To my father, John Kastrinos. I miss you every day.
To all the late parents of participants in this study: It was a great privilege to learn about you through the eyes of your children who love and miss you.
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This dissertation is dedicated to my father, John Kastrinos. John was a talented musician, surfer, artist, skateboarder, athlete, and composer. He was a loving father, husband, brother, and friend. In his 60 years, he lived enough for 100 lives and spent time working as a butcher, an electrician, a cartoonist, a software developer, a salesman of women’s designer cowboy boots, and a guitarist in a traveling 50’s show band. He had a drive to work incredibly hard at the things he loved to do – not to be better than anyone else, but to be the best he could possibly be. I think that is the same drive that pushed me through this program and to complete this dissertation. When I started my Ph.D., there was no more proud of me than my dad or more excited that there would be a “Dr. Kastrinos” in the family. I hope he knows I did it.
And now to end these acknowledgements, my dissertation, and my 10 years of studying at the University of Florida, I have to close with some words from Gainesville’s #1 Son:

*It's time to move on, time to get going.*
*What lies ahead, I have no way of knowing,*
*But under my feet, baby, grass is growing.*
*It's time to move on. It's time to get going*

Tom Petty
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EMERGING AND YOUNG ADULTS CARING FOR A PARENT WITH ADVANCED CANCER: UNDERSTANDING THE ROLE OF UNCERTAINTY AND INFORMATION SHARING ACROSS THE DISEASE TRAJECTORY

By

Amanda Kastrinos

August 2021

Chair: Carla Fisher
Cochair: Carma Bylund-Lincoln
Major: Mass Communication

This dissertation sought to identify the experiences of emerging and young adult (18-35) caregivers (EAC/YACs) of their parents with advanced cancer, with a special focus on the role of temporal factors and parent information sharing in EAC/YACs’ uncertainty and coping experiences. To isolate the role of time, I employed a turning point analysis (TPA) to capture how EAC/YACs’ communication, uncertainty, and coping evolved over the course of their parent’s disease trajectory.

In Study 1, I performed a systematic review of existing TPA to identify the contexts in which it has been used and the steps necessary to complete the study. In Study 2, a TPA was conducted with identifying turning points (TPs) in EAC/YACs’ uncertainty about their parent’s prognosis from their diagnosis to their passing. In addition to medical events and observable changes in their parent’s condition, EAC/YACs identified as turning points things they learned while searching online, including communication with their parent’s healthcare providers, and
information shared from their parents and other family members. I also examined the directional impact of TPs related to parents’ information sharing on prognosis uncertainty was also evaluated. It was discovered that prognosis uncertainty throughout the disease trajectory was determined by the EAC/YACs’ perception of their parent’s prognosis at the outset of their disease.

In Study 3, interview data collected during the TPA was used to identify the impact of information sharing (or lack thereof) on EAC/YACs’ coping and adjustment to their parents’ disease and eventual death. I identified several factors that affected the relationship between information sharing and coping, including the topic, the timing, and who was included. Study 3 revealed that information sharing determined the EAC/YACs’ involvement in caregiving and their ability to cope as a family. Practical implications for EAC/YACs, parents, and clinicians are provided.
CHAPTER 1
INTRODUCTION

Family communication is central to the ability of individuals and their loved ones to cope with cancer. As such, there is an increasing number of health interventions focused on enhancing family communication to promote better health outcomes, particularly within the context of caregiving (Kent et al., 2016). Emerging and young adult (18-39 years) children of diagnosed parents are both impacted by their parents’ diagnosis and commonly engaged in caring for their sick parent. In some instances, emerging and young adult caregivers (referred to as EAC/YACs for simplicity) indicate that they communally coped with their parent, viewing the cancer as “their” problem and taking on cancer together (Fisher et al., 2017; Lyons et al., 1998). EAC/YACs are more psychosocially distressed than other caregivers (e.g., spouses, older adult children) and yet, rarely do research or interventions focus on them in order to develop resources to enhance their caregiving and communal coping experiences (Litzelman, 2019).

One critical aspect of families’ and caregivers’ communal coping experience is information sharing. Although information sharing is widely studied in the context of medical decision making or caregiving skills, it’s less considered as a critical component to communal coping (Checton & Greene, 2012). Recent work informed by the Developmental-Contextual Model (DCM) (Berg & Upchurch, 2007) indicates that sharing cancer information is a primary factor in families’ ability to cope together (Magsamen-Conrad et al., 2015).

To understand how this model can extend to include EAC/YACs, it is critical to explore the role of human development (e.g., the age of the individual with cancer and the family members), temporal factors (e.g., cancer prognosis; cancer trajectory), and uncertainty (e.g., how uncertainty is managed and experienced across the disease and coping process) in the coping ability of EAC/YACs. The goal of the proposed dissertation study is to understand how these
factors impact EAC/YACs’ caregiving experience to inform the development of future psychosocial interventions tailored for caregivers in emerging adulthood.

**Communal Coping and Cancer Caregiving**

Coping as a communal experience has been studied among various health contexts and relationships, and scholars have developed numerous models of interpersonal coping (Berg & Upchurch, 2007; Bodenmann, 1997; Coyne & Smith, 1991; Revenson, 1994; Traa et al., 2015). The terms “dyadic coping,” “relation-focused coping,” “communal coping” and “collaborative coping” are often used interchangeably to describe similar coping processes (Staff et al., 2017).

Communal coping, originally proposed by Lyons et al. (1998), is identified as a three-step process: (1) shared appraisal, (2) communication about the stressor, and (3) cooperative action. To experience shared appraisal, one or more individuals in the dyad must view the stressor with a communal coping orientation. This involves viewing the issue as “our problem” rather than “my” or “your” problem and taking some responsibility for managing the stressor. Lyons et al. (1998) assert that details of the stressor must be shared in order to understand its impacts on the patient and their coping partner. Through communication and shared appraisal, the individual sees their partner’s support as cooperative behaviors, rather than as one-time support actions. Although communal coping identifies the pathways of coping, it does not account for key contextual factors that may facilitate or inhibit the dyad’s ability to cope together.

**Developmental Contextual Model (DCM) and EA Cancer Caregivers**

The Developmental Contextual Model (DCM) includes similar components to Communal Coping Theory, but it also incorporates age, disease trajectory, and illness uncertainty as factors that influence coping (Berg & Upchurch, 2007; Staff et al., 2017).
EAC/YACh of these components are critical to understanding the experience of communal coping for families with EAC/YACs.

Human Development

Because older couples are more likely than their younger counterparts to have encountered illness, research on coping has focused primarily on this cohort, identifying a number of generational factors that make it easier for older adults to cope communally (Berg & Upchurch, 2007). Illness is more normative during this period, meaning older adults have both greater experience with illness and are more likely to have social networks equipped to support them through it (Coyne & Smith, 1991, 1994; Revenson, 1990, 1994; Revenson & Pranikoff, 2005). Older adults also experience greater marital satisfaction and clarity of their self-concept in comparison to younger adults, which may ease the psychological distress associated with caregiving (Bluck & Alea, 2008; Carstensen et al., 1996).

Caregiving at a young age is a non-normative experience and can run in contrast to the typical developmental goals of EAs (Arnett, 2000). The responsibilities of caregiving can prevent EAC/YACs from pursuing higher education, career advancement, or romantic relationships, permanently altering their life course (Fruhauf & Orel, 2008; Pope et al., 2018). As a result, EAC/YACs often feel isolated and out of step with their peers, and they may experience unique mental health impacts (Aldridge & Becker, 1993; Bolas et al., 2007; Goldblatt et al., 2018; Granek, 2014).

Temporal Factors

Berg and Upchurch (2007) also explored the relationship between time and communal coping. As a patient moves through different phases of their disease trajectory, their ability to
cope with others may vary. Although few studies have looked longitudinally at communal coping, Maliski, Heilemann, and McCorkel (2002) found that patients and their coping partners experienced different coping strategies as their needs changed in response to disease progression. Focusing on disease trajectory also illuminates the impact of disease type on the coping experience. For example, a person who is suddenly diagnosed with advanced cancer has different needs than a person managing a long-term chronic illness (Gallant, 2003). Disease type can also impact relationship quality, as some diseases require more time and effort from the partner than others (Berg & Upchurch, 2007). The extensive time commitment associated with caregiving is particularly challenging for EAC/YACs. They often report missing school or reducing work hours more frequently than older adult caregivers (Fruhauf & Orel, 2008; National Alliance for Caregiving and AARP Public Policy Institute, 2015; Pope et al., 2018).

Additionally, Family Systems Theory purports that a sudden and aggressive cancer onset requires a recalibration of the family status quo. Family members must adjust to new rules and roles (Galvin & Young, 2010). According to Role Theory, individuals have traditional roles in the family unit and with these roles come family norms and behavior expectations (Phillips, 1957). When an EA or young adult becomes a caregiver, they often shift from being the one receiving care from a parent to the one giving care (for the first time in their relational history), and a fast disease progression forces an immediate adjustment to these new roles. This may exacerbate the already stressful experience of being a caregiver, as it requires adult children to reevaluate both their relationship with their sick parent and their own identity (Germino & Funk, 1993).
Uncertainty Management

The DCM was extended by Magsamen-Conrad et al. (2015) to incorporate prognosis uncertainty as a component of individuals’ and their partners’ shared appraisal. According to Uncertainty Management Theory, there are a number of ways that individuals manage uncertainty (Brashers, 2001). While seeking information to reduce uncertainty is a common management strategy, so is avoiding illness information to increase or maintain uncertainty (Brashers, 2007). Individual uncertainty management preferences within the dyad impacts the couple’s ability to both communicate effectively about the illness and ultimately, their ability to cope together (Miller, 2014). Previous studies have shown that EAC/YACs are more likely than older caregivers to rely on maladaptive coping styles, such as withdrawing emotionally and communicatively from the diagnosed parent, which compounds the harmful effects of this experience (Fisher, 2010).

Information Sharing and EAC/YACs’ Coping Experiences

Communication plays a central role in managing uncertainty, particularly in the illness context (Brashers, 2001). Research on information sharing has primarily focused on the initial disclosure of the diagnosis; however, coping with cancer can require almost daily decisions about what information to share and what to keep private (Clayton et al., 2006; M. Mishel, 1988, 1990; Y. Zhang, 2017). Within a family, generational differences play a significant role in determining how information about illness is shared (Galvin & Young, 2010). Social beliefs about competence, maturity, innocence, responsibility, and ability to cope are all embedded within the family’s perception of different generations (Boddington & Gregory, 2008; Gregory et al., 2007, 2010). Because of assumptions and expectations both culturally and within the family, age is largely determinate in who is entitled to information, who has decision-making power (i.e.,
parents of young children, adult children of elderly parents) and who remains in the dark for their own protection (Galvin & Young, 2010; Petronio, 2010).

Thus, in a family where one parent is affected by cancer, both parents become gatekeepers of illness information. Parents may avoid discussing the prognosis with their EA children in order to preserve normalcy, or to protect them from confronting the possibility of their death (Fisher, 2010; Venetis et al., 2015; Zhang & Siminoff, 2003). EAs exist in a unique space between adolescence and adulthood, and depending on their role within the family and parents’ perception of their maturity, their age could limit the amount of illness and prognosis information that parents feel comfortable disclosing (Arnett, 2015; Galvin & Young, 2010).

The cancer experience is filled with “illness events” (e.g., new treatments, symptoms, healthcare environments) that require decisions from the patient about what to disclose to others (Zhang, 2017). It is reasonable to assume that the parents’ ongoing disclosure decisions contribute to their child’s uncertainty management about the cancer. As communication is necessary to facilitate communal coping, a lack of disclosure from parents regarding the prognosis would heighten EAC/YACs’ uncertainty and limit the family’s ability to cope with cancer communally (Fisher et al., 2017; Lyons et al., 1998; Zhang, 2017).

**Dissertation**

The overall aim of this dissertation was to explore the intersection of uncertainty, parental disclosure (as a form of information sharing), and coping across the disease trajectory in the EA advanced cancer caregiving experience. In order to capture how these factors evolved and differently impacted EAC/YACs’ caregiving and coping experience as their parent moved through the cancer continuum, I conducted a Turning Point Analysis (TPA). TPA (Baxter & Bullis, 1986) is a lifespan interviewing method that allows researchers to capture retrospective
data longitudinally using a narrative approach that easily facilitates disclosure from participants and allows deeper exploration of the constructs under study. I first conducted a systematic scoping review of the TPA methodology to identify the method’s range and common methods of data collection and analysis. Second, I conducted a TPA measuring changes in EAC/YACs’ prognosis uncertainty across their parent’s disease trajectory. Third, I used the in-depth interview data collected during the TPA to examine the role of parent information sharing on EAC/YACs’ coping and caregiving experiences.

For the systematic scoping review of TPA, the following aim was explored:

• **Aim 1:** to describe how TPA has been used and to identify common methods of TPA data collection and analysis.

For Study 2, I conducted a TPA using the Retrospective Interviewing Method (RIT) (Fitzgerald & Surra, 1981) with EAC/YACs regarding their prognosis uncertainty and performed a thematic analysis of the interview transcripts and chart data to answer the following research questions:

• **RQ1:** What turning points influence EAC/YACs’ uncertainty about their parent’s prognosis?

• **RQ2:** What familial information sharing/withholding turning points influence EAC/YACs’ uncertainty about their parent’s prognosis?

For Study 3, I performed a thematic analysis of the interview transcripts examining the impact of parent information sharing (or lack thereof) on EAC/YACs’ caregiving and coping to answer the following research question:

• **RQ1:** What factors play a role in how parent’s information sharing / withholding affects EAC/YACs caregiving and coping experiences
CHAPTER 2
STUDY 1: SYSTEMATIC SCOPING REVIEW OF TURNING POINT ANALYSES

Systematic Scoping Review

Interpersonal communication is the pathway by which relationships evolve. Specific events can serve as catalysts, altering the trajectory of a relationship in healthy or unhealthy ways. The term “turning point” (TP) in interpersonal communication research refers to events or occurrences that significantly alter relationships (Bolton, 1961). Although turning points as a relational concept have long been studied, Baxter and Bullis (1986) originated a method of using turning points to measure change over time to capture relational development. In a seminal study, the authors sought to identify trajectories of relational commitment in heterosexual romantic relationships. Analyzing the turning points identified by participants allowed the authors to study these events both individually and within the context of the partners’ entire relationship course. Since the publication of the original paper introducing this method, Turning Point Analysis (TPA) has been applied in number of different ways to better understand change over time, including different levels of analysis (e.g., relational change, individual change, organizational, group, or familial system change) and varying contexts (e.g., health, family functioning, organizational identification or socialization).

As originally designed, the first step in TPA is to conduct a semi-structured interview using the Retrospective Interview Technique (RIT), in which participants are typically first asked to plot relational turning points on a graph (Fitzgerald & Surra, 1981; Huston et al., 1981). Usually this is done by printing the graph (if interviews are done in person) or emailing a copy of the graph to participants to plot turning points (if interviews are done over the phone or online). “Time” is typically represented on the x-axis (e.g., in years, months), and the construct of interest is on the y-axis (e.g., relational well-being or satisfaction, identity), which can be operationalized...
in a number of ways (see Figure 2.1). The y-axis variable was originally measured in a scale of 0-100, but there are variations using a smaller scale (e.g., 0-5, 0-10) or a semantic scale. Participants are asked to plot all points of change or “turning points” that affected Y (the construct represented on the y axis) that they experienced in the context of study that is typically also situated within a relationship (e.g., parent-child or patient-clinician, romantic couples) or larger relational system or group (e.g., blended family, divorced family, organization). Participants are also told to begin plotting these turning points at a certain pre-determined point in time and up until a pre-determined end point, oftentimes the present day. They are also asked to label EAC/YACh point with words of a short phrase so that they remember what that turning point was during the interview. Once they have completed plotting all turning points, they then connect the dots with a line to create a visual trajectory of turning points (or relational trajectory) experienced across time. The RIT graph is then used during the interview, serving as both an interview probe and guide. During the interview, the participant is asked to describe their experiences to elicit detailed rich information that captures the context of EAC/YACh turning point in a way that furthers knowledge about the construct(s) of interest. Both the visual trajectories and turning points can be analyzed using quantitative and qualitative approaches (e.g., Dailey et al., 2016; Kellas et al., 2008; Pitts & Miller-Day, 2007).

Although TPA was originally created to study relational development, this approach has been used in both health contexts and relationships within clinical settings (Ledford et al., 2020; Taylor III et al., 2020; Wolf, 2009). There is a significant need for feasible approaches in health communication that allow scholars to incorporate time as a variable of interest in illness experiences. Not only are developmental and temporal factors integral to disease coping and management (Berg & Upchurch, 2007; Gregory et al., 2010), but longitudinal studies are
expensive, less feasible, and involve low rates of attrition (Gustavson et al., 2012). TPA can be a valuable alternative as it enables researchers to capture experiences across time without the challenges of conducting a longitudinal study (Baxter & Pittman, 2001; Pitts & Miller-Day, 2007). Leading lifespan, aging, and health communication scholars have called for innovative methods to capturing lived experiences developmentally not only to provide more feasible design approaches but also to integrate lifespan factors into research, as opposed to designs that provide only a snapshot in time (Harwood, 2015.; Pecchioni et al., 2005). However, studies using TPA have not yet been rigorously reviewed and synthesized. At the time of submission, there are no systematic reviews published or registered on the Prospero database about TPA. The overall aims of this systematic scoping review are to describe how TPA has been used and to identify common methods of TPA data collection and analysis.

**Study 1 Method**

Studies were eligible for the review if they met the following criteria: (i) peer-reviewed journal articles and dissertations; ii) a study design that incorporated a TPA that replicates or modifies the original method as defined in Baxter & Bullis (1986); (iii) the authors provided a clear description of how the TPA was conducted and how the data were analyzed; (iv): study was published between 1986 – 2020. Exclusion criteria included: i) studies that did not include a detailed description of their procedures and analyses; ii) master’s theses, conference papers, and book chapters.

**Information Sources & Search Strategy**

The literature searches were conducted between May and July 2020 by the first author in consultation with a University of Florida librarian. The following bibliographical databases were searched using the terms “turning point analysis”: Academic Source Premier, Psychology and Behavioral Sciences Collection, APA PsycInfo, and ProQuest Dissertation and Theses Database.
Due to the uniqueness of this review, and the ubiquitous nature of the term “turning points” across scientific fields, performing a traditional literature search was ineffective in finding relevant studies. In order to maximize the possibility for appropriate studies, I also conducted forward tracking of the seminal paper on TPA from Baxter and Bullis (1986) to identify all of the articles that have cited it. I then used forward tracking again, as well as backtracking, on those articles to identify additional studies that use this method. Finally, I conducted Web of Science and Google Scholar searches using “turning point analysis” and “interpersonal,” as the method was developed in interpersonal communication research.

