Campbell-Salome, G., & Barbour, J. B. (2022). Managing uncertainty for and with family: Communication strategies and motivations in familial uncertainty management for hereditary cancer. *Qualitative Health Research*, *32*(8-9), 1230–1245. https://doi.org/10.1177/10497323221090191

Literature Review: The context of this study heavily relied on the application of uncertainty management theory in the context of family communication surrounding hereditary cancer diagnoses in a qualitative analysis of 42 dyadic family relationships. Previous uncertainty management research has focused on uncertainty management on a more individually-focused level, this study was primarily focused on the ability of the family members to play a role in health decisions, make recommendations for the family member affected that effectively supports the individual, as well as the members of the family that face hereditary cancer. Family dyads were also a central part of this particular study to examine the types of uncertainty management between partners, parent-child relationships, and siblings.

Method: A sample of family dyads was gathered through snowball sampling. All participants were 18 years of age or older, and met the 2019 National Cancer Institute guidelines for hereditary cancer (a list containing, but not limited to: widespread family history of cancer, pathogenic genetic variants, three or more relatives with cancer diagnoses). The participants were recruited through various support and patient advocacy organizations after verifying through a screening test that the previous list of qualifiers were accurate. The group consisted of 18-76 year old participants, and the amount of time passed since diagnosis ranged from 2 months to 20 years. Nearly 90% of the sample identified as white, and furthermore, 75% identified as female. Over 76% had undergone genetic cancer testing; and just under half of them had a personal history of cancer. From there, the participants were asked to select a family member who was involved in a supportive position regarding their hereditary cancer uncertainty management. Among the groups of dyads, there were 29 biological parent-child or sibling dyads, 12 spouse-dyads, and 1 family of choice dyad. From April to November of 2018, the dyads participated in phone interviews, of which the dyads were a part of the same interview session by either joining the call together in-person, or by merging separate calls for those who could not be in-person. A list of diverse questions were asked in order to be as applicable to various families as possible. The interviewer prompted both people in the dyad as the time that each spent talking provided contextual insight about the relationship. The dyads were asked about the family history and story, how they make sense of uncertainty, risk, and how they emotionally cope. The interview time length ranged from 22 minutes to 64 minutes.

Results/Discussion: It was found that a shift from individual to familial uncertainty resulted in higher appraisal and reappraisal among dyads. One of the ways this cycle thrived among family dyads was through sharing stories of family crisis, trauma, and loss revolving around hereditary cancer in the family. Sharing seeing a member of the dyad go through a cancer crisis, loss, or trauma were reasons for participants to reappraise the uncertainty in their family. When it came to loss especially, participants reported feeling a sense of "duty" to look after their health and wellbeing and get tested for hereditary cancer. The next strategy reported by participants for managing uncertainty was family planning decisions; which included planning genetic testing, and

potentially using reproductive technology when deciding about having kids as to avoid passing the genetic cancer diagnosis to offspring. Between partner dyads, there was some comfort found in the fact that one individual cannot control the choices or outcomes of the person at risk of hereditary cancer, but planning for the future surrounding reproductive uncertainty was an effective way to manage that threat of uncertainty. When it came to addressing the threat of cancer to existing children, partner dyads used both individual uncertainty management towards their child(ren) as well as uncertainty management as a parent on behalf of their child(ren). Appraisal for both their child individually and for themselves as parents of the child worked as a good dyadic balance to handle the uncertainty. Several other appraisal strategies for uncertainty management were described among dyads, such as forcing seeking information, recalling sacrifices made by other family members, and voicing the stress of uncertainty threat within the family. Overall, the study demonstrated the significance of both individual and familial centered uncertainty management. Storytelling was a prominent theme among dyads in motivating testing, as well as appraisal and reappraisal to communicate effective management.

Application: A large takeaway from this article that I want to incorporate into my infographic is the importance of dyadic relationships and communication in managing family health uncertainty. I think this perspective is especially important when it comes to family stories and recalling what other members of the family have experienced/witnessed, and how that affects how they plan for uncertainty within their own individual lives and their own family relations moving forward throughout their own autonomous lives. I think the discussion of partner, parent-child, and sibling dyads will be a great application for the infographic, potentially even as a graphic. For example: demonstrating how many of the various management results were used primarily by one group of dyads versus the other ones in something like a pie chart.

