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Message Convergence Message Convergence in Information Seeking and Decision Making among Adult Children Regarding their Parent's Diagnosis

by

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A Thesis
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ABSTRACT

Adult children have a unique role in caregiving and decision-making for a parent diagnosed with a life-threatening illness or condition. In this qualitative study, 15 individuals participated in one-on-one interviews to share their experience seeking information for their parent's life-threatening diagnosis. This study utilized deductive and inductive coding approaches through axial coding, and two coders analyzed the data through a lens of message convergence framework and uncertainty management. The results show participants engage in information seeking from personal connections to the medical field to retrieve additional information from a more familiar, trusted source. The participants managed uncertainty retrospectively by reassessing the stress of their parent's illness to reduce uncertainty about the event to help them continue to cope. Family history, relationships, and emotions sit at the forefront of discussions and decisions surrounding adult children and their parents throughout the experience of treating the diagnosis. The goal for this study is to gather testimonials to analyze the ways adult children interact and process their parent's diagnosis, which provides insight to decision-making, shifts in family dynamic and roles, and the overall experience facing families in the informal caregiving process. More research is needed to further investigate the complexities of health communication within the family, particularly surrounding caregiving and healthcare concerns, to provide more generalizable results.

Keywords: uncertainty management, message convergence, information seeking, adult children, end-of-life, caregiving

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DEDICATION

This thesis is dedicated to my late grandmother. As the only fellow Golden Eagle in the family, she was thrilled in my choice of college. She never failed to be one of the biggest cheerleaders of any goal I set my sights on throughout my undergraduate and graduate career. Although she was obviously biased, her love and support proved sincere. During the last few years of her life, we grew closer during the informal caregiving process, and she was a major source of inspiration for this topic.

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EOL	End of Life
HCP	Healthcare Provider
MCF	Message Convergence Framework
UMT	Uncertainty Management Theory

CHAPTER I - INTRODUCTION

“This is going to be the hardest thing we've ever done. You know that. We've all got to get along, we've all got to get through this, and we all need help.” – Study Participant

As young children experience the milestones of growth and change, their parents are often encapsulated in this part of their children’s livelihood, maintaining the heuristic idea that parents are, in one way or another, expected to care for and seek the utmost well-being for their child. This cyclical form of life can be reflected differently by what the child may experience in their adulthood surrounding not only their own care, but also their parent’s care. Experiencing and processing all the complexities and emotions that occur when a parent is suffering from illness, especially if their illness results in death, is a complicated and emotional experience for children that alters the dynamic of a family structure (Droser, 2020).

When life takes a turn in the proverbial circle, and the role of the child in the family is transformed into a caregiving role for their parent that requires collaboration and shifts into new or established roles (Ingersoll-Dayton et al., 2003), this change can yield itself to potential uncertainty among the family. This uncertainty can spark from ambiguity of diagnosis, by means of communication from medical provider to caregiver, through inconsistent details of severity, or through geographic location and access to adequate resources (Bevan, Jupin, & Sparks, 2011). Thus, when feeling uncertainty about communication either from a medical provider or the information coming from the parent, it is common that people seek information from external sources about an illness (Garden & Seller, 2016).

Even though, the act of aging and death is inevitable, the conceptual idea of this finality can potentially add to the ongoing sense of uncertainty surrounding the future. Thus, for individuals suffering with a terminal or life-threatening illness, conversations of diagnosis will become more common among the family and yield itself to plans of care for longevity and potentially even plans and preferences in death (Keeley, 2016). This change of environment and roles within the family is a large source of stress and uncertainty when a parent receives a diagnosis that requires additional care, leaving the family to adjust to caring for a parent and adapt to the changes to the pre-existing roles that had been instilled for years (Carmon et al., 2010).

However, when someone is given a diagnosis, there can be multiple sources of information regarding symptoms, causes and plans of care—the varying perspectives and opinions on that illness may cause medical misinformation or conflicting messages that cause further uncertainty and conflict for the family (Han et al., 2011). The message convergence framework (MCF) explains the ways in which people subconsciously or consciously analyze multiple sources of data or information to make their decisions or interpret some level of risk (Sellnow & Seeger, 2021). Since multiple pieces of information and differences in opinions often arise in medical decision making (Anthony & Sellnow, 2016), MCF is likely to arise in the information seeking processes of adult children when discussing their parent's diagnosis. This study seeks to continue to form a bridge between family and health communication by further understanding the complexities of family communication, specifically as adult children, when their parent receives a diagnosis that requires caregiving or ongoing medical attention. By gathering testimonials through open-ended interviews with adult children who have assumed the responsibility of medical decision making or caregiving for their parent, I will analyze the manners in which the family sought and processed information regarding the diagnosis. In addition, this study seeks to analyze how children disseminate conflicting information through a lens of message convergence.

CHAPTER II – LITERATURE REVIEW

Message Convergence Framework

The use of MCF is beneficial to understanding how different pieces of information and messages can converge together to solidify meaning in an argument, as well as informing how to make decisions based on their conclusion (Sellnow & Seeger, 2021). MCF originated from Perelman and Olbrechts-Tyteca (1969) with the discussion that pluralistic perspectives and meanings exist within an argument and have the potential to overlap, thus allowing the audience to construe meaning or reinforce a message. In the medical community, interprofessional collaboration is becoming more common among healthcare providers (HCP) to provide better patient centered care (Fox, et al., 2021). MCF in the medical community arises when physicians may experience cases where there may be multiple options for care which require converging multiple sources of information to one individual case in order to provide informed outcomes to the patient (Anthony & Sellnow, 2016).

Studies demonstrating MCF in risk and crisis communication not only show that the audience seeks to find credible, converging information, but also uses that information to interpret their own relevance or vulnerability to the issue or risk at hand (Anthony, Sellnow, & Millner, 2013). Message convergence is considered a priority and a challenge simultaneously in communication due to the understanding that some individuals seek out multiple sources of information to make informed decisions during crises for a variety of reasons. For example, one study reported audiences finding multiple sources to discern "exaggeration" or "sensationalism" in the media, seeking more information as not to jump to conclusions or judgements, and using multiple sources to understand alternate perspectives. (Anthony, et al., 2013, p. 356). Furthermore, organizational legitimacy plays a role in the interpretation of the message, depending on the different frames in which an audience can perceive the outgoing message or campaign (Woods, 2017). Sometimes, when messages are providing inaccurate or inconsistent responses from the audience, a new divergent message may need to be into the conversation to evoke new significance (Sellnow, Sellnow, & Martin, 2019). In a variety of ways, MCF is vital in not only understanding the receiver's interpretation of messages and arguments, but also vital for the message sender to understand persuasive rhetorical value of argumentation and varying messages (Perelman & Olbrechts-Tyteca, 1969).

Uncertainty Management Theory

Brashers (2001) developed uncertainty management theory (UMT) to further explain the ways uncertainty can be viewed in both a positive and negative way in some contexts through an individual's choice to maintain, reduce, or increase their uncertainty. Brashers posits that uncertainty does not necessarily yield itself to anxiety or unease, but that uncertainty is multifaceted and stems a variety of emotions and responses in an individual's experience. In many cases with health communication, the HCP and patient communication has an important role in the interpretation of uncertainty. The credibility of the HCP, communication styles, and existing patient knowledge of health systems are all factors that contribute to the management of uncertainty in medical cases (Brashers et al., 2006).

In some cases, uncertainty can be referred to as "more of an opportunity and less of a danger" and vice versa depending on their information-seeking behaviors (Rains &

Tukachinsky, 2015, p. 347); furthermore, these findings are consistent with studies associated with information seeking habits in health communication and the interaction between passively avoiding seeking information (increasing uncertainty) and actively seeking information (reducing uncertainty) on medical conditions (Brashers, Neidig, & Goldsmith, 2004). Individuals may increase uncertainty by avoiding information seeking behaviors to intentionally make their health concerns more ambiguous to reduce severity and increase deniability (Barbour et al., 2012). Uncertainty, particularly in medical information, is highly situational, which further demonstrates the uniqueness and complexity of the relationship between information-seeking and uncertainty management.

