to describe asking her sister questions like, "Should I say this to Mom? Should you say this to Mom? Should we say anything at all to her or just go to Dad?" Similar to Heather, Megan felt that this made her more prepared and competent in conversations with their mother.

In addition to being a source of advice and information, some adult children suggested that siblings were an important source of social support in this context. For example, Katie talked about how obtaining support from her sister helped her manage the role reversal:

> I would go to my sister all upset and she would be like, 'We can't do anything until we know.' And that would help me be like, 'Yeah, true, good point.' She knew I just needed to be reminded occasionally that I couldn't worry about everything. Like, if they run a test on Friday it won't help to worry about it until we hear back on Monday.

As these examples demonstrate, siblings were often an important part of the coping landscape for respondents. In particular, using siblings as a sounding board and providing one another with increased support helped some adult children manage the relational transformation.

Respecting the diagnosed parent's autonomy. Participants were sometimes unsure about how to respect their mother's autonomy during the cancer experience. Parent-child communication was especially delicate when respondents tried to encourage their mothers to modify or change health behaviors. Often, this manifested as a dilemma of providing supportive suggestions without overstepping the boundaries of the parent-child relationship. An inability to communicate in ways that respected the mother's autonomy threatened both identity and relational goals.

Several respondents discussed the difficulty involved in providing advice to a parent who was used to making decisions and not having others, especially their children, tell them what to do. Meredith recalled telling her mother that she was "completely concerned" and that she "had to do a lot of different things – she needs to start eating better, she needs to start being more active." In looking back, Meredith acknowledged that her blunt delivery, which did not acknowledge her mom's autonomy to make healthy choices, problematized the mother-daughter relationship:

> I told her, 'You need to be more healthy – you need to take these supplements. Just have fruit instead of mint peppermint patties – you're not doing yourself any good.' And she would come back at me with the whole spiel, 'I can't keep anything down, nothing tastes good, I don't know what the flavor is.' And I said, 'Well who cares what the flavor is!? Just eat properly! Take the supplements I got you!' But she wouldn't have it. It was one fight after another.

Connor recalled a similar scenario:

> I was like, 'Mom you've got to try!' 'Well nothing tastes good.' 'Well, how do you know it doesn't taste good, you haven't tried it!' Eventually I was just like, 'I don't care, eat a

fourth of a hamburger or something!' I was mad at her like, 'If you did what the doctor said – the doctor told you the stuff you should be eating!' You know, eat six meals a day instead of three and all that. So I was like, 'If you followed his guidelines, you might not have the toxic poisoning.' I was – well I regretted saying it afterwards but I felt like she needed to hear it. Like, I felt sorry for her but at the same time I was like – you're the one that didn't take care of yourself.

Scott also expressed how encouraging his mother to eat more healthfully complicated their relationship:

I'm a big proponent of keeping yourself healthy, eating right. She loves her sweets, her cakes, her cookies and whatnot. And I saw during this time period of her life she would sneak upstairs with a cupcake and I would say, 'What are you doing?' and she would sneak downstairs and grab another cupcake and I would say, 'Mom we just ate dinner a little while ago! Why are you eating this stuff? This is not good for you – it's all sugar and chemicals.' I was thinking if I could just drill it into her a little bit more she would stop doing it. And I know it pissed her off. So maybe what I was trying to do wasn't the best approach. It probably wasn't because it affected our relationship. I really was only trying to look out for her health as much as I personally could.

In these examples, adult children prioritized giving health-related advice and deemphasized their mothers' ability to make healthy choices. In reflecting back on these conversations, respondents appeared to recognize that their blunt delivery was not particularly effective in getting their mother to take their advice. What is more, they appeared to recognize that this approach might have damaged the parent-child relationship, possibly due to the lack of acknowledgement of identity and relational goals.

Strategies. Respondents suggested that the optimal way to provide advice or suggestions while also acknowledging their mother's autonomy was by *phrasing advice as suggestions*. In other words, adult children described framing messages of advice as sharing information or "ideas" rather than expressing opinions. Brooke found it most effective to give advice this way:

> I guess it was more like, 'Here's a piece of information for you.' And then I would go on to tell her my advice. Like I told her how a co-worker of mine had breast cancer and she wears this prosthetic boob and you can't even tell the difference. I try not to like – *tell* her what she needs to do because I think she needs to decide on her own. So I try to phrase everything like, 'Well here's an idea.' or 'Here's another option I heard of.' or 'What if you tried this?' kind of thing. Just like – positive suggestions.

Elise used a similar strategy when her mother expressed how much she hated taking tamoxifen:

> I would never tell her to do something, but I just suggestively told her that, 'Well maybe the medication is helping.' I mean, I really wanted her to take it, but I would never say, 'Mom you *have* to do it.' I would never tell my mom that she *has* to do something. But yeah, I was suggestive and subtle – just tell them how much you care about them and that you respect their decisions.

Both Brooke and Elise felt strongly that directly telling their mothers what to do would be inappropriate. Phrasing advice as suggestions allowed them to try to modify their mother's behavior while acknowledging identity and relational concerns.

Wording advice as suggestions was sometimes easier when an adult child had unique knowledge or experience with cancer. This manifested in a variety of ways. For example, Sandra felt justified in suggesting nutritional modifications because she was studying food science and dietetics in college. Similarly, Lisa talked about how, because she was "in college and studying

research," she was comfortable providing advice when her mother had questions about participating in a medical trial. In addition, Brooke explained that, because she is a nurse and "knew a lot more about medical background and medical choices and options," her mother was more open to hearing her opinions and "talking through" different treatment decisions with her.

Overall, adult children seemed to acknowledge the utility of emphasizing their mothers' autonomy in order to reduce the negative identity and relational implications of providing a parent with health-related advice. Further, some respondents phrased advice as ideas (e.g., let's do this together, here's a piece of information for you) in order to mitigate negative implications of giving advice.

Summary. Adult children acknowledged the dilemmas inherent in navigating shifting parent-child dynamics. Managing role reversals and respecting the diagnosed parent's autonomy were particularly challenging. Having an explicit discussion about the role reversal, turning to siblings for advice, and providing suggestions (rather than advice) helped adult children address these challenges.

Chapter 5: Discussion

Overview of Discussion

Cancer is currently the second leading cause of death in the United States (American Cancer Society, 2015). As the number of people affected by cancer increases, so does the impact on family members. For this reason, it is important to study the ways in which family communication influences cancer patients' and family members' (mal)adaptation to the disease. Indeed, as Afifi, Hutchinson, and Krouse (2006) observed, "Family members respond and adapt to stress based on their interactions with other family members. Their responses to stress are often a function of other family members' stress and their ability (effectively or ineffectively) to adapt to it, as well as their ability to cope by communicating with one another" (p. 383). Although Afifi and her colleagues suggested that family members might cope differentially with a cancer diagnosis, the majority of studies examining communication within the cancer context have only examined family communication between the patient and his or her spouse. This neglects the role of the larger family system (Caughlin et al., 2011; Sherman & Simonton, 2001). Some research has moved beyond the spousal dyad to explore parent-child communication, but these studies have focused almost exclusively on communication with young children or adolescents (e.g., Lewis & Hammond, 1996; Spira & Kenemore, 2000). Unfortunately, the small body of research that has focused on how adult children adapt to their parent's cancer diagnosis is limited to snapshots of communication upon initial diagnosis (e.g., Fisher, 2010) or at the end of life (e.g., Caughlin et al., 2011). The present study attempted to address these limitations by illuminating how adult children negotiate involvement in their mother's breast cancer experience across the illness trajectory.

Drawing on the normative approach (Goldsmith, 2001, 2004), the current findings extend the current literature and offer new insights into how adult children manage information, provide and receive social support, cope with geographic separation, and adjust to relational changes across their mother's breast cancer trajectory. This dissertation further substantiates earlier evidence (e.g., Donovan-Kicken et al., 2012; Stone et al., 2012) that cancer communication requires effortful management that includes unique responsibilities for family members, and that conversational strategies can be considered both helpful and unhelpful (Goldsmith et al., 2012; Goldsmith & Miller, 2015; Miller & Caughlin, 2011). In turn, these findings articulate more clear advice about what adult children can do to successfully manage the challenges and dilemmas associated with communication in this context. The following sections describe the theoretical and practical implications of this research for family communication about breast cancer. Limitations and directions for future research are also addressed.

Theoretical Implications

This dissertation provides insight into how adult children negotiate involvement in their parent's breast cancer experience. In related work on communal coping (Lyons, Mickelson, Sullivan, & Coyne, 1998), scholars have described coping constructed jointly among persons as a "shared relational appraisal" (in which both members of a dyad appraise a situation as stressful and experience it together; Berg, Meegan, & Deviney, 1998) or a sense of "we-ness" (e.g., Afifi et al., 2006). In the current study, the mutual management of a parent's cancer manifested as a "we" orientation when adult children discussed various ways in which their involvement helped their mother cope with breast cancer. In other words, a "we" orientation was highlighted when adult children constructed breast cancer as something only their mother "had" while at the same time being an experience they were both involved in. This is similar to the concept "help/support

seeking" in the communal coping literature (Lyons et al., 1998, p. 587). This orientation towards coping suggests that, although cancer was defined as a parent's "problem," adult children were mobilized to help their mother manage the disease. Viewed this way, adult children felt that they needed to negotiate coping efforts in ways that were mutually beneficial.

This study adds to the current literature by illuminating how adult children's involvement was continually negotiated across the course of a parent's illness trajectory. As adult children engaged in work (illness, biographical, everyday, and communication) during diagnosis, treatment, rehabilitation, and recurrence stages, they shifted in and out of individual and communal ownership of their mother's illness. For example, although adult children often wanted additional information, they recognized that their mother was the primary owner of the disease (e.g., "It's kinda a private thing – it's *her* thing."). Thus, although adult children expressed personal involvement in the illness experience through the mutual management of information and provision of social support, they often felt that it would be "self-indulgent" to receive support in light of everything their mother was going through. This suggests that adult children acknowledged their role in the parent's experience while largely characterizing cancer as the parent's problem (Lyons et al., 1998). By considering how adult children negotiated involvement over the illness experience, this study provides insight into variations in adult children's experiences when a mother is diagnosed with breast cancer. In particular, involvement in a parent's cancer experience appears to be defined and enacted in unique ways based on work undertaken across the parent's illness trajectory, the adult child's family roles, and geographic separation. The nature of adult children's involvement is represented in Figure 1.

