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Sacred silence in pediatric oncology:
A qualitative study of communication during difficult conversations

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An Abstract of
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Abstract

Sacred silence in pediatric oncology: A qualitative study of communication during difficult conversations

By Sarah Rockwell

Background: In pediatric oncology, communication between pediatric oncologists, children and adolescents with high-risk cancer and their families is imperative to facilitate therapeutic alliance. Communication is particularly important during conversations about disease reevaluation, which often necessitate parental decision-making in the context of emotional distress. Silence can be used to create space for emotional and informational processing. We are not aware of prior studies that have investigated the timing, content, and context in which silence engenders a sacred connection between provider and patient/family during bad news conversations for children with high risk cancer.

Objectives: To determine the frequency of sacred silences used by pediatric oncologists during recorded conversations around disease progression for children with high-risk cancer and their families; to explore the nature of statements that precede (i.e., prompt) and follow (i.e., emerge from) moments of sacred silence.

Methods: Serial disease reevaluation conversations between pediatric oncologists, children with high-risk cancer, and their families were recorded across the progressing illness trajectory. Following codebook development, MAXQDA v.2020 software was used to manage audio-recorded medical dialogue and to apply codes. Segments coded as Silence, within Bad News conversations, were further analyzed to identify profound moments surrounding silence, labeled Sacred Silence.

Results: Bad news conversations included 238 coded segments of Silence, almost half fit the definition of Sacred Silence. Qualities of the surrounding conversation identified as creating Sacred Silence included: giving bad news, patient/family questions, provider information, empathic statements, silence, emotion, and provider questions. Empathic statements often prompt silence and the subsequent emotional expression by patient/family.
Multiple silences employed within close proximity to each other, creating a series, were identified as Stacked Silences. The majority of Sacred Silence moments occur within a series of Stacked Silence. The repetition of silence at consistent intervals within a series creates a psychological space in which everyone in the room can sit together and process. Each subsequent silence helps to advance the conversation further into difficult choices about decreasing treatment, end of life care, and prognosis.

Discussion: Silence used in close proximity to bad news during disease reevaluation conversations has the opportunity to evoke a sacred moment, which can include the expression of emotion, questions, and empathic statements that connect the provider and patient/family. These data offer opportunities to develop targeted educational communication programs for pediatric oncologists to incorporate silence, specifically multiple silences in close proximity to each other, throughout bad news conversations. Further longitudinal studies are needed to examine how silence impacts therapeutic alliance across the illness course.

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Chapter 1. Introduction

For patients with refractory cancer, communication across the progressive illness trajectory involves conversations that can be difficult for providers and patients/families. The use of empathic and clear communication punctuated by moments of meaningful silence can build therapeutic alliance, reduce stress, and improve patient care by alleviating physical and psychological suffering (Tulsky et al., 2017). Therapeutic alliance can be defined as the collaborative bond between physician and patient (Mack et al. 2009). In the context of suffering and difficult conversations, certain types of silence can create pivotal moments of shared understanding, connection, and presence (Duriex et al., 2018). There is value added when providers employ silence during difficult conversations with parents and their children with advanced stage cancer.

Despite this value, barriers to the meaningful use of silence such as insufficient research and a lack of evidence-based curricula persist. Improving communication between clinicians, families and seriously ill patients has been named a critical national priority in healthcare (Duriex et al., 2018; Tulsky et al., 2017). Therefore, cultivating the use of silence that creates a connection between clinicians, patients and their families is of great importance in the education of clinical providers.

Existing medical and pediatric oncology literature describes strategies and techniques to improve clinician-patient communication; few studies (Back et al., 2009; Duriex et al., 2018; Bartels et al., 2016), however, describe the facets that make connectional silence meaningful, or describe the impact of this type of silence in clinical encounters. Foundational research framed silence in the context of decreasing provider interruption of their patient; by using a reflected question followed by silence to illicit further information from the patient (Byrne, 1980).

Subsequent research emphasized the choice of the clinician to not speak as an important measure of patient involvement in their care; focusing on the use of provider silence as a way to describe patient-engagement (Back et al., 2005). Yet, not all silence is equal. Silence described as an absence of speech alone has been shown to create awkward moments between clinicians and their patients having the unintended effect of being interpreted negatively (Back et al., 2005). A typology of silence exists in the literature to describe the differences between silence that represents connection, distance, or neutrality in the patient-clinician encounter (Duriex et al., 2018; Back et al., 2009). Of all silence types, those that create connection occur infrequently, while those that represent distance and neutrality are common (Duriex et al., 2018; Bartels et al., 2016). We are not aware of prior studies that have investigated the timing, content, and context in which silence engenders connection between provider and patient/family during bad news conversations for children with high risk cancer.

Improving the use of connectional silence requires systematic measurement of conversations as they occur in the natural clinical setting to better understand and incentivize high quality serious illness communication (Duriex et al., 2018; Tulsky et al., 2017). Research on the use of silence thus far suggests a lack of understanding and implementation of silence that represents connection. Prior research on connectional silence has focused on quantifying these events in a largely cross-sectional manner in adult oncology settings. We are not aware of prior studies that have analyzed the interplay and utility of multiple connectional silences employed within the same poor-prognosis conversation. Additionally, no published studies have analyzed connectional silence as a communication technique in the context of recorded conversations following disease relapse/recurrence in high-risk pediatric oncology patients.

The U-CHAT (Understanding Communication in Healthcare to Achieve Trust) trial was designed to study prognostic communication, of which silence is an important facet, to address this gap in the literature. U-CHAT is a prospective, longitudinal investigation of communication between pediatric oncologists, children and adolescents with high-risk cancer, and their families, in which serial disease reevaluation conversations are recorded across the illness course and subsequently subjected to analysis. The Therapeutic Alliance project involved codebook development and implementation to examine therapeutic alliance related to communication techniques/styles. Analysis of the Therapeutic Alliance project identified Sacred Silences as a key communication strategy/pattern that could be further understood within the highest-risk patient cohort. Sacred Silence entails a complete thought within a conversation in which the oncologist gives bad news while also experiencing a sense of shared understanding, sense of enlightenment, or expression of emotion with the patient/family, in the conversation within one minute before and after a silence.

Through the Sacred Silence sub analysis, we aimed to 1) determine the frequency of sacred silences in discussions around disease progression for children with high-risk cancer and their families and 2) explore the nature of statements that precede (i.e., prompt) and follow (i.e., emerge from) moments of sacred silence. Describing communication styles and strategies that occur before and after sacred silences may provide opportunities for clinicians to identify ways to engender these moments within their own practice. Oncologist recognition of sacred silence versus other silence types has the opportunity to increase the use of sacred silence thereby improving therapeutic communication between the provider and the patient/family.

Chapter 2: Literature Review

The diagnosis of cancer is an emotionally distressing and life-changing event for patients and their families. While more than 80% of children diagnosed with cancer survive, in the United States cancer is the second leading cause of death among children aged 1 to 14 years old (Siegel, Miller & Jemal, 2020). For patients with refractory cancer, communication across the progressive illness trajectory should include establishing a connection, eliciting values and goals, and delivering information regarding prognosis and treatment course (Tulsky et al., 2017). Communication within pediatric oncology has unique demands related to family structure, child development, caregiver decision making, and school interruption in addition to burdens of complex oncology medical care (Dobrozsi et al., 2019). Encouraging patients and families to express their emotions increases their sense of being cared for, conveys relationship, and facilitates understanding and decision making, effectively creating a therapeutic alliance (Tulsky et al., 2017). While there is current literature that discusses therapeutic alliance and empathic communication in adult oncology more research in pediatric oncology is needed, specifically, to understand the role of nonverbal communication techniques such as silence in the setting of poor prognosis conversations. Examining patterns of how clinicians employ silence in conversations with pediatric patients and their caregivers will address this existing gap in the literature.

The Need for Trust

Therapeutic alliance developed between oncologist and patient/family becomes crucial in giving accurate prognostic information, empathic responses, room for processing, and next steps in goals of care. This relationship develops over time, as a family builds trust with their provider, through clinical encounters and disease reevalauation conversations. Patients experience visits

with clinicians in a narrative way, and yet much of the research thus far addresses single discrete encounters (Epstein, 2007). There have been very few studies using recorded conversations longitudinally, and of these, none described or quantified changes in communication styles, strategies, patterns or quality over time (Kaye & Kiefer et al., 2018). A longitudinal approach enables the study of continuous healing relationships as they develop over time, meeting one of the goals set out by the Institute of Medicine's 'Crossing the Quality Chasm' report (Epstein, 2007).

One study was conducted using audio recordings during outpatient conversations between oncologists and families of children with cancer to describe the initiation, response, and content of emotional communication (Sisk, Friedrich, Dubois, & Mack, 2019). They found that parents of children with cancer often communicate distress through subtle emotional cues and concerns (Sisk, Friedrich, Dubois, & Mack, 2019). A limitation of the study by Sisk, Friedrich, Dubois, & Mack (2019) is the difference between encounters with families and clinicians who had previously developed relationships versus encounters with a clinical team during a second opinion consultation. The clinical team members without a prior relationship with the family may not have responded to emotional concerns that were not explicitly stated as well as the clinicians with established relationships (Sisk, Friedrich, Dubois, & Mack, 2019). This highlights the importance of establishing a relationship between patient, caregiver and physician to understand subtle communication hints by parents and adequately address emotional distress, through the development of therapeutic alliance.

A measure of therapeutic alliance was developed and validated between advanced cancer patients and their physicians to look at how this alliance effects end of life experiences and care (Mack et al., 2009). A scale to measure patient's sense of mutual understanding, caring, and trust

with their physicians was administered to 217 advanced cancer patients along with measures of attributes related to therapeutic alliance, including emotional acceptance of terminal illness (Mack et al., 2009). There is no evidence that end of life discussions harm patients' therapeutic alliance, instead a strong therapeutic alliance is associated with emotional acceptance of a terminal illness among patients with advanced cancer (Mack et al., 2009). The findings of this study on adult oncology patients can be used to draw inferences about therapeutic alliance between providers and pediatric advanced cancer patients and their families. More specific research in pediatric oncology end of life communication needs to be conducted to understand the nuances of therapeutic alliance in the patient/caregiver and clinician relationship.