To mitigate uncertainty surrounding their parent's diagnosis, children often desire to feel included in the discussions regarding their parent's care processes and withholding or omission of information often instigated further uncertainty and proved not beneficial for parent or child (Harzold & Sparks, 2006). Additionally, according to the study from Barbour et al. (2012), overabundance of information often yields overwhelming emotions surrounding health concerns, which can potentially lessen the idea of hope. Participants recorded that they felt it was necessary to establish information boundaries in some instances to maintain their individual understanding of their condition. UMT is useful understanding an individual's sense of control over uncertainty but can also serve as a guide for managing uncertainty and conflict collectively within familial units and dyads (Babrow et al., 2021).

Adult Children and Siblings

Adult siblings have a unique perspective within their family, as their relationships are some of the most formative and enduring relationships that people can experience (Myers & Kennedy-Lightsey, 2015). Siblings are connected not only genetically, but also socially, impacting their influences of who they are and their preferences on lifestyle (Cassinat & Jensen, 2020). Their influence on one another impacts their communication styles, both individually and with one another, developing an ability to establish a closeness with others. During adolescence and childhood years, siblings under the same household are subject to daily influence of one another. They develop emotional ties in their relationship, thus learning reactions and responses that mirror emotions from their siblings (Aksan et al., 2013). Koerner & Fitzpatrick (2002) argue that families are oriented together to create their social cognitive behaviors, both in communication and familial role. The roles and behaviors from each individual family member assist in creating an intricate family pattern that can be similar or generalizable to other families, but ultimately is unique to each family and each sibling.

Throughout childhood years until adulthood, sibling relationships can change, but siblings play an important role in the overall dynamic of a family unit simply by way of spending a large amount of time together, sometimes in the same home, participating in many social and family activities as a unit (Meyers, et al., 2011). The study from Meyers and colleagues (2011) highlights the importance of continued communication among adult siblings by studying the use of affectionate language (verbal and nonverbal) as a means of reinforcing and maintaining closeness among siblings as adults to preserve the nature of their relationships. Furthermore, siblings demonstrate a “dyadic nature of maintenance" in their relationships that can affect their perceptions of one another based on how they perceive the effort and satisfaction the other siblings are putting into their relationships (McNallie & Hall, 2015, p. 155). Even though sibling relationships are not impenetrable or stagnate, especially compared to their childhood nature, family dynamics can be viewed as a structure to some degree even with the aging process from adolescence to adulthood. These dynamics can create established family roles, consciously or unconsciously, that are subject to change in some contexts (Koerner & Fitzpatrick, 2002)—for example, the potential death of a parent (Scott & Caughlin, 2015).

In many cases, communication and roles within these family structures may shift from their pre-existing patterns – potentially due to the necessity for one or more siblings to step up and assume new, and sometimes differing, levels of responsibility (Droser, 2020). Once children age into adulthood, their relationship often shifts away from the daily contact of living under the same roof to a less frequent form of contact as they move into different phases of life as young adults (Hamwey et al., 2018). Since their communication and interaction shifted to a voluntary form of contact, their attitudes towards conflict can change and contribute to a more stable connection (Jensen et al., 2018). On the other hand, they still have their own perspective and opinions, which can lead to potential disagreements. Adult siblings are often encouraged, or required, to take responsibility for the care for their parents, which can highlight or trigger any previous disagreements in family history (Merrill, 1996).

End of Life Conversations

Previous studies highlight the significance end-of-life (EOL) conversations have on family relationships. EOL conversation avoidance is consistent with research in UMT and avoidance in information seeking behaviors to maintain hopefulness and limit information that may alter understanding of health conditions (Barbour et al., 2012). Often, families feel uncomfortable about the idea of discussing a terminal or life-threatening diagnosis due to not only the idea of preparing for an impending death, but also the idea that knowing the severity of a condition may lessen the hopefulness of recovery (Thompson, 2011). Siblings are likely to experience differing views on EOL discussion; for example, avoidance of the topic altogether is common, but is ultimately harmful to both the siblings and their families (Lillie & Venetis, 2020).

Scholars refer to the time frame beginning with the parent's initial diagnosis of a terminal illness to the day they pass as *terminal time* (Keeley & Yingling, 2007). During the terminal time, family members often spend more time with one another, participating in conversations about death and life in both positive and negative contexts, analyzing bigger pictures to life and viewing memories and meaning in a new light (Generous & Keeley, 2014). Even though medication often sits at the forefront of conversations about comfort during illnesses, communication among family members, both with the parents and their adult children, can serve as a form of comfort for families during an otherwise potentially traumatic process. Contrary to the idea that EOL conversations perpetuate a connotation of sadness, EOL conversations have the potential to influence positive emotions of gratefulness, allowing the dying family member to offer closure to their families. (Keeley, 2016). However, intra-family conflict is very common during EOL care and conversations, and impacts the stability of the family relationship, as well as the health of the ill family member (Wilson et al., 2021).

EOL conversations are not limited to just familial relationships; however, families can demonstrate such strong bonds apart from their emotional openness or closeness. Scott and Caughlin (2015) address that EOL conversations between families often occur among the older adult siblings and how intergenerational differences among siblings can lead to non-accommodation which can ultimately impact each siblings' perception of best EOL care and cause familial conflict. Both collectively and individually, obstinance to discuss death hinders EOL conversations to occur earlier. The objection to discussing death makes the positive side of EOL harder to communicate, because people generally choose to conceal EOL conversations until the actual moment approaches (Ruis-Fernandez et al., 2021).

Families experience conflicting moments of wanting to hold onto to their hope of life for their parent, while also wanting to let go and move forward (Ohs et al., 2015). EOL care can involve a patient designating a family member to step-in and make any medical decisions for that patient. This type of designation, and the communication surrounding it, can place stress on a family member and the family unit; therefore, it is common for family members to feel guilt or resentment for letting go or ending any life-sustaining treatment for their family member (Radwany et al., 2009). Although discussing life-threatening illnesses within a family can invoke stress in a variety of ways, EOL conversations can serve to optimize care for the patient, as well as emotional care for the families involved, by addressing any concerns early in the EOL care process (Bernacki & Block, 2014). Although the research regarding EOL care and conversations is extensive, this study seeks to highlight the perspective of the family members who were most impacted in participation of these conversations—specifically analyzing the quality of these conversations surrounding their parent's illness.

Shared Parental Caregiving

In a family unit with multiple adult children, sibling relationships can potentially play a role in caregiving and communication of care for their parent(s). Family relationships, especially the parent-child relationship, often contribute to an individual's response to trauma and change—families who show supportive and open communication often experience higher resiliency in response to stressful situations (Theiss, 2018). The parent-adult child relationship alone, as well as its history, plays an important role in perception of communication competence and openness within the relationship, which develops patterns of communication long before the child becomes an adult and often maintains or continues that structure (LaFreniere, 2020). Supporting this idea of openness in family relationships to caregiving process, Halliwell et al. (2017) explained several themes when adult siblings serve as the shared caregivers of a sick parent. Their findings demonstrate that stability within the sibling relationships is beneficial for the family unit; siblings should openly communicate care goals and concerns while also practicing empathy for one another. Families that demonstrate positive communication through flexibility and cohesive support are associated with functioning as a unit successfully and more likely to adapt to changes (Berryhill, Harless, & Kean, 2018).

Due to the emotional nature of loss, families may not even recognize the changes happening to their communication and established roles during the stressful time (Solomon et al., 2016). Siblings who offer support and gratitude towards one another foster a better environment for caregiving and can improve the quality of relationships for the family (Amaro, 2017). In addition, emotional support from siblings can decrease the sense of burden often felt during the caregiving process (Teixiera & Pereira, 2013). However, communication efficacy and open, descriptive conversations about health and health history is vital in maintaining understanding of all aspects of family health, especially since self-disclosure of health issues is sometimes linked to benefitting health outcomes (Thomas & Hovick, 2021). In Thomas and Hovick's (2021) study, normalizing conversations about health and wellness within the family allows for more comfort among young adults in the family to share health concerns. These conversations and boundaries of details often are distributed through a lens based on age, gender, or cultural identity (Hong, 2018).

In many cases, HCPs start the process of medical options for caregiving conversations through incorporation of palliative care. In the event of a life-threatening illness, HCPs often provide a plan of care to make the patient as comfortable as possible, and they must properly communicate that plan to a designated caregiver for the family (Ledford et al., 2016). However, most families do not discuss caregiving options before a diagnosis or illness is discovered (Pecchioni & Nussbaum, 2000). In Pecchioni and Nussbaum's (2000) study, it is revealed that particularly between the relationship of care-receiving mothers and caregiving daughters that discussions of caregiving prior to diagnosis is essential to facilitate better autonomy in medical decision making.