Before discussing adult children's work and the challenges they experienced across the parent's illness trajectory, it is important to note that adult children often (a) reported work as

recurring during multiple stages and (b) experienced one or more conversational dilemmas simultaneously. For example, an adult son might acknowledge the acute need to communicatively manage his emotional reaction when first learning about his mother's diagnosis. Then, during the treatment stage, he may again feel that talking about the emotional nature of painful treatments was an effortful form of work. Similarly, an adult daughter may struggle to maintain positivity in conversations with her mother at the same time that she tries to manage uncertainty by asking for updates. For this reason, the following categories should not necessarily be considered conceptually distinct and/or mutually exclusive.

Adult children's work across a parent's illness trajectory. The first contribution of this study is identifying adult children's lines of work during a parent's illness trajectory. In 1988, Corbin and Strauss suggested that managing a chronic illness entails sustained and coordinated efforts to manage multiple demands. Years later, Donovan-Kicken and her colleagues (2012) clarified that work includes the "assignment of workers' responsibilities (to oneself or to others); exertion of effort and demand for resources; coordination and organization of duties and resources; division of labor throughout various projects and phases; the expectation of perceived benefits; and management over time in the context of changing trajectories" (p. 642). As was expected, adult children in the current study were called upon to help with a parent's illness in unique ways during the diagnosis, treatment, survivorship, and recurrence stages of breast cancer. Lines of work often carried over into subsequent stages and interacted with one another to make involvement in the parent's experience more or less effortful.

Work during diagnosis. Following the parent's initial diagnosis, adult children talked at length about the work involved in waiting to hear news about their parent's diagnosis, reacting appropriately to their parent's news by prioritizing their parent, and helping their parent make

treatment decisions. Adult children seemed to recognize almost immediately that, although they were involved in their parent's illness experience through boundary linkages, their parent was the gatekeeper or original owner of information (Petronio, 2002). For this reason, adult children expressed that, by and large, their parent was "calling the shots" about when and how information was going to be shared and managed.

Respondents were often frustrated when they were not informed about the diagnosis earlier but felt it was not their place to chastise their parent for not including them sooner or for withholding information. This was especially true when adult children perceived their parent's decision to not share information as a protective measure. Past literature suggests that individuals often manage information in order to protect themselves, to protect others, and to protect relationships (Afifi, Caughlin, & Afifi, 2007). Indeed, a main theme guiding how women with breast cancer talk to their children is a goal to protect children from distress (Asbury et al., 2014). What the present study adds to this literature is that adult children seem to recognize that their mothers' disclosure decisions were based on the desire to *protect* rather than the desire to *avoid* communication. In other words, a mother was perceived to be thinking about her children in situations where she waited to share information until there was something definite or factual to or when she held back more when information was uncertain or unclear. For example, in reflecting on the fact that his mother's diagnosis was kept between his mother and father for some time "until they knew something definite to talk to us about," Scott felt that his mother's only motive was to "not scare or worry her children." Respondents seemed to realize that, although they wished their parent had disclosed the news soon after a diagnosis, there were a variety of factors that influenced the decision to share or withhold information. The adult child's role during this stage was to receive information when and how the parent was comfortable

sharing it.

Once information about cancer was shared, adult children moved into the acute phase of hearing the diagnosis, understanding and comprehending the diagnosis, and helping their parent make treatment decisions. In line with past research (e.g., McCubbin et al., 2002), the ability to reappraise the diagnosis was particularly important for avoiding crisis in this stage. In the current study, reactions to the diagnosis disclosure that capitalized on desirable identity and relational meanings were preferred to strategies that were focused on the adult child's emotions (such as sadness or fear). For example, Lauren described her reaction as being self-centered because she immediately started crying and saying how scared she was. Adult children felt more comfortable communicating about next steps and treatment decisions while deemphasizing their own cancer-related fears. As Shannon put it, talking about treatments was "easier" and "more practical" than dwelling on her shock and fear.

Talk about treatment decisions was another unique line of work during this stage; adult children were asked to help their parent make decisions related to receiving radiation or chemotherapy, deciding on a lumpectomy or a mastectomy, or possibly forgoing treatment. This often involved doing personal research on the Internet, talking to the parent's doctor(s), and coordinating talk with other family members. Respondents described communication about treatment decisions as a dilemma when they were unsure how to express their own opinions while avoiding negative identity or relational implications of talk. For example, some respondents decided not to express opinions about treatments because explicitly stating their opinion might threaten the parent's identity (e.g., allow their mother make treatment decisions) and the parent-child relationship (e.g., the perception that adult children should be supportive of their mother's decisions).

Work during treatment. As the parent moved into primary treatment, adult children experienced new, additional responsibilities. In line with Veach and colleagues' (2002) research, adult children often wanted to understand more about how to help their parent cope with different treatment regimens and their side effects. In contrast to Fisher's (2010) finding that adult daughters commonly help with everyday-life work (e.g., childcare, housework), adult children in this sample deemphasized everyday life work and rather emphasized their role in managing illness and biographical work by obtaining additional medical advice or providing verbal reassurances. Respondents often acknowledged how illness work (e.g., caregiving tasks) complicated the successful management of biographical work (e.g., helping their mother maintain her identity as a parent) during this stage. For example, Peggy described the relational "shift" brought on by seeing her mother naked for the first time following a mastectomy surgery. Talking about or seeing body parts that adult children had not previously expected to talk about or see is one specific example of how illness work threatened biographical work during this stage.

A particularly challenging responsibility during the treatment stage was the communication work involved in understanding and following the patient's preferences for sharing cancer-related information with other family members and friends. In the present study, adult children described their desire to control the flow of information in ways that conformed to their mother's preferences. Often, adult children navigated this challenge by explicitly asking their mother about the privacy rules surrounding sharing cancer-related information. This was often done with the intention of helping the diagnosed parent maintain control over her cancer experience. This coheres with research indicating that privacy is highly valued because it

enhances feelings of autonomy and empowerment (Donovan-Kicken et al., 2011; Petronio, 1994).

Although enacting control over information has been identified as an important coping behavior for cancer patients (Donovan-Kicken et al., 2011), it appeared to be problematic for adult children. Indeed, a parent's enacted control meant that adult children were not able to share information, or obtain support, until their mother decided to disclose to certain individuals. For example, Matthew and Leigh noted that their mother's desire to keep the diagnosis a secret meant that they were unable to go to some family members for support or additional information. Respondents described an obligation to "check in" with their parent each time they wanted to talk to someone outside the immediate family about her diagnosis. Needing approval created additional communication work for adult children as they sought to follow their parent's preferences for sharing information.

Work during survivorship. New lines of work emerged as a parent completed primary treatment. The beginning of the survivorship stage was described as being full of positivity. However, respondents acknowledged that "surviving" cancer did not mean that cancer-related fear dissipated. Rather, "surviving" encompassed all of the lingering health concerns and fears that come with having a mother who was diagnosed with breast cancer. Sandra, for example, talked about the extra planning (e.g., who would drive, where they would park, if there were places to sit) involved in going wedding dress shopping with her mother in light of the blood clots and nerve damage that resulted from her mother's botched mastectomy. Clearly, adult children's illness work did not end when their mother finished primary treatment.

Adult children also described the tremendous amount of biographical work needed to adapt to a life filled with uncertainty about whether the disease would recur. The current study

suggests that adult children sense a discrepancy between their own lingering cancer-related fears and the perception that their mother wanted to put cancer in the past. For example, Lisa said she often thought about how the cancer could "come back" in 20 or even 40 years. Yet, she felt unsure how to bring cancer up once the "crisis was over" because her mom probably "didn't want to talk about it as much." The majority of adult children in this study perceived that their parent wanted to avoid dwelling on illness, and several mentioned that bringing up cancer or talking about lingering fears with the diagnosed parent would contradict the desire to "react appropriately" and "remain positive." More specifically, this kind of talk was considered inappropriate when it drew additional attention to the parent's illness or made the parent feel responsible for her children's increased cancer risk. For example, Kaylin said: "Unless she brings up the topic, I don't want to bring stuff up. I want to let her rebuild her life and let things get back to normal. I think we've been through it so much that I don't feel like she even wants to talk about it anymore." This is in contrast to previous research (e.g., Sherman & Simonton, 1999), which suggested that family members often want to put cancer in the past while patients continue to struggle with increased feelings of vulnerability. In this study, adult children seemed to believe that their mother wanted to act like, and be treated like, her pre-cancer self once treatment concluded. In an effort to "match" what adult children perceived as the parent's preferences, adult children appeared to deemphasize their own lingering fears in conversations with the diagnosed parent. Indeed, Kaylin's quote demonstrates how avoiding talk about cancer was perceived as a way to both maintain her mother's identity as a healthy survivor while sustaining their own identity as a supportive child.

Importantly, it is quite possible that the perception that mothers wanted to put cancer in the past was incorrect. Indeed, Miller (2015) suggested that cancer survivors are dissatisfied

when they felt that family members altercasted them into the role of the pre-cancer self. Altercasting a cancer survivor into their pre-cancer identity is problematic in this context because it can result in a lack of social support following completion of treatment (Miller, 2015). In the current study, adult children's perception that their mother wanted to avoid talk about recurrence may have actually precluded mothers from talking about cancer-related fears with her adult children. Alternatively, adult children may have found it more difficult to bring up cancer once their parent concluded treatment because there were no longer follow-up appointments or tests to prompt communication. Because the parent had less frequent reminders of the disease, adult children seemed to feel bad "forcing" their mother to continue talking about (or thinking about) the experience. This extends previous literature by demonstrating that adult children may also struggle to communicate about cancer once primary cancer treatment concludes. In particular, adult children seemed to feel that their mothers wanted to avoid further discussions about their lingering health issues and risk for recurrence.