One study specific to pediatric oncology end of life communication was conducted using focus group discussions with twelve bereaved parents (Snaman et al., 2016). This study emphasizes the importance of relationship building and empathic communication, among other communication techniques, to foster therapeutic alliance between clinicians working with children with cancer and their families. Communication, both verbal and nonverbal, of health care providers with patients and families of children with progressive incurable cancer was explored during end of life care (Snaman et al., 2016). When discussing positive communication, 20% of coded segments were related to the theme of a strong relationship between family and staff (Snaman et al., 2016). Positive communication has been identified as having many aspects including, both passive actions, being physically present at a difficult time, and active behaviors, empathetic listening and showing emotions (Snaman et al., 2016). Further research can build on the responses of these bereaved parents to explore specific empathic communication techniques used by clinicians to maintain therapeutic alliance during difficult conversations.

The State of Clinical Communication Research

Effective communication can create a therapeutic alliance between providers, patients and their caregivers, and has been shown to improve goals of care and quality of life. Addtionally, developing a relationship between pediatric cancer patients, caregivers, and their physicians can positively affect communication. Most patients prefer that clinicians respond to their emotional distress with acknowledging and supportive statements that allow space for further disclosure (Sisk, Friedrich, Dubois, & Mack, 2019). In pediatric oncology, the parents and/or caregivers rather than the patient alone, are involved in disease prognosis conversations. For patients and family who experience a prolonged illness course with relapsed/refractory disease, or a poor prognosis, their treatment course becomes complicated with emotional distress and many decisional paths.

The literature shows that detailed, high-quality prognostic communication, regardless of the news being shared facilitates patient/caregiver adjustment to diagnosis, hope, and trust, and is associated with less upset (Dobrozsi et al., 2019; Mack et al., 2006). Despite this, physicians often tailor the prognostic information they are providing based on the emotional reaction of the parents, providing less details to parents who are experiencing greater emotional distress (Mack et al., 2006). A survey of 194 parents of children with cancer that measured parent rating of prognostic information as extremely or very upsetting found that the majority of parents wanted prognostic information about their children in as much detail as possible (Mack et al., 2006). It is common for patients and familes dealing with serious illness to have emotional distress and therefore, improving delivery of prognostic information and responding to parental emotional distress falls under the scope of the provider, and is a fundamental part of sensitive care (Visser & Schepers et al., 2018; Sisk, Mack, & Dubois, 2019; Mack et al., 2006). More research is

needed to understand how clinicians can best respond to parental emotional distress in the context of poor prognosis information.

The SPIKES protocol is a verbal and nonverbal communication technique that allows a provider to deliver distressing information in an organized fashion; Setting, Perception, Invitation/Information, Knowledge, Empathy and Summarize/Strategies (Kaplan, 2010). Communication techniques such as the NURSE pneumonic (Back et al., 2005) can be used within SPIKES to guide responses to emotional cues: Name the emotion, Understand the core message, Respect/reassurance at the right time, Support, and Explore emotional content and context (Sisk, Friedrich, Dubois, & Mack, 2019). The approach was initially developed for seriously ill adults and yet these techniques likely transfer to pediatrics, especially if clinicians focus more on asking open-ended questions and exploring emotional content rather than providing more information (Sisk, Friedrich, Dubois, & Mack, 2019). While these tools have significantly advanced the quality of communication during difficult conversations and make reference to nonverbal techniques, they are not inclusive of the impact and use of subtle nonverbal techniques across the illness trajectory.

While it has been established that nonverbal communication has a significant effect on patient outcomes, its measurement is less well developed (Tulsky et al., 2017). According to Tulsky et al. (2017), poor communication by health care professionals is one of the leading factors that contribute to patient's physical and psychological suffering. Tulsky et al. (2017) conducted a review of the state of communication science with the intent of providing a clear agenda for further research regarding communication. Five areas for research were identified to improve communication and to enhance patient care (Tulsky et al., 2017). They specifically identify the need for more evaluation of nonverbal communication and how it affects outcomes

(Tulsky et al., 2017). Tulsky's study summarizes the importance of communication in the provider-patient-family relationship and calls for urgent improvements in the quality of communication between health care providers and people with serious illnesses.

Given the importance of emotional communication, a National Cancer Institute consortium in 2007 defined 'responding to emotions' as a core function of patient-centered communication, and yet oncologists often miss these opportunities (Sisk, Mack, & Dubois, 2019). Medical communication literature suggests that physicians can help patients manage their emotions by exploring the expressed emotions and providing supportive and empathic statements in response to emotions (Visser & Schepers et al., 2018). Silence has been suggested as a nonverbal way to provide space in response to patients' emotions, which may encourage disclosure of concerns (Del Piccolo et al., 2011). Nonverbal skills such as silence, are not necessarily intrinsic and therefore can be identified and improved (Dobrozsi et al., 2019). Existing evidence-based communication training programs are focused on the care of adults with little to no programs specifically designed for pediatric clinicians (Dobrozsi et al., 2019). In future research on communication techniques it is critical to focus on pediatric-specific differences and the use of empathic and nonverbal communication to improve training programs.

In pediatric oncology there have been only a few studies that directly analyzed the communication of emotional content. It is suggested that pediatric oncologists are more likely to discuss medical information than emotions and yet these studies relied on the clinician's or family's recall after conversations occurred, subjecting the information to retrospective recall bias (Sisk, Friedrich, Dubois, & Mack, 2019). A more concrete basis of evidence regarding communication interactions and behaviors can be obtained using audio-recorded conversations (Sisk, Friedrich, Dubois, & Mack, 2019). Many studies have focused on initial diagnosis and

treatment rather than advanced disease. “Understanding emotional communication in advanced disease is particularly important because these conversations focus on life, death, and quality of life, often balancing hope for cure with more achievable hopes” (Sisk, Friedrich, Dubois, & Mack, 2019: page 2). In the future, longitudinally recording conversations can help normalize the recording process with the intention of minimizing any unintentional changes in emotional communication or behaviors by the participants (Sisk, Friedrich, Dubois, & Mack, 2019). More studies using audio-recorded conversations, longitudinally across the illness trajectory will uncover new information on communication between providers and their patients.

Intentional Silence

One type of nonverbal communication is silence, which is also described in the literature as; intentional silence, invitational silence, compassionate silence, connectional silence, emotion-oriented silence, or a pause (Back et al., 2009; Duriex et al., 2018; Visser et. al 2019; Bassett, 2018; Bartels et al., 2016). “Silences are filled with texture and feeling, and can have therapeutic, neutral, or destructive effects on the therapeutic relationship. While there are silences that feel awkward, indifferent, or even hostile, there are also silences that feel comforting, affirming, and safe. They resonate with the ease of a patient and clinician exchanging feelings and thoughts that do not quite make it into language” (Back et al., 2009: page 1113).

Back et al. (2009) propose a typology of silence used during clinician-patient encounters. They included previously existing research that categorized silence into “invitational” or “awkward”, and propose a new category of silence, “compassionate”. Awkward silence results from a clinician ‘using silence’ because of a directive to stop talking (Back et al., 2009). These awkward silences can be problematic as the feeling of awkwardness can be transmitted to the

patient and interpreted as something else, such as judgment, disapproval or withholding (Back et al., 2009). With invitational silence the clinician intentionally creates a silence meant to convey empathy, allow a patient time to think or feel, or to invite the patient into the conversation in some way (Back et al., 2009). The newly coined 'compassionate' silence occurs in a more spontaneous fashion from a clinician who had developed stable attention, emotional balance and naturally arising empathy and compassion (Back et al., 2009). These compassionate silences have a moment-by-moment character that can be experienced as a profound kind of being with or standing within a difficult moment that can nurture a mutual sense of understanding and caring (Back et al., 2009). This new typology of compassionate silence should be explored further in the context of pediatric oncology communication research.

The Palliative Care Communication Research Initiative multisite cohort study conducted a cross sectional analysis of audio recorded conversations in palliative care inpatient settings (Manukyan et al., 2018; Duriex et al., 2018). They determined that it was feasible and efficient to automate detection of conversational pauses in audio recordings during palliative care conversations (Manukyan et al., 2018). Connectional Silence in this study, which included two-second pauses or longer, was classified into three subtypes; Emotional (pause following expression of emotions or unfavorable information), Compassionate (acknowledgement and continuation of emotion after a pause), and Invitational (pause after a question related to values, hopes, goals, prognosis) (Duriex et al., 2018). Connectional silences were rare, only 32 identified in 100 minutes of conversation, accounting for only 5.5% of all two-second or longer pauses in conversations (Duriex et al., 2018). While Duriex et al. (2018) acknowledges that pauses can represent communicative connection, distance, or neutrality in human interactions they do not

elaborate further on the impact that therapeutic alliance between a clinician and patient can have on the type and significance of silences.

Two types of oncologists' communication, emotion-oriented silence and emotion-oriented speech, as compared to standard communication were studied using a randomized, experimental design study to investigate the impact on emotional stress and information recall (Visser et al., 2019). The study conducted scripted bad-news consultations with 217 participants in which the oncologist either: provided limited space for further disclosure of emotions (standard), responded with attentive silence until the patient resumed the conversation (emotion-oriented silence), or responded by acknowledging and/ or exploring the patient's emotional expressions and provided empathic and supportive statements (emotion-oriented speech) (Visser et al., 2019). Oncologists can reduce the emotional distress and enhance recall by emotionally engaging with a patient, this is done by conveying compassion or providing reassurance and ongoing support (Visser et al., 2019). In addition to helping patients to manage their emotions by exploring and acknowledging expressed emotions verbally and providing empathic statements, it has been suggested that oncologists can respond to patient emotions in a non-explicit way by adding silence (Visser et al., 2019). Emotion-oriented silence and speech resulted in better information recognition by patients than standard communication alone (Visser et al., 2019). The common factor in the two types of emotion-oriented communication is the increased amount of time available for the participants to process and store information (Visser et al., 2019).