However, according to Ngangana et al. (2016), adult siblings who share caregiving responsibilities report higher levels of stress and conflict among other siblings during the informal care-giving process. As their research states, most children are willing to support and provide any assistance for their ill parent despite the stressors applied to the process, which is supported by the statistic from Pew Research Center (2015) that 88% of adult caregivers describe the time and attention spent caring for their parent as rewarding to give back to their parent. However, adult siblings have strong desires for equity in a balanced distribution of the care-giving responsibilities, as distribution of responsibilities is often considered a main stressor (Halliwei et al., 2017). Although the desire to help presents itself in many cases, tensions still exist in the form of caregiving and information-seeking, especially among children who are practicing long-distance caregiving (Bevan, Jupin, and Sparks, 2011). A previous study conducted a focus group on role distribution among over 40 caregivers identifying equitable and inequitable practices of caregiving roles, the findings indicated that less than half of the siblings felt their distribution of responsibilities were equitable; however, the caregivers who felt they received adequate designation of responsibilities often took turns on certain tasks or distributed tasks based on expertise or previous knowledge (Ingersoll-Dayton et al., 2003). Having an equal balance of responsibilities can be subjective based on different siblings' perspectives—factors like income, geographic convenience, and much more can either cause tension or reinforce certain barriers in the family relationship.

Adult children providing care for their sick or aging parent is common transitional process within many families, stemming from individual narratives that weave into a larger collective interactive within the familial unit (Miller, et al., 2008). The current study will seek answer the following questions:

RQ 1: How do adult children seek and process information regarding their parent’s illness or condition when faced with uncertainty surrounding the diagnosis?

RQ 2: How do adult children negotiate the roles and responsibilities of decision making for their parent?

The purpose for this study is to provide insight in the family and health communication field to further understand the ways adult children interact to process and seek information about their parent’s diagnosis. The findings from the research will shed light on the transition of adult children into caregiving roles by offering narratives of lived experiences and practical, humanistic perspectives of families who are adapting to a new family dynamic while understanding the varying tensions and stressors associated with caring for a parent.

CHAPTER III - METHODS

The goal of the interviews will be to identify how adult children interpret uncertainty surrounding their parent's diagnosis, identify tensions in medical decision making (including caregiving), and the impacts on family communication throughout the process. This is a qualitative study, consisting of interviews of individual siblings through the lens of MCF and UMT to understand how families process and move forward with their parent's diagnosis placing emphasis on maintaining healthy communication and support within the family.

Participants

Participants were recruited through snowball sampling through a sharable Facebook post. To qualify for the study, the participants must be 18 years or older, have one or more siblings ages 18 years or older, and be able to speak about sibling communication over the lifetime. Additionally, the participants' parent(s) must have been diagnosed with or experienced a life-threatening illness or condition to ensure that conversations surrounding the parent's health and well-being occurred among the adult siblings. Adults are necessary for this study to identify any conflicts or stressors associated with their personal priorities in life while trying to care for their parent.

The sample included fifteen (*n*=15) participants all between the ages of 32-76 all residing within the southeastern region of the United States. Seven (*n=7*) of the participants identified as male, and eight (*n*=8) participants identified as female. All participants (n=15) in this sample are white. Participant age, gender, and number of siblings are listed below:

Table 1

Participants

Name	**Age**	**Gender**	**# of Siblings**
Diane	63	Female	3
Joe	64	Male	2*
Mary	59	Female	3
Mark	76	Male	1
Tom	51	Male	2
Liz	49	Female	4
Bill	52	Male	1
Eva	62	Female	3
Jane	56	Female	2
Keith	57	Male	10
Sandy	65	Female	4
Wanda	43	Female	1
Sarah	61	Female	3
Terrance	32	Male	1
Chris	48	Male	4

Data Collection

After receiving Institutional Research Board approval from The University of Southern Mississippi (See Appendix B), participants were recruited through a social media post. Potential participants received an email to schedule an interview date and time. The recruitment email contained the consent form, as well as additional descriptive information about the study. Before each interview, the participant was notified that their participation was voluntary, and they were reminded that mental health resources are available if their participation in the study were to impact their emotional or mental well-being in any way.

All interviews were conducted in-person except for one Zoom interview to accommodate a participant who lived out-of-state. The researcher asked each participant a series of 22 questions concerning their experience with their parent’s health (See Appendix A). Each interview was recorded verbatim and was transcribed through NVIVO transcription service. All recordings concluded once the participant indicated they were finished answering the final question of the interview. In all, the fifteen interview transcriptions totaled to 51,921 words over the course of 103 pages. The interviews lasted between about 15-49 minutes, totaling 371 minutes and 45 seconds, and the researcher gathered 41 pages of notes with about 2-3 pages of notes per participant. All personal identifiers were removed and replaced with pseudonyms prior to any secondary coding to ensure anonymity and to protect any sensitive family health information.

Data Analysis

After participants’ responses from the interviews were transcribed through NVIVO, the researcher re-listened to the recordings to ensure accurate wording on the transcriptions and also to make additional notes from the interviews. Additionally, the researcher took notes during the interviews to make note of any nonverbal language cues or changes in tone and mood to gather a larger understanding of any context surrounding the participant's family communication and relationships. Another researcher assisted in the coding of the data.

Deductive coding and inductive coding approaches were employed. First, the primary researcher developed a set of codes to analyze the data. The researcher coded the data deductively based on the message convergence framework and the extant literature using the following overarching codes: *information seeking behaviors, message convergence, emotional responses, relationships, decision making* and *managing uncertainty*. Then, the primary researcher and the secondary researcher/coder met to analyze the transcriptions and organize the data. The researchers also engaged in inductive coding by paying attention to other trends that emerged in the data. The second round of axial coding helped solidify the emergent themes (Lindlof & Taylor, 2011). The two coders met to organize the emergent themes, and any disagreements in coding were resolved through discussion. After thorough analysis, the primary researcher organized the data into sections and selected exemplary quotes.

CHAPTER IV – RESULTS

Throughout the interviews, the participants' extensive responses offered valuable narratives of a lived experience concerning their parent's health concerns. The researchers divided the sections as *sources of information, uncertainty management, complexities in decision-making, and relational influence.*

Sources of Information

> *"…if you really want to know the truth, our friends in health care are who we relied on for a lot of additional information." -Wanda*

Amid making decisions for an ill parent, participants acknowledged that they obtain information from various sources. The results reveal that although participants indicated that listening to their HCPs, 73% *(n=11)* discussed that their most trusted source of information was actually a personal connection (family member or friend) in the medical field. More often than not, this trusted source from whom they gathered information, relayed information, and often sought second opinions, were individuals in medical disciplines outside the scope of their parent's diagnosis. Liz, Jane, Sandy, Terrance, and Chris *(n=5)* indicated that they have a personal connection to a medical professional within their family, and that person played a large role in communicating details of their parents' health. Liz and Chris state that they both had a sister was a licensed social worker, and both indicated that their sister was designated as the primary caregiver due to her profession and existing knowledge in EOL care. Liz states, "I was familiar with [the hospital]. I knew what it was, so I took it upon that being a trusted source, and then relied on that information from my sister."

Additionally Sandy and Terrance both have sisters who are currently, or were previously, nurses. Both Sandy and Terrance discuss conferring with their sisters on designation of caregiving responsibilities as well as understanding medical terminology. When asked who she would go to with any conflicting information or questions, Sandy said, “First off, was always my sister. She is my oldest sister. Again, she has a medical background.” Terrance states that he “leans to his sister in that regard” as she has more “experience and knowledge” of how to care for someone who is ill.

Jane’s husband is a practicing physician, whom she often refers to in the event of any conflicting information regarding her parents’ health concerns. Jane states, “I talked to my husband who talked to other physicians, personal friends who are physicians.” She also reiterated that even though she sought information online, her main source of convergence was through “personal relationships in the medical field.”

Some participants *(n=4)* overcame potentially conflicting or unclear information from a close friend in the medical community. Tom and Wanda both indicated that although they see no issue contacting the primary care physician in their parents’ conditions, they have a close friend who works as a physician that they prefer to have as a mediator, confidant, or reference in the event of converging information. Tom relayed that while he trusts the family doctor, but “didn’t really know” the other doctors on his mom’s care team, so conferring with his close friend in the medical field was a source of comfort and familiarity in getting another opinion. When recalling the moments after her mother informed their family of her terminal illness, Wanda says, “So I picked up the phone immediately and called my best friend [who is a physician]” and later explained, “because that’s always just my go-to person.”