Adult children also described the communication work involved in having conversations about their own risk for breast cancer once the parent entered the survivorship stage. Unsurprisingly, daughters in the current study experienced more emotional distress when talking about breast cancer risk than sons did; sons were only marginally included in conversations about genetic risk and were not at all included in conversations about mammograms or other preventative measures. As was previously discussed, daughters often experience a psychological chronic risk following a mother's breast cancer diagnosis due to the dual fear of personal risk for getting the disease and the fear of recurrence or progression for their mothers (Kenen et al., 2003). Correspondingly, adult daughters in this sample struggled with lingering fears for both their parent and their own risk of being diagnosed with breast cancer. The current study extends

this research by highlighting the challenging nature of determining when and how to talk about this chronic risk. In particular, there was an apparent divide between adult children who were open to discussions about their own risk and those who did not want to engage in discussion about preventative behaviors.

Past research suggests that parent-child communication plays a central role in determining children's willingness to engage in health-promotion behaviors like getting a mammogram (Fisher, 2010; Fisher & Nussbaum, 2012). In particular, feeling able to talk about cancer and treatment with their parent, feeling listened to and understood, and receiving encouragement to be tested have all been identified as key parent-to-child health promotion behaviors (Wong et al., 2010). In line with that research, adult children in the current study acknowledged that a parent's conversational approach impacted how open they were to conversations about prevention. For example, adult children recalled their mother's use of both direct strategies (e.g., asking whether the daughter had gotten a mammogram) and indirect strategies (e.g., using humor) to talk about prevention. However, when the parent brought prevention up too frequently, or attempts to talk about prevention were perceived as impinging on the child's ability to make personal health decisions, these conversations were distressing and dissatisfying. These data suggest that parent-child conversations that are characterized by a give and take between the adult child and the diagnosed parent will be most effective in encouraging preventative behaviors.

Work during recurrence. Four adult children (Amanda, Bonnie, Heather, and Meredith) had experienced a parent's breast cancer recurrence. In keeping with past research (Zhang & Siminoff, 2003), these four adult children recalled struggling more to communicate about a cancer recurrence than they did with the initial diagnosis. Talk about death and dying was

particularly difficult during this stage. For example, Bonnie labeled her communication about her mother's mortality as being "Hollywood" because her family would just gloss over talking directly about death. These data comport with Krant and Johnston (1977), who found that 92% of family members had thought about the possibility of death following a cancer recurrence, but 78% had not discussed the possibly with their diagnosed family member. Similarly, in line with Shearman and Simonton's (2001) findings, adult children who regarded death as a taboo subject and avoided communicating about death had greater difficulty in this stage.

Interestingly, recurrence sometimes provided adult children with an opportunity to reflect back on and change previous dissatisfying communication processes. For example, Meredith talked at length about how, following her mother's second diagnosis, she was very blunt in telling her mother to be "straightforward" with her during the recurrence. In this way, adult children seemed to reflect on how communication during the recurrence could be improved based on what they learned about satisfying and dissatisfying communication during their parent's previous diagnosis.

Variation in work. These data provide several initial insights into the ways adult children's work may shift across a parent's illness trajectory. First, adult children's work appeared to, in part, depend on whether the parent's cancer was diagnosed in an early or a late stage. Respondents whose parents were diagnosed in a late stage (stage 3 or 4) reported spending more time preparing and planning for talk about their parent's cancer. Unlike adult children whose mother was diagnosed with an earlier stage cancer, a late stage diagnosis created unique concerns about openly expressing thoughts and feelings. In particular, fear of upsetting their mother and a belief in positive thinking prevented some adult children from talking about their concerns about their parent's late stage cancer. Adult children also reported increased symptom-

related uncertainty relative to how their mothers were "really" coping with a late stage diagnosis. For example, Elise, whose mother was diagnosed with stage 4 breast cancer, described being extremely distraught about all of the "what if's" related to being diagnosed at such a late stage. Sandra described a similar fear: "Especially because she was almost stage 4 – you just don't know. There are a lot of instances where people have surgery and then it still comes back." This can be compared to how adult children, like Shannon and Frank, talked about fear being diffused upon hearing that their mother's cancer was "caught early" and "only stage 1." Overall, adult children who experienced a parent's late stage cancer reported heightened uncertainties.

Although almost all adult children reported having conversations about their deepest fears and concerns with family members other than the diagnosed parent, adult children who reported on their mother's later stage cancer seemed to think that talking to other family members about sensitive topics was absolutely necessary. For instance, Elise reported that the only way she was able to put up a positive front in conversations with her mother was by talking to her siblings about fears that their mother might die. Although Elise acknowledged that her mother knew the children were upset, she did not want to become visibly distraught in conversations with her mom.

Another line of work that seemed to be unique to adult children who reported on their mother's later stage cancer was navigating discussion of "no treatment" being an option. Only Elise (stage 4), Ashley (stage 4) and Maci (stage 3) recalled ruminating about whether their mothers should continue or cease treatment. Indeed, Maci talked at length about how she wished she knew that not having any treatment and just "riding it out" was an option. Similarly, Ashley repeatedly bemoaned her mother's belief that having no treatment meant she was giving up. Ashley believed that stopping chemotherapy would have allowed her mother to live longer than

she did with treatment. The work involved in this context was overwhelming. Indeed, Ashley, Maci, and Elise all described obsessing over whether to present "no treatment" as an option. Yet, they did not end up having a conversation about this topic due to negative identity implications (e.g., that their parent would be "giving up" by stopping treatment) and relational implications (e.g., that they were "ready" for their parent to die). Importantly, all three reported that, if they could go back and do something differently, they would have tried harder to broach the topic with their parent. Ashley suggested that doctors who present no treatment as an option may help open the door for this type of conversation.

A second factor that appeared to create variation in the amount of work required across the parent's illness trajectory was whether the family had previous experience with cancer. Especially when a relative had died, previous experience with cancer shaped biographical, illness, and communication work in both positive and negative ways. For some respondents, previous experience with cancer complicated communication work due to fear and worry that history would repeat itself with their mothers. For example, Elise recalled having very little talk about her mother's cancer being stage 4 because the family was still coping with the loss of their father, who "only had stage 2 cancer." Because her father's cancer was less advanced and he had passed away, the fear surrounding her mother's diagnosis was enhanced. By contrast, other respondents described previous family experience with cancer as allowing for more positive conversations during the parent's illness trajectory. For example, Frank felt that his whole family was much more supportive and understanding of what his mother was going through because they had just gone through the same thing with his aunt.

Cognitively reframing their parent's experience as different or unique from other family members' experiences was one way to make work in this context feel more manageable. For

instance, Bonnie recalled talking to her mother about how cancer treatments had advanced greatly since her grandmother had passed and that her experience would be different. Similarly, McKenzie referred to her mother as the "rough draft" of the family because she was not going to follow the same "script" as other family members that had passed due to cancer. Reframing a mother's experience with breast cancer seemed to be an effective way to talk about a parent's experience in light of previous family experiences with cancer. In particular, the biographical work involved in reframing the mother's experience decreased cancer-related fears.

Effectiveness of adult children's strategies. Each of the challenges presented in chapter four posed potential dilemmas for adult children because the benefits of talk about their mother's cancer were often associated with the risks of talk. The challenges and dilemmas that emerged from these data demonstrate that, when adult children negotiate involvement in their mother's breast cancer experience, they recognize the identity and relational meanings behind patterns of talk. Considering how adult children worked to address the multiple meanings of communication about their mother's cancer is useful in this context because whether or not communication is deemed adaptive or maladaptive may depend on how families communicate. Indeed, according to Goldsmith's normative model (2001, 2004), conversational approaches that satisfy the multiple meanings inherent in talk are more successful than strategies that do not. This dissertation used the normative approach in combination with modified grounded theory methods to ground recommendations for communication in adult children's experiences.

Across the illness trajectory, adult children expressed a desire to communicate effectively with the diagnosed parent and other family members. For example, respondents wanted to communicate in ways that minimized stress for their diagnosed parent and regulated their own emotions. At the same time, however, respondents expressed the desire to fulfill their own

information needs. Expending the effort necessary to communicate in ways that balanced the benefits and risks of talk was worth it to adult children when it was perceived as aiding both their own and their parent's coping behaviors. This comports with Corbin and Strauss' (1988) statement that, "If people are to continue to put forth effort to do requisite or desired work, there must be some perceived payoff to motivate them" (p. 123). The sections that follow contextualize adult children's communication challenges in the broader literature on family communication about cancer and clarify why and when communication strategies are likely to be helpful in balancing the benefits and risks of talk in this context.

      Effectiveness of information management strategies. The results of this study pointed to a tremendous variability in information management strategies following a mother's breast cancer diagnosis. Information management was often conceptualized by adult children as a push and pull between wanting to talk about their parent's cancer while recognizing that their parent may not want to talk about some topics. For example, Brooke described communication with her mother as "open and willing to share everything" but then went on to say that she "hasn't really opened up a lot about her emotions." Similarly, Peggy characterized her communication as "pretty open," but went on to say that her mother avoided talking about feelings and emotions: "I mean, it's not that *I* want to avoid – but I know that it's something that *she* doesn't really want to show." The perception of a discrepancy between the adult child's desires for information and the parent's preferences created a dilemma of gathering information (task goal) versus respecting the parent's preferences for communication (identity goal) and norms of the parent-child relationship (relational goal).

      Adult children employed four strategies to address the dilemma of gathering additional information while balancing identity and relational implications of talk: gather information from

other family members, gather firsthand information from medical personnel, do research on the Internet, and obtain access to medical records. These strategies are likely helpful when they allow adult children to gather information (a) without having to bother the diagnosed parent or (b) when the diagnosed parent was not particularly forthcoming. Although adult children in the current study perceived all four strategies as being useful, the effectiveness of each strategy varied. Across situations, strategies for gathering additional information may be most effective when they allow children to capitalize on desirable identity and relational meanings of talk. First, using these strategies may allow adult children to avoid negative identity implications of "nagging" their parent for additional information. Second, these strategies may be especially successful for topics that would be particularly identity threatening for the parent (e.g., negative prognosis). Conversely, obtaining additional information from a third-party source may be ineffective when new information creates more uncertainty (rather than reduces uncertainty). Matthew, for example, recalled finding distressing information on the Internet that complicated communication with his mother.