Bassett (2018) conducted a review of published papers that describe professional caregivers' experience of silence as an element of care. Using a meta-ethnography approach, 18 papers were appraised, and their findings synthesized. "Silence as an element of care, is defined as silence which occurs, or is used, in interactions between professional caregivers, including

health professionals, social workers and chaplains, and their patients or clients with the intention of supporting the well-being of that person" (Bassett, 2018: page 186). There are three areas of focus described in the arguments of selected papers; the relationship of silence and speech, the use of silence, and the practice of silence (Bassett, 2018). Silence on the part of the clinician for the well-being of the patient is a decision often described in the literature as wise, intentional, deliberate, purposeful (Bassett, 2018). The relationship of silence to speech is described as a pause for listening and attending, and communicating beyond words (Bassett, 2018). The use of silence helps to convey qualities such as empathy, respect and support by facilitating reflection, and by shifting from "doing something for the patient to focusing on being with the patient" (Bassett, 2018). It has generally been agreed that therapeutic alliance is a pre-requisite for the use of silence (Bassett, 2018). However, existing research has examined discrete encounters rather than serial conversations, therefore it is possible that silence used skillfully can assist in building therapeutic alliance. Longitudinal research of providers and their patients could improve understanding of how therapeutic alliance develops in relation to how silence is used.

Audio data from a multi-site randomized trial looked at silences over two seconds long from 124 oncology office visits to characterize connectional silences (Bartels et al., 2016). The study developed a taxonomy to describe the strength of connection during these silences based on lexical and musical features such as pitch, volume and speaker turn-taking rhythm (Bartels et al., 2016). Patterns of communication 30 seconds before and after silence were observed to categorize connectional silence, which is defined as, "silence in which there was implicit or explicit patient emotional cue, doctor recognition of that emotion and an indication of emotional resonance between doctor and patient" (Bartels et al., 2016). Invitational silences, "opened up a conversation", and disengaged silences included "activities that distanced patient and doctor"

(Bartels et al., 2016). Out of 1211 silences that were longer than 2 seconds; 440 were disengaged, 700 neutral, 61 invitational, and 10 connectional (Bartels et al., 2016). The 10 instances of connectional silence were all located in the end two-thirds of only five discrete conversations, and often occurred in parts of conversations regarding treatment, future expectations and psychosocial discussions (Bartels et al., 2016). Connectional silence was often preceded by physician verbal expression of concern or empathy, or a patient/caregiver acknowledging a harsh new reality (Bartels et al., 2016). Further examination of these patterns of connectional silence related to timing and grouping during conversations could reveal common opportunities when therapeutic silence can be implemented. This research demonstrates the interconnected nature of empathic communication and the use of connectional silence in adult oncology and should be studied in pediatric oncology to reveal similarities and/or differences in the timing and patterns of silence during conversations.

There is current literature that discusses differences in communication between pediatric and adult oncology, therapeutic alliance, empathic communication in the setting of poor prognoses, and nonverbal communication techniques such as silence. Despite this existing research, there is a limited amount of literature that connects these topics. “In the context of suffering, some types of pauses that occur between patients and clinicians can represent pivotal moments of shared understanding and presence” (Duriex et al., 2018: page 1756). To further illuminate the ways that patients feel understood by their clinicians, qualitative research should be conducted to inform future research on improving the quality of continuous healing relationships (Epstein, 2007). Specifically, there is a need for deeper understanding of the qualities and impact of silence as an element of care and the benefits for clinical practice and patients in oncology settings (Bassett, 2018). Future research in communication should examine

silence in the context of poor prognoses conversations for pediatric oncology patients and their families, in relation to therapeutic alliance with providers.

Chapter 3: Methods

Overview

U-CHAT (Understanding Communication in Healthcare to Achieve Trust) is a prospective, longitudinal investigation of communication between pediatric oncologists, children and adolescents with high-risk cancer and their families, in which serial disease reevaluation conversations were recorded across the illness course and subsequently subjected to mixed methods analysis. The Therapeutic Alliance project involved analysis of these conversations to identify linguistic styles and strategies utilized by pediatric oncology clinicians to build therapeutic alliance. The Therapeutic Alliance project was the focus of this study, and the code "silence" was selected for further investigation and analysis.

Population and Sample

This study was conducted at St. Jude Children's Research Hospital, a large academic pediatric cancer center. The U-CHAT investigation was conceptualized and developed with clinicians and researchers in the field of pediatric oncology and palliative care with additional collaboration from bereaved parents of children who had died of cancer (Kaye et al., 2019).

The eligibility populations for U-CHAT included primary oncologists, parents of children with cancer, and pediatric patients. All primary oncology clinicians, defined as an attending physician providing medical care to solid tumor patients at St. Jude Children's Research Hospital, were eligible for participation in the pilot phase of the study. Eligible patient/parent

dyads were identified by reviewing outpatient clinic schedules and clinical trial lists. Patients with high risk neuroblastoma, any sarcoma, any carcinoma, desmoplastic small round cell tumor, incompletely resected or metastatic retinoblastoma, incompletely resected or metastatic Wilms tumor, or incompletely resected or metastatic melanoma were reviewed for eligibility (Kaye et al., 2019). An eligible 'parent of children with cancer' included caregivers who were biological parents, stepparents, or legal guardians 18 years of age or older with English language proficiency. Eligible patients were ages 0-30, had a solid tumor diagnosis with survival of 50% or less estimated by their primary oncologist, and were projected to have two or more future time points of disease reevaluations (Kaye et al., 2019).

For the purpose of the Therapeutic Alliance project within U-CHAT, eligibility was further restricted to only those patient-parent dyads who experienced disease relapse and/or progression while enrolled on study. These eligible patients were followed from the time of enrollment until the time of death or until 24 months from enrollment, whichever timepoint arrived first. The final study population for the Therapeutic Alliance analysis included 17 patient-parent dyads under the care of 6 primary oncologists and their respective clinical teams.

Research Design and Procedures

Data Collection

Data collection involved audio-recording conversations between primary oncologists, children with high-risk cancer, and their families at serial disease reevaluation timepoints across the illness trajectory. For the purpose of this study, a "disease reevaluation" was defined as any intervention that assessed disease status, including diagnostic imaging, lumbar puncture with cerebrospinal fluid analysis, bone marrow aspiration and/or biopsy, and surgical biopsy and/or

resection (Kaye et al., 2019). All discussions were audio-recorded in real-time regardless of the outcome of the evaluation, such that "good news," "equivocal news," and "bad news" conversations were all captured; this allowed for analyses of communication techniques across the entirety of the illness course, as well as precluded patient or parent association of the audio-recorder with the delivery of bad news. Recordings were uploaded into MAXQDA (Verbi GMBH, Berlin), a software program for qualitative data analysis.

Codebook Development

A review of the literature was conducted to identify communication techniques and theories specific to therapeutic alliance in oncology and palliative care. In the absence of consensus guidelines specific to building trust and therapeutic alliance in pediatric oncology, previously established gold standards for optimal communication, such as SPIKES and NURSES pneumonic frameworks, informed the development of the codebook (Kaplan, 2010; October et al., 2018). Codebook development was also informed by the NCI framework of core functions of patient-clinician communication and the core communication skills detailed in the ASCO Consensus Guideline for Patient Clinician communication (Epstein, 2007; Gilligan et al., 2017).

Thematic analysis was conducted to develop the Therapeutic Alliance codebook. Initially, one coder (SR) immersed herself in the audio recordings, composing iterative memos to distinguish and characterize distinct concepts within the data. Salient codes were identified and defined to create a preliminary codebook. Following initial development, the Therapeutic Alliance codebook was reviewed by the research team, with iterative changes to code definition, structure, and organization. An inductive approach was used to further improve content and specificity of the codes and code definitions. Two members of the research team (SR, EK)

familiarized themselves with the recorded data through repetitive focused listening, and serial memo writing within the audio transcripts (Birks, 2008). Recordings from each of the five participating oncologists were included in this pilot sample to ensure that the codebook was readily transferable across different communication styles and clinical practice representations.

Following independent audio review, the research team met to expand the coding schema, using recorded content to inform development of new codes and refinement of original codes. Researchers independently coded the same recordings in parallel and then met to reconcile variations and achieve consensus, modifying the codebook as needed. The codebook was finalized once intercoder agreement was achieved with negligible differences accrued when multiple coders applied the codebook across the same recordings. The finalized codebook, comprising 47 codes and subcodes, is described in Appendix A.

Code Application and Analyses

Using the revised codebook, two coders (SR, CW) working separately applied the Therapeutic Alliance codebook across all recorded disease reevaluation conversations for patients with relapsed and/or progressive disease. After double-coding, regular meetings were conducted with the research team (SR, CW, EK, MG, JB) to discuss examples of coding variations until consensus was reached for each coded segment in the adjudication process. Consistency in code segmentation was reviewed and standardized by multiple coders (SR, CW, EK, MG).

One code from the Therapeutic Alliance codebook, silence, was selected for the purpose of this analysis. The code was intended to capture silences that leave room for processing information and emotional expression. Therefore, we chose 5 seconds or longer as the threshold

for the silence code to ensure that we captured true silences that felt long enough to potentially open the door for further dialogue. We wanted to capture only those silences that were intentional as opposed to an accidental period of silence caused by outside factors such as computer usage or interruptions.

Code	**Definition**
Silence	Code for any uninterrupted pause that is 5 seconds or longer; a pause with intention to create space for processing or in response to an emotion; not including transitions.
Sacred Silence	A segment 60 seconds before and/or after a single coded silence: The provider gives information (or references having just given information) to patient/family related to scan results OR treatment options OR progression of disease OR goals of care OR prognosis **AND** at least one element below (before or after silence code): Sense of shared understanding/acknowledgement between provider and family **OR** Sense of enlightenment/catharsis. Can include provider responding to a question or making a statement that includes an element of truth-telling **OR** Expression of emotion by patient/family which preceded or followed statement by provider giving indication of shared emotions/recognition of expressed emotions. Can include provider invitation to continue expression of emotion.
Stacked Silence	A series of **Silence** codes can be linked together as one segment of conversation when there are no more than 90 seconds between the end of one silence and the beginning of the following silence.