In addition, Diane and Sarah referenced a family friend as the physician who initially discovered the illness as being a source to gather more information. Diane said that her mother's doctor was a friend of the family and how that was very "helpful and informative." Sarah echoed Diane in that she felt her personal connection to the medical field always had "a wealth of information." Alternatively, Mark felt that it was most important to listen to one person to eliminate confusion. His mother had seen multiple doctors at a hospital and then was sent to a nursing home. He felt most confident listening to one doctor who identified the cause of what was killing her. Mark stated a personal connection to the medical field, but utilized the patient advocate in the hospital and listened to the advice from the one doctor he trusted the most in the hospital.

Eva and Keith *(n=2)* reported being medical providers who utilized their existing knowledge and colleagues in medicine to strengthen their own ideas and understanding of their parents' conditions. Eva was the primary person communicating the details of her mother's condition to the rest of the family, and she relied on her pre-existing knowledge of EOL care to aid in decision making for her mother. However, she states, "when it's your family, it's completely different. Different perspective. Different outlook." She would listen to the advice and counsel of other people, but ultimately understood the terms of her mother's illness. Similarly, Keith used previous knowledge but also referred to colleagues to assemble the best-informed decisions and information to relay back to his family. He states, "as a physician, I have other physicians, so obviously I reached out to friends of mine to discuss the situations medically." The participants indicated utilizing a personal connection to the medical field to obtain a deeper understanding, to seek additional information, or to perceive more comfort in familiarity.

Uncertainty Management

Information Seeking Habits and Behaviors

Diane, Joe, Mary, Bill, Jane, Keith, Sarah, Wanda and Terrance *(n=9)* all indicate using the internet and retrieving more information regarding their parents' conditions. Mary and Sarah both described desperately and immediately looking for more information. Mary states "I got online, and I looked things up." She described how there was not resources for any outreach programs where her mother was being treated so she said, "all the information I got was from her doctor and in the research I did on my own," and she continued to say "I was *desperate* to take her somewhere to get a different diagnosis." Sarah said, "I researched and researched and researched. You know, I took the information we were given [at the hospital] and tried to break it down so I can understand it."

Bill and Terrance both described breaking down medical terminology through Google searches after their parent sees their doctor. Terrance would hear back from his dad about blood work and research the results; however, he reported a growth in maturity in his searches by "trying to find reputable information" and "using the internet more wisely" to seek out reliable information. Jane and Keith both mention using the internet to research utilities and tools that are needed and helpful in their parents' conditions. Keith states that they were "trying to find things that would make her activities of daily living better." Alternatively, Diane, Joe, and Wanda indicated that they initially started looking at information on the internet but stopped using that as their primary source of information. Diane stated how she would look up information about her mother's cancer, but ultimately stopped because her sister was finding out a lot of information to send to her. Additionally, Diane said she also “was wanting to be in denial” about what was happening to her mom. Wanda disclosed that she stopped seeking information on the internet, as well, as all her searches were “doom and gloom” and were even advised by some peers not to look to the internet for answers due to the negative nature of the results. Joe indicates that he stopped looking up the information about his mother’s cancer once it became inapplicable to his mother’s care. He stated:

> The majority of women who have ovarian cancer don’t survive. And my mother’s a long-term survivor. So at some point, the information I can research online was not useful. She was taking a lot of experimental treatments that worked for her, that did not work for a lot of other women.

The participants referred to the internet for surface level information to better understand the terms of their parent’s condition.

Retrospective Uncertainty Management and Processing

Some participants (*n=4)* reflected on their experience and engaged in retrospective uncertainty management and processing. These participants were seemingly applying new retrospective meanings to process and move forward. They seemed to process the uncertainty in a different lens. Mark frequently referenced his religious affiliations and the ways that his faith impacted how he processed the events leading up to his mother’s death. He described feeling pain in the moments of his mother’s death, but now reflects on the traumatic events through a lens of faith and protection. In relation to retrospective uncertainty management, he stated:

> But I firmly believe that in both cases, the Lord stepped in and the Lord saved us from the agony and aguish of having to make that decision. And He took them

> home. Now, I know that not medical, but that's my firm belief. And so it was really a blessing in disguise of the pain.

Another participant engaged in this same retrospective uncertainty management by way of her religious beliefs. Sandy stated, "Because there were sometimes that I think I don't know what I would do if I didn't have God's comfort, if I didn't have the Holy Spirit to just help me and hold me up through this." Both Sandy and Mark were referencing the pain that they undoubtably felt during the events leading to their parents' deaths, but as they reflected, they manage the uncertainty of those events through a lens of faith.

Mary demonstrated retrospective uncertainty management through emotional ties to her son, and not wanting him to feel as unprepared as she was and to reduce any future uncertainty for him. As she was recalling that experience of what she endured during the death of her mother, she thinks about the situation in a lens of what can be better for someone else she loves. She stated:

> Some parents, I'm sure, are not willing to do it [talk about EOL]. I haven't done it for my son, and I need to. But I think the least selfish thing you can do for your children is to make those arrangements…

Keith engaged in retrospective uncertainty management by incorporating his medical knowledge and discussing the influence of COVID-19 and the pandemic on the elderly populations. His aging mother was impacted severely by COVID-19 because her physical decline was obvious, but the lack of social interaction for her last three years impacted her will to live and the quality of life she was experiencing. He stated:

> Covid was a big variable in all of this because my mother, you know, her physical decline made her not want to do as much…but when covid happened, no social interaction, whatsoever. Nobody could come to the house. She couldn't see her grandkids…she couldn't go to parties. We didn't have the family events. The isolation, I think, killed a lot of people.

In these examples, the participants viewed the events in a lens that was not uncertainty management at the time of the diagnosis, or death, but it is a form of current uncertainty management that allows them to still process and move forward.

Increasing Uncertainty through Avoidance

Some of the participants *(n=7),* in one way or another, indicated that their parent would avoid discussing their illness, causing increased uncertainty among the family. Joe recalls how he and his brother were not made aware that their mother was sick until long after her diagnosis. He stated:

> My phone rang one Thursday morning about 6:00 a.m., and her husband said 'you need to come over here because your mother has not been totally honest with you. She has cancer, it is not a gastrointestinal trauma that's going to be solved with Rolaids.

Joe also mentioned how his mother did not communicate any details of her condition, and that she preferred for everyone to perceive everything as normal.

Mary described her increased uncertainty by not "addressing the elephant in the room." She stated that historically they never discussed many issues as a family, and this situation was no different. She recalled, "We just thought, I guess, that if we didn't talk about it, maybe it would go away." Diane described a similar source of uncertainty with her family and her mother saying, “We really never discussed it. I think we were all not wanting to face it.”

Liz stated that her mother also never wanted to talk about it, which increased uncertainty among the family. When Liz was reflecting on the situation, she mentions the patient having a role in “allowing” the family to discuss it, and how that openness would help everyone process. When Bill was asked about how his dad speaks about his condition, Bill was quick to say his dad does not talk about it much and stated that his dad wants to talk about “anything but that.”

Jane describes her dad as not being “much of a communicator” and that her mom sometimes opts to not share certain details of their health. Terrance reported similar sources of uncertainty through omission of information from his parents. He stated:

> And so like a week or two later, I’d call mom or dad to check in and they’d say, ‘Oh yeah, your dad was at the hospital last week.’ And I thought this would be important to know when it happened.

Each participant indicated some variation of stress or frustration regarding their parent withholding information, or not talking about their condition at all, revealing potential sources of uncertainty that exist within the family communication and not solely existing within the diagnosis.