**Study Selection**

Search results were saved using the reference management software Zotero and then uploaded to Covidence, an online software for managing systematic review data. I reviewed the title and abstracts of EAC/YACh paper along with an approved coder based on the inclusion/exclusion criteria, voting “yes,” “no,” or “maybe” on EAC/YACh one. Articles that passed the title/abstract screening process were moved to full-text review, where I and an approved coder independently examined full articles based on the inclusion/exclusion criteria and voted if these should be included in the final review. During both stages of screening, we discussed any discrepancies on the inclusion of studies until a consensus was reached.

**Data Items & Charting**

I developed the data-charting form and completed the extraction in two rounds. After EAC/YACh round, I discussed the extraction items with Dr. Bylund. I extracted context, relationship type, and variables measured by EAC/YACh study, as well as the authors’ data collection procedures and method for analyzing their TPA data. The data-charting form was continuously updated throughout extraction as the results were developed.
**Synthesis of Results**

I grouped studies first based on their use of or modifications to the TPA. I defined TPA adherence as authors’ combined use of the RIT graph and data collection via interviews. I then grouped studies by the type of variable under investigation in EAC/YACh paper: relational, individual, or organizational. I categorized the relationship or experience under study, identified the data use and methods of analysis, and summarized the methodology with a brief description.

**Study 1 Results**

The literature search yielded 2,064 citations, of which 880 were duplicates. Of the 1,184 studies screened for this review, 52 were included. The selection flow chart can be found in Figure 2-2.

**Characteristics of Sources of Evidence**

The study characteristics are outlined in Table 2-1. Seventeen studies included in this review were dissertations, and the remaining 35 were published in peer-reviewed journals. Most studies \( n = 41 \) used the TPA method as outlined by (Baxter & Bullis, 1986), utilizing both the RIT graph (with time on the x axis and the variable of interest on the y axis) and in-depth interviews. These studies are summarized in Table 2-2. The remaining 11 studies used a modified TPA approach, that could include data collection via questionnaires, modifying the RIT graph, or eliminating the RIT graph. These studies are summarized in Table 2-3.

**Relational contexts**

The majority of papers included in this review examined relationships \( n = 40 \), predominately family \( n = 19 \) and romantic relationships \( n = 10 \). Family relationships under study included parent-child, siblings, grandparent-grandchild, blended families, and families with specific experiences, such as families coping through disease and families with LGBTQ parents or children. Studies of romantic couples examined varying stages of the relationship trajectory (e.g.,
on-again, off-again relationships; marriages; post-dissolution or post-divorce relationships) but focused exclusively on heterosexual couples. Common y-axis variables in studies of all relationship types were commitment ($n = 9$), closeness ($n = 6$), and satisfaction ($n = 5$).

**Organizational contexts**

Six studies explored TPs in an individual’s relationship to an organization, specifically in the process of socialization or identification with an organization. Three studies focused on individuals’ relationships to their employer, two studies examined student employees and their academic institutions, and one looked at volunteers’ relationships to their organization.

**Individual contexts**

The final six studies examined change over time in individual experiences, with three exploring TPs in individuals’ healthcare. Two of these explored management of diseases (type 2 diabetes [Ledford et al., 2020] and fibromyalgia [Willett, 2015]). The third study examined patients’ and family medicine physicians’ perceptions of the health-promoting nature of medical acupuncture (Taylor III et al., 2020). The remaining three individual studies looked at new and first-generation immigrant experiences (Ahn, 2012; Erbert et al., 2003; Wang & Nuru, 2017).

**Methods of analysis**

In EAC/YACH of the studies included in this review, the studies’ authors analyzed either the TPs ($n = 28$), the relational trajectories created by the RIT graph ($n = 3$), or both ($n = 21$). For example, Dun (2010) used a qualitative approach to study just the TPs in first-time parents’ relationships to their own parents as they transitioned into new parenthood, but Baxter et al. (1999) examined TPs and developmental trajectories of the first four years of cohabitation in blended families. TPs and trajectories could be explored using a mix of qualitative and quantitative methods of analysis, but most studies used either only qualitative methods of analysis ($n = 26$) or mixed methods ($n = 21$). Few studies used only quantitative approaches to
analyzing TP data \( n = 6 \) (e.g., Johnson et al.’s [2004] comparison of friendship termination trajectories). Several studies examined the TPs through the lens of existing theories, coding schemes, or sensitizing constructs. For instance, four studies examined the importance of existing dialectical contradictions in EAC/YACh TP identified in their studies (Baxter et al., 1999; Erbert et al., 2003, 2005; Pawlowski, 1998).

**Synthesis of Results**

This analysis revealed common methodological decision points authors make when conducting a TPA. These include decisions made before, during, and after the data analysis. These decision points are synthesized in Figure 2-3.

**Study 1 Discussion**

In this systematic scoping review, I identified 52 studies employing TPA to examine change in relational, organizational, and individual contexts over time. These findings highlight the heterogeneity of research questions and methods of analysis employed within the framework of TPA, as well as the dissemination of TPA from interpersonal communication research into a number of different scientific fields.

TPA was developed to study relational development in romantic relationships (Baxter & Bullis, 1986). Although a number of studies in this review still use TPA in this context, this review shows that the range of TPA has been expanded to examine other familial relational contexts, as well individual phenomena and organizational socialization. The myriad of contexts in which TPA can be utilized speaks to the both the value of the method and its usefulness for research across social science fields. There have also been a number of creative deviations from the traditional method of using the RIT graph and in-depth interview that allow TPAs to be tailored to certain contexts and research questions (Anderson, 2016; Bernat, 2003; Pawlowski, 1998). Some of the more recent studies included in this review have applied TPA to study health
and disease-related phenomena (Karmon, 1997; Ledford et al., 2020; Routsong, 2007; Taylor III et al., 2020; Willett, 2015; Wolf, 2009). Because the TPA approach can capture change across a disease or intervention trajectory, TPA may be particularly beneficial in health research.

The methods of analysis used in the studies included in this review varied greatly. There were a number of different methods employed to examine the TP data, the trajectories created by those TPs, and combinations of both. Most common in this review were purely qualitative studies of TPs, without examining the trajectories. But even among the qualitative studies, there was much variance in methods used to categorize the TPs and the level of detail with which these methods were reported, making it difficult to place them into categories for this scoping review. The dearth of methods of analysis and the lack of clarity in reporting could make it difficult for scholars unfamiliar with TPA to incorporate the method into their work. One of the aims of this review was to identify steps for conducting a TPA in order to make it more accessible for researchers in a number of fields.

Based on the findings of this review, I have identified a number of decision points that scholars must navigate when conducting a TPA (Figure 2). The first decision is to develop the research question. Researchers must choose whether to examine a relationship, an individual experience, or organization. If the variable under study is relational or organizational, researchers must then decide from whose perspective the TPA will be conducted. For example, in a study of parent-child relationships, they must decide if the sample will be parents, children, or a combination of both. Similarly, in a TPA of organizational development, researchers must decide if the participants are from one member type (e.g., employees, management) or include members from all ranks of the organization. Once these decisions are made, scholars must then choose the variable to be measured on the y-axis of their RIT graph and set the time parameters for their x-
axis. Next, they must make decisions about data collection and whether to use the traditional in-depth interview or a questionnaire. Decisions should be informed by the type of data needed in line with the focus of study and how the data intends to be analyzed (e.g., TP data from graph only or TP data from graphs analyzed in conjunction with interview data to yield rich details about the turning point experiences). They must then decide their approach to the RIT graph, using either the traditional method or modified version that fits their unique study context. In the analysis stage, scholars must decide whether to examine the turning points themselves, the trajectories created by the turning points, or a combination of both. Finally, they must decide whether to use quantitative, qualitative, or mixed methods of analysis. By synthesizing the decisions points made by previous TPA authors, this review can help future scholars hoping to conduct a TPA in their field of research by providing a possible pathway to utilization. This both expands the applications of TPA and helps authors use a comprehensive, yet feasible method to capture change over time in their own fields.

There are several limitations in this scoping review, the first being that scoping reviews are inherently limited due to their focus on breadth rather than depth. In order to make the search more feasible, I was also unable to include books and book chapters. Though included in the original search, master’s theses were ultimately excluded due to the vast number of studies and the length of the dissertations and theses identified by the search strategy. Finally, I only included studies available in English, and thus, the findings are only generalizable to TPAs published in English.

TPA Utility in Study One

Since its introduction in 1986, TPA has expanded beyond the rEAC/YACh of interpersonal communication and evolved in methodological application, including in data collection method and analytical approach. This review demonstrates that TPA has utility in
multiple fields of social science and can be effective in capturing rich data that illuminates change over time without the expensive, time-consuming restrictions of the gold standard of a longitudinal study design. Given the variation in the methods of analysis and applications of TPA data, future studies should seek to look deeper into these differences and to provide more guidance to scholars new to TPA hoping to incorporate this method into their own work.
Table 2-1. Study Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Sample Size (n)</th>
</tr>
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<tbody>
<tr>
<td><strong>Paper Type</strong></td>
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<tr>
<td>Journal article</td>
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<td>Dissertation</td>
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<tr>
<td>Questionnaire</td>
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<td></td>
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<tr>
<td>Graph + RIT</td>
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</tr>
<tr>
<td>Modifications</td>
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<td><strong>Variable Type</strong></td>
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</tr>
<tr>
<td>Organizational</td>
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<td><strong>Sample size</strong></td>
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</tr>
<tr>
<td>M (min-max)</td>
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<td>Qualitative</td>
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<tr>
<td>Quantitative</td>
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</tr>
<tr>
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<td>Trajectories</td>
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<td>Both</td>
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<td>Population</td>
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</tr>
<tr>
<td>Relational</td>
<td></td>
</tr>
<tr>
<td>Bangerter, 2014</td>
<td>Grandparent-child</td>
</tr>
<tr>
<td>Baxter, 1999</td>
<td>Blended families</td>
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<td>Baxter, 1999</td>
<td>Heterosexual romantic relationships</td>
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<td>Baxter, 2001</td>
<td>Heterosexual romantic relationships</td>
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<td>Population</td>
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<td>Becker, 2009</td>
<td>Long distance + geographically close same-sex friendships</td>
</tr>
<tr>
<td>Bullis, 1989</td>
<td>Graduate student-mentor</td>
</tr>
<tr>
<td>DiVerniero, 2010</td>
<td>Stepfamilies</td>
</tr>
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<td>Dorrance Hall, 2017</td>
<td>Marginalized family members</td>
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<td>Dun, 2010</td>
<td>First-time parents and their parents</td>
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<td>Dun, 2017</td>
<td>First-time parents and their parents</td>
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Table 2-2. Continued

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<th>Author</th>
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<th>Data</th>
<th>Analysis</th>
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<tr>
<td>Durham, 2009</td>
<td>Child-free married couples</td>
<td>n = 32 couples, 64 individuals</td>
<td>Time</td>
<td>commit to being child-free</td>
<td>x</td>
<td>x</td>
<td>Identify trajectories of disclosure during couple's decision-making to stay child-free</td>
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<tr>
<td>Golish, 2000</td>
<td>Parents-adult children</td>
<td>n = 30 adult children</td>
<td>Time</td>
<td>Psychological closeness</td>
<td>x</td>
<td>x</td>
<td>Identify TPs and patterns of change in closeness in parent-adult child relationships and compare TPs in mother-child vs father-child relationships</td>
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<td>Graham, 1997</td>
<td>Post-divorce relationships</td>
<td>n = 35, divorced parents</td>
<td>Time</td>
<td>Commitment</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in and trajectories of post-divorce relationships</td>
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<td>Hollady, 1998</td>
<td>Grandmother-granddaughter</td>
<td>n = 42, granddaughters</td>
<td>Age</td>
<td>Relational closeness</td>
<td>x</td>
<td>x</td>
<td>Identify types of TPs and their impact of relational closeness in granddaughter-grandmother relationships</td>
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<td>Johnson, 2003</td>
<td>Friendships</td>
<td>n = 30, college students</td>
<td>Time</td>
<td>Closeness</td>
<td>x</td>
<td>x</td>
<td>Compare TPs and relationship development trajectories between three levels of friendship: casual, close, and best friend</td>
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<tr>
<td>Johnson, 2004</td>
<td>Terminated friendships</td>
<td>n = 162, college students</td>
<td>Time</td>
<td>Closeness</td>
<td>x</td>
<td>x</td>
<td>Identify trajectories and TPs in terminated friendships and compare differences in EAC/YAC/H by gender</td>
</tr>
<tr>
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<tr>
<td>Johnson, 2009</td>
<td>Long distance + geographically close same-sex friendships</td>
<td>n = 100, college students</td>
<td>Time</td>
<td>Commitment</td>
<td>x</td>
<td>x</td>
<td>Compare TPs and trajectories of commitment in LD and GC young adult friendships</td>
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<td>Karmon, 1997</td>
<td>Families affected by Alzheimer's Disease</td>
<td>n = 38, family members</td>
<td>Time</td>
<td>Commitment, closeness, and satisfaction</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in relationships with someone with AD and determine how TPs are related to closeness, satisfaction, and commitment</td>
</tr>
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<td>Ludema, 2010</td>
<td>Mother-daughter relationships</td>
<td>n = 6, mother-daughter dyads</td>
<td>Time</td>
<td>Relational satisfaction</td>
<td>x</td>
<td>x</td>
<td>Identify TPs and trajectories in the forgiveness process of mothers and daughters</td>
</tr>
<tr>
<td>Marsh, 2019</td>
<td>Parents-children-in-law</td>
<td>n = 36, children-in-law</td>
<td>Time</td>
<td>Relationship quality</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in in-law relationships and how TPs relate to communication privacy management theory and the negotiation of privacy boundaries</td>
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<tr>
<td>Mumm, 2010</td>
<td>Victims of obsessive relational intrusion</td>
<td>n = 42, victims</td>
<td>Time</td>
<td>Troublesome ness</td>
<td>x</td>
<td>x</td>
<td>Determine TPs and trajectories of obsessive relational intrusion and stalking as reported by victims</td>
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<td>Olson, 2002</td>
<td>Aggression in heterosexual romantic relationships</td>
<td>n = 31 individuals who experienced aggression</td>
<td>Time</td>
<td>Severity of aggressive behavior</td>
<td>x</td>
<td>x</td>
<td>Determine what TPs are associated with conflict and aggression in romantic relationships and identify patterns of aggression</td>
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<td>Parcell, 2014</td>
<td>Military marriages</td>
<td>n = 50, wives</td>
<td>Time</td>
<td>Martial satisfaction</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in military marriages before, during, and after deployment and compare to level of marital satisfaction at EAC/YACCh stage, as well as present day</td>
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<td>Parker-Raley, 2009</td>
<td>Romantic relationships</td>
<td>n = 104, college students</td>
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<td>Forgiveness</td>
<td>x</td>
<td>x</td>
<td>Determine trajectories of forgiveness in romantic relationships</td>
</tr>
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<td>Pitts, 2007</td>
<td>Field researchers + participants</td>
<td>n = 16, field researchers</td>
<td>Time</td>
<td>Partnership</td>
<td>x</td>
<td>x</td>
<td>Identify TPs and phases of relationship development in the field researcher-participant relationship</td>
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<td>Ramey, 2010</td>
<td>Parent-adolescent</td>
<td>n = 31, college students</td>
<td>Time</td>
<td>Autonomy</td>
<td>x</td>
<td>x</td>
<td>Examine TP in feelings of autonomy and developmental trajectories in adolescent’s relationship with their parents</td>
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<td>Routsong, 2007</td>
<td>Mothers with lupus + their families</td>
<td>n = 23, family members</td>
<td>Time</td>
<td>Importance to the family</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in the family experience of lupus as it relates to the Double ABCX model of family stress</td>
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<tr>
<td>Wang, 2014</td>
<td>First-generation college student-teAC/YACher</td>
<td>n = 30, FG students</td>
<td>Time</td>
<td>Likelihood to persist in college</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in FG students’ relationships with their teAC/YAChers and their impact on FG students’ likelihood to persist</td>
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<td>Wolf, 2009</td>
<td>Families who have coped through breast cancer</td>
<td>n = 64, family members</td>
<td>Time</td>
<td>Well-being</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in the fluidity of family talk about coping with breast cancer</td>
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<td>Graduate students</td>
<td>n = 28, graduate students entering master’s + doctoral depts</td>
<td>Time</td>
<td>relationship commitment</td>
<td>x</td>
<td>x</td>
<td>Identify TPs that facilitated communication within the family about family identity</td>
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<tr>
<td>Erbert, 2005</td>
<td>Organizational teams</td>
<td>n = 63, organizational team members</td>
<td>Time</td>
<td>Satisfaction with team interaction</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in organizational development and the importance of the 6 contradictions (autonomy-connection, predictability-novelty, openness-closeness, team-individual, dominance-submission, competence-incompetence) to EAC/YAC/point</td>
</tr>
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</table>

Table 2-2. Continued
Table 2.2. Continued

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<tr>
<td>Grant, 2006</td>
<td>Career transitions from private to public sector</td>
<td>n = 29, nurses</td>
<td>Time</td>
<td>Identification with the organization</td>
<td>x</td>
<td>x</td>
<td>Compare TPs in organizational identification between career transitions from the private sector to the public or non-profit sector, and career transitions within the same sector</td>
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<td>Kirk, 1991</td>
<td>Graduate student tEAC/YACHer s</td>
<td>n = 29, graduate student tEAC/YACHer s</td>
<td>Time</td>
<td>Identification with their department</td>
<td>x</td>
<td>x</td>
<td>Identify graduate student tEAC/YACHer's TPs in identification with their department</td>
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<tr>
<td>Sampson, 2003</td>
<td>Volunteers and their organization</td>
<td>n = 35, volunteers</td>
<td>Time</td>
<td>Identification with the organization</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in volunteers process of identification with their organization</td>
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<td>Sline, 1999</td>
<td>Health care staffing</td>
<td>n = 82, current employees ; n = 24, former employees</td>
<td>Time</td>
<td>Commitment</td>
<td>x</td>
<td>x</td>
<td>Identify TPs in employees commitment to organization undergoing turbulent change</td>
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Table 2-2. Continued

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<td>Erbert, 2003</td>
<td>US Immigrants</td>
<td>n = 53, immigrants</td>
<td>Time</td>
<td>Affiliation to US culture</td>
<td>x</td>
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<tr>
<td></td>
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<td>Identify TPs in U.S. immigrants’ socialization to American culture and the importance of the six dialectal contradictions (openness-closeness, predictability-novelty, group-individual, judgement/acceptance, directness-indirectness, independence-obligation) in EAC/YACh TP</td>
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<td>Ledford, 2020</td>
<td>Patients with Type 2 diabetes</td>
<td>n = 33, patients</td>
<td>Time</td>
<td>Health</td>
<td>x</td>
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<tr>
<td></td>
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<td>Identify TPs in patients’ experience with type 2 diabetes</td>
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<tr>
<td>Taylor III, 2020</td>
<td>Family medicine physicians practicing acupuncture + their patients</td>
<td>n = 15, physicians; n = 17, patients</td>
<td>Time</td>
<td>Perception of health promotion</td>
<td>x</td>
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<tr>
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<td></td>
<td>Identify TPs that changed patients and family medicine practitioner’s perception of acupuncture as health-promoting</td>
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<td>Wang, 2017</td>
<td>First-generation college students</td>
<td>n = 17, FG students</td>
<td>Time</td>
<td>Likelihood to persist in college</td>
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<td></td>
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<td></td>
<td></td>
<td>Identify TPs in FG students' communication with their family members during high school and college that impact their likelihood to persist</td>
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<td>Author</td>
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<td>Willet, 2015</td>
<td>Patients with fibromyalgia (FMS)</td>
<td>n = 7, women with FMS</td>
<td>Time</td>
<td>symptom experience, social support, communication</td>
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Table 2-2. Continued
Table 2-3. No RIT.