In contrast to the first four strategies, which focused on gathering information from third-party sources, other adult children addressed this particular dilemma by developing a "code" for situations when they wanted additional information that the parent might not want to know. For example, Lisa described her use of the phrase "Why don't you go get a cup of coffee?" for situations in which she wanted to ask her mother's oncologist about potentially upsetting information. When compared to the other four strategies for managing this dilemma, which involved finding ways to gather information when the parent was not present, this strategy may be especially effective for adult children who attend medical appointments. For instance,

developing a code may allow adult children to avoid negative identity and relational implications of information seeking when the parent is present.

Varying preferences for information management also gave rise to the dilemma of determining how much cancer-related talk was appropriate. This dilemma was particularly problematic when it meant that adult children had to choose between their own preferences for talk and imposing on their parent. Perceiving that talk about cancer would be make them look bad (negative identity implication) or that their mother would deem it inappropriate for her adult child to bring up breast cancer (negative relational implication) led many respondents to avoid communication about breast cancer. For example, because Nadine perceived that her mother felt that talk about more emotional or negative topics was inappropriate, she never brought up those topics. Similarly, Tom and Nicole described remaining uncertain about their mothers' treatments because they felt that asking for additional information would be considered "prying." Tom explicitly said that his mother would have shared information if she wanted him to know – it was not right for adult children to ask "prying questions."

In order to manage this dilemma, adult children nominated three strategies. First, it may be useful for adult children and their parent to have an explicit conversation about preferences for managing cancer-related information. This comports with research suggesting that one way for family members to negotiate co-ownership of private information is by creating individual and content specific rules about sharing and withholding information (Petronio, 2002). Having an explicit conversation about information management is likely effective when it reduces adult children's uncertainty about preferences for talk. Goldsmith and Miller (2015) found that unresolved differences (e.g., having one partner who wants to talk about feelings and another partner who did not) complicated couples' talk about feelings; partners were more satisfied when

they had agreed-upon routines for facing stress. In the current context, several respondents wished that their parent had offered more opportunities to talk about cancer or had been more explicit about times that talk about cancer would have been appropriate. Megan, for example, said that she wished her mom would have said, "Do you want to sit down and talk about this?" in order to open the door for additional conversation. Thus, having an explicit conversation about preferences is likely effective to the extent that the conversation reduces uncertainty about how much cancer-related talk is appropriate. More specifically, an explicit conversation may allow parents and adult children to better understand each other's information management preferences and frame the meaning of subsequent information seeking attempts.

Second, using humor was sometimes helpful for determining how much cancer-related talk was appropriate. A parent's use of humor appeared to help adult children feel more comfortable initiating talk about breast cancer. Similarly, adult children sometimes used humor to raise a topic in a lighthearted way. An example of this strategy comes from Jade, who used a humorous remark (i.e., Franken-boob) in order to spark a conversation about a difficult topic (i.e., breast reconstruction). Using humor is likely only effective if the parent is not offended by the humorous remark. Indeed, Davidihizar and Shearer (1996) found that humor in sensitive contexts must take the form of "laughing with" rather than "laughing at." This suggests that effective use of humor will manifest when both parents and children appreciate humor as a way to relieve strain. Because humorous remarks about serious topics (e.g., feelings, prognosis) are often considered to be dissatisfying (Harzold & Sparks, 2006), the effectiveness of humor as a conversational strategy may also depend on topic of conversation. More specifically, humor that is effective may be constrained to topics such as physical appearance whereas humor may be ineffective for serious topics such as death.

Adult children also tried to pick up on their mother's subtle cues in order to determine when conversation about cancer was appropriate. Indirect or subtle cues helped adult children decide whether or not to engage in a particular conversation. Using this strategy appeared to be an attempt to minimize possible negative identity and relational implications of a parent saying "I don't want to talk about that." Thus, this strategy was often perceived by adult children as an effective way of balancing the benefits and costs of starting a conversation about cancer. However, this strategy is likely only effective if the adult child knows that the parent will, at some point, be open to a conversation about cancer; if adult children only pick up on cues that conversation is not appropriate, and thus feel unable to talk to the parent, there is a risk of both parent and child not getting needed information and support.

In contrast to strategies for obtaining additional information and determining when talk was appropriate, cognitive strategies were also useful in managing dilemmas of information management. Cognitive strategies allowed adult children to reframe the experience or focus on positive aspects of their mother's breast cancer. For this reason, cognitive strategies are likely effective to the extent that they allow adult children to cope more adaptively. Cognitive reframing manifested in two contexts. First, respondents emphasized the benefits of cognitively reframing the mother's experience as unique or different from past family experiences with cancer. For example, when Bonnie highlighted the ways in which technological advances would make her mother's cancer experience better than her grandmother's experience, she was able to more effectively manage identity and relational implications of talk with her mother. Second, some children reported cognitively reframing avoidance as "maintaining hope." For example, Amanda's family considered avoidance of talk about death as key to maintaining hope that her mother "would pull through and that it wasn't the end." As these examples demonstrate,

cognitive reframing may be effective for families when avoidance decreases distress and increases functioning. Similar to the construct of "being open while avoiding" (Caughlin et al., 2011), cognitively reframing avoidance as maintaining hope appeared to be one strategy that allowed adult children to minimize distress without feeling like they were explicitly avoiding certain topics of talk. It is important to note, however, that Amanda's family did talk about death once her mother decided to forgo further treatments. Thus, it is likely that this particular type of cognitive reframing may only be an effective strategy in the short-term whereas reframing may actually be ineffective for families that use the strategy as a form of denial.

  Effectiveness of social support strategies. Adult children discussed an array of challenges and strategies for being supportive in the context of their mother's breast cancer experience. In particular, respondents described the challenging nature of enacting support by "being there" for their mother, providing reassurances, staying positive in conversations with their mother, and providing support while managing personal emotions. Respondents continually emphasized how providing support was particularly challenging because, although social support was seen as important to the parent's functioning, respondents often deemphasized their own support needs. For this reason, adult children often struggled to uphold identity and relational goals while providing their mother with support. Respondents managed these challenges with seven strategies: showing willingness to talk, communicating with the parent more often, using distraction tactics, focusing conversation on the future, talking to family members and social network members outside the family about complaints or worries, and focusing conversations on facts rather than emotions. These strategies were more or less effective depending on the parent's current state of mind and stage in the illness trajectory.

Showing a willingness to talk and communicating with the parent more often appeared to be effective strategies across the illness trajectory. Adult children often perceived, and parents often confirmed, that an important form of social support in this context was simply being there for the parent so she was not "going through the experience alone" (Lisa). Showing a willingness to talk was effective when it was perceived as allowing the parent to "express their feelings" (Darla) and "just say whatever she felt" (Brooke). Showing a willingness to talk and communicating with the parent more often were likely effective strategies because they emphasize positive relational and identity meanings of talk in this context. For example, enacting these strategies meant that the parent did not have to overtly ask for additional support. These strategies are likely also optimal for demonstrating that the adult child will be there if and when he or she is needed.

Interestingly, adult children felt that distracting their mother with videos or jokes and talking about the future were effective support strategies for getting a parent's mind off of cancer for a short amount of time. For example, Jade felt that distracting her mother seemed to help by providing the parent an opportunity to "take a short break from that part of her life." Similarly, Kaylin explained how talking about the future likely helped her mother cope adaptively. She said: "We would talk about how she was going to see my son graduate high school. That was so important to her. I would tell her that when she was struggling." Although adult children seemed to believe these strategies were effective, substantial research (Burleson, 1994, 2008, 2009) indicates that support that challenges the legitimacy of another person's feelings (e.g., refocusing talk on the future) and only implicitly recognizing the another person's feelings (e.g., distracting) are considered low in person centeredness (i.e., acknowledgment and legitimization of another person's feelings and perspectives that help the recipient make sense of their feelings). Messages

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low in person-centeredness are not particularly effective forms of support. More specifically, messages low in person centeredness are evaluated more negatively and have fewer positive outcomes than do highly person-centered messages (Burleson, 2008). Thus, although these strategies may be relatively easy for adult children to enact, it is entirely possible that distractions and talk about the future were not interpreted as particularly useful by the diagnosed parent. Anna provides an example that illustrates this point:

Sometimes my mom would say, 'I can't wait for this to be done. I'm sick, I'm disgusting, I have these steroids that are making me gain weight.' And I would say 'Well you know it will all go away, you will lose the weight it will be fine.' And it would just be like a 'Pshhhh' kind of thing. She didn't respond very well.

As this example demonstrates, adult children thought that some forms of support would be adaptive. However, these data provide indirect, preliminary evidence that some strategies may have actually been ineffective in helping the diagnosed parent cope.

Importantly, some adult children did seem to acknowledge that distractions and talk about the future were only effective to a certain extent or in certain situations. For example, no respondent suggested that distracting the diagnosed parent was a long-term solution or support strategy. Rather, the use of distractions was perceived as a way to allow the parent to think about something other than cancer, or get her mind off of cancer, for a brief amount time. This is in line with Burleson's (2009) suggestion that distractions can quickly and easily produce moderate to substantial changes in the feelings and behaviors of a distressed recipient. However, Burleson (2009) emphasized that these changes are usually temporary because refocusing attention does nothing to alter then fundamental cause of emotional distress. In sum, distracting the parent and focusing on the future likely varied widely in effectiveness. If the diagnosed parent interprets

these strategies as minimizing her experience or challenging the legitimacy of her feelings, offering distractions and focusing talk on the future were likely ineffective support strategies. Conversely, it is possible that these strategies were effective in some situations for altering the parent's immediate feelings of distress.

