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# End-of-Life Patient Communication: Exploring Comfort, Communication and Education of Healthcare Professionals For End-of-Life Care

Madison Gremillion

*University of Northern Colorado*

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University of Northern Colorado

Greeley, Colorado

END-OF-LIFE PATIENT COMMUNICATION: EXPLORING COMFORT,  
COMMUNICATION AND EDUCATION OF HEALTHCARE PROFESSIONALS  
FOR END-OF-LIFE CARE

A Thesis Submitted in Partial Fulfillment for  
Graduation with Honors Distinction  
and the Degree of Bachelor of Science

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MAY 2024

End-of-Life Patient Communication: Exploring Comfort, Communication and Education  
of Healthcare Professionals for End-of-Life Care

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## Abstract

Historically, the medical field has viewed death and dying as incurable ‘medical failures,’ and as a result, many healthcare professionals have difficulties when facing a patient who is dying or at the end of their life. These individuals will use avoidant behavior to avoid end-of-life (EOL) patients or can have difficulty providing essential aspects of care including communication, that contribute to building a strong relationship between the healthcare provider and patient. For the healthcare professional (HCP), this can stem from anxiety related to thoughts of death and a lack of educational support or experience. The study of death is where the sciences and humanities meet, and therefore can only fully be explored using interdisciplinary methods. For this study, healthcare professionals (MD/DO/Counseling) were interviewed with questions derived from the approaches used by psychology, philosophy/bioethics, and communication as well as the interdisciplinary research of healthcare. Questions included experience or education received, comfort in EOL interactions and communication, emotional processing and rituals, available mental/emotional support within the healthcare professional environment, and personal beliefs. Phenomenological qualitative thematic analysis using the program NVIVO was used to derive common themes from the interviews, integrated with published research. Themes include Supportive Techniques used by HCP to process challenging emotions because of working with EOL patients, the importance placed on patients experiencing a Good Death and subcodes in Work Environment such as Patient Support via Emotion, Colleague Inadequacy, Administrative Support, and Patient Provider Miscommunication. This research provides a foundation of data for future research paths implementing empathy and evidence-based practice standards into a greater diversity of specialties to

support the need for increased mental and emotional support from healthcare administration, and redefine professionalism in healthcare.

## **Acknowledgments**

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## **End-of-Life Patient Communication: Exploring Comfort, Communication and Education of Healthcare Professionals for End-of-Life Care**

Modern healthcare professionals (HCPs) are taught to view death as a medical failure and as a result, physicians are taught very little about how to appropriately communicate end-of-life care with patients and their families (Balaban, 2000; DeSpelder, 1983). When faced with dying patients, HCPs work toward treatment or solutions to death, rather than acknowledging and working with their patients toward the goal of comfort in life, such as developing goals-of-care (GoC). HCPs also experience death anxiety or negative feelings when faced with the reality of death. This affects patient care and relationship building, most notably seen in the way HCPs communicate with their patients (Lange et al., 2008, Braun et al., 2010, Peters et al., 2013). Much of the communication is impacted when discussing treatment outcomes, advanced directives, and an overall realistic understanding of their illness. Many HCPs display an avoidant coping mechanism in which they would “[avoid] or [delegate] conversations with patients about death” (Clare et.al, 2020, pg. 4).

Even when communication occurs, patients are often not given a full understanding of what they agree to. Many patients agree to life-sustaining treatments without fully understanding the limitations of those treatments, including low success rates and how incapacitated they would become (Balaban, 2000). A large part of HCP’s avoidant behavior stems from death anxiety, which changes their perceptions and attitudes on working with dying patients and the effectiveness of communication (Marlys, 2009; Braun et al., 2010; Peters et al., 2013; Clare et.al, 2020). Any resistance from HCPs to fully communicating a prognosis directly compromises cognitive-behavioral therapies

developed to help dying patients through the process of death acceptance, which includes facing the reality of death and identifying goals to be met in the patient's remaining time (Furer, P., & Walker, J. R., 2008). This communication deficit can impair lasting memories for HCPs and family and support members of the deceased.

Fortunately, there have been successful tools to help HCPs understand this limitation. Even by acknowledging one's own death anxiety, HCPs are able to identify avoidance behaviors and work toward more effective communication (Clare, 2020). Additionally, there are programs in which HCPs and the public can learn to properly communicate with EOL patients, such as Center to Advance Palliative Care (CAPC), Vital Talk, PESI, and the Conversation Project, which have videos and guides to assist with various EOL conversations. Despite these organizations, communication continues to be an issue within the field; therefore, it is important to continue producing research to maintain attention on this important issue. Additionally, new emerging themes have yet to appear which can offer different perspectives to why HCPs have difficulty working and communicating with dying patients.