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<td>n = 27, daughters-in-law</td>
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<td>n = 13, lesbian parents</td>
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<td>on-off again romantic relationships</td>
<td>n = 228, individuals</td>
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<td>n = 640, undergraduates</td>
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<td>Develop a typology of relational TPs between college tEAC/YACHers and students</td>
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<td>Time Commitment</td>
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<td>Interview</td>
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<td>Identify step-children's TPs in the relational development to their cohabitating step families</td>
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<td>Pawlowski, 1998</td>
<td>Interview</td>
<td>Heterosexual married couples</td>
<td>n = 15 couples, 30 individuals</td>
<td>&quot;Photo album&quot; method</td>
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<td>Identify TPs and the importance of the 6 dialectical contradictions (autonomy-connection, predictability-novelty, openness-closedness, inclusion-seclusion, conventionality-uniqueness, revealment-concealment) at EAC/YACH point</td>
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<td>n = 22, 11 parents + 11 LGBT children</td>
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<td>Identify TPs in the parent-LGBTQ child relational process</td>
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<td>Identified turning points for older Korean immigrants and determined their influence on travel styles</td>
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Figure 2-1. Sample RIT from Baxter & Pittman (2001).
Figure 2-2. Prisma chart.
Figure 2-3. TPA decision point diagram.
CHAPTER 3
STUDY 2: EMERGING ADULT CAREGIVERS OF A PARENT DIAGNOSED WITH AN ADVANCED CANCER: A TURNING POINT ANALYSIS OF PROGNOSIS UNCERTAINTY

Review of Emerging Caregivers

Cancer is described as a “disease of the family” given the reciprocal influence patients and families experience across the course of the illness (Sharf & Freimuth, 1993). Cancer coping and caregiving outcomes are tied to how patients and their families communicate (Kuijer et al., 2000; Manne et al., 2006, 2007). Not only is family communication a means of enacting helpful social support critical to disease adjustment (Ell et al., 1992; Helgeson & Cohen, 1999), but when families communicate openly about cancer, patients report better health outcomes (e.g., less fatigue) and patients and family members report better relational well-being (Berry & Pennebaker, 1993; Davison & Pennebaker, 1996; Fisher, 2014). However, research indicates that when parents are diagnosed, it is not uncommon for them to withhold information about cancer from their children, in an effort to buffer them from distress (Fisher et al., 2017; Galvin & Young, 2010). Yet, withholding information may not always be helpful as studies indicate it can make children, including adult children, feel more uncertain or distressed (Barnes et al., 2000; Fisher et al., 2017; Fried et al., 2005; Northouse, 2012). This may be more challenging for emerging and young adult caregivers (aged 18-35) of a parent diagnosed with cancer, particularly advanced cancer. Although emerging and young adult caregivers (referred to as EAC/YACs for simplicity) can be involved in their parents’ care (e.g., providing emotional, instrumental and informational support), EAC/YACs are transitioning from adolescence into adulthood, which may complicate what parents share or don’t share with them (Galvin & Young, 2010). Additionally, patients are known to have more difficulties sharing information during the
accelerated timeline of an advanced cancer diagnosis, which can be exceptionally difficult for family members as the speed of disease progression creates a high possibility of distress (Song et al., 2012; Shilling et al., 2017; Zhang & Siminoff, 2003).

When parents do not share information, EAC/YACs’ may have more uncertainty about their parent’s prognosis. This can have an impact on their individual well-being as well as their ability to cope communally (or jointly) with their parents, which is linked with healthier adjustment or disease coping (Magsamen-Conrad et al., 2015). Communal coping, also referred to as dyadic or collaborative coping (Staff et al., 2017), is a method of coping in close relationships where individuals frame their coping as an interpersonal process. In the combining of their coping resources, patients and their coping partners can be more successful at navigating stressors (Berg & Upchurch, 2007; Didymus, 2017; Donato et al., 2012). Communal coping has been linked to improved mental health (Bodenmann et al., 2008, 2011; Regan et al., 2014; Rottmann et al., 2015), physical health (Johnson et al., 2013; Korner et al., 2012; Meuwly et al., 2012; Rohrbaugh et al., 2008), and quality of life (Badr et al., 2010; Heinrichs et al., 2012; Kayser et al., 2014; Meier et al., 2011) for patients and their coping partners. Information sharing about the illness is linked to families’ ability to engage in communal coping (Lyons et al., 1998). Magsamen-Conrad et al. (2015) showed a lack of information sharing can increase caregivers’ uncertainty about the patient’s prognosis, which can in turn inhibit communal coping. Although information withholding (or a lack of sharing) may be motivated by a desire to protect loved ones, particularly the children of diagnosed parents, this communication pattern may do the opposite by inhibiting coping or creating distress for both parties (Fisher et al., 2017; Greene, 2009; Miller, 2014; Venetis et al., 2015; Zhang & Siminoff, 2003).
EAC/YACs are one of the most understudied caregiving groups and, yet, they undergo significant caregiving-related distress, which can be exacerbated by the parents’ decision not to share information (Bolas et al., 2007; Fisher et al., 2017; Fruhauf & Orel, 2008; Goldblatt et al., 2018; Granek, 2014; Pope et al., 2018). As EAC/YACs are already prone to withdraw from their diagnosed parents as a coping strategy, there is a need for research and interventions that lead EAC/YACs toward healthy coping practices (Fisher, 2010). The goal of the present study is to explore what turning points impact EAC/YACs’ prognosis uncertainty, as it can be an inhibitor to coping, with a specific focus on communication turning points related to information sharing (or lack thereof) from their parents. These findings could inform the development of future targeted interventions that attend to EAC/YACs’ unique needs.

EA Cancer Caregivers’ Unique Experiences

Arnett (2000) has argued that emerging adulthood is a developmental stage between adolescence and adulthood where individuals experience the freedom of adulthood without the accompanying responsibilities (e.g., marriage, children, career). Caregiving during emerging adulthood is a non-normative experience, and its demands can run in contrast to the typical developmental goals of individuals in this age group (Arnett, 2015; Erikson, 1980). A growing number of EAs are serving as caregivers for their parents or grandparents, and this cohort is only expected to increase in response to medical advancements that prolong life and increase the elderly population (Goldblatt et al., 2018; Pope et al., 2018).

The limited research on EAC/YACs shows that they suffer from greater mental health distress than both older caregivers and similarly aged non-caregivers (Bernard & Guarnaccia, 2003; Gillen & Roland, 2011; Greene et al., 2017; Pakenham et al., 2006). Caregiving during emerging adulthood can also leave a permanent mark on the life course, as the caregiving role
can come at the expense of career advancement, higher education, and romantic relationships (Bolas et al., 2007; Fruhauf & Orel, 2008; Goldblatt et al., 2018; Granek, 2014; Pope et al., 2018). As a result, EAC/YACs can feel isolated from their peers who seem to have left them behind (Goldblatt et al., 2018; Granek, 2014).

One reason for the fundamental differences in caregiving between spousal and EAC/YACs is the flow of information. In families where one parent is diagnosed with cancer, both parents control how much is shared about the illness with rest of the family (Galvin & Young, 2010). Some parents may talk openly about the cancer, while others may restrict knowledge to certain dyads or generational subgroups within the family. Age plays a significant role in who is privy to illness information and who is left in the dark (Boddington & Gregory, 2008; Gregory et al., 2007, 2010). As communication is essential to communal coping, the interaction between age and parental disclosure decisions greatly impact the ability of EAC/YACs to cope through their caregiving experience.

The important role of one’s age or developmental stage on coping has been explored in a number of lifespan focused theories and models (e.g., Carstensen et al., 1999; Fisher & Nussbaum, 2015; Pecchioni et al., 2005; Rolland, 2005), one of which is the Developmental-Contextual Model (DCM), which is particularly useful in exploring EAC/YACs’ experiences in the context of advanced cancer. The DCM further supports the notion that EAC/YACs’ experiences are unique and elucidates how key variables such as the developmental phase of life, information sharing, and prognosis uncertainty are all fundamental to understanding the ability of EAC/YACs and their families to communally cope (Berg & Upchurch, 2007; Magsamen-Conrad et al., 2015).
DCM, Cancer, and Communal Coping

The DCM highlights the influence of context on a communal coping system in illness (Berg & Upchurch, 2007). Research informed by the model is heavily focused on couples’ coping experiences and illustrates how three main components impact coping experiences: 1) contextual factors (e.g., gender, culture, age), 2) dyadic appraisal (e.g., how the illness is appraised), and 3) dyadic coping (e.g., communal coping) (Berg et al., 1998; Revenson, 1990, 2003). Thus, context (such as one’s developmental phase in life) affects illness appraisals (e.g., prognosis uncertainty) which in turn will have an impact on couples’ ability to communally cope (Magsamen-Conrad et al., 2015). The DCM is an ideal lens to emphasize the unique context of EA caregiving and highlight the need to focus on two specific variables: 1) the influence of time (e.g., developmental phase in life and cancer trajectory) and 2) prognosis uncertainty.

Research informed by the DCM has shown that time is a predictor of coping experiences. As noted, one particular aspect of time is an individual’s developmental phase of life. Although this model has not yet been applied to the study of EAC/YACs, research on caregiving during this phase of life shows that EAC/YACs have unique coping experiences (Bolas et al., 2007; Fisher, 2010; Fruhauf & Orel, 2008; Goldblatt et al., 2018; Granek, 2014; Pope et al., 2018). In addition, time plays a role in the cancer trajectory. Patients’ and caregivers’ emotional and physical needs vary dramatically across the cancer trajectory, and couples may be required to use different coping strategies to manage the demands of different stages of the cancer continuum (e.g., diagnosis, treatment, end-of-life care) (Gallant, 2003; Maliski et al., 2002). As such, a longitudinal focus on cancer coping is warranted.

Furthermore, an examination of temporality in disease coping highlights the role of disease type in the coping experience. An aggressive illness with a sudden onset and short
trajectory from diagnosis to death, such as metastatic cancer, requires different coping strategies than a long-term chronic illness (Berg & Upchurch, 2007). Advanced cancer also requires patients and caregivers to rapidly adjust to the illness experience, making their need to develop healthy coping strategies even more critical (Shilling et al., 2017). Additionally, patients diagnosed with advanced stage cancer may experience shock and anger that makes family communication difficult (Zhang & Siminoff, 2003). A longitudinal study of men with prostate cancer found that those with advanced cancer had less open communication with their partners than men in earlier disease stages (Song et al., 2012). However, we don’t know if this experience will be the same for EAC/YACs of parents with aggressive cancers and a short trajectory from diagnosis to death. This group is unique and warrants special consideration.

**Uncertainty and Information Sharing During Cancer Coping**

Uncertainty is an unavoidable part of the cancer experience for patients and caregivers (Zhang, 2017). EAC/YAC new illness event (e.g., new symptoms, healthcare settings, treatments, tests or scans) impacts the uncertainty that patient and caregivers must manage in order to cope with the stress of the illness (Mishel, 1988, 1990). Although uncertainty has been linked to negative physical and psycho-social outcomes, maintaining uncertainty can also be a vital part of disease coping (Germino et al., 2012; Hsu et al., 2003; Kazer et al., 2011; Kim et al., 2012; Mishel et al., 2005, 2009). Brashers’ (2001, 2007) Uncertainty Management Theory asserts that individuals can appraise their illness uncertainty as positive or negative, and this appraisal will determine what actions they take to manage it. If uncertainty is perceived as a threat, individuals may seek more information to reduce it. If uncertainty is perceived as comforting, they may avoid information to increase or maintain uncertainty, and thus, protect
themselves from distressing truths. For some, avoiding information may even be necessary to preserve hope (Zhang, 2017).

In the Health Disclosure Decision-Making Model, Greene (2009) proposed that a patient’s uncertainty specifically related to their prognosis is a key determinant of what health information they are willing to share with others. Checton and Greene (2012) extended the model, exploring how different types of uncertainty (e.g., uncertainty about the patient’s symptoms vs uncertainty about the patient’s prognosis) affected the information patients with chronic health conditions were willing to share with their coping partners. The authors’ differentiated symptom and prognosis uncertainty in that symptoms can be visible and the uncertainty related to them is immediate (e.g., “Do I make a doctor’s appointment or go to the ER?”), while prognosis uncertainty can be immediate (e.g., “Will I survive the weekend?”) as well as future-oriented (e.g., “Will I live long enough to see my child grow up?”). Checton et al., (2012) found that caregivers of patients with chronic health conditions felt the illness had more impact on their life when they had greater prognosis uncertainty, which also led to decreased confidence in their ability to discuss the illness with the patient. Magsamen-Conrad et al. (2015) examined prognosis uncertainty in the cancer setting, exploring its impact on communication and dyadic (or communal) coping in cancer patients and their spousal caregivers. They found that prognosis uncertainty inhibited patients’ and caregivers’ communication efficacy and ultimately, their ability to cope together and effectively manage the cancer.

Communication is key to managing uncertainty during the illness experience (Brashers, 2001). Communication between patients and caregivers can alleviate uncertainty and improve quality of life during cancer (Song et al., 2011, 2012). However, patients often withhold information from their family members in order to protect themselves and their loved ones from
distress. (Barnes et al., 2000; Checton & Greene, 2012; Fisher & Wolf, 2015; Greene, 2009; Song et al., 2012; Zhang & Siminoff, 2003). Patients can dictate the flow of information for caregivers, and they can choose to what to share and what withhold at any time, which can create uncertainty for caregivers. (Greene, 2009; Rees & Bath, 2000). Caregivers typically follow the patient’s communicative lead and will not ask direct questions or bring up certain topics for discussion if the individual has shut down the conversation in the past (Zhang & Siminoff, 2003). This may be particularly challenging in more aggressive cancer experiences. For instance, in a study of 26 families affected by late-stage lung cancer, two-thirds reported difficulties in communicating about cancer within the family (Zhang & Siminoff, 2003). In addition, research shows that EAC/YACs in particular respond to uncertainty by withdrawing from the parent, a maladaptive coping pattern that can also be perceived as unsupportive (Fisher, 2010).

Parents can also withhold information from family members, including EAC/YACs, in an effort to buffer them but, unintentionally, may emotionally isolate them from their cancer experience or inhibit communal coping (Fisher et al., 2017; Fisher & Wolf, 2015; Wolf, 2009). In both of these contexts, the lack of parental disclosure and communicative support contributes to both parents and their loved ones struggling to cope individually as well as communally or jointly. Thus, information sharing (or withholding) may inhibit EAC/YACs’ individual and communal coping with the disease, which could impact the physical and psychological health outcomes for both parties (Bodenmann et al., 2008, 2011; M. D. Johnson et al., 2013; Korner et al., 2012; Meuwly et al., 2012; Regan et al., 2014; Rohrbaugh et al., 2008; Rottmann et al., 2015).
**Research Inquiries**

By employing a pattern of information withholding, patients can inhibit their ability to cope communally with their partners and can actually facilitate more distress by creating uncertainty about their condition and prognosis (Fisher et al., 2017; Greene, 2009; Miller, 2014; Venetis et al., 2015; Zhang & Siminoff, 2003). Because research shows that parents are often unwilling to share information about their illness with EA children, EAC/YACs likely experience significant prognosis uncertainty during their caregiving experience (Fisher et al., 2017; Galvin & Young, 2010). To date, little is known about EAC/YACs’ coping and caregiving experiences after a parent has been diagnosed with an advanced cancer. Understanding what impacts their prognosis uncertainty across the disease trajectory (and the role of information sharing) is critical to better serve their needs in facilitating healthy coping and adjustment.

To capture EAC/YACs’ experiences across the disease trajectory, it is important to capture change across time. Turning points are transitions that incite change in a relationship and are experienced communicatively (Baxter & Bullis, 1986; Pitts & Miller-Day, 2007). Turning point analysis (TPA) is a method of inquiry that allows researchers to capture these events and the context in which they were experienced. TPA is an approach that has been critical to better understanding how relationships change over time (Baxter & Bullis, 1986). In this study, I employed TPA to capture a key variable (prognosis uncertainty), which allowed me to understand what communication events influence EAC/YACs’ prognosis uncertainty during their caregiving experience. To this end, I propose the following research question:

**RQ1: What turning points influence EAC/YACs’ uncertainty about their parent’s prognosis?**

In addition, given the aforementioned research, parent’s information sharing (or withholding) will likely play a role in EAC/YACs’ prognosis uncertainty. While I planned to
explore this in RQ1 (e.g., if information sharing or withholding emerge as a turning point that impacts prognosis uncertainty), I also wanted to provide a more in-depth analysis of information sharing/withholding so I posited the following inquiry:

RQ2: What familial information sharing/withholding turning points influence EAC/YACs’ uncertainty about their parent’s prognosis?

Study 2 Methods

Sampling & Recruitment

Inclusion criteria for participants included (1) aged 18-35; (2) lost a parent due to cancer no longer than five years ago; and (3) parent’s disease trajectory from diagnosis to death was less than 12 months. Purposive sampling was used to recruit EAC/YAC using two strategies. First, I sent recruitment messages via ResearchMatch, a U.S. national health registry that has a large population of volunteers who have agreed to be contacted by researchers about health studies. Messages were sent via email to over 50,000 randomly selected volunteers between the ages of 18 and 35 over the course of the three months. Potential volunteers were sent a link to an online screening survey hosted by REDcap to determine their eligibility (Appendix A). Participants who met the requirements had the option to submit their contact information to schedule an interview. Second, I recruited via the online social media site Reddit, posting an advertisement for the study in cancer, caregiving, and grief support groups. The contact message and list of groups can be found in Appendix B. The message included a link to a website for the study hosted by UF Studies and a link to the screening survey described above. Eligible participants were contacted by phone or email to schedule a phone or Zoom interview. They received $35 as compensation for their participation. The University of Florida Institutional Review Board approved this study.
Procedures

The Retrospective Interview Technique (RIT), the technique widely used with TPAs (Baxter & Bullis, 1986; Fitzgerald & Surra, 1981), was used to conduct in-depth, semi-structured interview with EAC/YACs. RIT is an interview method used in TPA in which participants retrospectively report their experiences by plotting turning points on a graph (Appendix C) marking events that triggered a change in the designated variable. Upon IRB approval, participants were sent a link to a survey to be completed before the interview where written consent was obtained. Participants completed two RIT graphs, both with time from the parents’ diagnosis to their death on the x-axis. Before the interview, participants completed a RIT graph measuring their communication quality with their sick parent, with “high communication quality” to “low communication quality” on the y-axis. Participants completed a second RIT graph during the interview with prognosis uncertainty on the y-axis (“high prognosis uncertainty” to “low prognosis uncertainty”). Given the complex nature of prognosis uncertainty, adding an additional RIT graph measuring communication quality to be completed before the interview gave participants the opportunity to reflect on their experience and ensure the validity of their prognosis uncertainty graph. Participants completed their graphs via MarkUp, an online editing tool. Once an interview was scheduled, I sent participants a personalized MarkUp link to an empty RIT graph measuring communication quality and a list of instructions (Appendix D).