In addition to the previously reviewed support challenges, adult children found it personally difficult to express strong emotion; even when adult children wanted to talk about emotion, concerns about upsetting their parent further prevented them from doing so. This complicated support provision. For example, an adult son may want to be supportive but prefer to not talk about cancer as a means of avoiding emotional overload. Similarly, an adult daughter may feel uncertain due to lack of information about her mother's prognosis, but perceive that talk about the prognosis would be upsetting to her mother. These examples highlight how the desire to provide support while managing personal emotions created a dilemma for adult children. Adult children who experienced this dilemma were faced with continuing to avoid talk about emotions but possibly damaging the relational dynamic or maintaining the relational dynamic but possibly becoming emotionally overwhelmed. Each option had the possibility to result in dissatisfaction for both the adult child and his or her mother.

By highlighting how adult children also struggled to simultaneously manage their own and their parent's emotions, this finding builds on past research suggesting that cancer patients must work to manage the emotions of others (e.g., Donovan-Kicken et al., 2012). Protection of both self and other has often been cited as a rule for revealing and concealing information from family members (Caughlin & Golish, 2002; Goldsmith & Miller, 2015). For example, families sometimes engage in avoidance for reasons of *mutual protection*, whereby both patients and family members protect each other from being exposed to a harmful situation (Zhang & Siminoff,

2003). In the current study, adult children felt that certain conversations had the potential to erode their mother's positive outlook. Based on this belief, respondents were convinced that their overt expression of sadness and fear would weaken their mother's morale. Thus, avoidance of those conversations was considered preferable. As Elise explained, there was always a potential for the diagnosed parent to get even more upset if they saw their child upset. This coincides with Caughlin and his colleagues' (2011) examination of topic avoidance in the context of adult children coping with a parent's lung cancer diagnosis. Specifically, Caughlin et al. found that adult children sometimes entirely avoided talk about specific topics related to lung cancer when such topics could cause emotional upset or potentially discourage family members' hopes for recovery.

Adult children who struggled to talk about their own or their parent's feelings often found it easier to discuss facts rather than emotions. This is in line with past research (Lewis & Deal, 1995; Pistrang & Barker, 1992), which suggests that some families find it easier to discuss medical aspects of cancer than to express feelings. Adult children noted a preference for asking for updates or having "check in" conversations while avoiding talk about their own or their mother's emotions. Talking about facts rather than emotions is likely effective when it facilitates coping or helps adult children avoid dwelling on negative aspects of the illness. In addition, talking about medical facts rather than emotions may be effective to the extent that it allows adult children and their diagnosed parent to safely discuss cancer without becoming emotionally overwhelmed. Darla, for example, noted that talking about fears would just "hurt the situation."

Although adult children generally considered focusing on facts rather than emotions effective, a normative perspective suggests that avoidance of talk about emotions could also have undesired identity and relational meanings. Indeed, this strategy seemed to be ineffective when

adult children steered conversational topics away from emotional talk in a way that made the topic taboo or minimized their mother's concerns. For example, avoidance of talk about emotions was likely ineffective when adult children were aware that avoiding conversation about emotions could have been interpreted by the diagnosed parent as apathy or disinterest. Michelle, for example, expressed how she wished she had "expressed more concern" so her mother would have known the depth of her distress. This strategy also seemed ineffective when adult children felt it was unlikely that they would ever move beyond talking about facts. Nicole, for example expressed dissatisfaction that she never talked about the "serious-seriousness" with her mother. Thus, although she recalled several conversations about the medical aspects of her mother's disease, Nicole wished she could go back and prompt her mother to have more conversations about feelings and emotions. Finally, avoidance of talk about emotions seemed ineffective to the extent that it was conceptualized as a result of the respondent's own communication deficits. For example, Maci talked at length about how she regretted never having an "actual conversation" about her mother's prognosis. She said, "I think overall that's the biggest thing that really gets to me – we didn't know how to talk about it ever… had I pushed a little more for that, maybe things could have at least gone a little better for her." This is in line with Caughlin et al.'s (2011) finding that lack of efficacy appeared to be a common explanation for why adult children avoided conversation about emotional aspects of their parent's cancer. Thus, despite the utility of topic avoidance as a communicative strategy, some adult children recognized how avoidance of talk about emotions could have negative relational and identity meanings.

Adult children often found an outlet for difficult conversations by talking to other family members, especially other adult siblings. Reaching out to siblings facilitated adult children's coping because they did not have to worry as much about the negative identity implications of

communication about emotions. What is more, adult children felt that talking openly about fears, frustrations, and concerns with a sibling meant that they were better able to provide support to their diagnosed parent. This strategy was likely effective because it allowed adult children to fulfill both identity and relational goals in conversations with the diagnosed parent. For example, Frank explained how talking to his sister about his frustrations and fears allowed him to be more empathetic when talking to his mother about her desire to go back to work. In turn, he felt that this strengthened the parent-child relationship during the treatment stage. This finding extends previous scholarship by suggesting that, when adult children seek support from other family members, they perceive that it also relieves emotional burdens placed on their diagnosed parent. This was important to adult children due to the belief that expressing a personal need for additional information or support would detract attention from their parent. As Shannon eloquently put it, "it feels a little self-indulgent to really express your anxieties to somebody who is dealing with a lot of stuff on their own unless they invite you to." This is problematic because relatives who do not feel that their own emotional needs are relevant or valid may express less distress and thus receive less support (Foster et al., 2015; Kristjanson & Ashcroft, 1994).

Taken together, the strategy of talking to other family members, especially adult siblings, is likely particularly effective when it allows adult children to express their innermost fears and concerns, receive social support, and, in turn, uphold more positive relational and identity goals in parent-child interactions. Yet, adult children often felt disappointed when they turned to a family member for support and did not receive it. For example, Elise described situations when going to her adult sister for support actually resulted in having to provide more support while not receiving any in return. Thus, utilizing the larger family network for support may be ineffective if the resultant support is perceived as inadequate.

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Adult children's challenges and strategies related to social support suggest that assuming a diagnosed parent is always the recipient of support (and that the adult child is always the source of support) ignores the multiple meanings inherent in conversations about a parent's breast cancer. Adult children who need to ask for support may worry about negative identity implications (e.g., feeling that they are not entitled) or negative relational implications (e.g., that they are burdening the parent during a time that the parent is most requiring of support). Talking to social network members inside and outside of the family and focusing on facts rather than emotions were commonly used (and sometimes effective) strategies for addressing this particular dilemma.

Effectiveness of geographic separation strategies. The current study also provides insight into how adult children manage the challenging nature of being geographically separated from their parent during the breast cancer experience. Broadly, adult children reported that geographic distance from their ill parent or other family members was a challenge because it created additional stressors, which in turn influenced their communication. Knowing more about geographic separation provides insight into how and why adult children see particular communication behaviors as helpful or unhelpful in this context.

Geographically separated adult children struggled most with obtaining truthful and complete information about their parent's condition. Similar to proximal respondents, geographically separated adult children believed that information was often withheld because their mother did not want them to worry. Unique to this group of adult children was the added distress of not being able to see firsthand how things *really* were. Indeed, because geographically separated respondents were not usually present at their mother's medical appointments, they were unable to enact strategies that proximal adult children employed to obtain additional information

(e.g., see the parent face-to-face, attend medical appointments, drop in on the parent unexpectedly). Having to rely on secondhand information or updates that may have been censored seemed to result in more distress for geographically separated respondents. Amanda, for example, felt her brother was not "really divulging the full reality of things" over the phone. Among other reasons, censored information was problematic because adult children were unprepared for the reality of seeing their parent face-to-face. Previous research suggests that seeing dramatic physical changes upon reunion can trigger elevated levels of anxiety and distress for geographically separated family members (Basinger et al., 2015; Bevan, Vreeburg, Verdugo, & Spars, 2012). In the current study, adult children described feelings of anger and disappointment when proximal family members did not make them aware of the extent of the situation. Kevin, for example, recalled his frustration upon seeing how rundown and tired his mother looked when his father and sister had been telling him she was feeling "pretty good." In line with past research (e.g., Koerin & Harrigan, 2002), distance seemed to create a heightened uncertainty regarding how their mother was progressing in terms of the illness.

In order to address dilemmas created by geographic separation, many adult children visited the diagnosed parent. A reason why this strategy was often considered effective is that it reduced uncertainty about how the parent was "really doing." Visiting allowed adult children to obtain firsthand information and get visual confirmation about their parent's condition. Conversely, visiting the parent was likely ineffective when it heightened uncertainties. For instance, geographically separated respondents sometimes reported heightened uncertainty regarding when to visit their parent. Lauren, for example, recalled wanting to visit her mother during the treatment stage, but her father said she should wait until her mother was done with treatment and would be able to enjoy the visit. This meant that Lauren was unable to use this

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particular strategy. Even adult children who were unable to travel to see their diagnosed parent felt that expressing a desire to visit was helpful in minimizing negative relational and identity implications of not being there.

Adult children also suggested that maintaining regular communication by using communication technologies strategically was an effective way to manage challenges of geographic separation. Many adult children in this sample had daily phone conversations with the diagnosed parent. Others reported speaking to their parent numerous times throughout the day or exchanging regular emails and texts to stay in constant contact. Beyond maintaining regular communication, strategic use of communication technologies was likely an effective strategy because it allowed geographically separated children to obtain (and avoid) certain types of information. Some respondents preferred cue-rich channels like the telephone that would allow them to hear the emotion in their mother's tone of voice. Past research has suggested that emotions in the context of communication and cancer are commonly conveyed through nonverbal means like touch, facial expressions, and vocalics (Trees, 2000). Adult children seemed to realize that voice conversations could serve as an important source of information in terms of gathering information about how their parent was actually feeling. Conversely, other respondents preferred cue-lean channels like instant messenger or texting so their parent would not hear the fear in their own voice, or so they would not hear pain in their mother's voice. Choosing a communication technology that matched adult children's interaction goals (e.g., hide emotions or figure out how the parent was really feeling) was viewed as an effective strategy for geographically separated adult children.