Coder, M. (2020). Information needs and information seeking by family members and friends of terminal cancer patients: An exploratory study. *Journal of Hospital Librarianship*, *20*(1), 1–26. https://doi.org/10.1080/15323269.2020.1702838

Literature Review: The diagnosis of cancer is often an unpredictable diagnosis, and certainly a diagnosis that is ground shattering to the individual as well as the loved ones close to them. A terminal cancer diagnosis leaves everyone involved in a diverse and desperate need for management, support, information, decision making, and more. The pursuit for information is urgent and immediate, and previous research has revealed that the beginning stages of the cancer journey are when information and support from family/friends is most needed. The impact of the diagnosis greatly impacts the surrounding friends and family given that the uncertainty is deeply upsetting and complicated. This study examined the ways in which family members and friends close to loved ones diagnosed with terminal cancer go about their information seeking behaviors during the cancer trajectory.

Methods: Previous research laid down the groundwork for developing a questionnaire survey for participants of the study, much of which was developed from previous research by Chen and Fourie on fibromyalgia patients. The researcher for this study also used her personal experience of being

involved with her father's terminal cancer diagnosis to formulate the survey. The survey consisted of multiple choice and open-ended questions, as well as likert scale questions. The majority of the survey questions (19 to be exact) were information resource sections that included a text-box for the recipients to respond and reflect. The participants were collected through email invitations to a university (including faculty, staff, and students), announcements on library boards, announcements to a medical education research list, email invitations to local hospices, flyers posted in oncology clinics in waiting rooms where both patients and visitors could see the flyers, and personal networks for possible participants. The participants of the study were at least 18 years old, fluent in English, and personally dealt with the terminal diagnosis of a loved one close to them. The survey was anonymous and was open from August 1 of 2018 to November 30, 2018.

Results/Discussion: 82 participants started the quantitative survey, and 74% of them actually completed the survey. Respondents were composed of parents, children, siblings, friends, partners/spouses, and other family members such as grandparents and grandchildren. The majority of respondents indicated the patient close to them was given three months to one year to live (64%). This was followed by more than a year (22%), less than three months (7%), and unclear timeframe (7%). The questionnaire started by asking if the participant wanted to immediately seek out information about the diagnosis; the majority (72%) said "yes", but was followed by 13% that said "maybe", 7% that said "no", and 8% that said "Other (please explain). Reasons for choosing "other" included responses that revealed the participant was just a kid when the diagnosis took place, or that they were in shock, denial, or could not mentally cope with the reality. The participants selected a multiple choice response to their satisfaction regarding communication with medical personnel about the diagnosis, satisfaction with the material and informational resources provided by medical personnel, their perceived level of reliability of the resources provided, usefulness of the materials, and the information seeking obstacles they experienced; such as avoidance from information overload. It was concluded that the family/friends of the patient are impacted greatly by the terminal cancer diagnosis of a loved one, and that their information needs on a diverse range of topics holds a strong connection. Particularly, there is a significantly strong connection between information needs and information seeking on both their own personal behalf to understand the diagnosis, but also for the diagnosed individual because they were taking on much of the information bearing responsibility in taking care of their loved one. Respondents reported that making many medical decisions was an overwhelming part of the role the loved one played for the patient, which greatly motivated their need for information and was a driving reason for seeking additional information. Another important finding was the level of satisfaction understanding the healthcare professional and the medical terminology used by the professional. The most dissatisfaction that was reported was a result of the complexity and lack of understanding surrounding medical terminology being used. It was proposed that librarians could be a helpful solution for understanding explanations. The integration of librarians into the hospital setting can bridge informational gaps between healthcare professionals and families by using a checklist referral system at the end of appointments. This could assist the family in finding extra resources that are more accessible to those who are not medically educated. Since doctors, family, and nurses were reported as being the primary sources for seeking information, an additional medical librarian could help sew together any remaining informational gaps by being well versed in explaining medical terminology in an easier-to-understand way.

Application: I am personally *fascinated* by the suggested solution of medical librarians in hospital/clinic settings to help families and close loved ones of a broad range of ages to better understand the information they so desperately are searching for in a physically and emotionally very difficult time. I would LOVE to integrate a hopeful suggestion like this into my infographic, potentially as a part of the wrap up/result section of the infographic. Especially since there seems to be a broad desire across all the articles I have selected for family members to feel they have a grasp on understanding medical uncertainty in the family- this idea could serve as an excellent connecting suggestion for improvement in my final section of my infographic. As long as I can accurately build up the problem that spans across my four articles throughout my infographic, this article could be very helpful for me to create a hopeful and suggestive conclusion based on the research I have done for the project.

Scheinfeld, E., & Lake, P. K. (2019). Why is it just so hard? making sense of end-of-life communication between adult children and their terminally ill parental figures. *OMEGA - Journal of Death and Dying*, *83*(3), 611–629. https://doi.org/10.1177/0030222819859163

Literature Review: Within this article, it was stated that by the year 2050, one fifth of the U.S. population will be 65 and older, and furthermore will experience chronic health conditions that require care and support. Chronic health conditions are among the top 10 causes of death for 65+ year olds. Because of these statistics, the importance of end of life (EoL) communication should be a larger concern than it seems to be in reality. Less than half of adult children report discussing EoL issues with their aging parents/guardians. The study sought to discover prevalent coping themes, how individuals are cared for, as well as how they discuss Eol between aging parents and their adult children through a quantitative scale.