Using participants’ RIT graphs as a guide, I conducted semi-structured interviews to capture the communicative context of EAC/YAC turning point. Once they had explained all the points, I sent participants another personalized MarkUp link to an empty RIT graph, this time measuring prognosis uncertainty. After giving them time and privacy to fill out the graph, I asked participants to explain EAC/YAC of the points on this graph. I asked probing questions
related to their management of prognosis uncertainty (e.g., “Where did you go to get more information about your parent’s prognosis?” “How did you cope in the times when your uncertainty was high?”). Upon completion of the interviews, participants were debriefed and provided cancer specific grief and bereavement resources in case the interview caused any mental distress. Interviews ranged from 40 – 113 minutes.

Analysis

The interviews were audio recorded and transcribed using a professional transcription service. Transcripts were managed using Atlas TI software. Data from both the interview transcripts and the RIT graphs measuring prognosis uncertainty were included in this analysis. I first immersed myself in the data by listening to the interview audio recordings and reviewing the transcripts, keeping operational and thematic memos (Lincoln & Guba, 1985). As I identified patterns, I developed a codebook that was used throughout the analysis. I followed the procedures for thematic analysis in my data analysis using the constant comparative method, as outlined by Glaser and Strauss (1967), and steps described by Strauss and Corbin (1998). I first open coded data, identifying concepts in the text and assigning them labels (i.e., codes). As data became more saturated, I collapsed codes into categories based on the criteria for Owen’s (1984) thematic salience (repetition, reoccurrence, and forcefulness). Once categories were saturated, I axial coded data associated with EAC/YACh theme to determine properties of EAC/YACh category and identify relationships among themes. Multiple verification strategies were used across the study design to ensure rigor including :1) setting specific eligibility criteria for participation that ensures participants will be knowledgeable of the experience under study (Morse, 1991); 2) keeping memos throughout the process of data collection and analysis to ensure a rich description of themes when presenting the results (Lincoln & Guba, 1985); and 3)
using *in vivo* labels when possible, meaning they were taken directly from participants’ words, to ensure the trustworthiness of the findings (Burnard, 1991; Castleberry & Nolen, 2018). Participant names and other identifying information were removed from the transcripts prior to analysis. In the presentation of the findings, the quotes are attributed via the participants’ age and relationship to the patient.

**Study 2 Results**

The sample consisted of 33 EAC/YACs, whose age at their parent’s diagnosis ranged from 19 to 34 (M(SD) = 26.39(4.18)). The sample was predominately white (72.72%) and female (57.58%). The sample included caregivers of patients with a number of different cancers, with the highest frequencies being pancreatic cancer (21.21%), lung cancer (18.18%), and brain cancer (15.15%). Table 3-1 lists the full demographic information of the sample. One participant was later removed from this analysis, as they were not aware of their parent’s diagnosis until after they had died and the time parameters of this study are from date of diagnosis to death.

EAC/YACs described five types of turning points: 1) *medical events*, 2) *online research*, 3) *observable condition changes*, 4) *clinician communication*, and 5) *parent/family communication*. Thematic properties of EAC/YAC theme are discussed below. Further detail can be found in Table 3-1. Turning points were interrelated and occurred in all categories throughout the disease trajectory.

**RQ1: Turning Points**

EAC/YACs described turning points related to medical events that typically signified disease progression or their parent’s declining health. These turning points both increased and decreased prognosis uncertainty. They described four types of medical events as turning points:
1) starting treatment, 2) being admitted to the hospital, 3) encountering severe health changes, and 4) joining hospice care.

First, some EAC/YACs shared how when their parent starting treatment impacted how certain or uncertain they were regarding their parent’s prognosis. For EAC/YACs who believed their parent would not survive after receiving their diagnosis, starting treatment (or even learning that treatment options were available) increased prognosis uncertainty, as it lessened their certainty that the cancer was terminal. For example, this participant described: “[Her father’s physician] started giving more information on treatments, and then that’s when my certainty started declining. And I started becoming more uncertain about his prognosis, more doubtful that it was going to be such an immediate death” (Daughter, 25). Other EAC/YACs experienced increased prognosis uncertainty as their parent started treatment because they were unsure how their treatments would affect their parent, as this participant explained:

When he was starting to get treatment, there were some uncertainty about whether he was going to stick with it, how it was going to go. … A lot of uncertainty about whether it was going to work. “Is it going to help? Is it going to make him really sick?” (Daughter, 33)

Second, EAC/YACs explained how their parent being admitted to the hospital affected their prognosis uncertainty in that it revealed to them the seriousness of their parent’s cancer. For example, EAC/YACs who lived away from their parents recalled rushing home when their parent was hospitalized, believing this meant they may not have much time left to live. As this participant reported, “I was going to the hospital knowing that he was going to die” (Son, 27). Another participant echoed this sentiment: “I would put her last trip to [hospital] as solidifying my fears and illustrating to me that her end was near” (Son, 23). For others, the hospital visit increased their prognosis uncertainty, making them unsure what would happen while they were there or if they would ever come home. This participant described how his father’s hospital visit
led to high prognosis uncertainty: “The hospitalization resulted in the development of other symptoms. At the time, we were uncertain of how the outcome would be” (Son, 31).

Third, similar to hospital admissions, when parents were encountering severe health changes, EAC/YACs’ prognosis uncertainty was impacted. They described these turning points as indications of the severity of their parent’s cancer and included serious complications, serious treatment side effects, and effects resulting from the cancer or its spread. For instance, a participant described how a complication resulting from her father’s treatment decreased her prognosis uncertainty: “The writing was kind of on the wall because he developed heart failure. … So, it was just becoming more apparent that they’re not going to be able to keep him on treatment that much longer” (Daughter, 28). Others experienced increased prognosis uncertainty, worrying it may be the complications that caused their parent’s death and not their cancer, as this participant recalled:

She was in the hospital a couple of times to drain some fluid from around her lungs, because it would get so bad that she couldn’t breathe, and I was always worried that something would happen to her during those visits. (Daughter, 28)

Finally, parents joining hospice care impacted EAC/YACs’ uncertainty toward the end of their parent’s disease trajectory. EAC/YACs indicated that when their parent entered hospice, it signified to them that no more treatment options were available and, thus, their parent would not survive the cancer. As this participant shared, some EAC/YACs’ prognosis uncertainty ultimately decreased: “[Starting hospice] really reinforced to me that he was definitely going to die. No uncertainty about that” (Daughter, 33). However, other EAC/YACs reported that starting hospice was a turning point that increased in their prognosis uncertainty as they knew their parent would die, but they did not know when. EAC/YACs were at times uncertain if they would
have days, weeks, or months left to spend with their parent, and this uncertainty created additional stress, as this participant explained:

Every day they were like, “Okay, maybe not today.” But it was like that for two weeks, and so no one wanted to leave. No one wanted to leave to seek out resources because you wanted to just be there in case it happened. (Daughter, 28)

**Observable condition changes**

EAC/YACs described turning points related to observable condition changes that affected their prognosis uncertainty. These changes indicated either the seriousness of their parent’s cancer or the likelihood that they may improve. Condition changes and medical events intersected, as serious complications or hospital admissions were at times tied to changes in the parent’s condition. EAC/YACs described as turning points three types of observable changes in their parent’s state: 1) *condition declines*, 2) *condition improves*, or 3) *condition is unstable*.

First, EAC/YACs reported *condition declines* in their parent’s state as impacting their perception of their prognosis. These included extreme physical declines (e.g., in severe pain, unable able to care for themselves, loss of cognitive function) as well as more subtle changes (e.g., spending most of the day asleep, having difficulty remembering or speaking). Some reported that they knew their parent was getting sicker because they no longer looked like themselves as they lost hair or weight and became “skin and bone” (Daughter, 30). EAC/YACs varied in how these declines impacted their prognosis uncertainty. When EAC/YACs had the mindset that their parent was going to die, their condition declining confirmed their beliefs. Other EAC/YACs’ experienced increased prognosis uncertainty when their parent’s condition declined, as this contradicted their belief that their parent would survive. This participant described: “I always thought he was going to be fine … [His decline] was like another gut punch … like, ‘Oh, he's not invincible. He's not Superman’” (Daughter, 19).
Second, EAC/YACs reported that when their parent’s *condition improved*, their prognosis uncertainty was altered. Again, the directional impact was determined by their mindset after their parent was diagnosed. If they assumed their parent would survive their cancer, seeing their condition improve decreased their prognosis uncertainty, as this participant explained: “He was eating again, and he was reading. … That to me was like, ‘Okay cool, we're on the mend.’ … I'm going to live my life. By the time I come back, he will be better” (Daughter, 26). In contrast, when EAC/YACs believed their parent was going to die, seeing them respond to treatment increased their prognosis uncertainty. This participant, who knew her mother’s cancer was terminal, explained how she felt seeing her mom’s condition improve:

> I got a little bit of a confidence booster after my mom had five chemotherapy treatments … She was at my niece's birthday party, and she was running up and down ramps and water slides … If you didn't know at that point that she had cancer, you wouldn't be able to tell. … That was the highest point [in my uncertainty]. (Daughter, 27)

Finally, at times EAC/YACs reported that their parent’s *condition was unstable*, seemingly improving one day and being severely ill the next. These frequent changes were described as a “rollercoaster” (Son, 22), as they experienced “up and downs” (Daughter, 23) that made it difficult for EAC/YACs to know what their parents’ prognosis would be. EAC/YACs only reported increases in their prognosis uncertainty as a result of this instability. For instance, this participant recalled how the confusion these changes created increased her prognosis uncertainty:

> There were some days where we had no clue what was going on, and then other days where he was coming out of it. And he was chatting and laughing, and things were great. … The prognosis was super uncertain. We had really no clue what was going to happen, because EAC/YACs day was so different. (Daughter, 24)
Online research

EAC/YACs identified three types of turning points associated with their online information seeking: 1) survival rates; 2) finding the disease was “one of the worst most aggressive cancers you could have”; 3) reading survivor stories; and 4) seeing a discrepancy between online information and information clinicians provided.

First, searching for the survival rates of their parent’s cancer greatly affected prognosis uncertainty. If they were unable to learn their parent’s prognosis directly from their parents or their parent’s clinicians, reading the statistics on survival online is at times where EAC/YACs learned their parent’s cancer was terminal. This participant described how reading the survival rate online affected him: “I started having more confidence, more belief that she wouldn't make it when I started reading more on the literature of the survival rate for the type of cancer at her stage” (Son, 23). Searching for the survival rate early on in their parents’ illness could affect EAC/YACs’ prognosis uncertainty for the rest of the disease trajectory. This participant explained how knowing the statistics of her mother’s cancer from the moment she was diagnosed affected her prognosis uncertainty:

I knew that there wasn't much chance because I had done all of my preliminary research … I knew that there is a 5% survival rate, I knew that from day of diagnosis to death was approximately six months. I knew all of this going in. (Daughter, 27)

Second, some EAC/YACs identified as a turning point online searches early in their parent’s disease trajectory that made them realize their parent had “one of the worst, most aggressive cancers you can have” (Daughter, 34). This was reported by EAC/YACs of parents with particularly aggressive cancers, like late-stage pancreatic, brain, or lung cancer. For them, a cursory Google of their parent’s cancer type was met with grim statistics about the likelihood of their survival. One participant recounted his family’s experience searching online immediately
after receiving his mom’s diagnosis of glioblastoma grade IV: “We all went home and got on a computer and started typing it in. … Pretty much the first hit on Google is ‘not curable’” (Son, 33). EAC/YACs reported that knowing the seriousness of the cancer at the time or immediately after their parent was diagnosed affected their prognosis uncertainty for the remainder of their illness. This participant explained: “As soon as they said there was a lesion on the pancreas, I was like, ‘Oh shit, this is not good. This is definitely pancreatic cancer.’ … I was already grieving my dad when we got the diagnosis” (Daughter, 25).

Some EAC/YACs sought out online support groups or survivor stories of people with the same cancer their parent had in order to give them hope that their parent might pull through. Reading survivor stories especially helped EAC/YACs of parents with the aggressive cancers discussed in the discussed above, who had low prognosis uncertainty at the outset of their parent’s disease. Learning that there were survivors increased their prognosis uncertainty, as it made them less confident their parent would not survive. This participant described:

I would just look up like pancreatic cancer and miracle stories. … I remember spending a lot of the time looking at videos of people who survived pancreatic cancer and thinking, “Okay, maybe that could be us. Maybe my mom could beat it.” (Daughter, 30)

Other EAC/YACs reported seeking out survivor stories as way to cope with their high prognosis uncertainty. Some felt these stories helped them stay positive about their parent’s survival even when the other information they found online told them otherwise, as this participant explained:

It was really uncertain on what way it would go. I was very hopeful and thinking, "This isn't going to happen to me or him." … I remember going through Facebook groups of people with esophageal cancer and hearing those stories where they had stage four and they recovered and it's fine. So, I stayed hopeful. (Daughter, 22)
EAC/YACs reported changes in their prognosis uncertainty when the information found created *discrepancies between online research and clinician communication*. Typically, EAC/YACs would receive information from their parent’s clinician and then read something online that contradicted what they were told. In one case, an EAC/YAC received information from their parent’s care team that conflicted with what they read online. No matter the order the information was received in, the discrepancies resulted in an increase in prognosis uncertainty as EAC/YACs were not sure which source of information was true. This participant explained:

> The oncologist at the [De-identified] said three to eight months. … All this stuff online and these other centers were saying, or seem to be saying from the articles, that they really conflicted with what the doctors were saying. And [that] got us really confused, making us feel like there was a chance for even full recovery. (Daughter, 25)

### Clinician communication

EAC/YACs reported three types of turning points resulting from direct or indirect communication with their parent’s healthcare clinicians: 1) *learning their parent’s cancer stage or type*, 2) *clinicians recommended to stop or not to start treatment*, and 3) *clinician gave EAC/YAC hope*.

First, some EAC/YACs reported as turning points the moment their parent’s *clinician informed them of their parent’s cancer type, stage, or extent of spread*. EAC/YACs would learn from their parents’ clinicians that their cancer was late stage or a particularly aggressive cancer type, which was not the news they had hoped for. This affected their prognosis uncertainty as it impacted their perception of how severe the cancer was. One participant described how it felt to learn her father had an aggressive brain cancer and the impact it had on her prognosis uncertainty:

> I think about it like you're going on a road, and there's all these other roads that branch off … At first you're like, “Oh, maybe it's not cancer,” or “Maybe it was there for a really long time. There's a really slow growing cancer.” … We got to
the point where there were no real other exit options. There were no other things this could be. The only things that you could do to prolong life were the radiation and chemotherapy. (Daughter, 34)

For some EAC/YACs, this was also the moment they learned the cancer was terminal and their parent only had a few months or years left. For EAC/YACs who already thought their parent would not survive, learning this news from their clinician confirmed their beliefs and decreased their prognosis uncertainty. This participant explained:

[Her clinicians] basically told us, “We don’t know if it’s one year or five years, but this is terminal.” The diagnosis was sort of a formality. It was pinpointing more of that one- to two-year range, but I think I’ve already started thinking about the broader, “She won't be at weddings. She won't see grandkids.” (Son, 22)

Others reported an increase in prognosis uncertainty, as they felt unsure of what would happen in their parent’s specific case, as this participant recalled: “They told us 12 to 18 months, and we were like, ‘Well, who knows?’ … We knew Mom was a really strong person, and we just thought, ‘Well, maybe she's going to be in the 2%’” (Son, 33).

Second, EAC/YACs identified as turning points moments where their parent’s clinician told them to stop or not to start cancer treatment. This had an impact on prognosis uncertainty. Some EAC/YACs were frustrated that throughout their parent’s illness their clinicians would not give them a prognosis. In finally sharing that they should stop treatment, clinicians gave EAC/YACs the certainty they were looking for, and this turning point ultimately decreased prognosis uncertainty. This participant recalled:

We were trying to maintain that positivity that there could be another option for him. And they were trying to keep our minds open, staying positive that he would get into trial. … That's when they basically put him into hospice, essentially, by saying his heart wasn't strong enough. So, I think that was the beginning of the realization that we didn't have a lot of time. (Daughter, 28)
For those whose parent’s clinicians recommended not starting treatment at all, this turning point informed their perception of their parent’s prognosis for the rest of the illness. This participant described how that conversation impacted her prognosis uncertainty:

[Parent’s clinician] didn't feel like there was any point in my dad getting chemo. He thought that he'd have a better quality of life if he didn't even bother … It was like, "Oh, no, they do really think he's going to die." So, the prognosis uncertainly would have dropped all the way back down below to 40%. (Daughter, 25)

Finally, EAC/YACs identified as turning points in their prognosis uncertainty moments where their parent’s clinician gave them hope that their parent would recover. This could be their clinician simply talking about available treatments or it could be clinicians speaking optimistically or sharing that they thought their parent had a chance to survive. For EAC/YACs who believed their parent would survive their cancer, the clinician giving them hope decreased their prognosis uncertainty. This participant described:

I got the reassurance from doctors that things were going to be okay. So, I didn't feel stressed or uncertain about what was going to happen. There was obviously a little bit of uncertainty, because that comes with every cancer diagnosis, but it was fairly low I think, because we were given reassuring words. (Daughter, 30)

For EAC/YACs who felt confident their parent would not survive and had typically low prognosis uncertainty beginning at diagnosis, feeling hope resulting from conversations with their parent’s clinicians reportedly increased prognosis uncertainty. This participant explained:

Me and my sister were there for a doctor … admitting that statistically, it wasn't too likely, but [my father] definitely still had a chance to beat it. And he could heal up, recover. And so that threw me into – I had no idea like, maybe he was going to recover and be fine? … So, that would have been the highest uncertainty. (Daughter, 24)

**RQ2: Familial Information Sharing Turning Points**

Familial information sharing did emerge naturally as a turning point in EAC/YACs’ reports. They shared instances in which communication (or lack thereof) from both parents as
well as with other family members impacted their prognosis uncertainty. EAC/YACs described four types of familial information sharing turning points: 1) *parents speaking positively about the diagnosed parent’s condition*, 2) *parents and other family members discussing the possibility of the parent’s death*, 3) *belief or realization that parents were withholding information*, and 4) *family struggles to relay information from clinicians*.