In contrast to visiting and using communication technologies strategically, some adult children cognitively reframed geographic separation as a benefit instead of a challenge. This

small minority emphasized that they were grateful to be away from home so that they could avoid seeing their mother's health deteriorate. This diverges from Basinger and her colleagues' (2015) finding that emerging adult children experience geographic separation as a dialectical pull between wanting to be with their diagnosed family member while also wanting to throw themselves into school work to avoid thinking about cancer. The current study adds additional nuance to Basinger et al.'s results by highlighting complexities that are present when adult children cope with a parent's breast cancer diagnosis from a distance. In particular, adult children who reframed geographic separation as a benefit did not seem to experience this dialectic. Rather, they felt distance made it easier to not constantly think about their parent, which, in turn, allowed them to cope more adaptively. Thus, even though this group of adult children experienced guilt that other family members had to engage in extra work to involve them and keep them up to date, they did not express a desire to reduce physical distance during their mother's cancer experience.

Proximal respondents also recalled the difficulties of informing and involving geographically separated family members. Similarly, geographically separated siblings acknowledged that proximal siblings took on additional responsibilities both in terms of helping the diagnosed parent and keeping other family members in the loop. In order to acknowledge this challenge, some families created a system for sharing information with the whole family. For example, Heather recalled that, when she would email her sister a question, her sister would get into contact with her father who would then get information from her mother. Information would then follow the chain in the opposite direction; her father would get back in touch with her sister, and then her sister would respond to the original email. This strategy was likely effective because it established an agreed upon routine for sharing information, which, in turn, reduced relational strain for proximal and long-distance adult siblings. In particular, this strategy was likely helpful

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because it emphasized the interdependence of family members in coping with the illness; long-distance respondents knew that their proximal family member(s) had a plan for sharing information and proximal family member(s) knew that long-distance individuals would be able to remain involved.

Effectiveness of relational strategies. Some adult children framed their parent's cancer diagnosis as a relational transition that changed the way they viewed the parent-child relationship (Knobloch & Solomon, 1999). This particular transition seemed to prompt a role reversal that required renegotiation of communication and behavioral patterns. Finding that adult children struggled to communicatively adjust to this role reversal is not surprising considering the extent to which communication rules and privacy boundaries are often routinized in families (Petronio & Caughlin, 2005). For example, when children are raised to interact with their parents in a particular manner (e.g., avoiding challenging their decisions, discussing their thoughts and opinions openly) dealing with changes to these dynamics can be difficult. In the current study, adult children recognized a shift in the parent-child relationship as they took on caregiving responsibilities, sometimes for the very first time. Navigating this relational transition was especially difficult for adult children who recognized possible negative identity and relational meanings of the role reversal. For instance, although adult children perceived that their mothers appreciated task-related support, they also worried that being too direct or overinvolved could violate the hierarchical nature of the parent-child relationship.

Adult children nominated two different strategies for addressing this particular challenge. First, adult children suggested that explicitly addressing the role reversal in conversations with the diagnosed parent might be helpful. This strategy is similar to, and likely useful for the same reasons as, having an explicit conversation about preferences for cancer-related talk. In particular,

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an overt discussion about the role reversal may help reduce the adult child's uncertainty about how to navigate role changes by clarifying the meaning of subsequent caregiving behaviors. This is quite different than the second strategy, which was using siblings as a sounding board. This strategy was likely effective when it allowed adult children to both get advice about how to communicate with the parent and obtain needed support. This strategy was perceived as being particularly helpful for navigating the role reversal when sibling communication led to more positive parent-child interactions.

Previous work in this area suggests that helping a loved one maintain his or her pre-illness identity is important for family members (Goldsmith & Miller, 2013; Miller, 2015). The current study highlights how negotiating involvement in the parent's breast cancer experience often required adult children to question the implications of communication behavior on their relationship. Similar to Goldsmith and Fitch's (1997) findings about advice giving as social support, adult children were faced with the dilemma of providing a parent with honest advice about their health behaviors or withholding their thoughts and opinions and, in turn, potentially not changing their parent's behavior. Several adult children discussed the dilemmatic nature of communicating advice about healthy behaviors. In particular, respondents recognized how providing advice had the potential to create relational challenges if their approach threatened their mother's highly valued identity as "the Mom." For example, some adult children, like Elise, said they would never directly tell their mother to take a certain action or stop a particular behavior. Other respondents, like Scott and Connor, did not realize that providing advice could have negative relational and identity meanings until they gave blunt advice and it damaged the parent-child relationship. Goldsmith and Fitch (1997) suggested that interpretations of advice as helpful and supportive or unsolicited and intrusive depends on how that advice is communicated.

The current investigation lends support to that work by suggesting that adult children's strategies for providing advice can also vary in effectiveness based on delivery.

In order to manage this dilemma, respondents worded advice as suggestions, ideas, or collaborative endeavors. This strategy can be effective because it alleviates the possibility of adult children offering unwanted advice that may be identity threatening to the parent. Brooke, for example, recalled using the phrase "Here's a piece of information for you." This strategy was considered a positive alternative to directly telling her mother what she thought was best. Indeed, Brooke explained that phrasing things as an idea or "another option" allowed her to contribute personal opinions while allowing her mother to "decide on her own." Similarly, Sandra highlighted positive relational meanings of talk in this context by framing her advice to be more active and eat more healthfully as a bonding activity that she and her mother could undertake together.

The current findings are in line with the notion that effective communication of advice in illness contexts requires consideration of both identity and relational goals. Goldsmith and her colleagues (2006) proposed that providing advice is difficult because it can remind patients of their identity as an "ill" or "unwell" person. For example, although adult children wanted to encourage their mother to engage in certain healthy behaviors, giving advice could have unwanted implications for their mother's identity. Goldsmith and her colleagues (2006) concluded that using indirect strategies to suggest healthy diet and exercise choices could be particularly effective because this conversational strategy avoids negative identity implications for the patient. This appears to also be true in the context of parent and adult child communication about breast cancer. Indeed, adult children's attempts to alter their mother's health behavior were viewed as most effective when advice messages also achieved secondary

goals of minimizing negative identity implications and relational distancing. Thus, framing advice as suggestions was likely an effective strategy because it allowed adult children to uphold their mother's autonomy while also maintaining closeness and acknowledging power differences in the parent-child relationship.

Summary. Given that adult children experienced a variety of communication dilemmas relative to managing cancer-related information, providing and receiving social support, coping with geographic separation, and navigating relational changes, it is important to understand both the benefits and drawbacks of talk in this context. This dissertation demonstrates the complexity of cancer-related communication across a parent's illness trajectory. A normative approach (Goldsmith, 2001, 20014) implied that there are better or worse ways that adult children can communicate across their parent's illness trajectory. Adult children implicitly recognized the value of communication with positive relational and identity implications and, therefore, carefully weighed the risks and benefits of communication. For example, many adult children reported wanting to gather additional information (task goal) or be supportive (relational goal), but being unable to manage the display of their personal emotions (identity goal) during those conversations led to talking about medical facts rather than emotions, only discussing difficult issues if their parent initiated talk, or talking to family members other than the diagnosed parent about especially upsetting topics. Having an explicit conversation about how much cancer-related talk would be considered appropriate helped some respondents reduce uncertainty about how to engage in subsequent conversations by framing the meaning of subsequent information seeking attempts. Results like this broaden our knowledge of better or worse ways to talk in this context by connecting different ways of talking to more or less desirable outcomes. In the section

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that follows, I highlight ways this research can be used to improve family communication in the context of a parent's cancer diagnosis.

Practical Applications

The current investigation suggests several avenues for integrating adult children into a mother's breast cancer experience. For example, adult children often expressed a desire for additional information about their mother's diagnosis and prognosis. Practitioners could suggest that patients (a) schedule appointments at a time that adult children would be able to attend and (b) invite adult children to medical appointments in early stages of diagnosis and treatment. If that is not possible, practitioners could allow adult children to be present via webcam during office visits. This would be especially helpful for geographically separated children who expressed frustration at the lack of firsthand information during their mother's illness trajectory. Practitioners who suggest that adult children might want to attend medical appointments may give adult children an opportunity to receive firsthand information about the illness and ask questions. Even if the patient decides to not include their child in medical appointments, this suggestion could stimulate family communication by implying that adult children might want to be involved.

Second, these data point to the importance of developing interventions for adult children. Adult children in this study experienced a variety of challenges with respect to both coping with their parent's diagnosis and communicating with the diagnosed parent and other family members. Individual services could be provided to adult children to ensure their needs are met. In particular, this dissertation provided a better understanding of the task, biographical, and communication work adult children undertake across a parent's illness trajectory. This information could be used to help adult children anticipate the next steps of their parent's illness so they are not taken off

guard as the disease progresses. In addition, this information could be communicated to breast cancer patients so they know that their adult children may experience different challenges at different points in the illness trajectory. Interventions for adult children could also provide strategies for recognizing and managing difficulties involved in sharing information and obtaining social support. For instance, adult children in this study struggled to determine when and how to talk about cancer in ways that conformed to their parent's preferences. Practitioners could communicate with family members about how to coordinate information management and social support preferences in ways that are satisfying to each individual. In turn, this information could be used to help adult children better understand and address their own support needs while also serving as a source of support for the diagnosed parent and other family members.

Third, these data point to the unique challenges of negotiating involvement in a parent's breast cancer experience from a distance. Geographically separated adult children in this sample experienced feelings of guilt that they were not able to be more involved during their parent's experience. Yet, some respondents highlighted the benefits of not having to see their mother suffering during primary treatment; *hearing* about their mother's treatments or pain over the phone was considered easier than actually *seeing* the physical effects of treatment. As Basinger and her colleagues (2015) previously suggested, normalizing these feelings of guilt and gratitude may help adult children cope more adaptively. In addition, results of this dissertation suggest it is important to emphasize how communication technologies can be used strategically in order to accomplish different goals of interaction. Acknowledging that adult children can leverage communication technologies during especially upsetting conversations may help both parents and children navigate talk about difficult topics from a distance. In addition, popular press

materials that provide practical information about how coping at a distance is different from proximal coping could help adult children more effectively communicate in this context.

In general, outreach to adult children should be considered following a mother's breast cancer diagnosis because doing so could potentially improve outcomes for both the patient and family members. Likewise, researchers should continue to consider how family communication might impact adult children in this context. In the section that follows, I outline several directions for future research in this area.