Instruments

MAXQDA v.2020 software was utilized for managing data, listening to audio recordings, and applying codes from the codebook. Descriptive statistics were used to quantify the frequency and distribution of segments coded as silence across audio recordings to describe how this communication strategy was used around disease progression by oncologists in the context of disease reevaluation conversations.

Data Analysis

Given that the majority (nine-tenths) of segments coded as silence occur during bad news conversations, we chose to narrow our subsequent analysis solely to these audio recordings. In order to analyze and interpret results we created segments of data that included the conversation surrounding a coded silence. These segments begin and end with a complete thought, and last no longer than 60 seconds before and 60 seconds after a single silence code. Using these inclusive silence segments, we wrote memos on themes and concepts identifying profound moments surround a silence. We developed a definition for these profound moments surrounding silence and labeled them Sacred Silence.

We systematically reviewed the frequency and influence of co-occurring codes from the Therapeutic Alliance codebook on moments labeled as Sacred Silence. We explored themes and interactions between a variety of co-occurring codes and silence with the Sacred Silence moments. Patterns were further studied to identify common themes emerging from the co-occurrence of codes and Sacred Silence, as well as the context or dialogue prompting silence in these difficult conversations.

IRB Approval

This study was reviewed and approved by the Institutional Scientific Review Committee and the Institutional Review Board at St. Jude Children's Research Hospital [U-CHAT (Pro00006473); approval date: 7/12/2016].

Limitations

Some initial challenges identified in conducting this study included: buy-in from clinicians, patient/family recruitment, monitoring enrolled patients, logistics of capturing audio recordings and building rapport with the clinical environment (Kaye et al., 2019).

This study has several limitations that may influence transferability. First, it represents the experience of a single large academic cancer center that treats a large volume of high-risk patients and families from across the country and internationally. Second, racial and ethnic minorities are underrepresented in this cohort, affecting transferability of findings; future investigation should target broader inclusion of underrepresented patients and families whenever possible. Third, five primary oncologists participated in the majority of recorded conversations; these clinicians comprise a range of styles and years of clinical practice, however they are not necessarily representative of all oncologists' practice styles and strategies. Fourth, a small percentage of discussions were not recorded due to logistical and/or staffing issues or at the request of the participating patient or parent. While there was no apparent pattern in regard to missed recordings, missing data has the potential to influence synthesis and interpretation.

Chapter 4: Results

Silence contributes to a deeper understanding of bad news during discussions around disease progression for children with high-risk cancer and their families. Nine-tenths of all segments coded as silence occurred during bad news conversations. During bad news conversations between oncologists**,** children with cancer, and their families, silence is used to enhance empathic statements made by the provider, creating sacred moments. There was wide variation in the length of silences captured during sacred moments. The minimum silence length

was five seconds, per our code definition, while the longest silence captured lasted for 102 seconds.

Of the silence in bad news conversations, totaling 238 coded segments, almost half of these segments fit our definition of Sacred Silence. Sacred Silence moments were identified in at least one audio recording for more than three-quarters of the study participants. We identified the conversation surrounding silence, in these sacred moments, as full of empathy, outlined by co-occurring empathic statements coded from the Therapeutic Alliance codebook.

During analysis, we also identified a novel phenomenon in which multiple coded silence segments were found in close proximity to one other. This series of silences created an effect that we have described as Stacked Silence.

Sacred Silence

Initially we defined Sacred Silence, subsequently during analysis we described common characteristics heard in the conversation adjacent to silence, which were seen across all audio recordings, within segments of Sacred Silence. While each Sacred Silence followed a different pattern and arrangement of these associated characteristics, they maintain a similar effect regardless of the order or ratio. The themes within Sacred Silence include bad news, patient/family questions, provider information, empathic statements, silence, emotion, and provider questions.

The bad news theme includes moments in which the provider makes a statement to the patient/family regarding poor prognosis. In most instances of bad news within a sacred silence moment, this bad news prompts a silence. These bad news statements include information that there is a recurrence of cancer, usually revealed by indicating new spots on scan results.

F2 Oncologist: *Unfortunately, there is no good way to tell you. The CT does not look good. There are a couple spots in your lungs that I'm really worried about.*
Mom: *Do you think that's the spots that were there before?*
Oncologist: *No, no these are … they are real little the biggest one is only about 7 mm but there … you know, they light up on PET scan. That's part of what's taking so long, cause I've been wrestling with the radiologist and looking through all this stuff.*
Silence [7 seconds] audible crying
Oncologist: *Sorry*

A3 Oncologist: *The PET looks worse, and there's a couple of new bone lesions also. So, everything is getting worse unfortunately.*
Mom: audible crying
Oncologist: *But she doesn't appear to be feeling it right now, it seems like her quality of life is still... the same. But the lesions are getting worse and it's a likely possibility that she could start having more symptoms.*
Silence [5 seconds]
Oncologist: *I wish I had better news. Her scans last time were definitely better.*

Bad news also includes statements that the current treatment is no longer effective, the cancer is still growing, and that there is more treatment risk than benefit to the patient.

D1 Mom: *We talked today and what we know that it's a bad cancer … and we were just hoping that we could buy time or a cure.*
Oncologist: *Right, yeah. If that's part of our goal is to you know, to put things out as much as possible …you know then… maybe we want to do that without getting into really intense things that are gonna get you stuck in the hospital and things like that. Uhh you know, to me that seems like it would be a very, that would be a very reasonable goal, and a good goal to have.*
Mom: *At this point, we know you know more about this than we do. And you know we told her today, we don't want her suffering.*
Dad: *No, I don't want her hurting.*
Oncologist: *Nor do I.*
Silence [8 seconds]

A1 Oncologist: *One of the things that I sometimes tell my patients is that you always can try something, there's always else we can give you. The issue is when do you continue or when do you stop? And that's a conversation we will have to have. From what I am hearing from you right now you still want to give it a shot no matter what and that's why I'm going to give you these options for you to review and we can talk about that more next week. After you go home today.*
Silence [32 seconds] Mom audibly crying

The bad news statement can be in relation to discussing goals of care for the patient. Goals of care conversations often involve the provider and patient/family focusing on the quality of life, minimizing side effects of medications, and maximizing comfort measures.

> **D1 Oncologist:** *There's even the choice to do less than that and focus less on the rhabdomyosarcoma itself and focus more on you and how you're feeling every day when you get up. So that you know you're maximizing the way that you feel and that you can get the most, get the most out of every day. Ummm... And you know none of those are wrong choices, it's just a matter of what. At this point, what you feel is the most important goals for you. I'm sorry sweetie.*
> Silence [27 seconds] Audible crying

> **C3 Oncologist:** *So, it's a matter of what your goals are for him, in terms of treatment and treatment effects. In what you… how you want him to spend the time that he has here with us. We don't know how long that is. But you know the more treatment that he gets, and the more times it comes back, it makes it harder to go away. So, in light of…*
> **Mom:** *You keep saying how long he's gonna be here. Are we not expecting...? What are you all expecting?*
> **Oncologist:** *Umm… I'm expecting this to keep going. I don't have a clear treatment that will make it go away.*
> Silence [9 seconds]
> **Oncologist:** *Our goal, if you want to do treatment, our goal of treatment would be to slow things down.*

The subject of curability is discussed within bad new conversations. Most often curability or lack thereof is implied in these conversations. A provider explicitly states that there is no cure for the patient's cancer in some instances. Statements indicating no chance of a cure for the patient are often made in conjunction with statements about decreasing aggressive treatment and increasing comfort care.

> **D5 Oncologist:** Y*ou know let you guys come back after Thanksgiving and try to get something running then. You know, we have some flexibility on what we can do, and it's really based on what you guys are feeling.*
> Silence [7 seconds]
> **Dad***: So, even with the treatments that you have up your sleeve, you're still pretty sure it's probably not gonna have any effect? And by effect, I mean cure … I don't mean …I know I'm all the way on this one, I'm not going to beat around the bush on this.*

Oncologist*: Thank you, I take your meaning. I think knowing what we know about recurrent metastatic Ewing's Sarcoma …umm...I would have to say that the odds would be long to meeting the goal of long-term cure.*

A provider occasionally makes statements that reference the possibility of death, without specifically saying words such as death or dying. These statements are commonly discussed in conjunction with conversations about the patients' disease being incurable and other bad news statements.

A3 Oncologist: *So, you know if we're not doing good by giving her chemo*[therapy], *potentially bad, we're doing her harm.*
Mom: *Would 6 months, with the heart and the brain and the lung, would that be overstretched?*
Oncologist: *I think you are looking somewhere in the 2-4-month range. I think.*
Silence [8 seconds]

In the conversations in which the provider makes a statement that the patient could die or gives an estimated length of time until death, the provider is usually responding to an explicit question from a patient/parent about death.

D5 Oncologist: *And I think that if we do those things, and even if we don't meet that goal, that doing so may allow us to meet other goals. Of if we are not able to cure her …how long … can we put that off for as many days and as many months as possible. Umm you know what can we do for her in the meantime that's going to prevent Ewings Sarcoma from being something that affects her, in her daily life, and allows her to go to school and play with her sister and do all the things that she wants to do.*
Silence [9 seconds]
Dad: *And if we do nothing? How long?*
Oncologist: *That's a really difficult question to answer. And I wish I could tell you something with more certainty. You know the thing is right now* [patient name] *has no symptoms. Umm. We identified this based on imaging surveillance, which is very typically the case when you have lung disease. So, it's hard for me to say exactly how long that would be. I don't think that we'd be talking about weeks* [of life] *… I think left completely uncontrolled I also don't think we'd be talking about years.*

A1 Oncologist: *You have gone through the standard therapy, right? Which is [drug names listed], transplant. So right now, we are really just going to try to find a drug that could potentially work, the likelihood of that happening is relatively*

low, but we can try a variety of experimental agents to see if they can work against this tumor.
Patient: *Could I die?*
Oncologist: *You could potentially die from this, yes.*
Silence [21 seconds]
Oncologist: *I do not think that there is anything acute that needs to be taken care of today.*

Following the bad news statement, the patient and/or family frequently ask questions to illicit more information from the provider. In these questions, the patient/family is trying to understand or clarify what was just said to them. This can be viewed as an invitation to the provider to continue to give more information and details regarding the bad news. These questions are important to open the door for the provider and the patient/family to come to a point of mutual understanding of the patient's disease state. The questions also occur directly following silence, after the patient/family appears to have begun processing the bad news.