First, EAC/YACs reported that *parents speaking positively about the diagnosed parent’s condition* both increased and decreased prognosis uncertainty, even if the intended effect in both situations was to make the EAC/YAC more hopeful about their parent’s prognosis. The directional impact on prognosis uncertainty was informed by what they believed would happen at the beginning of disease trajectory. If they knew their parent’s cancer was terminal, seeing their parent or parents speak positively increased prognosis uncertainty. For example, one participant described how his mother making plans for the future increased his prognosis uncertainty, as she was given a 12- to 18-month life expectancy by her clinicians:

> She was planning a vacation. … She had things on a list. She's like, "I'm just going to do these things, and I'll get better." She was optimistic, and we were. We weren't thinking, “Okay, well, 12 - 18 months?” Maybe, but not right now. Doesn't seem like it at this point. (Son, 33)

When EAC/YACs felt their parent would survive, hearing positivity about the prognosis from their parents could decrease prognosis uncertainty. This participant described how she felt when her father would tell her that her mother was going to get better despite being very ill:

> I believed him. I felt like she really was going to get better. Up until she passed away, I thought she was going to get better. Or I was hoping because I felt that if I didn't think that she would get better than it was just no hope from there. (Daughter, 26)

Second, in the inverse of the previous property, EAC/YACs reported changes in their prognosis uncertainty when encountering *parents and other family members discussing the*
possibility of the parent’s death. These conversations indicated that their parent knew they would not survive, which decreased prognosis uncertainty. One participant described what this conversation was like for her family regarding her father’s cancer and the impact it had on all members’ prognosis uncertainty:

[My sister] was saying that he had weeks or months left at most. … If there was a turning point where any of us stopped having any optimism that he might pull through, then that probably would have been it for anyone who had any doubts left. (Daughter, 21)

In addition, seeing their parents or other family members show emotion about their parent’s possible death, particularly if they had only spoken optimistically about their condition in the past, also impacted EAC/YACs’ uncertainty. At times, this provided evidence that even their parent no longer believed they would survive and typically decreased EAC/YACs’ prognosis uncertainty, as this participant described:

She just started like to cry. … She would just turn away from me and face the wall. … It was a short moment. It was like those moments of weakness that … [are] pivotal in demonstrating—in illustrating the seriousness of a situation. (Son, 23)

Third, some EAC/YACs reported their prognosis uncertainty being impacted by a belief or realization that parents were withholding information. For EAC/YACs who were convinced that their parent’s prognosis would be death, learning information was withheld was evidence that their suspicions were correct, decreasing their prognosis uncertainty. For example, this participant explained the impact of his father’s reluctance to share information about his mother’s condition:

My dad would not keep me up to date on what [my mother’s doctors] were telling him. … I could guess what they’re telling him, but I couldn't get it out of him. … It was just more evidence towards my inference that it's nearing the end. (Son, 23)

Additionally, EAC/YACs reported that when their parent withheld information it led them to believe that no news was good news and their parent must be improving, also decreasing
prognosis uncertainty. For instance, this participant, whose family members agreed to keep information about her father’s condition a secret from her, illustrated this: “I didn't know that was happening, I was under the impression that he was getting better. … I felt better about his condition, and then I stopped worrying. So, I didn't know that it was deteriorating” (Daughter, 26). In some cases, EAC/YACs’ non-diagnosed parent would be dismissive or even misleading in response to EAC/YACs’ requests for information. EAC/YACs described realizing their parent was withholding information, which impacted prognosis uncertainty. For example, this participant described how her mother had lied to her when giving updates over the phone about her father’s condition, making him seem much healthier than he was. She recalled the conversation she had with her brother when he told her the truth:

My mom was like, “Everything’s okay. He’s feeling good. He’s taking little naps and stuff.” And after three weeks, my brother calls me like really, really upset and mad at me. He was like, “Why are you not here? My dad is dying.” (Daughter, 32)

Withholding information was also associated with increases in prognosis uncertainty, as the lack of information caused EAC/YACs not to know how much their parents were struggling or how serious their condition was. This participant recalled how her father’s refusal to share information impacted her uncertainty about how much time she had left with him:

I knew [he was] definitely dying and within probably the next couple months, but I wasn't really sure how much pain he was in. I guess at that point, I still wasn't sure, "Are we talking about days? Are we talking about weeks?” (Daughter, 33)

Finally, EAC/YACs’ uncertainty about their parent’s prognosis was impacted when their family struggles to relay information from clinicians. Although this pattern emerged with less saturation, EAC/YACs’ reporting this experience recalled challenges interpreting information they received about the cancer due to their parents’ and other family members’ difficulty
relaying information from their diagnosed parent’s care team. They also all described this experience increasing prognosis uncertainty, as this participant explained:

He would relay [information] to me as best he could, but he was really in and out of it so I was only getting half the story. And my mom would give me the best she could. … It’s kind of like telephone. She’s only repeating what she remembers or wrote down, but a lot of those are—it’s medical jargon and stuff I’m unfamiliar with. … It’s like when you listen or you watch Netflix, and it's not dubbed but you have the subtitles. And it's just kind of lost in translation.” (Daughter, 19)

**Study 2 Discussion**

The aim of this study was to identify turning points that affected the prognosis uncertainty of EAC/YACs caring for a parent with advanced cancer, with a heightened focus on turning points related to familial information sharing. Coping with advanced cancer is especially challenging for familial caregivers (Gallant, 2003; Shilling et al., 2017; Song et al., 2012; Zhang & Siminoff, 2003), and EAC/YACs in particular are known to be more psychosocially distressed and also the least supported (Greene et al., 2017; Levine et al., 2005). Previous research has shown that when individuals are more uncertain about their loved one’s prognosis, it negatively impacts their coping and caregiving experiences, including inhibiting their ability to communally cope with other family members (Magsamen-Conrad et al., 2015). Findings from the current study help us to understand this further by illustrating what turning points affect EAC/YACs’ prognosis uncertainty in the advanced cancer context.

These findings both highlight the impact of some expected and more medically focused turning points (e.g., medical events like hospitalizations or observable changes in condition like loss of weight or energy) as well as the profound impact communication has on prognosis uncertainty and, as such, coping experiences. These communication turning points especially highlight the powerful role of information sharing (in both clinician communication and familial communication contexts) on EAC/YACs’ prognosis uncertainty. Moreover, the methodological
approach enabled a rich characterization of these turning points, bringing to the forefront the importance of understanding prognosis uncertainty and information sharing/withholding within a unique relational-developmental-cancer context (parent-EA child relationships and advanced cancer). Exploring these communication-focused turning points in context (information seeking, patient-clinician communication, family communication) can be especially insightful in identifying ways to enhance EAC/YACs’ coping experiences after a parent’s advanced cancer diagnosis, both in terms of helping EAC/YACs and clinicians.

**Online Information Seeking Behavior and Prognosis Uncertainty**

Many EAC/YACs reported online as the major influence in developing their beliefs about their parent’s prognosis. They also acknowledged that searching for this information was a way to cope with their prognosis uncertainty and reduce their stress. EAC/YACs of parents with cancers known colloquially to be aggressive recalled their first Google searches of that cancer as the moment where they lost all hope. In comparison to older generations, Millennials (who along with Gen Z make up the majority of today’s EAC/YACs) are more likely to hold fatalistic beliefs about cancer, which are further increased if they perceive challenges in seeking online health information (Paige et al., 2021). The online sources that have such an impact on EAC/YACs’ prognosis uncertainty also may not always be accurate or applicable to their parents’ cancer. A recent systematic review of available online cancer resources indicates that their quality and usefulness to caregivers is severely lacking (Monton et al., 2019). The authors of the review suggest that to find online resources that will address their specific information needs, caregivers should seek recommendations for online resources from the patient’s care clinicians.

Previous studies on patient-clinician communication show that clinicians can be critical in helping cancer patients interpret online health information and encouraging them to be active in their care (Shen et al., 2015). Clinicians’ assistance in interpreting information EAC/YACs
found online could be essential in helping them manage prognosis uncertainty, especially given that EAC/YACs reported experiencing uncertainty due to the conflict between what they read online and what they heard from their parent’s clinicians. Although not all EAC/YACs had access to their parent’s clinicians, those that did cited communication with their parent’s care team as a critical source of information for EAC/YACs that impacted their prognosis uncertainty. Because EAC/YACs are typically absent from cancer caregiving literature (Greene et al., 2017; Levine et al., 2005; Pope et al., 2018), clinicians likely have not received training on communicating with family members across the lifespan with EAC/YACs about their parent’s cancer prognosis. Many may not be aware that they can at times include EAC/YACs in care discussions in the same way they would an older adult caregiver. It may also be a way to help parents include their EAC/YAC in the caregiving and coping experience, and parents may find such a suggestion from clinicians as helpful as the navigate what to share (or not) with their children. Clinicians could play an important role in facilitating parent’s conversations about their care and prognosis with EAC/YACs, educating them about the impact their information withholding can have on EAC/YACs’ coping and encouraging parents to have conversations about their cancer with their EAC/YACs.

**Family Information Sharing and Withholding**

The findings of the study also revealed the impact of parents’ information sharing (or withholding) on EAC/YACs’ prognosis uncertainty. Information withholding did not necessarily lead to an increase in EAC/YACs’ prognosis uncertainty, just as information sharing did not always decrease it. Parents have been known to withhold information in order to protect their children from the reality of their mortality (Barnes et al., 2000; Fisher et al., 2017; Galvin & Young, 2010; Petronio, 2010). However, these findings show that in many cases, withholding information did not prevent EAC/YACs from learning the truth, as they had other information
sources—sources that could contradict information received. EAC/YACs in this study who reported their parent’s withholding as turning points generally stated that it caused a decrease in uncertainty, as they interpreted their parent’s information withholding to mean their parent’s prognosis was not good. In many cases, parents’ refusal to share information or have conversations about their prognosis with their EAC/YAC meant that the EAC/YAC had to process the news of the terminal illness without them.

Communication and information sharing are essential to coping (Donovan & Farris, 2019), and open family communication during cancer has been linked to improved mental and physical health outcomes for patients and their caregivers (Berry & Pennebaker, 1993; Davison & Pennebaker, 1996; Fisher, 2014; Fisher et al., 2017). These findings show that a parent’s decision to withhold information about their cancer may not protect their child from painful truths about their prognosis. At the same time, information withholding could limit their family’s ability to cope communally during their illness and affect healthy adjustment after their passing. Parents should know about the impact their disclosure decisions can have on EAC/YACs’ coping and seek to have conversations with their EA children about their information needs throughout the course of their illness, as these findings revealed the critical impact of time on prognosis uncertainty.

Unique Context of Advanced Cancer

The TPA approach helped to illuminate not only changes that impact EAC/YACs’ prognosis uncertainty but also how the same changes (or turning points) can both increase or decrease prognosis uncertainty. Ultimately the impact of these TPs on uncertainty was driven by how the individual perceived their parent’s prognosis early in the cancer trajectory, further revealing the unique context of advanced cancer. This finding underscores the importance of timing both in managing uncertainty and in parent information sharing, especially in the
advanced cancer context. Extant literature in coping tells us that the speed of disease progression and place in the disease trajectory affects our information needs (Berg & Upchurch, 2007). These findings show that these factors also affect information interpretation, and the impact they have on prognosis uncertainty.

In an advanced cancer setting, parents appear to be less likely to communicate openly (Shilling et al., 2017; Song et al., 2011, 2012; Zhang & Siminoff, 2003). But EAC/YACs can, at any time in their parent’s disease trajectory, find out their likelihood for survival with a simple online search, impacting any conversations they may have with their parents going forward. This finding also highlights the utility of TPA. The methodology’s ability to capture change over time is what allowed for the identification of timing as a complex, relevant factor in prognosis uncertainty, which may not have been detected in a traditional in-depth interview. The results suggest that future scholars hoping to study any factors in the caregiving experience across the disease trajectory might find TPA especially useful in capturing time-sensitive experiences and how changes are impacted by information sharing or withholding early in the cancer continuum.

The results of this study have implications for EAC/YACs, their parents, and clinicians. This study highlighted the numerous sources of information available to EAC/YACs and the impact these had on prognosis uncertainty, identifying that online information and healthcare communication are particularly influential in addition to parent information sharing. Parents of EAC/YACs should be aware that while their information sharing and withholding is a major influence on EAC/YACs’ prognosis uncertainty, and ultimately their coping and disease adjustment, they have access to other information sources. Parents should engage in conversations with EAC/YACs about their information needs, and if applicable, encourage communication between EAC/YACs and their clinicians. Parents, and EAC/YACs, should seek
assistance from their care team in identifying and interpreting online information, as it was a key determinant of EAC/YACs’ prognosis uncertainty. Clinicians should recommend credible online resources, and when applicable, seek to educate parents of EAC/YACs about the coping implications of their disclosure decisions and encourage parents to engage in open conversations.

There are several limitations to this study, the first being that participants were recruited via social media support groups and a research volunteer registry. These participants could be more likely to seek out information or be more involved in their parent’s care than the typical EAC/YAC. Additionally, retrospective interviewing techniques have inherent limitations. There is a risk that the participant may not accurately remember and relay the events under study, or that their interpretation of past events may be colored by their present-day knowledge. Finally, the sample for this study was predominately White, and the findings do not account for cultural differences.

Examining Emerging Adult Caregivers

This the first study to examine prognosis uncertainty as it relates to EAC/YACs and to identify EAC/YACs’ sources of information regarding their parent’s illness. This is also one of a few studies to look at the EA caregiving experience, particularly across the disease trajectory. EAC/YACs identified communication from their parent’s clinicians and independent searching online as major influences in their prognosis uncertainty. Temporal factors were pertinent to their interpretation of these sources, both in terms of the advanced nature of their parent’s diagnosis and the time in their parent’s disease trajectory when they learned it. Parent information sharing and withholding also impacted uncertainty, both increasing and decreasing it depending on the individual and the context. Parents hoping to shield their EAC/YAC from the truth of their prognosis should know that that may not be possible. Engaging in conversations with their
EAC/YAC about the truth of their prognosis early in their disease trajectory may allow for EAC/YACs to enact better coping strategies.
Table 3-1. Participant Demographics

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CHAPTER 4
STUDY 3: UNDERSTANDING THE ROLE OF PARENT’S INFORMATION SHARING AND WITHHOLDING ON EAC/YACS’ CAREGIVING AND COPING WITH THEIR PARENT’S ADVANCED CANCER DIAGNOSIS

Descriptions for Parental information Sharing

Cancer is a disease of the family, affecting the patient and the broader family system (Galvin & Young, 2010). When families face an aggressive or advanced cancer diagnosis, how they communicate impacts their ability to cope and psychologically adjust (Donovan & Farris, 2019). Certain coping strategies (e.g., humor, narratives, and positive framing) are known to be more helpful for caregivers adapting to their new roles within the family (Alpert & Womble, 2014). Although research supports the notion that sharing information or openness is linked with better coping and health outcomes, deciding what to share (or not to share) is challenging, particularly for diagnosed parents (Compas et al., 1999; Figueiredo et al., 2004; Hilton & Koop, 1994). Research indicates their information sharing decisions with children are motivated by needing support as well as a desire to buffer their children from additional disease-related distress (Fisher & Wolf, 2015; Wolf, 2009; Zhang & Siminoff, 2003), even with their emerging or young-adult children (aged 18-35) who are involved in their care (Galvin & Young, 2010). Yet, withholding information may result in unintended effects that negatively impact emerging or young-adult caregivers (referred to as EAC/YACs for simplicity) experiences (Fisher et al., 2017; Greene, 2009; Magsamen-Conrad et al., 2015).

Understanding how parents’ information sharing/withholding can impact EAC/YACs’ coping and caregiving is important to generating supportive resources for EAC/YACs. Currently there are no known communication-focused, supportive resources targeting EAC/YACs of parents diagnosed with advanced cancer. This is noteworthy as EAC/YACs describe struggling to connect with interventions developed for other groups, noting that they feel too old to relate to
resources designed for adolescents and too young to benefit from interventions for older adults (Levine et al., 2005). Moreover, EAC/YACs of diagnosed parents are especially in need of supportive resources as they have more mental health distress than spousal caregivers and similarly aged non-caregivers (Bernard & Guarnaccia, 2003; Gillen & Roland, 2011; Greene et al., 2017; Pakenham et al., 2006). They’ve been described as a “hidden” cohort of caregivers that are only expected to rise as the Baby Boomer generation is aging and greatly in need of ongoing support (American Cancer Society, 2019; Litzelman, 2019). In this vein, this study seeks to better understand how parents’ information sharing can affect EAC/YACs’ caregiving and coping experiences as well as how it might inform their ability to cope together (communally) as a family.

Communal Coping and Cancer

Research on family coping and illness using a communal coping lens has demonstrated (in a number of health contexts) how this approach can be helpful or health-promoting for patients, family members, and their caregivers (Berg & Upchurch, 2007; Bodenmann, 1997; Coyne & Smith, 1991; Revenson, 1994; Staff et al., 2017). According to Communal Coping Theory (Lyons et al., 1998), coping is a three-step process that involves family members: (1) having a shared appraisal of the illness (i.e., this is our “problem” our experience as opposed to my parent’s health challenge), (2) engaging in communication jointly about the illness, and (3) enacting collaborative action (e.g., pooling resources or working together to cope with health challenges). Communal coping is facilitated by family members through various communication processes such as joint problem-solving, expressing feelings, and information-sharing (Helgeson et al., 2019). Communal coping is linked with better quality of life outcomes, including improved mental and physical health for patients and caregivers (Badr et al., 2010; Bodenmann
et al., 2011; Heinrichs et al., 2012; Johnson et al., 2013; Kayser et al., 2014; Korner et al., 2012; Meier et al., 2011; Meuwly et al., 2012; Regan et al., 2014; Rottmann et al., 2015). However, not all families engage in communal coping, and this form of coping can be challenging to achieve. This may be especially true for EAC/YACs, as they are prone to using more maladaptive communication patterns (e.g., avoidance, withdrawal) when coping with a parent’s cancer diagnosis (Fisher, 2010; Greene et al., 2017). Identifying ways to help facilitate communal coping is important could lead to better adjustment and well-being for a caregiving population especially prone to mental distress (Greene et al., 2017; Levine et al., 2005; Pope et al., 2018).

Communal coping is often idealized in the literature as the “right” way to cope and yet, there is no one approach to coping that applies to all individuals and circumstance. For instance, a major factor in facilitating communal coping in the family is being open (disclosure) or sharing information with family members (Helgeson et al., 2019; Lyons et al., 1998), a communication pattern that is also associated with healthier outcomes (Compas et al., 1999; Figueiredo et al., 2004; Hilton & Koop, 1994). However, there are a number of reasons why a patient might prefer not to communicate openly and to withhold illness information from their loved ones. For example, at times patients and their loved ones may want to hide information or feelings at various phases of the cancer trajectory in an effort to cope, particularly topics related to death or dying (Goldsmith & Miller, 2015). This is true within the parent-child bond as well. Parents may avoid discussing the prognosis of their diagnosis with their children in order to create normalcy or to protect them from confronting the possibility of death (Barnes et al., 2000; Fisher et al., 2017; Galvin & Young, 2010; Venetis et al., 2015). Because of assumptions and expectations associated with age, generational differences largely determine who holds the right to be informed and contribute to family decision-making about illness (Galvin & Young, 2010;
Petronio, 2010). As EAC/YACs are between adulthood and adolescence, parents may be unwilling to share information about their illness, prognosis, or pain with EAC/YAC (Fisher et al., 2017; Galvin & Young, 2010).