Complexities in Decision Making

Decreased Independence and Autonomy

Many participants *(n=10)* indicated a balance of understanding decreased independence of the parent, but also the desire of them maintaining autonomy in decision making. When reflecting on his mom’s diagnosis, Joe recalled growing up and the relationship between his parents and the ways that they were so different from each other due to his parents' "strong will" and how he "never thought they would appreciate my opinion." He later described that the diagnosis of cancer was not as hard as seeing his mom go from a very strong-willed and independent woman to someone who "accepts other people guiding her life so much…without argument"

Of the parents that were involved in the decision-making process, their children still played large roles in opinions of care and execution of the parent's wishes. Keith described how his mother was very much a part of the decision-making process prior to her death, but it was difficult at first when her kids shifted into caregiving roles because she "didn't want to give up her independence." Ultimately, she accepted it, and would listen to the recommendations and opinions of her son, Keith, but still have the freedom to make her own decision. Keith described how his mother even planned her own funeral before she passed. Similarly, Diane described the shift in their family dynamic as being hard because her parents did not want to burden their children, but the children recognized they needed help. She explained the shift as going from "being the child to the adult in the relationship." Diane described her parents' reluctance as not wanting to give up their role at the matriarch and patriarch and be dependent on anyone, especially their children.

Mark's mother was very much involved in making decisions for herself, as he described her mind as still "sharp" for her age. However, she slowly started losing autonomy the more her condition worsened. He said:

> She would tell us what her decisions were, and then we would help her implement whatever the decision was. But when it finally came down to worse, when she

> went into the hospital from pneumonia, from then on, all the communication from her to us stopped. And then it was just left us to us to find out whatever we could from whoever we could in order to be able to make educated decisions.

Mark presented his mother with details from the medical providers to help her understand the options and the context surrounding her condition for her to feel included in the conversation and decisions, but ultimately Mark and his brother were making the decisions. He said, “She probably felt that we were helping her make the decision, but we were actually making the decision. But we leading her in the direction that we felt she needed to go.”

Wanda’s father was still living and healthy at the time of her mother’s diagnosis of cancer, so her parents were largely involved in the decision-making process. Her mother still maintained her autonomy and made her own decisions regarding her healthcare, and often chose to withhold some information from the doctors to the rest of the family. Wanda said, “Mother withheld a lot of, what I would say, things that she thought were overly negative pieces…[other family members] would call me and say, ‘I don’t think your mom’s telling us the whole story.’ And she probably wasn’t.

Terrance described a similar feeling of having a valued opinion in the decision-making process of his father’s care, stating that his opinion is “recognized” among his family. Although Jane’s parents are both still living, she describes her parents as being ultimately very understanding and even “accepting” of her help in the decision-making process even though they still have autonomy. Diane and Sarah both mentioned how their other living parent oversaw a lot of EOL decisions, and their parents had made previous arrangements that the other spouse would never make it the responsibility of the children to make a life-ending decision for their parent. Sandy describes the family making decisions for her mother to keep her comfortable, understanding her wishes to not go on life support. Sandy said, “My mother loved life, so she wanted to live, but she didn’t want to go through hell to live.”

Participants who indicated that their parent had dementia or Alzheimer's were placed in roles to intentionally make those decisions for their parent. Mary’s father had Alzheimer's, which placed her in the decision-making role due to the decreased independence of not only her mother, but especially for her father. Eva’s father had already passed, but her mother’s diagnosis of Alzheimer’s impacted her autonomy in her decision-making. Eva said:

> The day I took her car keys, she was mad at me. She was going to call the law, and I explained that her doctor had wanted this to happen, which was not true. But we just knew it was not safe to drive anymore. And that was the hardest, taking her car keys, taking her independence from her. She did not like that at all.

Participants expressed the desire for their parent to maintain autonomy and make their own decisions, but the relationship between parent and child functioned for the child to step in, when necessary. Based off the narratives from their children, the parents perceived to struggle with loss of independence, but the children understood the reality of their parent’s livelihoods.

Struggle of Comfort, Relief, Guilt, and Denial

When describing the emotions surrounding their parent’s diagnosis, many participants *(n=10)* demonstrated being in denial of their parent’s condition and yielded itself to a common theme among the participants included a balance of children not only wanting to keep their parent comfortable throughout the process of their illness, but also the ways relief and guilt play a role in the end results of the decision-making process. Parents also demonstrated this struggle of emotions in the ways they would shield information or make decisions apart from their children. This was done, as perceived by some participants, to maintain the protective parent role and limit the potential amount of guilt experienced by the child. Jane's parents are both still living, and she has a role in their care and aids in decision-making. But she understands the role of her mother to be the caretaker for her father and how that creates stress in the caregiving and decision-making process. She noted that her mother often shields information from her to not be a burden on her daughter. Jane stated:

> It's funny because my mom, she's smart enough to where she sometimes hides things from me…She'll just know something's not right with him [Jane's dad]. Well it's just like, 'Mom, you should have told me this was happening. How long has this been going on?'

Expressions of guilt and relief in decision-making were demonstrated in Tom's caregiving for his mother. Tom stated that his mother was relieved when he stepped in to start the caregiving and decision-making process for her, but he also expressed feeling guilty at the end of her life at his own relief that her pain was over. Mark's interview also conveyed a sense of relief on the part of his parent to step in and help make decisions. When asked how she reacted to seeing her child move into a caregiving role, he said, "She did not resent it like you would have thought for an independent individual like her…She was almost relieved that we were stepping in and helping."

Diane, Joe, Mary, Bill, Jane, Sarah, and Terrance *(n=7)* had one parent still living at the time of the other parent's diagnosis. They indicated the importance of the patient's spouse to be in decision-making roles, as well. Based on the interviews with the adult child, the caregiver parent in these families accepted the child's help but established a pattern that they would be the one primarily making EOL and health decisions. Sarah's mom did not want their children to live with the aftermath of taking her mother out of a coma, but she stated:

> "All four of us [Sarah and her siblings] would have not let her go on as long as Dad did. But they had always said they would never put any of the children to make that decision, that only mom would make it for dad and only dad would make it for mom. Which took a lot of pressure off of us, but at the same time, we knew it [staying on life-support so long] wasn't what she wanted."

Mary's dad had Alzheimer's and therefore could not make decisions for his wife, Mary's mother. Mary's mother ultimately accepted that she needed help. Sandy's brother informed her that their mother "broke down" and cried one night after remaining very strong and optimistic about her condition. Sandy said, "I think it was a relief for me that she finally did." Sandy and Mary looked to their parents to find that relief to continue and move forward with their care.

Hard Conversations

One of the largest underlying themes in decision-making and EOL care was the hard conversations occurring, or lack thereof, by the families. Bill mentioned how he recognized the importance of the conversations and encourages all families to partake in EOL conversations before it is too late. He stated:

> Being open has been a key. Being able to talk about things and not say, 'Well I can't deal with that because it's too deep a subject, too heavy a subject.' You just got to be able to talk about stuff and just work through it.

Eva, who works in the medical field, discussed how her family was not as receptive to the conversations, but in her line of work she recognizes the necessity to have communicate the patient's wishes as a family. She stated:

> It was hard because they didn't understand some of it that you just don't know. Sometimes it's death with dignity and you just have to let go. And they didn't understand. It's just hard. Yeah, most family members that don't have a medical background just don't let go. It's your mom, and it's just hard.

Keith and Wanda also discussed the concept of dying with dignity and understanding the delicate balance of their desires and wishes for longevity for their parent while being mindful of how uncomfortable they may be making their parent in the process. Keith discussed his family having to manage their desires to keep their mother alive and well, knowing that she may be miserable in the process. Wanda discussed a previous death in her family where other family members took extreme life-saving measures, and she knew her mother's wishes to go with dignity. Wanda said that "children who are caregivers don't always remember that."

Wanda and Terrance claimed that their families did not discuss these hard conversations. Instead, they described the power of listening in EOL care. For example, Wanda said her dad was needing a new suit, but casually mentioned that he did not like suits and did not want to be buried in a suit. Similarly, Terrance's parents mentioned that they sold their grave plots next to each other and realized they would rather be cremated.

Keith, who is a medical provider, reiterated the need for all families to discuss death and dying because "it's something everyone needs to learn about because we all deal with it sooner or later." He mentioned that no one is ever fully prepared to bear the conversations but having them helped them cope with the outcome. He stated:

> My mother planned her whole funeral. She picked out everything. She had a will, and we had the power of attorney in place. We had the health care directive. We had all this stuff. So we knew her wishes. We knew her plan. She made all those decisions.

Understanding that the conversations will not be easy is a large part of the process, but having the conversations, although they exist in different ways to different families, helps in the long run in the context of how the family views the situation in retrospect.