A1 Mom: *So, if we do the clinical trials and do more chemo, I mean are we talking about quantity or quality of life?*
Oncologist: *That is a very good question.*
Mom: *I don't want to be like no I don't want to do this, but I don't want to do this to her and make her sick and it not even help anything.* Audible crying
Oncologist: *It is a very very good point and that is why we are having this conversation.*
Silence [6 seconds]

D4 Oncologist: *I'm really sorry Buddy. Do you need a minute? Do you want us to step out? Do you want to talk to your mom and dad about anything?*
Silence [15 seconds] Audible sniffling
Patient: *If a surgical resection were possible, what would our options be?*
Oncologist: *You know, I think it would have to be something, at this point, very aggressive.*

B4 Oncologist: *You have a ton of support and a ton of people who love you.*
Silence [5 seconds]
Mom: *So, since it's already metastasized, what are the odds I guess you could say, of it going away?*
Oncologist: *I think it's really really really low. You mean for long term? That's just me being 100% honest.*

In the majority of sacred moments, the provider gives further information to the patient/family to clarify the meaning of or implications of the bad news. Most commonly this information is provided following a question from the patient/family. This can be heard as a natural flow of conversation with question and response. In situations in which the patient/family do not ask any questions, the provider makes statements giving further information interlaced with empathic statements.

A1 Patient: *Is it umm… impossible to do a bone marrow* t*ransplant since I've had a stem cell transplant or is that still an option that we have?*
Oncologist: *No, I would not transplant you again, you have had the most powerful, toxic and active agents against Ewing's* [Sarcoma]. *I would definitely not transplant you again.*
Patient: *Not even with all of the disease dead?*
Oncologist: *No, I think it would be incredibly toxic, and I don't think that he* [radiologist] *would do that either.*
Silence [43 seconds]

A3 Oncologist: *But unfortunately, this disease has come back very very aggressively.*
Silence [17 seconds]
Palliative Care Practitioner: *Can you share what you understood from all of that? Cause that was a lot.*
Oncologist: *And you don't have to make a decision today, you have time to think about it.*
Mom: *Yeah, I have no clue which direction to go in.* [crying]
Oncologist: *Yeah. And we don't expect you to. We don't.*

Empathic statements in these segments of Sacred Silence represent connection and enhance therapeutic alliance between the oncologist and their patients and patients' families. Empathic statements are important not only for the patient/family, but for the provider as well. These statements give reassurance that the provider is feeling similar emotions. The use of empathic statements by the provider establishes that everyone involved is going through the process of cancer treatment, disease progression, and possible death of the patient, together.

Silence surrounding these conversations is important for the patient/family and provider to stay in the moment longer, to strengthen the empathic statements.

A5 Mom: *I mean, she's scared now.*
Oncologist: *Of course*
Mom: *Before she was kind of like dealing with it. But now she's like afraid. She's not like as brave as she was at that time*.
Oncologist: *There's no reason to be brave about this thing, it is a horrible thing.*
Mom*: I know.*
[Conversation about patient having trouble taking pills]
Silence [10 seconds]

D1 Oncologist: *And you've been working on this so hard. And you deserve to do those things. You deserve to get to go to prom and go to Disney world and all of those kinds of things. And part of our goal should be to help you do that. Absolutely.*
Mom: *If we don't* [do treatment] ...
Silence [6 seconds] [Audible crying]
Mom: *Is she goin' to hurt?*
Silence [8 seconds]

The silence in these difficult conversations give both time and space for the provider and patient/family to process together. While silence indicates no audible speech, it does not always mean that no sound is heard on the audio recording. The silence can include audible expression of emotion, most commonly by the patient/family but occasionally by the provider as well. Sounds of movement to provide comfort such as giving tissues, hugging or patting on the back can be heard during some silences as well.

The audible expression of negative emotions by the patient/family can be heard at different points before, during, and after silence. This emotional expression includes crying, sighing, sniffling, and a wavering voice while talking. Expression of emotion can both prompt and emerge from a silence. In both instances, provider use of silence indicates an acknowledgment of emotion and allows for the creation of space to express emotions.

D2 Oncologist: *I'm sorry sweetheart, I wish I had better news for you today.*
Silence [10 seconds] [Audible Crying]

Finally, Sacred Silence can include the provider asking the patient/family questions. These questions are most often used in conversations in which the patient/family are not asking a lot of questions. The provider is encouraging the patient/family to learn more information or to solidify their understanding of the bad news and information provided to them. These questions also encourage the patient/family to express or continue to express emotion. The provider questions help focus the conversation, remaining in the space of talking about the bad news, to ensure that there is shared understanding by all.

C3 Oncologist: *I'm going to ask her … to talk to you a little bit about enrolling* [patient name*] in hospice as well. … Guys, I'm sorry.*
Silence [10 seconds]
Oncologist: [Father's name] *is there anything I can talk to you about?*
Silence [22 seconds] [audible crying]
Oncologist: *So, look, no matter what we're still here for you guys.*

F6 Oncologist: *All those spots are worse on your bottom and there are some spots in your lung now too. And I think almost certainly it's the tumor.*
Silence [5 seconds]
Oncologist: *Sorry.*
Silence [6 seconds]
Oncologist: *Do you have questions?*
Dad: *We going to keep needing chemo?*
Oncologist: *Well obviously the chemo she is getting isn't working. I mean the hard part with this tumor is that all the medicines that we know work were in her first, you know, recipe. And the chances of cure are very very low if at all. There is different chemo that may slow it down and get a response but, umm you know, the chances of curing this is very very low.*

Sacred Silence and Empathic Statements

The elements that make up a moment of Sacred Silence in a bad news conversation include rich information on the interaction between the themes detailed above and the moments

of silence. This subset of data, Sacred Silence in bad news conversations, allowed us to examine and describe connections between an oncologist and patient/family through the expression of empathy in these moments. We identified the importance of empathic statements by providers, used in conjunction with moments of silence, to strengthen therapeutic alliance with a patient/family. Three-quarters of all Sacred Silence segments within bad news conversations include an empathic statement by the provider. These empathic statements include multiple codes previously defined in this project's codebook.

> **D4 Oncologist:** *I'm sorry, I'm sorry buddy, this is not what we wanted to talk about obviously.*
> Silence [7 seconds]
>
> **B4 Oncologist:** *We are ready to go whenever. Okay?* I'm just so sorry.
> **Mom:** *It's scary.*
> **Oncologist:** *It is scary. I'm sorry.*
> Silence [15 seconds]
> **Oncologist:** *I'm so sorry*
> **Mom:** *You guys are so wonderful*
> **Oncologist:** *You guys are so wonderful. And I can only imagine how hard this is too, because you have lost a lot of friends*.
> **Mom:** *It does make it difficult.* [Audible crying and hugging]

We identified common themes in terms of the proximity to- and frequency of- empathic statements in relation to silence. Notably, most of the empathic statements made by the oncologist during Sacred Silence conversations, immediately precede and/or follow segments of coded silence.

An empathic statement immediately follows a silence in nearly half of all Sacred Silence segments. These empathic statements emerging from silence create a quality of invitation to continue emotional expression or acknowledgement of previously expressed emotion.

> **F2 Mom:** *If that's the plan then could we think about the trip?*
> **Oncologist:** *The QOLA people are right outside and already anxious to help with that, if that's something that you want to do* [patient name]. *They can try to push the*

buttons and try to see if they can make it happen. But I wouldn't probably do that until the radiation is done.
Mom: Yeah. *After the radiation is finished?*
Oncologist: *Assuming she feels good enough, that would be the time to try that.*
Silence [8 seconds] [audible crying]
Oncologist: *I'm sorry* [oncologist voice wavers]
Silence [37 seconds] [audible crying]

Nearly half of the time, in Sacred Silence moments, an empathic statement was spoken by the oncologist directly prior to a silence. The oncologist provides a statement of empathy directed toward the patient/family then all parties in the room collectively withhold any further speech. This prompts the subsequent silence, creating a quality of shared understanding, emotional processing, and acknowledgment of the gravity of the situation. Often this empathic statement is followed by an audible expression of emotion by the patient/family, such as crying, sighing, or sniffling prior to and/or throughout the silence. This expression of emotion may encourage the oncologist to remain silent.

D2 Oncologist: *I'm sorry sweetheart, I wish I had better news for you today.*
Silence [10 seconds] [Mom audibly crying]

A1 Oncologist: *I know that she is very resilient and that she is very positive, and that she is probably in denial. Which is perfectly understandable. But I know she doesn't feel good.*
Mom: *I know she doesn't feel good.* [crying]
Oncologist: *She just doesn't look the way she normally does*.
Grandmother: *I think she has lost a lot of her fighting spirit too.*
Mom: [Audible crying]
Oncologist: *I'm sorry.*
Silence [10 seconds]

Providers use NURSE (Naming, Understanding, Respecting, Supporting, Exploring) statements frequently during bad news conversations with a patient and their family. These NURSE statements are made by providers as empathic statements and are a communication

technique that is pivotal to encourage acceptance of patient emotions. Out of the 198 NURSE statements used in bad news conversations, more than half are used in close proximity before and after a silence during a Sacred Silence moment.

In our research, that more than half of NURSE statements, within Sacred Silence moments, lead to silence. Segments coded as Understanding and Supporting are used more frequently before a silence. Using these NURSE statements prior to silence appears to create an opportunity for providers to acknowledge and accept a patients' and their familys' emotions.