When a parent is diagnosed with cancer, they control the flow of illness information throughout the rest of the family, including to other adults (Galvin & Young, 2010). A study of adult daughters of breast cancer patients found that mothers were not disclosing enough medical information to meet daughters’ uncertainty needs, requiring them to seek outside information sources (Rees & Bath, 2000). For EAC/YACs, who may not be allowed to accompany their parent to appointments, lack of parental disclosure can have consequences for their psychological adjustment to their parent’s disease. In a study of communication between breast cancer patients and their EA daughters, Fisher et al. (2017) found that mothers practiced “benevolent concealment” and declined to share illness information or share their fears for the future with their daughters. Mothers temporarily withheld diagnoses and hospital stays, angering and emotionally isolating their daughters once they learned the truth. Mothers and daughters mirrored EAC/YACs other’s preferences for open or avoidant communication, and daughters felt uncomfortable bringing up topics such as mortality or disease recurrence if their mother hadn’t set a precedent of open communication. As communication is central to communal coping, low parental disclosure could limit the family’s ability to cope communally and add to the psychological stress of being an EAC/YAC (Donovan & Farris, 2019; Lyons et al., 1998; Magsamen-Conrad et al., 2015). Ultimately parents’ decisions to share or withhold information (i.e., these patterns of disclosure) may create uncertainty for EAC/YACs, which could lead to fear, anxiety, and isolation (Checton et al., 2012; Fisher et al., 2017). Uncertainty is also known
to make coping difficult in caregiver dyads, particularly if the patient and caregiver have different preferences for managing uncertainty (Brashers, 2001, 2007).

Research on parental disclosure in illness typically focuses on the initial decision to reveal their diagnosis. However, progressing through the cancer continuum continually requires new decisions about what to share and what to withhold from others (Clayton et al., 2006; Greene, 2009; Venetis et al., 2015). Patients may change the frequency and type of information they want to discuss at different stages in their disease trajectory (e.g., preferring to discuss facts and medical information at diagnosis rather than feelings) (Brashers et al., 2002; Goldsmith & Miller, 2015). This may be especially complicated in the context of aggressive or advanced cancer diagnoses, where the accelerated timeline both makes patients more reluctant to share the distressing news and increases the risk for EAC/YACs’ mental distress (Greene et al., 2017; Shilling et al., 2017; Song et al., 2012; Zhang & Siminoff, 2003).

The goal of this study was to examine the impact of parent information sharing (or lack thereof) on EAC/YACs’ caregiving and coping experiences. To this end, I propose the following research question:

**RQ1:** What factors play a role in how parent’s information sharing / withholding affects EAC/YACs caregiving and coping experiences?

**Study 3 Method**

**Sampling and Recruitment**

Inclusion criteria for participants included (1) aged 18-35; (2) lost a parent due to cancer no longer than five years ago; and (3) parent’s disease trajectory from diagnosis to death was less than 12 months. Purposive sampling was used to recruit EAC/YAC using two strategies. First, I sent recruitment messages via ResearchMatch, a U.S. national health registry that has a large population of volunteers who have agreed to be contacted by researchers about health studies.
Messages were sent via email to over 50,000 randomly selected volunteers between the ages of 18 and 35 over the course of the three months. Potential volunteers were sent a link to an online screening survey hosted by REDcap to determine their eligibility (Appendix A). Participants who met the requirements had the option to submit their contact information to schedule an interview. Second, I recruited via the online social media site Reddit, posting an advertisement for the study in cancer, caregiving, and grief support groups. The contact message and list of groups can be found in Appendix B. The message included a link to a website for the study hosted by UF Studies and a link to the screening survey described above. Eligible participants were contacted by phone or email to schedule a phone or zoom interview. They received $35 as compensation for their participation. The University of Florida IRB approved this study.

**Procedures for Study 3**

The Retrospective Interview Technique (RIT) was used to conduct in-depth, semi-structured interviews with EAC/YACs (Baxter & Bullis, 1986; Fitzgerald & Surra, 1981). Upon IRB approval, participants were sent a link to a survey to be completed before the interview where written consent was obtained. Interview questions pertained to EAC/YACs’ communication with their parents, uncertainty management, and coping throughout the disease trajectory (e.g., “Did you feel your parents were telling you all the information they knew?” “Did you feel like your family was coping together or separately?”). I also inquired about their relationship with their family post death (e.g., “How did your parents’ death affect your family as a whole?”). The full interview guide can be found in Appendix E. Upon completion of the interviews, participants were debriefed and provided cancer specific grief and bereavement resources in case the interview caused any mental distress. Interviews ranged from 40 – 113 minutes.
Analysis

The interviews were audio recorded and transcribed using a professional transcription service. Transcripts were managed using Atlas TI software. I first immersed myself in the data by listening to the interview audio recordings and reviewing the transcripts, keeping operational and thematic memos (Lincoln & Guba, 1985). As I identified patterns, I developed a codebook that was used throughout the analysis. I followed the procedures for thematic analysis in my data analysis using the constant comparative method, as outlined by Glaser and Strauss (1967), and steps described by Strauss and Corbin (1998). I first open coded data identifying concepts in the text and assigning them labels (i.e., codes). As data became more saturated, I collapsed codes into categories based on the criteria for Owen’s (1984) thematic salience (repetition, reoccurrence, and forcefulness). Once categories were saturated, I axial coded data associated with EAC/YACh theme to determine properties of EAC/YACh category and identify relationships among themes. Multiple verification strategies were used across the study design to ensure rigor including: 1) setting specific eligibility criteria for participation that ensures participants will be knowledgeable of the experience under study (Morse, 1991); 2) keeping memos throughout the process of data collection and analysis to ensure a rich description of themes when presenting the results (Lincoln & Guba, 1985); and 3) using in vivo labels when possible, meaning they were taken directly from participants’ words, to ensure the trustworthiness of the findings (Burnard, 1991; Castleberry & Nolen, 2018). Participant names and other identifying information were removed from the transcripts prior to analysis. In the presentation of the findings, the quotes are attributed via the participants’ age and relationship to the patient.
Study 3 Results

The sample consisted of 33 EAC/YACs, whose age at their parent’s diagnosis ranged from 19 to 34 (M(SD) = 26.39(4.18)). The sample was predominately white (72.72%) and female (57.58%). The sample included caregivers of patients with a number of different cancers, with the highest frequencies being pancreatic cancer (21.21%), lung cancer (18.18%), and brain cancer (15.15%). Table 1 lists the full demographic information of the sample.

In general, EAC/YACs tended to describe their parents’ information sharing more positively in comparison to when their parents withheld information, which was typically described more negatively. The following three factors played a role in how their parents’ information sharing/withholding affected EAC/YACs’ caregiving and coping experiences: 1) the topic matters, 2) the timing matters, and 3) who is included matters. The influential role of these factors is illustrated using EAC/YACs’ narratives, and EAC/YAC factor (i.e., theme) is further defined by thematic properties (italicized below). To emphasize the translational value of these findings for intervention development, for EAC/YAC factor (represented in themes), findings are presented to juxtapose the impact of information sharing versus information withholding on EAC/YACs’ adjustment across the disease trajectory. This will highlight how the factor warrants consideration as parents decide whether to share or withhold information.

The Topic Matters

EAC/YACs described how parents’ information sharing/withholding about two topics notably impacted their coping and caregiving experiences. They stressed the importance of talking about mortality/end of life and talking about treatment/careplan/illness information.

Talking about mortality/end of life

EAC/YACs described how their parents both shared (or addressed) end-of-life issues as well as withheld information (or avoided talking about) their parent’s mortality. Addressing this
topic (i.e., parents’ information sharing) gave EAC/YACs the opportunity to be more involved in their parent’s end-of-life care and more prepared for their parent’s forthcoming death. When parents acknowledged the reality of the terminal prognosis, it opened the door for honest conversations about death. This allowed EAC/YACs to be more involved in end-of-life caregiving. For example, this participant expressed how discussing the reality of his mother’s cancer with his father and sister helped them better manage the time she had left:

We had to be very pragmatic about it. [Her death] was going to happen whether we were going to talk about it and admitted or not. So, we had to decide, prioritize things, and try and figure out the next 12 to 18 months. (Son, 33)

EAC/YACs also described how this type of communication helped their family prepare financially and logistically for their parent’s passing. As this EAC/YAC shared, “A lot of my mom and I's conversation was, ‘What are we going to do after he passes?’ The stuff we have to sell, logistics like how to take care of him” (Daughter, 22). Although less commonly discussed, some EAC/YACs described how these realistic and candid conversations helped them prepare emotionally for their upcoming loss. This EAC/YAC participant described her diagnosed mother talking openly about death and the impact this had on her and her sister’s communication in preparing for their mother’s passing:

I don't think [mom] was excited, but she was in so much pain that it pretty much was a relief. And she would talk about like, “Oh, will she would see her mom again?” Or that my dad was there. … So, we never wanted to sugarcoat. We never wanted to just say, “Oh, well, she'll be fine. And she'll be completely recovered and back to her old life.” When it came to the point that we had to talk about what the future was going to be like without mom, we had to talk about it and move on and be honest with EAC/YAC other. (Daughter, 28)

While information sharing promoted EAC/YACs’ care involvement and preparation for their parent’s death, when parents were unwilling to share information about mortality EAC/YACs described less positive experiences. They shared how information withholding
inhibited their ability to cope and adjust both in the moment and while grieving. For instance, EAC/YACs explained how their parents sometimes withheld information about the severity of their prognosis, specifically that it was either terminal or had a high likelihood of death.

EAC/YACs were frustrated by this, as the following participant articulated in coping with her father’s diagnosis:

> It was also frustrating because I felt like [my mom] was kind of treating me like a child instead of an adult. I felt like as an adult I could handle the truth and not just what she's telling me. (Daughter, 30)

EAC/YACs described how parents tended to focus on “staying positive,” and how withholding discussions about mortality could inhibit EAC/YACs’ coping and adjustment, as this participant described with his diagnosed mother:

> I felt like she was sort of in denial or very guarded about her diagnosis. She never wanted to discuss it with me or acknowledge that this was terminal. … I came home on leave really ready to have serious discussions, and I kind of confronted my mother. … [I said] “I'd really like us to talk about what you want to do with this time, and how I can support you and making the most of this and finding your pEAC/YACe.” And she was still kind of in denial. She didn't really want to talk about it, and I think that was very painful. (Son, 22)

In addition, when parents refused to share information about death or their terminal prognosis, EAC/YACs described being afraid to bring up the topic for fear of upsetting either parent. This withholding of information seemed to make EAC/YACs uncertain as to how to cope with their parents in the moment, which could have lasting effects on their grieving, as this EAC/YAC of a diagnosed mother shared:

> I wanted to be around her, but I didn't know how to be around her. And also, where my head was, … if I asked her all these things about her life, she's going to think that I know that she's going to die. And I didn't want her to think that. … That's one of the regrets that I have now, that I should have asked more questions about everything that was going on when I had a chance because she deteriorated so fast. (Daughter, 26)
Similarly, this participant described how her diagnosed father’s refusal to talk about his end-of-life wishes affected her well-being during and after his passing:

We spent a lot of time after he passed away, especially trying to figure out what he would have wanted. And it frustrated me sometimes. He had an opportunity to help with that and to figure out what he even, like beyond his assets, what he wanted in terms of a memorial, how he wanted to be remembered, and how he wanted us to do things. And he just didn’t. It was frustrating to me, and it's still is kind of frustrating to me. And it’s a weird emotion and one I struggle with, because you don't really want to be mad at your dad that died of brain cancer. (Daughter, 34)

EAC/YACs recognized that talking about their parent’s death was challenging for everyone and contributed to their parent’s information withholding. At times, EAC/YACs expressed a desire for help facilitating this discussion, believing it would have enhanced their ability to cope as a family prior to and after their diagnosed parent’s death, as this participant explained:

I think had [hospice care] offered someone to come to us, … we could have had conversations to help us process what was happening. I wish he could have been part of that conversation. … He was still communicating with us at the very beginning, but it went, within a couple days, he couldn’t really speak to us anymore. So, it was kind of like we missed that opportunity to have that conversation with him. But I think it would have been nice to have [hospice care] come or at least offer us that opportunity. But that didn't happen. (Daughter, 28)

There were some EAC/YACs who felt that their parents’ decision to withhold information about mortality positively impacted their experience. They described being grateful that their parents withheld information from them, noting that being unaware of the severity of the diagnosis or details of their parents’ cancer helped them cope both during and after the illness. This participant explained how not having that information helped him stay positive during his mom’s cancer and the impact that had on his well-being: “I was already struggling a lot, and I still kind of am. But I think I would have been in a way worse state if it had started off with the thought of her dying” (Son, 19). Similarly, this EAC/YAC shared: “I am glad we didn't
talk about it. I think that would have put a lot of more negative feelings and a lot more sadness to the situation. … It would have been a lot harder to handle” (Daughter, 19).

**Talking about treatment/care plan/illness information**

EAC/YACs reported that their parents both shared and withheld information related to their cancer or their treatment. Including EAC/YACs in conversations about the state of their illness or their treatment plan allowed them to have greater participation in their parent’s care and take on more caregiving responsibilities, which helped some EAC/YACs cope. This participant recalled how being included in conversations with her father’s clinicians about his treatment was a positive experience for her:

[My parents] also would both let me, particularly me, in on conversations with his doctors. So, I talked to his oncologist. I talked to the surgeon who is performing his brain surgery. I really appreciated that. … [My mom] wanted to make sure if we had any questions for the doctor, we were able to address them just as though we were there, which is very appreciated. Yeah. It was very cool of her. (Daughter, 34)

When information about the treatment plan was shared with EAC/YACs and their siblings, they were able to cope communally with their family and collaborate in providing support to their diagnosed parent during their treatment, as this participant described:

We fully processed what we were dealing with. We were able to communicate the initial treatment plan, which was chemo. And we were just ready to be there, and be supportive, and just ready to support him through this being a supporter while he fought this disease. That’s really all we could do. (Son, 27)

For some EAC/YACs, parents sharing illness information enabled them to take on caregiving tasks and be involved in decision-making about treatment. This participant reported that her parents gave her the tasks of researching possible treatment options and coordinating consultations with specialists. She explained how taking on these tasks ultimately helped her and her father cope, even though he passed before he could try any of the treatments:
On the day that he passed away, I said something to my mom like, “I guess that [research] was all for nothing because we never really got to do it.” And she was like, “That brought him so much hope throughout all of this.” So I am thankful for that still. I do grasp science pretty easily, I think more than my parents, and more than my grandma. So that was – I felt like it was kind of my job since I could understand it. (Daughter, 23)

However, when cancer and treatment information was not shared, EAC/YACs were not able to take as active a role in their parent’s care or treatment. Some EAC/YACs reported this negatively affecting their caregiving experience because they were unable to help their parents when they needed it most. This participant explained how her father rejected her offers to accompany him to his appointments or speak to his clinicians:

My dad didn't really want any of us involved in that kind of stuff. … I had made myself available so that I would be happy to go if he seemed interested in that. …. I told him, "I can take off work." "No, no, you're a [occupation]. You got to go help all these people. You got to go to your work." … I was willing to make the time, and he just seemed like he didn't really want us going with him. (Daughter, 33)

EAC/YACs described parents withholding general illness-related information (e.g., treatment, appointments) as well information about disease severity (e.g., stage, cancer type). Some EAC/YACs felt their parents withheld details to protect them. For example, this participant reflected on the time he asked his father about his disease stage: “He said he didn't ask [his doctors], which I thought that was kind of weird. But I learned later … He did ask. It was a stage four. He didn't want me to look it up or anything” (Son, 27). But while some EAC/YACs recognized their parents were being protective, they also described how their parents’ withholding of illness-related information created stress, frustration, and complex emotions that affected their caregiving experience. This participant shared this regarding her diagnosed father:
It's awful because then you're like, “Really, just freaking tell me. I just want to freaking - Just tell me so we can get this figured out!” But I think that's when you start to form resentment, right? I definitely had a tiny bit of resentment, and I definitely think my mom did as well, which sounds awful because these are sick people who are freaking dying, and you're getting mad. (Daughter, 25)

Although withholding information negatively affected some EAC/YACs’ caregiving and coping, others felt it helped them cope to not know in great detail what their parents were going through, as this participant described:

I didn't really want to know like, “This is her blood count,” or “This was what the surgeon said.” … I didn't really want to know the gritty details. I wanted to kind of preserve my relationship with her and learn that she would be okay. (Daughter, 28)

**The Timing Matters**

EAC/YACs reported that the timing of parents’ information sharing or withholding also played a role in their experiences. It was not uncommon for EAC/YACs to be geographically distant from their parents. As such, they were completely reliant on updates from their parent to know how their diagnosed parent was doing or whether the cancer was progressing. EAC/YACs described how the timing of information sharing influenced their coping and caregiving experiences and the importance of *knowing their parent’s current condition* (i.e., how they were doing both on a daily basis as well as when their condition deteriorated).

Parents varied in when or how often they shared updates, which also varied across the cancer continuum. When parents shared daily or frequent updates, EAC/YACs also described how this contributed to their ability to cope day to day, both in terms of managing their uncertainty and in facilitating family communication. For instance, when EAC/YACs received frequent updates about their parent’s condition (including daily) they reported having less uncertainty across the course of their parent’s illness. EAC/YACs described how this information sharing helped them to not worry about how their parent was doing on a daily basis,
and notably, they did not report experiencing the stress and uncertainty described by those not given these updates. EAC/YACs who were privy to information about daily condition changes also described experiencing an overall increase in communication with their parents and family members, as this participant expressed: “My family just kept EAC/YAC other in the loop a lot. … We were talking in our group text and checking in with everybody pretty much every day” (Daughter, 30).

In contrast, when parents withheld day-to-day condition changes, EAC/YACs shared how they struggled with uncertainty and frustration because they had no idea how their parent was doing every day. They described how this affected their ability to cope. For example, this EAC/YAC recalled the challenges of getting daily updates about her father’s condition:

The first thing I would do in the morning was text my family and be like, “How's dad doing?” I wouldn't text him directly … because he was also getting so many texts from his friends all the time. And he's not like a big texter, so I know that frustrated him. … When he went to the hospital, the first thing that I would do every morning was call the nurse and check in there, so that was hard. … It kind of limited our communication because I didn't want to call him. I waited for him to call me, which is way less frequent than me calling him. (Daughter, 23)

For some EAC/YACs, the lack of communication from their healthy parent created tensions that made it more difficult to cope. This participant described what it was like trying to get frequent updates from her mother and knowing she was holding back details about her dad’s condition: “I was pretty frustrated, especially because she was not telling me everything. She was telling me that she wanted to be open and honest, and I didn't want to call her on that especially after the circumstances” (Daughter, 30).