Limitations and Future Directions

This study had several limitations. First, the sample was limited in depth and variation; only 20% of respondents were male, and 87% identified as Caucasian. As a result, these findings apply largely to Caucasian females who grew up in two-parent households with both birth parents. In addition, although parent type was not restricted to mothers, no participants reported on a father who had been diagnosed with breast cancer. This further limits the variation of the data. Because gathering qualitative interview data is extremely time consuming, which makes including large numbers of participants impractical, future research might employ an online survey technique that allows for (a) a larger sample and (b) a global reach (Evans & Mathur, 2005).

Second, the findings of the current study are specific to breast cancer, which represents a very specific portion of the cancer experience. The experiences of adult children coping with a parent's breast cancer may be quite different from those whose parent has another type of cancer, such as more stigmatized types like lung cancer (Caughlin et al., 2011; Stone et al., 2012). Future work that explores family communication in various cancer contexts would benefit from using an iterative qualitative approach (Tracy, 2013) that acknowledges the dilemmatic nature of

family communication about cancer. In the current study, this approach shed important light on the processes involved in collectively managing communication during a parent's breast cancer experience. For example, a focus on the "how" and "why" of human behavior (Charmaz, 2006; Tracy, 2013) illuminated why certain strategies may have been used to address conversational dilemmas. Similarly, moving back and forth between participant data and the normative perspective allowed for a more complete assessment of the effectiveness of each conversational strategy. In particular, although a normative perspective suggests that conversational strategies that address the multiple meanings inherent in a particular context are considered most normatively effective (Goldsmith, 2001, 2004), highlighting participants' beliefs and interpretations of effectiveness (Charmaz, 2006; Tracy, 2013) and intervening conditions (Cresswell, 2012) enhanced assessments of effectiveness. Employing a similar framework in future studies will allow scholars to continue grounding analyses within participants' experiences and current theoretical frameworks.

Third, the study design is limited because it did not allow for an examination of particular breast cancer trajectories. Particularities of each parent's cancer trajectory would affect the intensity and length of the cancer experience, and, in turn, would likely impact the ways adult children negotiated involvement in that experience. In the current study, some adult children reported on a mother who was newly diagnosed or in her first round of treatment whereas others reported on a mother's experience following a recurrence or death due to breast cancer. Adult children's knowledge of their mother's diagnosis and treatments was also variable. For instance, some respondents did not know what stage their mother had been diagnosed in. Similarly, some respondents knew whether their mother had a lumpectomy or mastectomy whereas others just knew that their mother had "surgery." Future research that explores what difference variations in

diagnosis and treatments might make would be especially useful in understanding whether some challenges are especially problematic, or whether certain conversational strategies are more or less effective, in particular breast cancer trajectories.

Fourth, some respondents had considerable difficulty recalling specific conversations during each stage of the parent's illness. This difficulty was compounded when the parent had a cancer recurrence; in that instance, respondents could more readily talk about conversations during the recurrence but largely could not recall conversations during the first diagnosis. Because the data are from retrospective reports, not observations of parent-child interactions or daily diary reports, findings may not provide a complete picture of communication in this context. Scholars interested in moving this line of research forward should consider using a daily diary method in order to capture day-to-day communication (Bolger et al., 2003). Alternatively, conducting a series of interviews during each stage of a parent's cancer (e.g., one interview before the parent starts treatment, one interview during treatment, and yet another interview when the parent concludes treatment) could better capture communication in context.

Finally, and perhaps most importantly, these data are limited because they relied solely on the adult child perspective. Certainly, understanding subjective perceptions is a worthwhile endeavor (Caughlin, 2002). Indeed, understanding adult children's subjective perceptions is a significant contribution of this dissertation. Yet, by not including the perspective of the diagnosed parent, the present study cannot corroborate adult children's interpretations of conversations or behaviors (Charania & Ickes, 2006). For example, geographically separated adult children felt hearing their mother's voice over the phone allowed them to gather context clues and thus successfully gauge their mother's feelings. The current data do not allow for conclusions concerning whether adult children were assessing the situation accurately. Future

work that seeks to provide advice for how to communicate effectively in this context should acknowledge both the parent and child perspective. For example, adult children reported that distracting their mother or forcing their mother to "focus on the positives" helped their mother cope more adaptively. This is in direct opposition with previous research on social support (e.g., Burleson, 1994, 2008, 2009) that indicates how denying somebody's right to feel a certain way and distractions are especially ineffective forms of support. It is possible that adult children enact particular support strategies to make themselves feel better, or avoid support strategies that might lead to emotionally upsetting conversations. Future research that obtains patients' (and former patients') perspectives would illuminate whether (and when) adult children's conversational strategies actually helped parents cope more adaptively with a cancer diagnosis. This type of research is important because discrepancies between the support patients want and the support patients receive from family members can actually exacerbate distress in this context (Reynolds & Perrin, 2004).

Conclusion

This study adds to literature on family health communication generally and on the specific role of adult children in a parent's cancer experience. In particular, these data highlight the myriad responsibilities adult children undertake across a parent's illness trajectory. Negotiating involvement in the parent's breast cancer experience was particularly challenging for adult children as they managed cancer-related information and provided social support. These challenges were often exacerbated by both geographic separation and shifts in the parent-child relationship. This dissertation has implications for clinicians who seek to help families communicate following a breast cancer diagnosis and for researchers interested in family communication and cancer. Ideally, future research will continue to consider the perspectives of

family members other than the patient and his or her spouse in order to build a more complete

picture of how families communicate following a cancer diagnosis.

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TABLES AND FIGURE

Table 1

The Nature of Adult Children's Work Across the Parent's Illness Trajectory

Diagnosis Stage
    1. Work is determined by parent's disclosure decisions
    2. Prioritize the diagnosed parent
    3. Helping with treatment decisions

Treatment Stage
    1. Helping parent cope with the realities of treatment
    2. Personally coping with the realities of treatment
    3. Helping parent navigate the health care system
    4. Asking about privacy rules

Survivorship Stage
    1. Managing lingering fears for parent and for self
    2. Coordinating talk about prevention

Recurrence Stage
    1. Having hard conversations about treatments and mortality

Table 2

Summary of Adult Children's Strategies and Challenges

Information Management

Challenges	Strategies
Managing differences in information management preferences	1. Talk to other family members 2. Gather first hand information 3. Develop a code 4. Researching breast cancer on the Internet 5. Get official access to health records
Determining how much cancer-related talk is appropriate	1. Have an explicit conversation about appropriateness 2. Pick up on parent's subtle cues 3. Use humor
Navigating shifting boundaries towards openness	1. Highlight pragmatic reasons for openness
Navigating shifting boundaries towards closedness	1. Cognitively reframe avoidance as maintaining hope 2. Acknowledging needing help having difficult conversations
Contextualizing previous family experience with cancer	1. Cognitively reframe mom's experience as unique or different
Managing uncertainty in illness	1. Ask for updates about the disease progression 2. Minimization

Social Support

Challenges	Strategies
Enacting support by "being there"	1. Be available and open for discussion if and when parent wants to talk 2. Communicate with parent more often
Enacting support by providing reassurances	1. Use distraction tactics 2. Focus conversations on the future

Table 2 (cont.)

Maintaining positivity in conversations with the diagnosed parent	1. Talk to social network members outside of the family 2. Expressing fears and doubts to siblings and the healthy parent
Providing support while managing personal emotions	1. Talk about facts rather than emotions

Geographic Separation

Challenges	Strategies
Managing difficulties gathering and trusting information	1. Use communication technologies strategically 2. Visit the parent 3. Cognitively reframe geographic separation as a benefit
Involving and informing geographically separated siblings	1. Create a system for sharing information

Change to the Parent-Child Relationship

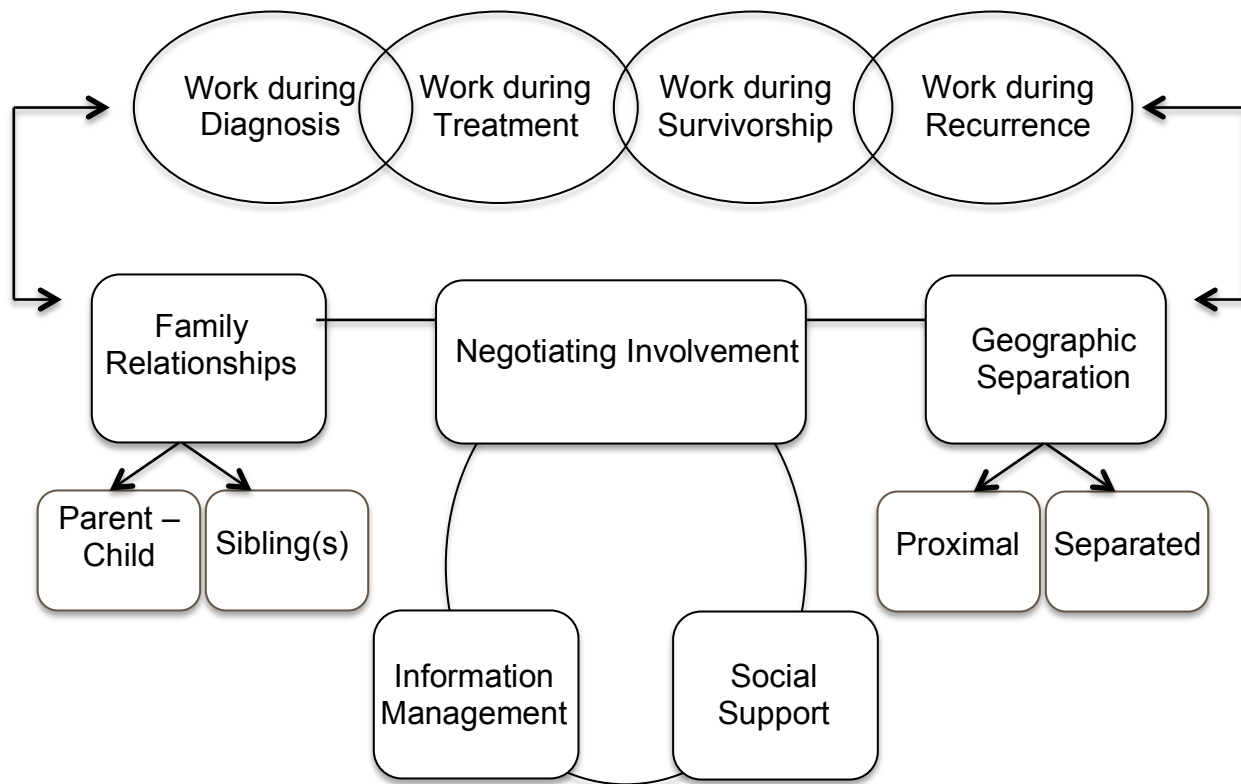| Challenges	Strategies
Managing role reversals	1. Explicitly address the role reversal 2. Use siblings as a sounding board
Respecting the diagnosed parent's autonomy	1. Phrase advice as suggestions

Figure 1. Visual depiction of adult children's negotiation of involvement in a parent's breast cancer experience.