A3 Oncologist: *When it's diffuse like that, really our options are chemotherapy cause that will just go through everything.*
Silence [5 seconds]
Palliative Care Provider: *I'm sorry, I know that's not the news you wanted to hear today.*
Oncologist: *I'm really sorry.*
Mom: *We were already prepared.*
Oncologist: *I think you were, but you know what, you never need to hear that things have gotten worse.*
Silence [12 seconds]
Mom: *Okay, so now we just have to make decisions.*

All of the statements by providers that are coded as Lack of Abandonment occur within bad news conversations. Given the gravity of illness that is captured in these bad news conversations, the frequency of this code was expected. Interestingly, more than three-quarters of the Lack of Abandonment codes occurring in the segment of conversation surrounding silence, co-occur with Sacred Silence. This demonstrates a sense of connection between the oncologist and the patient/family during Sacred Silence moments. We identified two themes that describe the nature of segments coded as Lack of Abandonment, within Sacred Silence.

The first theme, used most frequently, describes emotional support from the oncology team giving a sense of solidarity with the patient/family. These statements by the oncologist give the sentiment that the entire oncology team is present throughout the whole process, that the

patient/family is not doing this alone. This is meant not just in the literal sense of being at appointments but encompasses the emotional and psychological presence of the team with the patient/family throughout the journey of cancer treatment. These statements demonstrate a connection between the oncologist and patient/family that surpasses the confines of a clinical patient-provider relationship.

> **D1 Oncologist:** *We love you and we are all going to do this together okay? This is a marathon and we are all just going to keep running.*
> Silence [8 seconds]
> **Dad:** *Thank you.*

> **B4 Oncologist:** *Were you surprised? Or did you think that this … You thought this is what it was.*
> **Patient:** *I always knew whenever they first found them, I was like it's probably…whenever they first found them, I was pretty sure that's what it was.*
> Silence [10 seconds] Audible sighing
> **Dad:** *I'm sorry I'm touching your shoulder and your chest.*
> **Oncologist:** *Yeah, I think your dad would spoon you if he could get in the bed with you. I would like to see you guys both hop in this bed. With a bounce pad on the other side, right?* [laughs]
> **Dad:** *That'd be a good idea.*
> **Oncologist:** *We are here for you; we've been here for you the whole dang time. None of that changes. And we hold on to hope, right? There are things that happen medically that I will never be able to explain, and I am A-okay with that.*

The second theme encompasses statements in which the oncology team discusses Lack of Abandonment focusing on two different paths of the treatment plan. The first path includes the sentiment that the oncology team will still be a part of caring for the patient, even when treatment options or intensity of treatment are decreasing/stopping. The type of care may change, to focus instead on managing symptoms and meeting the patient/families' goals of care, but the oncology team will be present. Given that the medical profession is commonly focused on treatment and cure of patients' illnesses, the reframing of the provider caring for the patient while decreasing treatment with the intention of cure is poignant.

A5 Oncologist: *The other choice would be to manage her symptoms … and for you to be at home as much as possible. And for her to enjoy her life at home … but still be very involved with her care to manage all of the symptoms she might have. And I think what will eventually happen is that pressure will build in her brain and she will become more and more and more sleepy. And eventually there will be enough pressure that her breathing system will not be able to take it and she will stop breathing. And I think that is what is going to happen*.
Silence [10 seconds]
Oncologist: *What do you think* [patient name] *would like to do?*
Mom: *I don't know, umm this last episode she got out of it but she didn't come back fully.*

The second path encompasses the provider expressing they are willing to keep trying treatments, as long as the patient wants to try. These two elements appear to be dichotomous, as one focuses on stopping treatment and the other encourages further treatment, but they are similar when discussed in the context of Lack of Abandonment. Both statements indicate the commitment of the provider to stay with the patient/family throughout the course of the illness.

F6 Oncologist: *As long as you want to try something, we are willing to try something. Right now we can't because it would be unsafe with your counts this low. Okay? We gotta wait until your counts get better and then we can try something.*
Dad: *Keep fighting it kid. We gonna keep fighting.*
Silence [85 seconds] Patient audibly sobbing

A3 Oncologist: *But we are willing to try whatever you want us to try from oral medication to IV medication, to see if she wants to go on an experimental therapy even if it means that you would have to spend time here. And you can discuss this, we've done this before over a week or so. She's due for her bisphosphonate next week anyway and we could talk about this again. I don't think there is anything emergent that needs to be treated today. But unfortunately, this disease has come back very very aggressively.*
Silence [17 seconds]
Palliative Care NP: *Can you share what you understood from all of that? Cause that was a lot.*

Most commonly segments coded as Lack of Abandonment occur before a silence, as opposed to after, which is true in the case of both Lack of Abandonment themes.

More than three-quarters of all segments coded as Affirming, occur during bad news conversations. Of the Affirming codes in the segment of conversation surrounding silence, more

than two-thirds co-occur with Sacred Silence. Similar to segments coded as Lack of Abandonment, Affirming statements most commonly occur before a silence as opposed to after. We identified two situations that describe the nature of segments coded as Affirming. The first reflects moments in which the oncologist appears to give the patient/family control over decision making and treatment goals. These statements indicate a transfer of power from oncologist to patient/family. As expected, the majority of Affirming codes in segments of Sacred Silence fall under this theme.

> **B4 Oncologist:** *We really want you to come up with that, come up with lists so we can together all make the best decisions for you guys. With you guys, not for you, it's with you. Okay?*
> Silence [7 seconds] [Audible sniffling]
> **Oncologist:** *I'm sorry.*
> Silence [5 seconds]

The second situation encompasses statements in which the provider is explicitly telling the family that that there is no wrong choice for the patient at this time. Similar to the first situation, this is used in the context of the patient/family making decisions about treatment and goals of care. Instead of statements that focus only on the patient/family being in control and needing to make decisions, this provides reassurance and validation to the family that whatever they choose is correct for the patient.

> **A3 Oncologist:** *At this stage also, I think what we want to convey to you is that whatever decision you and* [patient name]*'s dad make is the right decision and we will support you 100%. And we are gonna be there all the way regardless of what you decide to do.* [further conversation]
> Silence [60 seconds] [Mom audibly sighing]

Inductive Theme: Stacked Silences

We expected this research to reveal descriptive information about singular moments of silence and the nature of statements surrounding these moments in bad news conversations. We did not anticipate the frequent occurrence and profundity of multiple silences employed within close proximity to each other. Therefore, we labeled this phenomenon 'Stacked Silence' and defined it as:

> A series of **Silence** codes can be linked together as one **Stacked Silence** segment of conversation when there are no more than 90 seconds between the end of one silence and the beginning of the following silence.

Stacked Silence occurs within bad news conversations for the majority of the research participants. Of all silences in bad news conversations, three-quarters occur within segments of Stacked Silences. The series of silences range from a minimum of two distinct silences within 90 seconds of conversations to a maximum of twelve distinct silences within eight minutes of conversation.

More than three-quarters of the 103 Sacred Silence moments within a bad news conversation occur in a series of Stacked Silence. The same themes of conversation, described above in regard to Sacred Silence moments, occur around each silence within a series. These characteristics continue to exist in a variety of patterns and organizations, with the difference being that another silence occurs within one minute of the first silence.

In the majority of Stacked Silence moments, roughly one silence occurs per minute of conversation, creating a series. These intervals indicate a rhythmic pattern to the conversation. The relatively consistent intervals of repeating silences create a psychological space in which everyone in the room can sit together and process. Each subsequent silence helps to advance the

conversation further into difficult choices about decreasing treatment, end of life care, and telling the patient their prognosis.

A5 Oncologist: *Would you like for us to talk to* [patient name]? *Do you want to talk to her? Do you want her to talk? What would you like us to do?*
Mom: *Well you decide amongst yourselves*. [Mom chuckles]
Silence [5 seconds]
Oncologist: *Can you tell me what you think would be the most appropriate thing to do?*
Mom: *Basically, what you said, that it's not working and that we'll try some other stuff.*
Oncologist: *Or not right? I mean we're not promising her we're going to try something else because that still needs to be just… I just think that for now, you know we are going to go home, and we are going to control your symptoms and we are going to think about any other potential options. Cause if we say we are going to try something else then we are already committing to something we don't know if we are going to do or not.*
Mom: *Okay.*
Oncologist: *Would you like us to tell her that? Would you like to tell her that? I'll do whatever you want us to do.*
Mom: *Y'all can tell her.*
Silence [7 seconds]
Oncologist: *I'm very sorry.*
Silence [22 seconds]

In some instances, a silence has been used in a profound conversation but there are some distracting discussions about logistics or planning which take attention away from the conversation. In these situations, the use of another silence has the effect of bringing the conversation away from logistics and focused back into the serious and emotional, allowing the sacred moment to continue. This return to a shared space of silence allows for continuity of the conversation with a focus on the patient and prognosis despite the temporary distraction of logistical details.

A1 Oncologist: *No, I think it* [transplant] *would be incredibly toxic, and I don't think that he* [radiologist] *would do that either.*
Silence [43 seconds]
Mom: *I'll do whatever you want to do, okay baby?*
Patient: *I don't care what you gotta inject in me, I don't care if it makes me lose toes or fingers, as long as I don't die*.

Oncologist: *Okay, so that's pretty clear what we need to do. So the first step today, so we can get that going, is to ask your permission to send some of the tissue that we had, you know from the previous biopsies. Unfortunately, we cannot do that stain here, we need to send it to* [name of laboratory] *which is the company that's sponsoring the study. It takes about 7-10 days but at least we can get that going.* [continues with more details about how the lab works for 22 seconds]
Patient: *I mean you basically have my permission to try anything. Because I done fought too damn hard to have this happen and me just like die.*
Oncologist: *I know sweetie.*
Silence [13 seconds]
Patient: *I'm not saying that's gonna happen I just… I'm tryin' to get a point across here.*
Oncologist: *And we are listening loud and clear and that's why we are having this conversation.*
Silence [5 seconds]

Multiple silences can follow within a few seconds of each other, with minimal conversation between them. This most commonly occurs when someone in the room, usually the provider, says a word or short phrase and then everyone allows the silence to continue. The provider may ask an open-ended question or expresses an empathic statement. Rather than two segments of silence separated by conversation, the provider speaking is an interjection in the middle of one longer continuous segment of silence.