Parents’ information sharing about the diagnosed parent’s condition varied across the disease trajectory in some EAC/YACs’ experiences. For example, at times EAC/YACs described receiving frequent updates at the beginning of their parents’ illness, but as their cancer progressed and their parent’s health worsened, the updates tapered off. This change in
information sharing contributed to EAC/YACs’ uncertainty and negatively affected their coping, as this EAC/YAC illustrated:

[My mother] started calling me less and less. And typically, she'd be the one to call me, but then I had to remind her to tell me what's going on. And I ended up being the one to call her more. … [My stepdad] was busy making sure that their hotel arrangements and everything was fine, and that she was fine. So, neither of them could really relay any information. … It made me way more anxious about it because I couldn't really see what's going on … I can't tell what was progressing and what was stable or not stable. And for a while at school, it was really hard for me to focus … I think I just started getting a bit depressed. (Son, 19)

EAC/YACs shared that they understood that maintaining the same level of information sharing about their parent’s condition was hard for their parents as the disease progressed. This participant explained:

In the beginning, they were very transparent. They were very, “Hey, here's my last labs. Take a look at them.” … Then the closer we got to the end, I think for them, it was just exhausting. And they didn't want to worry me because everything that happened, it was like, “Oh God, another thing.” And I think they became desensitized, right? When you just continuously have things pop up what you do with cancer and chemo, you don't want to update people on everything because it's something new every day. (Daughter, 25)

Not receiving condition updates was especially detrimental to EAC/YACs living away from their parents. The lack of day-to-day or frequent updates meant they also had no idea how quickly their parent’s condition was deteriorating. Some EAC/YACs described their shock and frustration upon realizing their parent had not shared information with them on the severity or progression of their parent’s illness. For instance, this participant recalled experiencing this upon seeing her father in person for the first time after his diagnosis: “I realized, ‘Oh, my God, like he's actually wasting away.’ He was tiny compared to the last time I saw him. And I was like, ‘Why did nobody tell me that?’” (Daughter, 25). When parents withheld this information, it negatively impacted EAC/YACs’ coping both during their parent’s illness and in their grief
process after their parent’s death. This EAC/YAC shared how her parents’ decision to hide the
truth of her father’s condition led her to make decisions she regretted now that he’s gone:

I wish I had known the truth because at the end of the day, I dropped my school.
… I left my job. I got a new lease for a new apartment, and I shouldn’t have
gotten that. And I would have been spending more time with my dad. (Daughter, 30)

Who is Included Matters
EAC/YACs reported parents’ sharing or withholding of information set the tone for who
was included (or not) in their coping experiences. Parents could function as a gatekeeper of
information, which impacted EAC/YACs’ coping and their caregiving role. Ultimately, parents’
disclosure decisions ended up controlling family involvement in both caregiving tasks and
communal coping within the family.

Controlling Family Involvement
EAC/YACs shared how when they received information from their parents it facilitated
their involvement in caregiving and enabled their coping both individually and communally.
Ultimately, information sharing functioned to allow EAC/YACs more opportunities to be part of
their parents’ illness experience. EAC/YACs described how being included in caregiving roles
(e.g., providing support; taking on responsibilities in their parents’ care) also helped them to
cope better individually and as a family. For instance, EAC/YACs reported that when they could
provide tangible support to their sick parent and lessen the burden on their other parent (the
primary caregiver), it helped them cope and adjust. This participant, who was geographically
distant, recalled sending food delivery when her mother shared that she was feeling too sick to
cook. She described how providing support to her mother in this way lessened her feelings of
helplessness: “It gave me some kind of control over the situation. It gave me control over my
feelings as to what was happening with her” (Daughter, 27).
When information was shared with the EAC/YAC and other family members, EAC/YACs described getting to join together with their siblings to keep EAC/YACs informed and provide support for both their sick and caregiving parents. This EAC/YAC recalled how her siblings would share information and make sure all family members were kept in the loop: “If somebody in the family found out more information, I think they would readily tell the rest of us. Family didn’t want to keep EAC/YACs other in the dark” (Daughter, 24). When information was shared freely with EAC/YACs, and their other family members, they reported being able to collectively process information, share the caregiving responsibilities, and cope across the cancer trajectory as a family.

Conversely, when parents withheld information, they limited EAC/YACs’ care involvement and ability to provide support to their parents. For instance, without information, EAC/YACs were left out of treatment decisions and discussions. This led EAC/YACs to feel like they were not supportive or there for their parents in their time of need, which negatively affected their coping and adjustment both during their parent’s illness and after their passing. Some EAC/YACs recalled their sick parents asking them not to come with them to medical appointments or to not come home and visit if they lived out of the area from their parents. This participant described how her father’s insistence that she stay away from him while he was sick negatively affected her because she wasn’t able to help him or her mother, his primary caregiver:

I also knew that the caregiving that my mom was having to do was getting more and more overburdening … and it sucked. … There was only so much I could do from where I was. Even though I wanted to be there, I knew he didn’t want me to be there, so it definitely sucked. (Daughter, 27)

Other EAC/YACs recalled feeling frustrated or helpless when their parents tried to keep them out of the treatment process, as this participant shared as she recalled a conversation with her father:
I told him, “If you don’t tell me what to do or anything, I cannot help.” And he was like, “Yeah, you don’t have to do anything. That’s fine.” So it was very frustrating. (Daughter, 30)

Some EAC/YACs expressed how their siblings would sometimes serve as an information source when their parents were withholding information, as this participant described:

I always talked to both my sisters because they were there. So if I physically couldn’t be there to badger [mom] and get the information out of her, because you could always hang up on a person, I would ask my sisters. And my sisters would badger her the next time they saw her. (Daughter, 27)

In some cases, parents even withheld their diagnoses from their children, which, once the EAC/YAC learned the truth, caused them frustration and regret. They reported feeling robbed of the time they could have spent with their parent before they passed. One EAC/YAC discussed how her parents left the country immediately after her mom’s diagnosis and did not share the truth about her having cancer until they came back a few months later. She recalled how difficult it was for her the day her mother came back and shared the news of her diagnosis:

I wasn't a support system for her. And that's what I felt the worst stuff about – that I couldn't be there for her when she's always been there for me when I've been in trouble or anything, or sick. And I just felt really bad. (Daughter, 26)

Similarly, this EAC/YAC who was not informed of his mother’s cancer diagnosis until after she died (which was only three weeks after her diagnosis) explained how challenging his grieving process has been because he didn’t know she was dying during that time:

I kind of wasted those three weeks. I could have spent those three weeks more with her. … Frustration is probably the most it's been in that sense. But [there is] deep regret that I didn't see what was going on – I didn't realize – that I didn't make better use of that time. (Son, 29)

While at times parents withheld information from EAC/YACs thereby controlling their involvement, in other instances, parents did share information with them but also asked them to
withhold that information (e.g., details about the severity of their illness) from their younger siblings or other family members. This negatively affected their caregiving experience because it restricted their other family members’ involvement which, in turn, inhibited the EAC/YACs’ ability to jointly cope with their siblings (or other family members). This participant recalled how her parents kept her father’s diagnosis from her youngest brother, which affected how much she and her other brother communicated with him during their father’s cancer:

The thing that was tough was the youngest brother. They didn’t really tell him. … I think they told him that it was pancreatic cancer, but I don’t think they told him what stage. … Me and my younger brother were kept in the loop pretty well, which was good. … Him and I kind of talked more. (Daughter, 25)

This also meant EAC/YACs could not share the mental and physical burdens of caregiving with their siblings. For example, this participant described how she was restricted from sharing information about her mother’s cancer with her brother, even though he was only two years younger. She described the complicated feelings this created for her, as she did not feel fully prepared to take on this role alone:

I was not satisfied with the information that she was telling me my brother. For example, I felt like I was the kind of designated confidant and caretaker. And somehow my brother was too young, even though there's only two years of difference between us. … It's kind of a double-edged sword, right? Because on one side, you have that like, “Well, mommy trusts me” - kind of attitude, and “I'm a big girl, and I'm going to take care of the family.” And on the other side, I don’t know what the hell I was doing. (Daughter, 23)

**Study 3 Discussion**

EAC/YACs are described as both a hidden and, as such, unsupported population of caregivers even though they encounter more psychosocial distress than other caregivers (including spouses), with long-lasting effects on their well-being. Research on interpersonal cancer coping has pinpointed information sharing (or withholding) as a key aspect of caregivers’ ability to cope and adjust (Donovan & Farris, 2019; Lyons et al., 1998; Magsamen-Conrad et al.,
Findings from this study highlight the largely adaptive functioning of parents’ information sharing juxtaposed with the negative outcomes associated with their information withholding. Furthermore, EAC/YACs’ authentic lived accounts provide further insight into important factors that contribute to how parents’ information sharing/withholding can promote better EAC/YACs’ experiences. The three factors identified by EAC/YACs help illustrate how parent’s disclosure decisions ultimately function to promote/inhibit EAC/YACs’ care involvement and coping (both individually and communally). To further explore these, it is first important to consider the parent-child relational dynamics that influence parent’s information sharing/withholding communication.

**Parent-Child Communication and Cancer Coping**

Diagnosed parents and their partners typically control the flow of information related to their cancer throughout their family. Parents can be withholding of information with their children, even once they become adults. This is particularly true for EAC/YACs because of their age and perceived maturity, as they have newly transitioned to adulthood (Galvin & Young, 2010; Petronio, 2010). Moreover, parents are motivated to withhold information from their children as a means to protect them (Barnes et al., 2000; Fisher et al., 2017; Galvin & Young, 2010; Venetis et al., 2015). However, while parents’ intent may be to buffer their children from distress, the withholding may not always be helpful to their coping or caregiving involvement. My findings echo those of Fisher et al. (2017) that parent withholding can inhibit EAC/YACs’ coping experiences. The findings of my study show further show that withholding information can negatively affect EAC/YACs coping. It can both limit the role EAC/YACs are able to play in their parents’ care and contribute to coping challenges, including regret about the way EAC/YACs spent their time during their parent’s illness. This study enhances the literature by isolating key decision-related factors (e.g., the topic, the timing, who is included) that can play a
role in whether parent’s information sharing/withholding is helpful to EAC/YACs’ adjustment or not.

Information Withholding and EAC/YACs’ Coping Experiences

In addition to relational dynamics playing a role in information sharing/withholding, EAC/YACs have typically recently transitioned out of their parent’s home and may live geographically distant from their family of origin. Participants in this study lived away from their parents and were not able to see daily changes to their parents’ condition. As such, the parents were the “gatekeepers” of that information. The findings showed that this could negatively affect EAC/YACs coping and caregiving experiences in a number of areas.

First, not receiving updates caused additional stress and uncertainty. This uncertainty also made it more difficult for them to cope individually and focus on their own daily lives, like school and work responsibilities. Family caregivers of advanced cancer patients can feel crippling uncertainty related to their lack of control or ability to make plans, which can dominate their thoughts and affect them in all areas of their life (Mosher et al., 2016; Shilling et al., 2017). Second, not knowing the truth about their parent’s condition led them to feelings of regret and even resentment once informed, compounding the difficulty of their coping after their parent passed. For some EAC/YACs, their parent’s information withholding even contributed to EAC/YACs making major life decisions (e.g., leaving their job or educational opportunities). In the Health Disclosure Decision-Making Model, Greene (2009) explains that beyond initial disclosure of diagnosis patients undergo a continual disclosure process regarding their treatment options, coping, and disease progression. It is important for parents to be aware of how these ongoing disclosure decisions can emotionally affect EAC/YACs’ individual coping and adjustment in the long term, including with their grief process.
For instance, EAC/YACs shared how their parent’s information sharing (or lack thereof) during their cancer was critical to coping with grief. For instance, EAC/YACs with parents who shared the reality of their prognosis and their feelings about dying were more prepared for the eventual outcome and had better adjustment to their passing. When parents withheld information specifically related to mortality, some EAC/YACs felt less prepared when the time came and struggled significantly both in the moment and in the present day. However, wanting information about mortality wasn’t true for all EAC/YACs, indicating other variables are likely important to explore. For instance, some EAC/YACs preferred not to know details or have discussion about their parent’s prognosis or end-of-life care. It is important that future research explore how developmental maturity may play a role as this sample included a spectrum of early EAC/YACs and also YAs. Moreover, some EAC/YACs may be more psychologically affected by their parents’ cancer, and conversations about their death may cause unnecessary harm.

These findings show that is no singular approach to information sharing related to mortality that works best for all EAC/YACs. Previous studies have linked end-of-life communication to better quality of life for patients (Starr et al., 2019) and caregivers (Wright et al., 2008), as well as reduced caregiver burden (Fried et al., 2005; Zhang et al., 2009) and improved caregiver adjustment during bereavement (Detering et al., 2010). The findings of this paper affirm those of existing literature on the many barriers to these conversations, including the patient’s desire to the sick person to protect oneself and their loved ones (Fisher, 2010; Fisher et al., 2017; Venetis et al., 2015) and caregivers’ reluctance to be the one to initiate these conversations (Shilling et al., 2017; Zhang & Siminoff, 2003). This means it is parents’ responsibility to talk to their EAC/YACs and ensure they are having their information and coping needs related about their parent’s daily condition changes and prognosis, as not having
these conversations can have consequences that extend beyond their parent’s passing (Im et al., 2019). The findings of this study also demonstrate the urgent need of parents and EAC/YACs for support and assistance from their care team in facilitate these critical conversations.

**Information Withholding’s Impact on Communal Coping**

These findings revealed that information sharing and withholding can dictate who is allowed to participate in their parent’s caregiving which seems tied to communal coping as well. EAC/YACs in this study who were either not told about their parents’ diagnosis or were misled about its seriousness experienced regret and adjustment difficulties after parent’s passing. They regretted not getting to spend time with their parent or provide support to them in the time where they needed the most. They also missed the opportunity to cope with and receive support from their parents. The same was true when EAC/YACs were instructed not to share information with their EA siblings. This limited their ability to share support with their siblings and lessen their caregiving burden by sharing responsibilities. In numerous studies on interpersonal coping, information sharing, or communication efficacy, is deemed essential to patients’ and their caregivers’ ability to cope together (Donovan & Farris, 2019; Helgeson et al., 2019; Lyons et al., 1998; Magsamen-Conrad et al., 2015).

There are numerous studies linking communal coping to better health outcomes for patients and caregivers (Bodenmann et al., 2008; M. D. Johnson et al., 2013; Korner et al., 2012; Meuwly et al., 2012; Regan et al., 2014; Rohrbaugh et al., 2008; Rottmann et al., 2015). Withholding information both from the EAC/YAC and from other EA children robs them of the opportunity to develop healthy coping skills and to benefit from support of their family in the time they need it the most. This is particularly important for EAC/YACs, as research shows they are more prone to maladaptive coping styles than caregivers of other ages (Fisher, 2010; Greene et al., 2017). Parents in this difficult situation likely do not realize that the ultimate effect of their
decision to withhold information is not the protection from pain related to their death that they intended and should be aware of the coping ramifications of their disclosure decisions.

These findings show that while parents’ information sharing tends to be perceived mostly positively (whereas withholding information is perceived more negatively), there is no prescription for what level of information sharing will be best for all EAC/YACs. However, there are consequences for EAC/YACs’ adjustment and coping resulting from parents’ decisions about what to share (or not). The findings help draw out factors that might be helpful to parents as they make complex decisions about what to share with their EA children with EAC/YACs’ narratives clearly illustrating how these disclosures (or lack thereof) can either inhibit or promote healthier adjustment.

Parents should consider these three things when deciding whether or not to share information with their EAC/YACs to better facilitate their coping and role. First, they should have conversations with their EAC/YACs to ensure that information needs (including topic, level of detail, and frequency) are being met. Second, they should continually check in to determine if those information needs have changed, as they are likely to evolve as the cancer progresses. Finally, they should seek assistance from their care team or other support resources to facilitate these conversations and promote healthy coping and caregiving involvement from EAC/YACs.

This study was limited in that participants were recruited from cancer and grief support groups. It is possible that there is self-selection bias, as EAC/YACs may be attracted to these groups and to this study because they struggled with coping and need support. This study is also limited by the diversity of its sample. Given the homogeneity of participants, these findings may not account for cultural differences and should be tested in other cultural settings to ensure they are applicable beyond this sample.
Information Sharing Requirements

Parents facing an advanced cancer diagnosis must manage a challenging negation between what they can share and not share with their EA children, but the consequences of shutting EAs out of the caregiving process are too great not to engage in these conversations. Their decisions about information sharing control EAC/YAC’s role in their care and as a part of their support system, which can have long-lasting impacts on their ability to cope after they are gone. Parents who develop a pattern of information withholding to protect their EAC/YAC should know their decisions may not have its intended impact. Having conversations with their EAC/YAC about their information needs could lead to better coping for their whole family.
CHAPTER 5
DISCUSSION

The aim of this dissertation was to examine the intersection of uncertainty, parental disclosure (as a form of information sharing), and communal coping across the disease trajectory in the EA cancer caregiving experience. Using a three-study approach, this dissertation: 1) synthesized over 30 years of studies employing TPA in a number of different fields through a scoping review; 2) identified turning points in EAC/YACs’ prognosis uncertainty; and 3) examined factors that affect the impact of parent information sharing and withholding on EAC/YACs’ caregiving and coping experiences. The collective findings from these studies can be used to develop communication interventions designed specifically for caregivers in this age group that could be targeted at parents, clinicians, and EAC/YACs and speak to the utility of TPA as a methodology for studying caregiving experiences across the disease trajectory. The following section will explore key findings of the individual studies, identify areas of overlap, and discuss future directions for research.

In Study 1, I conducted a scoping review of TPA papers published since the advent of TPA (Baxter & Bullis, 1986). The findings revealed that there is much variance in the methods of analysis of TPA data. While this speaks to the adaptability of the method to a number of different research contexts, the heterogeneity and disparities in reporting may make it difficult for future scholars, particularly early career researchers like myself, to incorporate the method into their own research. In the results of Study 1, I developed a diagram of common decision points in conducting a TPA synthesized from the methods of the 52 studies included in the review. This diagram is descriptive in showing how people have made decisions about how to conduct their TPA (e.g., interview vs questionnaire) based on the needs of their study. This diagram was informed not only from my own experience translating those findings into a plan
for my own TPA, as Study 1 helped me make decisions about how to conduct and analyze my
TPA in Study 2 and Study 3. This diagram may also be useful to instructors teaching qualitative methods and for new scholars wanting to use TPA without having oversight by an expert in it.