APPENDIX A: Participant Resources

University Resources

University of Illinois Counseling Center
610 E. John Street, Champaign, IL
217-333-3704
http://www.counselingcenter.illinois.edu/

Community Resources

Family Service Counseling
217-352-0099
http://www.famservcc.org/

Community Elements 24-Hour Crisis Line
217-359-4141
www.communityelements.org

National Alliance on Mental Illness (NAMI)
800-950-NAMI (6264)
www.nami.org

This is participant #_____ and the date is _____. First, thank you again for agreeing to participate. Today we are going to talk about your family communication across your parent's cancer trajectory.

If you would like to stop and take a break at any time, please let me know. I'll also check in with you at several points throughout the interview to see if you would like to take a break. Keep in mind you can skip any questions that you do not wish to answer.

Do you have any questions before we begin?

RELATIONAL & COMMUNICATION CHANGES

➢ First, can you tell me a little bit about your parent's cancer experience? For example, what stage was his/her breast cancer upon diagnosis, what type of cancer treatment did your parent choose, did his/her cancer go into remission after treatment or did it recur?

Transition: Okay now that I know a little bit about your parent's cancer experience, I am going to ask you to recall conversations you had with your parent starting right after your parent was diagnosed with cancer and moving through (treatment, remission, and recurrence – depending on parent's situation).

➢ Let's start by talking about your family communication <u>right after your parent was diagnosed with cancer</u>.
   o Tell me about one of the most useful or helpful conversations you had with your parent during this stage.
      ▪ What made this conversation helpful?
      ▪ Did this topic come up again at later points in your parent's cancer experience?
   o Tell me about one of the most challenging conversations you had with your parent during this stage.
      ▪ What made this conversation challenging?
      ▪ How did you handle that?
      ▪ Did this topic continue to be challenging during your parent's cancer experience?

➢ Think back to when your parent started <u>his/her cancer treatment.</u>
   o Tell me about one of the most useful or helpful conversations you had with your parent during this stage.
      ▪ What made this conversation helpful?
   o Tell me about one of the most challenging conversations you had with your parent during this stage.
      ▪ What made this conversation challenging?
      ▪ How did you handle that?

- - Did this topic continue to be challenging during your parent's cancer experience?

➢ (if appropriate) Think back to when your parent's cancer <u>went into remission.</u>
  - ○ Tell me about one of the most useful or helpful conversations you had with your parent during this stage.
    - - What made this conversation helpful?
  - ○ Tell me about one of the most challenging conversations you had with your parent during this stage.
    - - What made this conversation challenging?
    - - How did you handle that?
    - - **PROBE:** did you and your parent ever have differing opinions about how much to continue talking about his/her cancer?
    - - **PROBE:** Were any cancer-related topics *easier* to talk about once your parent was in remission?

➢ (if appropriate) Now I would like you to think back to when your parent's cancer recurred.
  - ○ Tell me about one of the most useful or helpful conversations you had with your parent during this stage.
    - - What made this conversation helpful?
  - ○ Tell me about one of the most challenging conversations you had with your parent during this stage.
    - - What made this conversation challenging?
    - - How did you handle that?
    - - **PROBE:** Was there anything that was particularly difficult to talk about during this stage?
      - • (if yes) Why do you think it was difficult?

➢ Thinking across your parent's entire cancer experience, were there any times when you wanted <u>more </u>information about your parent's cancer diagnosis than he/she was willing to share?
  - • (if yes) At what points in the illness trajectory did you want more info?
  - • (if yes) Did you talk to your parent about wanting more information related to that/those topics?
    - ○ Please describe what that conversation was like (e.g., what did you say, how did the other person respond)
  - • (if yes) Did you talk to other family members about wanting more information related to that/those topics?
    - ○ Please describe what that conversation was like (e.g., what did you say, how did the other person respond)
  - • **Probe for each stage (diagnosis, treatment, remission, recurrence)**

➢ Were there any times during your parent's cancer experience when you wanted <u>less</u> info about your parent's cancer diagnosis?
  - • (if yes) At what points in the illness trajectory did you want less info?
  - • (if yes) Did you talk to your parent about your preference for less information?

- o Please describe what that conversation was like (e.g. what did you say, how did the other person respond).
  - • (if yes) Did you talk to any other family members about your preference for less information?
    - o Please describe what that conversation was like (e.g. what did you say, how did the other person respond).
  - • **Probe for each stage (diagnosis, treatment, remission, recurrence)**

- ➢ Were there any topics that you didn't talk about with your parent, even though you wanted to?
  - • (if yes) Describe one of those topics.
    - o Probe: which stage did this occur in?
    - o Why didn't you talk about that topic with your parent?
    - o If you had talked about it with your parent, how do you think he/she would have reacted?

- ➢ Were there any topics that your parent wanted to talk about that you didn't want to discuss?
  - • (if yes) Describe one of those topics.
    - o Probe: which stage did this occur in?
    - o Why didn't you want to talk about that topic with your parent?
    - o How did your parent know that you didn't want to discuss that topic?

- ➢ **If you'd like, we can take a break at this point.**

  Transition: Next, I am going to ask you a few questions about how your relationship with your parent changed across the cancer trajectory.

- ➢ Please describe your relationship with your parent BEFORE diagnosis.
  - • **Probes:** Closeness, Topics of talk, Frequency of talk, Time spent together, Health-related talk – how much did you and your parent talk about health-related issues? How much did you and your family talk about health-related issues?

- ➢ Do you think your relationship with your parent changed after his/her cancer diagnosis?
  - • Describe one of those changes.
    - o Did you talk to your parent about that change?
      - ▪ (if yes) Was there anything that was particularly difficult to talk about?
        - • (if yes) Why do you think it was difficult?
    - o **PROBES:** time spent together, topics you talked about, frequency of talk
  - • Did you talk to your parent about changes to your relationship when your parent started treatment?
    - o (if yes) If you can, think back to one of those conversations. Please describe what that conversation was like.
    - o **PROBES:**
      - ▪ Did you talk about that topic with your parent once or multiple times? (multiple stages?)
      - ▪ In what ways did your relationship stay the same?
  - • Did you talk to your parent about changes to your relationship when your parent went

into remission?

- o (if yes) If you can, think back to one of those conversations. Please describe what that conversation was like.
- o **PROBES:**
  - Did you talk about that topic with your parent once or multiple times? (multiple stages?)
  - In what ways did your relationship stay the same?
- Did you talk to your parent about changes to your relationship when your parent's cancer recurred?
  - o (if yes) If you can, think back to one of those conversations. Please describe what that conversation was like.
  - o **PROBES:**
    - Did you talk about that topic with your parent once or multiple times? (multiple stages?)
    - In what ways did your relationship stay the same?

➢ Were you geographically separated from your parent at any point during your parent's cancer experience?
- (if yes) Describe a conversation you had with your parent about being geographically separated during their cancer experience.
- **PROBES:**
  - o Was geographic distance from your family ever a challenge during your parent's cancer experience?
    - Describe those challenges.
  - o What communication technologies were most useful for staying in contact with your family while geographical separated?
    - Were any communication technologies particularly unhelpful?
  - o During which stage(s) was geographic distance most challenging?
    - Describe a conversation where distance was a challenge for you.

➢ Were any of your immediate family members geographically separated from your parent during his/her cancer experience?
- (if yes) Describe a conversation you had about your family member's geographic separation.
- **PROBES:**
  - o Did you find it challenging to keep this family member informed at any point during your parent's cancer trajectory?
  - o What communication technologies were most useful for staying in contact with this family member?
    - Were any communication technologies particularly unhelpful?
  - o Describe a conversation where a family member's geographic distance was a challenge for your family.

WRAP UP QUESTIONS

Transition: In this final section, I have a few questions about your general family communication during the cancer trajectory.

➢ What was the most meaningful conversation you had with your parent during their cancer experience?
   - o What made this conversation so meaningful?

➢ If you could go back and "re-do" one conversation with your parent, which conversation would that be?
   - o Why would you choose that conversation?
   - o What would you do differently?

➢ If you could give advice to other individuals about how to best communicate with a parent during a parent's cancer experience, what would that advice be?

➢ Is there anything that we have not discussed yet that you would like to talk about? Anything else you would like to add?

Thank you for your time and for sharing your experiences with me.

Demographic Questionnaire

1. What is your sex?
_____ Male
_____ Female

2. What is your age? _____

3. How many brothers and sisters do you have?

# of Brothers ___   # of Sisters ___

# of Stepbrothers   # of Stepsisters ___

4. Where do you fall in the birth-order in your family?

First born   Somewhere in the middle   Youngest

5. Which of the following best describes the cultural/racial heritage of your family? (Mark more than one if appropriate)
_____ Caucasian
_____ African-American
_____ Hispanic
_____ Asian
_____ Pacific Islander
_____ Native American
_____ Other (please specify) _____

6. What is the sex of your parent that was diagnosed with breast cancer?
_____ Male
_____ Female

7. Which kind of family form best describes your current family? (Please indicate the option that BEST describes your situation. If your parents live in separate places, indicate the family that you most often live with when you go home.)

_____ two-parent household with birth/adoptive parents
_____ single-parent household with mother
_____ single-parent household with father
_____ stepfamily with mother and stepfather
_____ stepfamily with father and stepmother
_____ other (please describe)

_____