An open-ended question from the provider can be seen as an invitation or an opportunity for the patient/family to come out of the silence and continue the conversation by sharing their thoughts and emotions.

A3 Oncologist: *We are gonna be there all the way regardless of what you decide to do. But unfortunately given how quickly this has come back and how resistant it has been, I do not believe there is an actual cure for her disease. I don't think she can be cured. There may be a very very slim possibility of controlling it with something. But I do not believe there is a cure for her disease unfortunately.*
Silence [60 seconds] [Mom audibly sighing]
Oncologist: *What is going through your mind now? What questions do you have for us?*
Silence [20 seconds] [Mom audibly sniffling]
Mom: *I guess I just have to talk to her dad…*
Silence [8 seconds] [Mom audibly crying]
Mom: *Every bit of the mom in me would lean toward the experimental… you know.*
Oncologist: *Of course, that's understandable.*

The interjection from the provider of an empathic statement between two silences feels like an offering of reassurance to the patient/family that they are comfortable sitting in a continuous silence together. The provider statement of empathy in between silences can also act as a clue to a patient/family that they are welcome to continue expressing emotions.

A1 Oncologist: *What can I do for you?*
Mom: *You've done everything. I mean…* [Mom audible crying]
Silence [25 seconds] [Mom audible crying]
Oncologist: *You've done everything too.*
Silence [54 seconds] [Mom audible crying]
Oncologist: *I'm so sorry.*
Silence [9 seconds] [Mom audible crying]

D5 Oncologist: *We know that we are dealing with something really tough. We want to make sure that whenever we're doing something that it's something that ...that we are doing the things that you think are good for you. And that you know, your voice is just as important as your mom and dad.*
Silence [5 seconds] [Patient audibly crying]
Oncologist: *I'm sorry* [patient name], *I'm sorry honey.*
Silence [5 seconds]
Oncologist: *You know ...We knew, we knew this was gonna be an uphill battle from the beginning. You know we talked about that upfront and said this is a really tough thing to deal with. We always knew there was a possibility that something like this could happen.*

Chapter 5: Discussion and Recommendations

High-quality communication between providers and patients and their families is important to the clinical treatment course and can improve psychosocial outcomes while facilitating therapeutic alliance in pediatric oncology (Kaye & Kiefer et al., 2018; Sisk, B.A., Mack, J.W., Ashworth, R., & DuBois, J., 2018). An abundance of research exists demonstrating the value of and need for improved clinician-patient communication in the field of medical oncology (Institute of Medicine, 2015; Sisk, B.A., Mack, J.W., Ashworth, R., & DuBois, J., 2018; Tulsky et al., 2017; Kaye & Kiefer et al., 2018). However, the frequency, timing and

context of silence during disease reevaluation conversations for children with high-risk cancer and their families has not been thoroughly studied. Our research advances the literature on communication in pediatric oncology by giving an in depth look at the components of sacred moments during difficult conversations. The identification and description of sacred moments and their characteristics enables clinicians to consider what communication approaches they could use to create the experience of Sacred Silence.

Bad news conversations are a necessary and unfortunate part of disease reevaluation clinical encounters in pediatric oncology. These bad news statements of poor prognosis and/or disease recurrence are facts that the patient and their family do not want to hear, and that the provider does not want to have to say. Our research demonstrates that silence in close proximity to bad news has the opportunity to evoke a sacred moment, which can include the expression of emotion, questions, and empathic statements that connect the provider and patient/family.

Existing research highlights the value that patients/families place on a provider's recognition and respect of their emotions during difficult conversations (Sisk, Friedrich, Dubois, & Mack, 2019; Visser & Schepers et al., 2018; Del Piccolo et al., 2011; Visser et al., 2019). Our findings support this research and emphasize the importance of using silence as a tool to amplify the acknowledgement of and creation of space for patients/families to express their emotions. Providers should recognize that expression of emotion on the part of the patient and/or family can prompt the need for a silence, to encourage further expression. Additionally, emotions can emerge from a silence, indicating that the silence was meaningful for emotional processing.

The majority of sacred moments within bad news conversations include an empathic statement by the provider. Our research indicates that these empathic statements, whether employed prior to or emerging from a silence are likely associated with good therapeutic

alliance. Our study supports the current literature on the importance of therapeutic alliance between clinician and patient/family (Visser & Schepers et al., 2018; Visser et al., 2019; Bassett, 2018; Back et al., 2009). Our research emphasizes the interconnection between empathic statements by the provider, expression of emotions by the patient/family, and the use of silence to create space as crucial elements that make up these sacred moments in disease reevaluation conversations. The creation of space in these sacred moments can be filled by emotions, processing, and/or further questions from the patient/parents. Our research suggests that silence allows families (or patients) to ask a question that they otherwise may not have asked.

Notably, more than half of all NURSE (Naming, Understanding, Respecting, Supporting, Exploring) statements in bad news conversations are used in close proximity before and after a silence which contributes to engendering a sacred moment (Back et al., 2005). These NURSE statements made by providers act as pivotal empathic responses and acceptance of patient emotions (Back et al., 2005; Sisk, Friedrich, Dubois, & Mack, 2019). The provider should consider the framework revealed in our research that indicates a NURSE statement of empathy plus a silence can lead to connectedness between provider and patient/family promoting the creation of more sacred space.

Additionally, statements made by the provider affirming the patient/family's control over decision making as it relates to treatment and goals of care are present in sacred silence moments. The transfer of power from oncologist to patient/family that occurs with these affirming statements is enhanced when used in conjunction with silence.

Strikingly, out of 238 silences in bad news conversations, more than three-quarters of these silences occur within segments of Stacked Silence. Importantly, Stacked Silences convey a feeling that the provider is not in a rush to get through the conversation, that they will experience

this moment with the patient/family. The time that a provider spends with a patient/family feels purposeful and profound when multiple silences are used in close proximity to each other. Stacked Silences give a nonverbal clue that the provider has nowhere else to be during the conversation. The majority of Sacred Silence moments occur within a series of Stacked Silences. This finding suggests that multiple adjacent silences create more opportunities for sacred moments. This is the first study to suggest prioritizing the use of multiple silences in close proximity to each other as a communication technique to enhance poor prognosis conversations for children with high-risk cancer and their families. Only one prior study on silence between oncologists and their patients has noted the phenomenon of silences grouped together within one minute of each other (Bartels, 2016). To our knowledge, there has been no further description of or investigation into this phenomenon, therefore our research is novel in its exploration of these Stacked Silences.

Recommendations

After conducting an analysis of the use of silence during difficult conversations between pediatric oncologists, children with cancer and their families, there are two clear ideas to be addressed in the future. First, there needs to be an increase in purposeful teaching of clinicians on the importance and use of silence as a therapeutic communication technique during difficult conversations. There is a need for improved communication between providers and their patients (Tulsky et al., 2017; Institute of Medicine, 2015). The literature demonstrates a lack of effective communication training programs for medical residents and pediatric hematology/oncology providers more specifically (Nasca et al., 2012; Weintraub et al., 2016; Dobrozsi et al., 2019). Within existing training programs there is a competency which focuses on the provision of

emotional support or empathic communication yet, the specific importance of silence during these difficult conversations is not discussed (Epstein et al., 2017; File et al., 2014). Our study fills a gap in the literature as it relates to the use of silence in the content of these trainings. Of the limited literature describing oncology communication skills training programs only one study mentions the importance of silence, and then only in the context of a clinician pausing after delivering bad news (Gorniewicz et al., 2017). Our research highlights that silence should be employed throughout difficult conversations and not solely following a provider statement of bad news.

Second, further studies are needed to examine the phenomenon of multiple silences used in close proximity to each other, during difficult conversations in pediatric oncology. Additionally, our research supports the need for more longitudinal studies, which encompass the course of the patient's illness and enable us to see how therapeutic alliance and communication techniques such as silence evolve across the advancing illness course (Cannone et al., 2019). Our research demonstrates the significance of Stacked Silences in the creation of a shared space between provider and patient/family. Multiple silences occur in relatively consistent intervals during these Stacked Silences demonstrating a reproducible pattern that future clinicians can follow to create Sacred Silence moments that continue to expand as the bad news conversation continues. We advocate for further research on silence and the development of a framework for future oncologists use along with the inclusion of silence as a crucial tool to be included in communication trainings.