Relational Influence

Family Context and History

Whether it was explained verbatim, or alluded to in the context of the interview, family history plays a large role in the adult children processing and caring for their parent. All participants *(n=15)* discussed their family history and mentioned either one or more siblings with whom they were frustrated with throughout the process, siblings who did not partake in the process, or siblings who they trusted most in the process. Diane's interview indicated a very positive communicative experience with her siblings, and she contributes their experience to the fact that they are a military family and moved around a lot as kids, forcing them to always rely on one another. Keith, Joe, and Tom are children of divorced parents, and their relationships with their families contributed to how they made decisions on their parents' health concerns. Keith was close with his mother and described how he and his 6 siblings experienced the shared trauma of the divorce and the death of one of his older brothers. Through this heartbreak, they became extremely close as a family unit. Although he felt that some of his siblings did not pull as much weight in the caregiving process, he described a strong closeness among the siblings that aided in communication throughout the EOL process for their mother. Alternatively, Joe and Tom described not being as close with their siblings or their parent at some point. Joe was not informed of his mother's diagnosis until much later, and Tom revealed that he was primarily raised by his grandparents, but in his later years became the caregiver for his mother. Tom shares a half-sister with his mother, and he directly stated that he did not want her participating in the caregiving process for his mother. He stated that he "didn't trust her [to be a part of the process] and she didn't volunteer anything." Another participant, Chris, demonstrated resentment to one of his sisters who was the lead caregiver in the process, and specifically mentioned being frustrated with her a lot while caring for his mother. Chris said he relied heavily on his sister he was closest to, and not the lead caregiver sister, to give him "just the facts." Although Joe's brother participated in the caregiving process, Joe described not having a close relationship with his brother or his parents. Joe and his brother operate as a team but under a business-like mindset of compromise and understanding.

Joe, Chris, and Tom (*n=3)* demonstrated an emotional distance from their parents due to their upbringing, and although they care for their parent and wanted the best care for them, their history reveals a tension in the caregiving process and communication with their families. Mark's relationship with his brother was described as a loving and respectful relationship, but Mark referred to opinions on their mother's care as the following: "his thoughts were priority thoughts, and my thoughts were just guesses," which could yield itself to historical sibling rivalry or strife. Family context and history infuse many of the discussions surrounding the participants' decisions for their parent's care.

Friendships

Some participants *(n=7)* mentioned having a confidant outside of their family or a close friend who had been through the caregiving and EOL process before to help them emotionally. Mary said that her friend was "somebody who had been through it and could tell me what to expect." Sandy referred to her friend as a "lifeline" for her, because she knew that she had someone she could talk to that understood what her family was going through. Sandy said:

> One of the most wonderful blessings, a blessing above all blessings: I have a very dear friend who has been caring for her mother…Having my friend, Amy, that not only been through it, but was going through it, and had already been through all the steps that I had, to have her that I could call, to sit down and talk to, and knowing there was somebody that understood…thank God.

Jane, Keith, and Sarah all recalled discussing their parents' health concerns with close friends who had gone through, or were currently experiencing, the caregiving process. Wanda discussed her mother's health with her best friend who is a medical provider, but also discussed it with people that were "part of our larger community that we knew" to help gather support. Regardless of the closeness of the siblings and how interactive they were as adults, having an outsider who is a close friend emerged in the data, showing the influence of other relationships on the caregiving and decision-making process.

Emotional Response

The EOL and caregiving process surrounding their parent's diagnosis evoked a complex variety of emotions ranging from frustration to sadness to anger among the participants. Many participants who described having closer relationships with their parents *(n=12)* recalled being heartbroken and devastated over the news of the diagnosis. Liz recalled feeling physically sick and shocked for days after hearing of her mother's diagnosis. She stated:

> I felt sick, nauseated for about a week. But at the time, she had gone through a year of testing and seeing doctors and no one really knowing what was wrong. Just the shock of it all. We were grateful she got a diagnosis, but sick because we knew she was terminal.

Eva described a similar response to her mother's declining health and memory by saying she "cried for days" and described her hurt when her mother did not recognize her anymore. She said:

> But she did have some congestive heart failure issues and I worried, actually I *prayed*, that God would take her heart first. I worried about her not knowing me, which it did come to that…But it hurts really bad to see your mom not knowing what is coming.

Terrance described the conversations surrounding dad's health decline as "uncomfortable" because it was new to him. He felt that his dad not being as active, going to work every day, and not being able to do his normal activities felt like it was not the man he knew growing up. Terrance described his admiration to his father by saying:

> He’s been pretty stalwart or stoic in how he’s faced it. Like, I mean, he gets upset sometimes but I think he gets upset more because of how it’s disrupting his life and not how it’s affecting him…Which for me is kind of helpful because, rather than see him have breakdowns, it’s been encouraging to see him remain more steadfast in the face of adversity.

Jane said that her family tries to be “honest and calm” in the way they handle decisions regarding their parents’ care. She said, “We try to be reasonable, and we try not to let our emotions get the best of us, and we really do try to put our parents first and not our own wishes.” Mary described opposite emotions felt between her and her mother, as well as her and her brothers. She recalled feeling “slighted” and “cheated” in the process due to the way they found out about her diagnosis of cancer once it was too late, and how she did not believe her mother received the best care. She describes not wanting to face the truth that her mother was terminal saying she was “desperate to take her somewhere to get a different diagnosis.” She never wanted her mother to give up hope and wanted to believe that her mom may overcome her diagnosis. While she was concerned for her mother, her relationship was becoming more and more “volatile” among her brothers. She recalled her brothers commenting to her wondering “where she gets the nerve” to step in the way she did. Retrospectively, Mary understood that their tension as siblings was coming from a place of stress within the family understanding that they did not want to face the future.

Jane, Liz, Mark, Mary, Tom, Wanda, Keith, and Chris *(n=8)* described experiencing various frustrations at some point. Jane, Liz, Tom, Keith, and Chris primarily mention frustrations among their siblings on not offering physical help or emotional support. Jane's father lived with her for 18 months while battling a serious disease, and she expressed her frustrations with her brothers in the process for not checking in enough. She said:

> [It was] frustrating in that when they were here, and I was the caretaker for 18 months, my dad was sick and in and out of the hospital here. And no one ever called to say, 'Jane, how are you holding up?' or 'Do you need anything?'

Along with being frustrated for her brothers' lack of empathy to her situation, she mentioned that she was frustrated with his disease—what was ultimately causing the strife within the family.

Wanda, Mary, and Mark mentioned emotions of frustration among the medical community regarding their parent. Mark's mother was sent back and forth from the hospital to the nursing home to be treated for pneumonia and sepsis. Mark stated:

> I felt frustration with the nursing home, especially at the early stage, because they were supposed to be treating her for pneumonia, and they weren't. So I was frustrated with that. I was frustrated with the hospital for what I said, actually just kicking her out. But they have Medicare rules that they have to go by, and according to them, Medicare was dictating all that…It was extremely frustrating.

Wanda also describes always feeling frustrated with communication within the medical community stating:

> Always the physicians and always just really bad communication…One thing I think they do is they don't overshare information to people that they don't always think will understand it. I think physicians curate their messages around who they think the receiver is, which is not always bad. But, you know, I would ask very specific questions about a certain chemo regimen, and I don't know that they always wanted to answer to that.

The majority of participants either mentioned certain emotions in response to questions or discussed those emotions when giving narratives of a particular experience, indicating that the caregiving process for them was a very emotionally charged process. However, Joe, Tom, and Chris *(n=3)* indicated that they were not very close with their parents either growing up or as adults. All three participants had less emotional responses to caregiving for their parent. Joe, who stated that he was not very close to his mother, did not have a large part in the caregiving process for his mother initially. Joe said:

> Because my mother lived eight hours away, her husband did most of the communicating with us. And sometimes we felt like we were not totally welcome to be involved in the process. And the two of them dealt with it together. And mostly he was in charge, a little more than mostly. And we were almost like outsiders…We were supposed to accept what information we received and not necessarily become deeply, deeply involved.

However, once Joe's stepfather died, his mother moved to his town, and he now shares overseeing her health with his brother. He now views his role as a caregiver more as a responsibility to his mother as the "adult thing to do." Chris mentioned how he was very withdrawn from the process due to his professional responsibilities and his own family responsibilities. Tom described how he was sad but understood that "there was not much he could do" in regards of his mom's diagnosis. He described following any instruction made by the doctors on her case and said he was prepared for her declining health saying, "I knew it was coming, so it was not unexpected." The three participants who described more emotional distance between their parents perceived to view their caregiving responsibilities as a moral obligation, whereas the participants who described stronger emotional relationships with their parent were more likely to describe the experience through a deeply rooted emotional lens.