Methods: To conduct this quantitative study, the researchers used a combination of open-ended interview questions and survey tools to provide accurate insight into the reality of discussions between adult children and their parents about EoL. The goal was to better understand how the beliefs of the participants related to their care, hope, and coping as it related to the EoL experience. The participants were collected via use of flyers hung in local hospices, grief support groups, a Southwest college community, outreach through social media, and individuals who were known by the researchers to fit the criteria. The participants then signed up for one-on-one interviews and chose the location to have the interview based off of where they would feel more comfortable. All 14 of the participants had reported losing a parent within the last 5 years. Participants ranged between ages 24 to 67, and were either White or Latino/a. 11 of the 14 participants were identified as being female, the remaining 3, male. There was also a wide array of religious beliefs represented by the participants. The procedure started with a 10 minute written reflection prompt which asked the respondents to answer the question: "when it comes to final conversations, I remember…". Following this, they were given 15 minutes to complete a survey asking questions about daily health communication, patterns of family communication, coping mechanisms, and various demographics. Lastly, an interview investigating the EoL communication that took place with their terminally ill parent. This pertained to what stood out to them in their memory of the conversation, the relationship they had with their parent before and after the conversion, the logistics of it,

thoughts and concerns, as well as care and hope. On average, the interviews lasted 20-40 minutes and were audio recorded. The study also gathered information on the sex, age, ethnicity, diagnosis, length of diagnosis/illness, place of death, and the timing of the EoL discussion with/of the parent.

Results/Discussion: Six major themes were identified after analyzing the data: Protection (of both child and parent), the meeting of needs, guilt and regret, control (who felt who was in control of the situation), family dynamics, and the type of communication (nonverbal vs. verbal). When the child was demonstrating protection for the parent, it was usually expressed by installing hope in their parent, which took the form of hope that the pain wouldn't last forever. Some instances of hope were more unrealistic, and while the child recognized that, they still used it as a way to shield their parent. Another way adult children tried to protect their parent was by avoiding the topic of death and dying, preferring instead to focus on other things to keep them distracted or to make the most of the time they had left. Adult children reported doing anything they could to comfort their parent throughout the length of their illness, and another way they attempted to protect them was by doing anything they could verbally and nonverbally to ensure their parent was in minimal pain. In terms of the parent trying to protect their adult child, the most common forms of protection recorded during the study were the parents doing what they could to avoid the topic of pain, death/dying, and their illness. Adult children recognized that their parent was trying to protect them by sticking to positive topics and keeping conversation light. Some of the participants spoke about how their parent didn't want to be a "burden" to their child. The next theme revealed was the meeting of needs. A main focus of the meeting of needs for participants were tasks that were related to EoL, such as discussion access to the will, funeral arrangements, decision making with doctors, and signing documents. Participants expressed that ensuring these tasks were taken care of made the EoL process smoother and slightly easier for everyone involved. The third theme explored the common feeling of uncertainty many of the participants expressed as being guilt and regret. These feelings were correlated with the process of making decisions for their parent, and worrying about whether or not it was the "right decision". Several participants revealed feeling regret about not knowing how to correctly emotionally support their parent. Guilt over what was or wasn't communicated with their parent throughout their lifespan, or even feeling the EoL conversation never really happened and the adult child was left wondering if the decisions they had to make for their parent were what their parent really wanted. The fourth theme of control was reported as an issue for both parent and child. Control over the situation was a shared struggle, similarly to protection. The struggle for control was expressed both verbally and nonverbally between the child and the parent and this tug of war between the two was especially present when deciding what to do in the aftermath of death. One participant reported that her mother ultimately refused to make a final decision about what she wanted in the aftermath of her death- therefore maintaining control over the situation. When it came to family dynamics as the fourth theme, step parents and siblings were commonly brought up. Depending on the family dynamic as the parent reached EoL, some of the children found themselves surprised by the influence of others dynamic in the family relationship; some taking more control than the child expected, and some taking less. In one case, a participant reported the dynamic between her terminally ill mother and her sister was unhealthy to the point that she was asked to not leave her mother alone with her sister and instead stay to serve as a mediator and ensure her mother was safe. Lastly, the theme of communication type was one of the most broad of the six themes. It primarily focused on the differences between verbal and

nonverbal communication. For example, saying goodbye could take the form of verbal farewells and demonstration of love and care, or nonverbal ways of communicating such as holding hands, caressing, or eye contact. On the other hand, verbal goodbyes included messages of love but also conversations about the wishes the parent had for after their death, funeral specifics, paperwork, and bodily related decisions.