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Appendix A

HUMAN CONNECTION	
Oncologist Remembers = Onc_Rem	**Oncologist recalls information that is personal and/or important to the patient's/family's life, <u>unprompted</u>.** *e.g. Remembering to ask about a trip to see grandma months afterwards* *How did he enjoy Disney?*
Oncologist Shares = Onc_Share	**Oncologist contributes personal information about themselves/their life in an effort to find common ground with patient/family. Such as character, emotions, personal life, work habits etc.** *e.g. I'm very visual myself* *Oncologist talking about their own children*
Friendly Conversation = Friendly	**Oncologist use of <u>small talk</u> that does not include symptom discussion, treatment plan, medical care, emotional support etc. Includes back and forth small talk between parent and oncologist. [Try not to double-code: especially with comedy]** *e.g. I can't wait to hear about how your birthday went* *How is dad? Is he just holding down the fort with the other kids?* *Does not include laughing*
Affection **Subcodes**	**Any time the <u>oncologist, parent, or patient</u> expresses sentiment/feeling of fondness towards each other. [May double-code with ribbing]** *e.g. Using pet names, sweetie* *Giving hugs* **Love =** Any time the phrase "love" is used in affectionate way toward a person. *e.g. I love you* *We love you all.*
Parent Statement of Confidence = Parent_Trust	**<u>Parent/patient</u> expresses gratitude and/or trust directed at oncologist/team/institution.** *e.g. We feel like we can trust you and what you do.* *Thank you.* *You all have the toughest job delivering bad news* *We have been missing you (oncologist away)* *We love Doctor …*
HUMOR	
Comedy	**Oncologist use of comedic relief, attempt at humor, and joking during conversations.** *e.g. Singing and/or laughing.* *I cannot see a thing on my phone, it's not big enough* *Enjoy the fair and all those rides that don't work-don't go on one that is stuck upside down*
Ribbing	**The use of playful teasing by the oncologist.** *e.g. Look at your hair, it's wild!* *You like weird animals like rats.* *You tripped over your purse? Maybe your purse is too big*
Matching Maturity Level = Mature	**Oncologist matches the tone/language/maturity level of a patient to connect with them. [Can double-code]** *e.g. Playing up teenage animosity with parents* *Calling patient, a "turd"* *Oncologist changes tone of voice to connect with patient*

EMPATHIC CARE	
Standing in Your Shoes = In_Ur_Shoes	**Oncologist using empathetic statements to respond to emotions. Includes validation of emotions and sharing grief.** *e.g. I have to say, my heart totally broke when I saw this* *I know this is not what you expected to hear today…* *I can't imagine how difficult this must be…*
Naming	**Naming the emotions displayed by the patient/family.** *e.g. I can see that you are upset…* *It looks like you are angry…*
Understanding	**Acknowledging and appreciating the patient's/family's situation; validating emotions.** *e.g. I know this is scary…* *I can't imagine how this feels.* *It is completely normal to feel that way.* *It is understandable to feel overwhelmed…*
Respecting	**Offering praise whenever appropriate. Oncologist provides statement of reassurance and encouragement to parent/patient.** *e.g. Nothing you did made this happen, you've done everything right.* *I think you are doing a great job managing all of his medications.* *You are a wonderful parent…* *That's a great question.* *It's okay that you haven't brought him to the dentist yet, he is still young.*
Supporting	**Expressing concern and a willingness to help.** *e.g. What do you need from us?* *I support your decision…* *We are here to help* *And if you are tired of taking these medicines, that's okay.*
Exploring **Subcodes**	**Giving the patient/family an opportunity to talk about whatever they are feeling/processing. Exploring sources of conflict (e.g. guilt, grief, culture, family, trust in medical team etc.) Exploring values behind decisions. Needs to have a Probing question.** *e.g. I have given you a lot of information. What are you feeling?* *What has this been like for you?* **Tell me more** = Any time the phrase "tell me more" is used. *e.g. Tell me more about how you are feeling.*
Sorry	**Any time the phrase "I am sorry" is used by oncologist.** *e.g. I'm really sorry* *I'm so sorry that you had to wait.*
PARTNERING	
Lack of Abandonment = Lack_Abandon **Subcodes**	**Statements that indicate Oncologist will be there to share the entire life/clinical experience with Parent's/Patient's. In it for the long run.** *e.g. I will be with you on this journey* *We are not going anywhere* *We are here for you guys no matter what* **Give_Up =** Any time that the phrase "give up" is used *e.g. We won't give up*

Team Together	**Any time statements are used that align/join the Oncologist/Family in collaborative goals and decision making. Includes <u>"we" statements,</u> indicating oncologist and family are a team/unit.** *e.g. Obviously we want him to be with us as long as possible* *I'm hoping we can wipe out every last cancer cell out* *If these medicines are not allowing you to live with your arms wide open, then we have to have a different plan* *I don't make decisions by myself, this is about what you want for your life* *As long as you want to try something, we are willing to try something.*
Subcodes	**I_Wish** = Any time the phrase "I wish" is used *e.g. I wish this didn't happen* *I wish that I could say that chemotherapy always works…* **Hope =** Any time the provider uses the phrase "I hope", "My hope", "We hope", "Hopefully" *e.g. I'm hoping it's not recurrence* *My hope would be that…* *We hope she will make it to graduation*
Accommodate	**Discussion of logistics that anticipate needs and/or accommodate life events of the patient/family.** *e.g. Adjusting appointment times/treatment/scans around family trips/desires.* *Medication refills/appointments have been planned before family asks* *Can we go home today and move our appointment for tomorrow until next week? Oncologist says go home, get out of here.* *We can start your chemotherapy after Christmas so that you don't feel sick* *Your medications are already at the pharmacy.*
ONCOLOGIST HONESTY	
Warning Shot = Warn_Shot	**Oncologist opens with a statement that gives patient/family a moment to emotionally prepare for hearing <u>bad news</u>.** *e.g. I have something serious we need to discuss…* *I don't have good news…* *The scans didn't show what we had hoped…*
Be_Transparent	**Oncologist uses statements that attempt to transmit/highlight realistic prognostic assessment related to delivering good/bad prognosis. A linguistic choice that captures oncologist attempt to bond through transparency.** **[Don't code prognostic content]** *e.g. I am just going to tell you* *I will give you as much information as I can about your options* *In our opinion, incurable.* *I have concerns…* *I want to be clear…*
Subcodes	**Be_Honest =** Any time a phrase includes "being honest" *e.g. It's a lot harder to cure. I'm being really really honest.* *I'm going to be honest and open always.* **I_Worry =** Any time the phrase "I worry" is used. *e.g. I'm really worried* *It makes me worried that this is his cancer coming back.*

	I_Wonder = Any time the phrase "I wonder" is used. *e.g. I wonder how you would feel about…* *I wonder if there are some other options we haven't considered. Would it be okay to explore some of those with you today?*
Summarize **Subcodes**	**The oncologist uses a summary statement to reiterate results/treatment/scans etc.** *e.g. Just to recap…* *To summarize…* *So that we are on the same page…* **Clarify_Positive =** Any time summary statement reiterates/emphasizes the positive nature of results/treatment/scans/quality of life etc. e.g. This is good news So far so good
Oncologist Gives Opinion = Give_Opin **Subcodes**	**Oncologist uses statements of ownership including "I think" "I feel" "I recommend" "I believe" or synonyms, while discussing treatment plan. Statements that show ownership/personalize opinion while building alliance/partnership with patient/family. [Don't code treatment plan]** *e.g. I think it would be better to…* *I recommend…* *I feel like this is the best option for her* *I don't think she would be a candidate for that treatment.* *I don't believe that will help her.* **Avoid_Opin =** Any time the oncologist avoids giving their personal opinion when requested by parent/family. **If_me =** Any time the phrase "If it were me/my child" is used be oncologist. Can be in response to a direct question from parent/patient of "what would you do?" **Avoid_If_Me** = Any time the oncologist avoids responding to parent/patient question related to "If it were you/your child" Can be in response to a direct question from parent/patient of "what would you do?"
INCLUSIVE COMMUNICATION	
Open_Door **Subcodes**	**Oncologist uses language that prompts discussion of patient's/family's hopes, wishes, opinions, or goals of care. This may be in relation to treatment options, location of care, or end-of-life preferences. [Not coding the GOC content]** **Any time an open-ended question is used.** *e.g. How do you feel about staying in the hospital?* *Tell me what you are hoping for…* *What are your thoughts about doing more chemotherapy?* *How much do you want to do?* *Do you agree?* *Can you share what you understood at this point?* **Patient_Dir =** Any time questions are directed specifically at patient [not the parent] *e.g. What is good quality for you?* *Where is your head at?*

	Ask = Any time oncologist asks patient/family if they have any questions/concerns. *e.g. Do you have any questions?* *What questions do you have for me?*
Affirming	**Statements that validate patient/parent as important in decision making, and integral to the process. [Can double code with open door]** *e.g. It's your body…* *You know yourself/your child the best…* *What you have been going through, nobody else knows but you. We really follow your lead.* *If you would rather wait until the next appointment, you could do that.*
Pair_with_Sx	**Any time the oncologist links patient's symptoms/pain with scan results/disease progression to provide clarity/understandable medical information** *e.g. What do you feel like your body is telling you?* *The pain that you are having in here in your hip matches what we see on the scans***.**
Clarity	**Any time the oncologist uses an analogy and/or a prop in an attempt to provide clarity/understandable medical information.** *e.g. Oncologist draws picture*
Show_Scan	**Any time the oncologist shows the patient/family the MRI/PET/CT/XRAY (or will show in the near future) in an attempt to provide clarity/understandable medical information. *Only when you can hear that they are actually showing scans*** *e.g. Do you see this spot right here?* *Let me pull up the scan and show you.* *I don't have access to the PET scan on this computer, I will show you tomorrow.*
TIME	
Oncologist Being Present = Be_Present	**Oncologist makes direct comments that indicate they are available and fully in the moment with the patient/family. Comments that indicate the oncologist is not rushed and are purposefully giving their time to patient/family.** *e.g. I can be here as long as you need* *You have my full attention* *I will turn my phone off to minimize interruptions* *If called out of the room-says let them know I'll be there later*
Sub codes	**Time_Doc =** Any time oncologist uses the word "time" in terms of availability/presence is used. *e.g. I can take as much time as you need* *I will make time* **Time_Parent =** Any time parent uses the word "time" in terms of availability/presence of oncologist. [May be double coded under Parent_Trust] *e.g. Thank you for taking the time to be here*
Silence	**Code for any uninterrupted pause, in response to an emotion, that is 5 seconds or longer in length. Pause with intention to create space for processing. Not including transitions. *Code entire length of silence as one segment***
Sacred Silence	Within the 60 seconds before and/or after a single coded silence:

	The provider gives information (or references having just given information) to patient/family related to scan results OR treatment options OR progression of disease OR goals of care OR prognosis **AND** at least one element below (before or after silence code) Sense of shared understanding/acknowledgement between provider and family **OR** Sense of enlightenment/catharsis. Can include provider responding to a question or making a statement that includes an element of truth-telling **OR** Expression of emotion by patient/family which preceded or followed statement by provider giving indication of shared emotions/recognition of expressed emotions. Can include provider invitation to continue expression of emotion.
Stacked Silence	A series of **Silence** codes can be linked together as one segment of conversation when there are no more than 90 seconds between the end of one silence and the beginning of the following silence.