Matriarch as Foundation of Family

Majority of the participants indicated having close relationships with their parents *(n=12)*. Of those twelve participants, many of them participated to discuss their mother's illness *(n=9)*. Even though the remaining three participants (from that group of twelve) focused primarily on their dad's illness, they relied heavily on their mother's input and role in the family. The role of the matriarch infused many discussions of physical and emotional health and well-being within the family. Diane, Wanda, and Jane described their relationships with their mothers as more resembling a friendship regarding closeness, all perceiving a great relationship. Mary, Mark, Liz, Bill, Eva, Keith, Sandy, Sarah, and Terrance each describe having some variation of a wonderful relationship with their parents, but specifically mention their mothers at some point being a resounding leader or rock within the family.

Sandy described her mother's tendency to be strong and resilient saying, "It's just from what we had seen of our mother being so strong and [able to] bounce back, none of us could believe it [her condition]." Sandy described her mother wanting to stay strong after experiencing a life-threatening stroke and reminisced on how her mother never cried until toward the end of her life. Wanda described the shift in dynamic between her and her mom in the caregiving process stating her mom did not want to be a burden to her daughters. Her mom would frequently say, “I hate that you are having to do this for me.” She explained it by saying, “That flip between the moms and dads taking care of the babies, becoming adults and then taking care of them, that whole life cycle is already probably tough for parents.” After her mother died, Liz shifted into a new role in her family as she assumed more of a role as a matriarch after her mother passed, hosting all family event and being a peacekeeper for the group.

Eva and Keith, who both work in the medical field, described the experience as being “different” when it is “your mom.” Eva stated that she is very open about death and dying but it is “more intense than when you’re dealing with other families.” Keith, who consulted with physicians in the appropriate specialties, understood what happened when an aging parent passes away, but he still chose to read a book on the subject to know what to recognize when the time came for his mother to die.

Diane reflected on her last months with her mom as “heartbreaking” and “really hard to see my mother go down like she did.” Diane also described being in denial and “not wanting to face it. Not with our matriarch.” Mary mirrors this mother-daughter relationship reminiscing on her uncertainty of wondering how their family will ever be able to move on after describing her mother as “our rock.” Liz described the ways her mother openly discussed not wanting to be a burden on any of her kids, and how that contributed to her mom’s emotional health. Liz said, “She was never angry about it. Just, sad. Kind of saddened that we had to step into those roles.”

Even for Terrance and Bill, whose interviews were focused primarily on their father’s health, would lean to their mothers as a source of either comfort or guidance in the process. Bill’s mother spearheads all caregiving responsibilities for his dad, and she is the person Bill goes to for guidance outside of the medical community. Terrance discusses going to his mom if he disagrees or sees any concerns regarding his father’s care. He stated, “[If] I disagree with what’s happening, I’ll talk to Mom. She tends to be, between my dad and my sister, she tends to be the most levelheaded.” He also referred to his mother as a “voice of reason” within their family. Jane discussed how her mother still maintains a protective role of wanting to shield her children from certain aspects of their health but being grateful for her children’s input and availability. Mark and Jane both referenced their upbringing and the type of household they lived in being a driving factor of their responsibility to take care of their parents, and how they are grateful for their lives provided by their parent.

CHAPTER V – Discussion

The results of this study indicate that adult siblings seek and process their parent’s life-threatening diagnosis by seeking more information from their personal connections to healthcare providers and through their outside friendships. In addition, the parents and adult children demonstrate a pendulum of reluctance and acceptance of their role reversal in the parent-child relationship throughout the caregiving process. Adult siblings demonstrate convergence in two main ways: (1) through their personal connections in the medical field, who may not practice under the scope of the participant’s parent’s illness, and (2) through their relationships with someone outside of the family who has experience in caregiving for their parent. Participants like Tom, Wanda, Diane, and Sarah, who indicated close family friends in the medical field would converge their information about their parent’s diagnosis to verify, solidify, or even potentially contradict, the original information provided. Whether it was making sure they knew to ask the right questions, they were interpreting the information given, or if they were inquiring if the treatment is effective enough, the siblings were using their medical community contacts outside of their parent’s HCP for their condition. MCF demonstrates ways an individual verifies information, reinforces opinion, or relates the message to themselves. The participants in this study verify their parents’ caregiving details and diagnoses with their trusted personal sources.

Some participants indicated having a personal relationship with a medical provider within their immediate family, either as a sibling or spouse (Jane primarily relied on her husband for convergence). A trend in the data showed some resistance within participants who indicated that their sibling was their personal medical contact. In the case of Liz and Chris, they felt their sister who was the medical contact was the end-all be-all voice for their parent's care. Like Sandy's relationship with her sister who is a nurse, she assumed an attitude of resistance to her sister, specifically regarding her sister's response to an issue with a home health nurse. The participants who had a sibling in the medical community communicating the details of their parent's health demonstrated characteristics of a matured sibling rivalry that is rooted more in concern for their parent (Wong et al., 2015).

However, the siblings in this study also demonstrated a sense of retrospective relief that that their sibling had medical knowledge and experience to offer a more tangible support system, revealing the complex nature of adult sibling relationships, especially with the tension that exists surrounding their parent's well-being. Additionally, two of the participants indicated that they are a HCP, and they used their pre-existing knowledge to assist their families in the EOL and caregiving process; however, both Eva and Keith demonstrated the difference in practicing with other families versus their own family. Eva, although she serves as a long-term care nurse practitioner and exposes herself to death and dying and caregiving regularly, reiterated how painful it was to watch her mother suffer and how she relied on her relationships with the doctors on her mother's team for more information. In addition, Keith was very knowledgeable of the process, but still conferred with colleagues on what to expect and read *On Death and Dying* (Kübler-Ross, 2002) to recognize what he, despite seeing it regularly, will see in his mother as she declined in health. Despite their extensive knowledge on the subject matter, the HCPs in this study, also, actively sought more information.

The participants in this study reveal that each family has unique relationships and roles that are subject to change, especially when it comes to one day caring for an aging or ill parent. The results in this study are consistent with the concepts presented by Hemway et al. (2018) that as children age into adulthood, their shift from a forced proximity closeness into a voluntary relationship requires more effort and intentional contact to maintain a sense of closeness and stable connection (Jensen et al., 2018). Many of the participants who had more than one sibling noted that they were closer to one individual sibling compared to the others, whom they contacted more frequently. However, regardless of the closeness felt between the siblings, many participants reported a non-family member who had been through the caregiving process, who would offer guidance and support throughout the process of navigating their parent's life-threatening diagnosis, which can be seen as another type of message convergence. This non-family member, typically described as a close friend or community member, played a large role in the information seeking and decision-making process through sharing their own experience. The interaction among participants who consulted with a friend can be described more or less as someone they can vent to, but those participants allude to a sense of validation and resonation after hearing what other people recommend, or how they applied their own family relationships to the experience, which can potentially impact how one sibling chooses to handle a particular situation based on their convergence.

Adult children in this study processed the events through a lens of retrospective uncertainty management surrounding their parent's diagnosis by processing the events through a new perspective in hindsight. Some participants retrospectively discussed their uncertainty and the decisions they made from a faith-based perspective. They described how God was taking care of them, giving wisdom, and disguising blessings through the pain. Additionally, some participants practiced retrospective uncertainty management through basing other events occurring at the time, like the pandemic or other pre-existing illnesses, as causes of uncertainty that led to the decline in health. Alternatively, some participants demonstrated their retrospective uncertainty management by lessening the uncertainty for their own children after learning a hard lesson from their personal experience, and now view the uncertainty surrounding their parent's illness as a means of providing better care for their children.

From the myriad of emotions, family history, context surrounding the illness, and the participants' personal lives, the findings indicate the importance of practicing empathy and respect within the family. Whether it is by *self-respect* through understanding the call to help and assuming that role as more of a moral code, or by *respect for their parent* through gratefulness to childhood upbringing and emotional ties to the relationship with their parent, majority of the participants demonstrated this desire of respect within the family and understanding the circle of life. Even the participants who indicated less closeness with their parents, their responses indicated a call to being a good steward of your family and being mindful of the illness that affects them.