Application: This article was very difficult emotionally to get through, and as I include the findings about the six major themes discussed in this article, I want to propose this information in a gentle and gradual way. I think that this is an important topic to include in my infographic because, whether related to illness or not, families always experience death, and in the context of family health communication (especially between children and parents) it is important for families to be aware of the long lasting effects of not discussing these major themes surrounding EoL. I think for my infographic I would like to briefly break down each of the six themes into digestible pieces so that viewers of the infographic are not left in the dark by what each of them mean, but I would like to also spend a lot of time introducing the themes and how to handle the difficulty of discussing them.

Weber Falk, M., Eklund, R., Kreicbergs, U., Alvariza, A., & Lövgren, M. (2021). Breaking the silence about illness and death: Potential effects of a pilot study of the family talk intervention when a parent with dependent children receives specialized palliative home care. *Palliative and Supportive Care*, *20*(4), 512–518. https://doi.org/10.1017/s1478951521001322

Literature Review: This article relied on the use of Family Talk Intervention (FTI) to promote communication within the family when a parent is in the face of a serious illness. It is an understatement to say that it is extremely difficult to balance a serious health issue while working, supporting a family, maintaining routines, and more. Parents are often concerned about the welfare of their own children especially when it comes to communication surrounding the illness, understanding the illness and it's consequences, coping mechanisms, support, and how the illness affects everyone's experience in the family's story. The main exploration of the study was to use FTI to understand the effects of specialized palliative care.

Methods: This study actually took place in Sweden at a specialized palliative home care facility. A total of 20 families who had dependent children were recruited through two different palliative care homes to participate in an interview and questionnaire. The qualitative study took place over the course of a year, the families completed "baseline" questionnaires between March of 2017, and March of 2018. There were 6 interviews that were 1-2 hours long, and were conducted in intervals of 1-2 weeks. Interviews were led by FTI-educated interventionists. The first two interviews as well as the fourth interview included just the parents and the interventionist. The third interview was between the children and the interventionist, and finally the fifth and sixth interview included the whole family and the interventionist. The meetings between the interventionist and the parents focused on sharing the story of their own story and illness and setting the intervention goal for the family. In the third meeting, the children focused on sharing their understanding of their parents' illness with the interventionist while the interventionist focused on risk and resilience presented by

the children. The fourth meeting served as a summary of the first three interviews and then created a family intervention plan based on the summary- which took place in meeting five. The sixth and final meeting was a follow up for the family to present to the interventionist about how they felt the plan was going. The family participants were collected between two palliative care services in Stockholm, Sweden. All participants met the following criteria: the diagnosis of a parent with a serious illness, having at least one child that was between the ages of 6 and 19, and the ability to write and speak Swedish. There were a total of 20 parents that were ill with a serious condition, 11 of which were male, and 9 that were female.

Results/Discussion: There were four major findings using FTI, the first one being talking together as a family. Participants reported that the verbal communication helped each other gain and understand the various perspectives of the situation, and that they felt they had gained much from the communication that took place as a result of the interviews. Another finding unique to the way the study was conducted was a feeling of gratitude for the interventionist to help guide communication. Participants felt encouraged to participate in vulnerable topics of discussion that previously had been avoided before the FTI. The next significant finding was about sharing illness-related information. The patients reported an increase in satisfaction regarding illness-oriented family discussions between just the first two FTI meetings. Many opened up about the topic of symptoms, treatment, side-effects, and prognosis in hopes to alleviate uncertainty and worry the family was experiencing. It became important for both the patient and the rest of the family to increase widespread understanding of the illness through FTI. The third significant finding was maintaining family relationships. After participating in the FTI, families reported prioritizing fun family activities more than they did previous to the FTI. After the first follow up, nearly half of the families reported relational improvement between their partner and/or children. The communication strategies taught to the parents during the FTI helped increase open communication and problem solving with their children. The final FTI finding revealed increased security and decreased worry regarding the future. Several parents shared that the FTI contributed to them feeling more secure knowing that their family members better understood everyone's perspective in the family. FTI helped to ensure parents that their children would be more honest and open about how they were feeling in the lead up to the death of their parent. Interventionists aided this process further by arranging for family counseling and therapy when it came to this difficult progression.

Application: Overall, I think this article was almost the most versatile for my infographic as it examined how to better communicate between parents and children of a wide range of ages as it relates to illness and death. I think the four major findings are very applicable to family communication surrounding health and illness, whether the illness is terminal or just chronic, and ranging in severity. I think I would like to highlight these four major results in my infographic, possibly near the top and following the introduction.