Study 2 was also novel in that I developed a method for collecting TPA data online. Typically conducting a TPA in person or over the phone, collecting chart data via paper. In order to conduct my retrospective interviews via phone or video conferencing software, I utilized an online using a graphic design tool called MarkUp to capture chart data. MarkUp allows multiple users to make edits to the same image. Participants were sent a private link to an image of an empty RIT graph, where they were able to mark where they wanted their points to be and provide comments for EAC/YACh point. Both the participants and myself were able to view the graph at the same time once it was completed, which allowed us to both see the data as we discussed EAC/YACh point in their interview. By writing about this method in Study 2, future researchers hoping to conduct TPAs online can use the same method.

The findings of Study 2 highlight the utility of TPA as a methodology, particularly in the health and cancer contexts. The analysis also gives a trajectory of events or turning points that can affect EAC/YACs’ prognosis uncertainty: 1) medical events, 2) observable condition changes, 3) online searching, 4) clinician communication, and 5) family communication. One of the key findings was that the same turning points (e.g., hospital admission, learning survival rates, parent’s condition declining) could impact prognosis uncertainty in different directions depending on EAC/YACs’ narrative about what their parents’ prognosis would be. TPA was key to highlighting this impact of timing, both in how prognosis uncertainty evolved throughout the disease trajectory but also how temporal factors played a significant role in how EAC/YACs’
interpreted turning points and ultimately, their directional impact on prognosis uncertainty. What seemed especially important was how prognosis was framed early on or soon after the diagnosis was shared (e.g., was it perceived as hopeful or that mortality was imminent). By discovering how timing affected information sharing, I was able to identify specific points where future interventions could help EAC/YACs navigate their prognosis uncertainty and ultimately, cope and adjust to their parent’s cancer and eventual death.

In Study 3, I examined the impact of parent information sharing and withholding on EAC/YACs’ coping and caregiving experiences, finding that the implications of parent’s disclosure decisions persisted after their passing and into the present day. At times, information sharing prepared EAC/YACs’ for their parent’s forthcoming death, promoted communal coping within the family, and allowed EAC/YACs to take on caregiving responsibilities and be involved in their parents’ care. Conversely, information withholding at times limited EAC/YACs’ ability to cope with their parents (and other EA siblings), barred EAC/YACs from participating in their parent’s caregiving or decision making, and impaired EAC/YACs’ adjustment to their parents’ illness and death. Experiences with death are often listed as central to one’s life story (Glück & Bluck, 2007; Mroz et al., 2020), and losing a parent and experience death of a loved one early in the lifespan is nonnormative and will affect EAC/YACs for their rest of their lives (Baltes, 1987). Identifying strategies to improve their adjustment can help and encourage adaptive coping may improve EAC/YACs’ well-being and reduce the negative impacts of this experiences.

While the DCM (Berg & Upchurch, 2007) highlights the importance of temporal factors in cancer coping, including age and the speed of disease progression, this study is the first to apply this model to the parent-EA child dyad (and in the context of advanced or aggressive
cancer) and explore how these factors may affect this dyad in unique ways. This is also the first study to qualitatively examine Magsamen-Conrad et al.’s (2015) extension of the DCM that incorporates prognosis uncertainty and communication efficacy as critical to dyadic coping, looking at how they impact coping in this particular dyad. By taking this approach and examining how these factors evolve throughout the patient’s disease progression, these studies were able to identify how the external factors that affect coping (identified by the DCM) and the internal factors (identified by Magsamen-Conrad et al. (2015)) are interrelated for in the interpersonal coping of diagnosed parents and EAC/YACs.

EAC/YACs are noticeably absent from cancer caregiving and interpersonal coping research (J. Greene et al., 2017; Pope et al., 2018). This dissertation places a spotlight on EAC/YACs and illuminates the family communication and coping issues unique to caregivers in this age group. The findings of these studies have identified three facets of communication that are key to EAC/YACs’ caregiving and coping experiences: 1) online searching, 2) communication with clinicians, and 3) communication with parents. Study 2 revealed that information learned online was instrumental in shaping EAC/YACs’ perceptions of their parents’ prognosis, which colored all of their communication and uncertainty experiences going forward. Study 3 emphasized the impacts to EAC/YACs’ caregiving, coping, and eventual bereavement adjustment that result from parents’ information sharing and withholding decisions.

In the future, I hope to use these findings inform future studies on this caregiving population and ultimately develop interventions to improving EAC/YACs’ experiences by targeting EAC/YACs, their parents, and their parent’s providers. For EAC/YACs, I would like to adapt Drs. Bylund and Fisher’s Healthy Communication practice intervention targeted at adult child caregivers to address the unique needs of EAC/YACs of their parents with advanced. This
intervention targets three key communication competencies: online information, communication with their parent’s clinicians, and communication with their parents and other family members. My findings have shown that these three areas are critical to EAC/YACs’ caregiving and coping experiences as well, demonstrating that this framework may be beneficial to this population. I hope to use these findings of this dissertation to help tailor the intervention for this specific population. I would also like to use these findings to inform future research with diagnosed parents of EAC/YACs and their spousal caregivers in order to one day develop a communication support intervention to help parent’s facilitate open and adaptive communication with their EAC/YAC. Finally, I hope to develop a training intervention targeted at cancer clinicians to aid in their communication with EAC/YACs and their parents. In conducting this research, I found that at time EAC/YACs serve as the primary caregivers for their diagnosed parents and communicate with their parent’s care team on their behalf. Other EAC/YACs identified their parents’ clinicians as a key source of information and a major influence on their uncertainty regarding their prognosis. I hope to use the findings of this dissertation to inform, as well as future studies, to inform an intervention to train clinicians to communicate specifically with EAC/YACs, as well as educate parents of EAs about the coping implications of their information sharing decisions and encourage their healthy communication with their EAC/YACs in order to promote adaptive coping and adjustment.
APPENDIX A
SURVEY QUESTIONS

1. Did you lose a parent to cancer within the last 5 years?
2. What is your current age?
3. How old were you when your parent was diagnosed?
4. How long ago did you lose your parent?
5. How long was the period of your parent's illness from diagnosis to death?
6. Which parent did you lose? (e.g., mother, father, stepparent, etc.)
7. Would you be willing to be interviewed about your experience during your parent's illness and complete an additional survey? Interviews will be conducted over Zoom and last 60 - 90 minutes. The survey will take 20 minutes, after which you will be compensated with a $35 Amazon gift card.
8. What is your first and last name?
9. What is your email address?
10. What is your phone number?
11. Preferred method of contact?
12. How did you hear about this study?
APPENDIX B
RESEARCH MATCH

ResearchMatch contact message

A study team seeks to learn the experiences of young adults who have lost their parent to cancer through online interviews. By sharing your story, you are playing an important role in improving cancer communication for future families. Compensation is provided for participating.

You can participate if…
• You are an adult 18 – 35 years old
• You have lost a parent to any type of cancer in the last 5 years
• You have access to phone or Internet for interview and questionnaire

Start the online survey here to see if you qualify.

Reddit contact message

Post
Research study for young adults who have a lost a parent to cancer

Hello. I am a doctoral student at the University of Florida working on my dissertation to develop resources for others who lose their parents to cancer. I lost my father to cancer when I was 24, and I found that supportive resources for people in my age group were incredibly lacking. My hope is that through this study I can develop supportive resources for adult children like us.

I am hoping to speak with adults 18-35 who have lost their parent to cancer in the last 5 years through a telephone or Zoom interview. Compensation is provided for your time.

You can get started by completing a short survey here: https://redcap.ctsi.ufl.edu/redcap/surveys/?s=TCX7XPFPJH

You can also visit the study website to learn more: https://ufhealth.org/research-study/cancer-communication-online-study-young-adults

Thanks!

Moderator

Hello,

My name is Amanda Kastrinos and I am a researcher at the University of Florida. We are seeking young adults 18 – 35 across the nation who have lost a parent to cancer to participate in an online or phone interview. Compensation is provided.
You can read more about the study on our university website here: https://ufhealth.org/research-study/cancer-communication-online-study-young-adults

I was hoping you would allow us to post the following IRB approved content in the subreddit. Our team will monitor comments and answer inquiries related to the study:

"Hello. I am a doctoral student at the University of Florida working on my dissertation to develop resources for others who lose their parents to cancer. I lost my father to cancer when I was 24, and I found that supportive resources for people in my age group were incredibly lacking. My hope is that through this study I can develop supportive resources for adult children like us.

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You can also visit the study website to learn more: https://ufhealth.org/research-study/cancer-communication-online-study-young-adults

Thanks!"

List of Reddit groups where the advertisement was posted

- r/Cancer
- r/CancerFamilySupport
- r/PancreaticCancer
- r/BrainCancer
- r/ProstateCancer
- r/CancerCaregivers
- r/CaregiverSupport
- r/Oncology
- r/breastcancer
- r/Grief
- r/leukemia
- r/lymphoma
- r/testicularcancer
- r/braintumor
- r/lynchsyndrome
- r/Genz
- r/Millenials
- r/death
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• r/thyroidcancer
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## Turning Points during EA Caregiving Experience

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## Turning Points during EA Caregiving Experience

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**APPENDIX D**

**TURNING POINT INTERVIEW INSTRUCTIONS**

**Instructions:** You have received link via MarkUp to a turning point graph. We will use this graph as a guide for our discussion. Please complete it prior to our scheduled interview. Please also know that there are no right or wrong answers to this graph. Everyone who completes this graph will have different turning points and a unique representation of their experience.

I would like you to use this graph to plot “turning points” (i.e., experiences) that affected the quality of your communication with your parent during his or her illness. The turning point could be something that enhanced the quality of your communication or it could be something that made the quality of your communication worse.

The y axis (horizontal line) represents the quality of your communication with your parent, ranging from low to high quality. High quality represents the best or optimal quality of communication (e.g., productive, intimate, healthy, enjoyable, etc.) whereas low communication is not what would be optimal to you (e.g., not effective, unhealthy, upsetting, less productive or unproductive). This could mean different things to all of us as we all have unique relationships.

The x axis (vertical line) represents time. You’ll start with what is called a “baseline.” Plot to the left of the graph how you would rate the quality of your relationship with your parent shortly before his or her diagnosis. Then on the first vertical line, plot the quality of your communication when your parent shared the diagnosis. Then plot any turning points that impacted the quality of your communication up to your parent’s death.

For EAC/YAC turning point, label it with a phrase that will help you recall what happened or what the turning point was. The turning point might something tangible like an event (e.g., I found out h/she hid something from me; We went fishing which we love to do together and had a meaningful talk) or it might be something less tangible (e.g., I decided I didn’t want to be upset anymore). Consider how the turning point impacted the quality of your communication with your parent indicating on y axis it if enhanced it (moving up the y axis) or negatively impacted it (moving down the y axis). Plot all turning points you experienced.

**MarkUp:** You have received a link to create your turning point graph via MarkUp, which is an Internet editing service that always users to mark specific points on a photo and add notes. When you enter the document, you should see a black and white turning point graph with the header “Turning Points During the EA Caregiving Experience.” MarkUp works best on your computer, although it can still be used on a smartphone.

You can click to the left of the first vertical line to mark your “baseline.” Once you click, a comment box will pop up where you can add your notes on the quality of communication with your parent before their diagnosis. When you are finished typing, click “post” in the bottom right corner of the comment box to post your turning point. Repeat this process for the rest of the turning points during your caregiving experience.

When you click on a turning point you’ve already posted, all of your turning point notes will appear in a window on the left-hand side of your screen. Clicking a turning point note in this window will give you the option to edit or delete it. If you edit a turning point, try not to click the green “Resolve” button in the comment box, although if you do, this can easily be fixed during our discussion.
MarkUp will automatically number your turning points in the order in which they were posted. It is okay if your turning points are not in the correct number order, as we will discuss them in chronological order (left to right on the graph) during our interview.

If you experience any difficulties using MarkUp or completing the graph, please call Amanda Kastrinos at 407-913-5964.
APPENDIX E
INTERVIEW GUIDE

Welcome Introduction

Thank you for agreeing to do this interview. As you know, this study is part of my dissertation research that is part of my work towards my PhD in family health behavior. I’m interested in learning more about young-adult children’s experiences with what it’s like to care for or lose a parent diagnosed with advanced cancer. I became interested in this area because of my own family’s experience. My father was diagnosed with advanced cancer when I was 24 and passed away 7 months after he was diagnosed. I noticed that there were really no supportive resources for people like me. My goal is to change that by getting more resources out there.

Please know there are no right or wrong questions to any questions I ask. I’m not looking for any specific information. I’m here to learn from you, and anything you feel like sharing with me will be helpful. You don’t have to talk about anything that makes you uncomfortable, and we can stop this interview at any time. Do you have any questions for me before we start?

Contextually Situating the Interview

Before we get into the graph and talking more about your experiences after your mother/father’s diagnosis, please just tell me what your relationship was like with him before the diagnosis – anything you think is important for me to know…

Now please tell me a little about your relationship with your other parent… (KEEP IN MIND THEY MAY HAVE MULTIPLE…)

Part 1 (RQ1ab): Quality of Parent-Child Communication and Disease Trajectory

Now I’d like to talk with you more about your experiences with your parents across the course of his disease. I’m interested in learning about any experiences or turning points you encountered that affected the quality of your communication with your father. We can use the turning point graph that you completed to help guide our discussion. We will use this to talk through your experiences, starting with the “baseline” rating up until your mother/father’s loss as well as to the present day for your mother/father.

I’ll interject with questions to learn more about EAC/YAC turning point as we move across the graph. Does that sound okay? Any questions before we get started?

- **BASELINE**: Let’s start with the baseline rating. Please tell me a little about why you chose to rate it as you did.
- **DIAGNOSIS**: Please explain to me your rating here as well and share anything you think is important for me to know about how you learned about your father’s diagnosis?
- **Uncertainty probes:**
How did you respond?
Did you ask them any questions? Did you have questions that weren’t answered?

What were you questioning? Did you feel satisfied with your answers? Was that satisfying to you?
What were those questions for you? “Are they going to be okay? What’s the treatment plan?”
Did you talk about that with your parent?
Were you avoiding those conversations?
Did this cause any changes in your life?

Coping probes:
Huge thing to learn that your parent has cancer, what did you do to cope with that?
I know when you’re waiting for tests results it can be really difficult to not know. How did you cope with that?
What do you remember doing to cope with that at the time? What was most helpful to you?
Was there anybody in the family that helped you? That you wish you could have gone too but couldn’t? Who was helping you?
What helped you?
What did you do to deal with that? Do you remember what you did to deal with that?
Do you remember how that made you feel? What was going through your head? Can you give me an example of how you coped together?

“just being there”

Death probes:
How was your life changed since then in career, family, relationships?
How do you view your cancer risk?
Were you coping together or separately?
Support from friends?

Covid probes:
How was your illness experience affected by covid?
Funeral? Hospice?

- **POST-DIAGNOSIS THROUGH LOSS.** Now please take me through all the turning points you plotted after diagnosis and share in as much detail what you recall about the turning point and anything you feel is important that I know regarding how it impacted the quality of your communication. I’ll interject with questions as we go along.
• **DIAGNOSED PARENT’S DEATH.** Now please share with me your rating of your communication when your parent passed away—anything that you remember about that time that informed how you rated it.

• **POST LOSS (LIVING PARENT).** Please share with me about the turning points that impacted the quality of your communication with your _______ since the loss of your _____.

(lots of probes!!)

**Part 2 (RQ 2-3): Prognosis Uncertainty & Parents’ Information-Sharing/Disclosure**

*(if talked about…)* Previously you mentioned that at times your parents were forthcoming with how your dad was doing and what their prognosis was and at times, you felt in the dark. I’d like you think about those experiences of when you parents decided to share information with you (or not) and how that affected your feelings of uncertainty about your parent’s prognosis across the course of his experience with cancer. The term “Prognosis uncertainty” refers to any feelings of uncertainty you experienced about the seriousness of your mom/dad’s illness. This could refer to uncertainty about not knowing whether or not your dad would survive his cancer. This could be related to communication you had (or didn’t have) with your parents or other experiences (like receiving test results). Remember the turning point graph you plotted? I’d now like you to do the same but on a new graph and think about any experiences you had that impacted your feelings of prognosis uncertainty.

*(if not talked about)* One difficult issue for adult children is feeling uncertain about their parent’s cancer prognosis. Remember the turning point graph you plotted? I’d now like you to do the same but on a new graph and think about any experiences you had that impacted your feelings of uncertainty about your mother/father’s prognosis or how he was doing. “Prognosis uncertainty” refers to any feelings of uncertainty you experienced about the seriousness of your dad’s illness. This could refer to uncertainty about not knowing whether or not your mom/dad would survive. This could be related to communication you had (or didn’t have) with your parents or parents as well as other experiences (like receiving test results). Remember the turning point graph you plotted? I’d now like you to do the same but on a new graph and think about any experiences you had that impacted your feelings of uncertainty about your mother/father’s prognosis or how he was doing.

I will mute my video and audio feeds to give you privacy while you complete your graph. Please take as much time as you need. When you’re finished, you can just speak up or send me a message in the chat.

[Same interview approach]. Let’s now talk through EAC/YACch of these turning points….

**Part 3(RQ4): Communal Coping**

*(if talked about…)* Previously you mentioned…(and refer to a particular instance)
(if not talked about…) I wanted to also ask you about any experiences you had that helped you cope together as a family as well as experiences that in which you didn’t feel like you were coping together as a family ...

Friends/peers?

Coping probes:

Huge thing to learn that your parent has cancer, what did you do to cope with that?
I know when you’re waiting for tests results it can be really difficult to not know.
How did you cope with that?
What do you remember doing to cope with that at the time? What was most helpful to you?
Was there anybody in the family that helped you? That you wish you could have gone too but couldn’t? Who was helping you?
What helped you?
What did you do to deal with that? Do you remember what you did to deal with that?
Do you remember how that made you feel? What was going through your head?
Can you give me an example of how you coped together?

Was there anything you felt like you wanted to talk about it, but we didn’t get to?

Discussion of compensation, dissemination of findings and notes of gratitude and farewell.


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BIOGRAPHICAL SKETCH

Amanda Kastrinos received her Ph.D., master’s, and bachelor’s degrees from the University of Florida College of Journalism and Communication. She also received graduate certificates in Health Communication and Gerontology from the University of Florida. As a health and family communication scholar, her primary research focus is examining caregiving communication from a lifespan developmental perspective. Amanda’s research program explores family communication and coping in the cancer context, particularly the impact of cancer type, disease trajectory, and the place of family members within the lifespan of the family’s communication support needs. She is a mixed-method scholar with experience in multiple areas of health communication research, including patient-provider communication in rural communities, genetic testing and mental health, and HPV vaccine uptake.

Amanda was a member of two communication labs while at UF, Dr. Carma Byund’s Communication in Healthcare lab and Dr. Carla Fisher’s Family-Health-Lifespan Communication Lab. She has worked on a number of grant-funded projects, including research funded by the Leukemia and Lymphoma Society, and she received a pre-doctoral grant for her dissertation research from the University of Florida Health Cancer Center. After graduating with her Ph.D., Amanda will become a Research Fellow in Psycho-oncology at Memorial Sloan-Kettering Cancer Center in New York City, NY.