Additionally, themes of matriarchal strength and independence are connected to the children's response to care. Whether describing their mother as independent and strong, or as their best friend and confidant, most of the children in this study revered this idea of motherhood being a foundation within their unit. Henceforth, their mother's health and well-being was perceived as not only a priority, but also a large source of stress and uncertainty in maintaining the structure of the family. This concept of relationships from child to mother supports claims made by LaFrenier (2020) that patterns of communication develop throughout childhood relationships within the family, and in this case, their reverence to their mother and their upbringing contributed to their response to care.

Also, the analysis from this study indicated a unique trend within the children in this study recognizing their parent's decreased independence and the desire for them to maintain autonomy. Parents were often looped into the decisions made for improving their activities of daily living, but their dependence on their children remained a tension in the family dynamic. Based on the participant responses, most of the parents struggled with the idea of being a burden to their children, even if they were aware they needed help which is consistent with Pecchioni and Nussbaum's (2000) findings. According to their study, discussing the caregiving process prior to diagnosis is vital to understanding the balance of shifting into the caregiving role but still granting the parent the autonomy to make their decisions.

Consequently, most participants felt unprepared or unwilling to discuss EOL care prior to their parent's diagnosis but agreed that EOL conversations are important within the family to maintain desires of the parent, and potentially yield more stability in sibling relationship. Consistent to previous research on EOL care, many tensions exist within conversations regarding death and dying (Keeley, 2016). Most participants indicated a reluctance and discomfort is discussing their parent's diagnosis (Thompson, 2011), in fear of speaking an undesirable outcome into reality. Avoiding EOL conversations increased uncertainty within the families and harmed some relationships due to added stressors to the caregiving process by either not knowing what the parent wants, disagreeing with their siblings on varying opinions, or not being informed on the actual diagnosis itself (Lillie & Venetis, 2020). Many participants in this study stated a desire to normalize discussing dying, because death is a reality facing everyone, and not discussing death is more harmful to the family in the long run.

Practical Implications

HCPs can begin the process of initiating EOL conversations within the family by encouraging families to discuss the matter earlier, prior to any life-threatening diagnosis, to normalize the discussion. In this study, any EOL conversations occurred after receiving a diagnosis, which added to additional stress and uncertainty among the family balancing a sensitive topic with the physical and emotional demands of caregiving. If families initiate EOL conversations prior to any diagnosis, the conversation presents itself in an informative manner that allows the family to possess a general knowledge of what their parent wishes in the event of their death. In a usual doctor's visit, an HCP or family health professionals can provide the patient with suggestions and tips on ways to navigate these conversations with their families in a way that is most appropriate, thus allowing the family members to think about their wishes without feeling the pressure of making a decision immediately for a family member.

Additionally, HCPs can receive trainings on ways to improve their own communication with their family and friends since the results of this study indicate that personal medical connections are vital in the information seeking process. This training should consist of ways to encourage EOL and caregiving conversations among their peers and their family members. Many participants indicated that their personal connection to the medical field served as a trusted confidant, sibling, or friend. Therefore, if they feel more comfortable discussing health matters with that one person, that individual in the medical field could recommend successful ways to begin EOL conversations. Based on the findings from this study, the adult child would then be more likely to report that information back to their family and feel more comfortable taking initiative to discuss such health matters within the family.

CHAPTER VI – Conclusion

Adult siblings have a unique role in decision-making for their parent after receiving a life-threatening diagnosis that results in caregiving. They often seek their information through their personal connections to the medical field while also seeking support from their close friends who have experienced the process within their own families. Families tend to demonstrate retrospective uncertainty management to process their decisions in a more comprehensive and palatable way to move forward. Each family tends to experience changes in roles among the shift from caregiver to care-receiver, isolating the roles of caregiving as a group effort with one or two siblings as the lead caregivers based on their professional experience or personal availability. This sample is not diverse racially or geographically, therefore this study limited to its lack of generalizability. The results are likely to vary if the participants were spread across different regions outside of the southeastern region of the United States, commonly referred to as the Bible Belt, which is known to place stronger value on faith, prayer, and obligation to family (South & McDowell, 2018).

In addition, this sample unintentionally included many participants that had personal connections to the medical field indicating privileged positions or connections that some individuals may not possess. Additional research can investigate further into the role of class and privilege in family communication surrounding their parent’s life-threatening diagnosis or condition. This sample included adults who have other adult siblings, so another possible insight for further research could be to apply the contents of this study to adult children with no siblings, thus opening up the scope of the sample to yield more generalizable results.

Ultimately, the results from this study highlight those tensions, emotions, and complexities within family communication among adult children when a parent is suffering from a life-threatening diagnosis or condition. More importantly, the results indicate that a large part of health communication exists outside of explicit health settings like the hospital or clinic in which an individual receives a diagnosis. Many conversations occur once the family is home, sitting around a dinner table or living room, and sharing the life altering news they received at their most recent doctor’s appointment. This study applies a qualitative, humanistic approach to understanding what happens after families leave the clinic, go home, and move forward with their new reality. The results from this study can be used in healthcare settings to understand the shift in family communication. However, the study is intended to be a reminder that HCPs, healthcare scholars, and professionals in academia can study and practice every measure in the book to prepare for the inevitable (facing the death of a loved one) and still feel the rug pull from underneath them. Recognizing and understanding that this curve in the circle of life—death—is unavoidable, and using pre-existing experience and knowledge is something that can help families avoid further strife and tensions, and hopefully maintain stability as a unit moving forward.

APPENDIX A – Interview Questions

Family history and relationships

- How would you describe your relationship with your parent(s) as an adult?
- How would you describe your relationship with your sibling(s) as adults?
- Do you feel like your family has meaningful conversations about the health and well-being of family members? Describe why you think that is so?

Initial symptoms/diagnosis and information seeking

- Recall the moment when you were informed that your parent was sick. Was it at the time of diagnosis or was it prior to the diagnosis (noticing symptoms, scheduled visit with specialist, etc.)?
- Who in your family was communicating the details of the symptoms and diagnosis?
- In what ways, if any, did you seek information to learn more about your parent's condition?
- Did you find or hear conflicting information regarding your parent's condition at any point? How did you interpret that information (or how did you come to a conclusion)?
- How have you noticed your parent responding and communicating about their condition? Does that contribute to any conflicting emotions or information about their condition?

Uncertainty

- Describe the ways you experienced uncertainty after receiving news of your parent's condition.
- Did you experience any frustrations with the communication or inconsistent explanations of your parent's condition? With whom were you frustrated? Elaborate.
- When faced with conflicting information or questions about the diagnosis/condition, who did you go to for answers and why?

Caregiving and decision-making

- Was there additional care, or certain caregiving responsibilities necessary for your parent's condition? If so, how did your family determine caregiving responsibilities?
- Did you and your siblings experience any conflict among discussions regarding caregiving? If yes, describe that conflict.
- Did you feel that you had a voice in decisions for your parent's care?
- When faced with conflict among distribution of responsibilities, was there a particular person in your family you would go to for resolution? Why?

- How has your parent reacted to having their children shift into caregiving and decision-making roles?

Longevity and End-of-Life

- Do you notice more conversations among your family regarding comfort and longevity for your parent? Did you feel prepared for these types of conversations?
- Has someone in your family initiated End-of-Life (EOL) conversations (i.e. understanding patient’s desires/wishes in the event of a traumatic event, getting affairs in order, plans for treatment/comfort in the event of failing health, etc.)? How did those conversations begin?
- Who all participates in these conversations?

Successful/positive communication

- What advice would you give to another family going through a similar experience?
- Was there any quality or characteristic you noticed among your siblings (yourself included) throughout the process that aided in successful communication?
- Is there anything else you would like to add about your overall experience with communication among your family regarding your parent’s condition?

APPENDIX B –IRB Approval Letter

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Research Integrity

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NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident submission on InfoEd IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.

PROTOCOL NUMBER:	22-1109
PROJECT TITLE:	Message Convergence in Information Seeking and Decision Making among Adult Children Regarding their Parent's Life-threatening Diagnosis
SCHOOL/PROGRAM	School of Communication
RESEARCHERS:	PI: Collyn Leggett Investigators: Leggett, Collyn~Anthony, Kathryn~
IRB COMMITTEE ACTION:	Approved
CATEGORY:	Expedited Category
PERIOD OF APPROVAL:	30-Aug-2022 to 29-Aug-2023

Donald Sacco Jr.

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

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