### **Literature Review**

Death is an experience that cannot be researched within a single discipline. It is a process that the physical body undergoes, the mind processes, and the spirit embraces. This work is necessarily framed through the Human Sciences, which states that, "...works of the spirit and human experience cannot be reduced to the realm of causal science, and require different methods" (Turner, 2015, p.380). The foundation of research surrounding healthcare and death has been formed from Dr. Elisabeth Kübler-Ross's interdisciplinary seminar, which resulted in the psychology study published titled *On Death and Dying*.

This literature review will discuss how various disciplines address the issue of death and dying, and how they can contribute to the understanding of EOL care.

### **Philosophy**

Philosophy represents the beginning of humans exploring concepts surrounding death and dying and is a central topic of concern with religion. Philosopher Arthur Schopenhauer states, "the fear of death is the beginning of philosophy, and the final cause of religion" (Durant, 1977, p. 328). In the hospital setting, philosophy is most observed as the study of bioethics where ethical concepts are explored regarding human health and medicine as well as philosophical concepts of metaphysics and value theory. Bioethics has four main principles (Beauchamp et al., 2017):

- Principle of Respect for Autonomy: to respect a patient's decision for their own health, seen through informed consent
- Principle of Nonmaleficence: to avoid causing unintentional harm
- Principle of Beneficence: to always work toward providing good health to the patient or prevent disease
- Principle of Justice: to provide care equally

However, when working with dying patients, the lines of these principles get blurred. In this research, every interviewee acknowledged HCPs avoiding communicating a terminal prognosis and instead suggesting treatments that, if successful, only prolong life by a few months. That time is often painful as the patient recovers from surgery. Questions like whose responsibility it is to tell a patient they are dying comes with insecurity in the accuracy of that prognosis and what could happen if the HCP is wrong.

Metaphysics explores the fundamental nature of reality, the permanence of objects and things which can lead an individual to questioning their own existence, leading that individual to denial of their own death (Becker, 1973). Thoughts on these

topics inherently arise while discussing death, and I've noticed HCPs creating a separation between themselves as a professional and as a person to handle facing existential questions. Value theory is a theory which includes any situation where a value can be applied, such as something being "good" or "bad" (Ziff, 1960). In the case of this study, HCPs often apply the concept of "good" or "bad" with regards to the quality of a patient's death and how the perception of that quality affects HCPs emotional response or association to that death. It is important to acknowledge metaphysics, values, and bioethics in interview questions as they represent the fundamental nature of the HCP as they navigate EOL care.

### **Psychology**

Psychology explores the dying experience in many ways. Worm at the Core is a concept that suggests death anxiety is the root of all human motivation (Solomon et al., 2015), and there are many factors which can affect death anxiety, such as gender, socioeconomics, perceived age, self-esteem, and health (Baltes et al., 1999; Kotter-Gruhn et al., 2009). It has also been well established that grief goes through five stages (denial, anger, bargaining, depression, and acceptance), and this understanding has allowed HCPs to have a better understanding of the reaction their patient and their patient's family to a terminal prognosis (Kubler-Ross, 1969; Varga, 2015).

Death anxiety is the experience in which individuals, having awareness of their own mortality, experience emotional discomfort. This anxiety can stem from many reasons, including fear of the unknown and the potential pain experienced while dying, and can be affected by various lifestyle choices and perceptions. We can predict who may experience death anxiety using the analysis of demographics, especially gender,

socioeconomics, perceived age, and health. Additionally, positive self-perception factors show lowered mortality risks and positive perceptions on death (Kotter-Gruhn et al., 2009; Baltes et al., 1999). As mentioned before, one aspect of death anxiety is fear of the unknown. Older individuals with greater religiosity, positive self-esteem, better physical health, and more support correlated with a lower fear of the unknown (Cicirelli, 2002).

However, it is to be expected that HCPs themselves will experience death anxiety, which will affect the care they provide. There are some established self-reporting Likert scales which quantify death anxiety, including The Collett-Lester Fear of Death and Dying Scale (CFDS) and the revised version (RCFDS), the Multidimensional Fear of Death Scale (MFODS), Templer's 15-item Death Anxiety Scale (TDAS), the Revised Death Anxiety Scale (RDAS), the Death Attitude Profile-Revised (DAPR), and the Frommelt Attitude Toward Care of the Dying (FATCOD), all of which explore HCPs attitudes for caring for dying patients, their own death anxiety, and other emotions or experiences associated with EOL care (Nia et al., 2015). This research integrates these attitudes by exploring the HCP's relationship with the death of their patients and how patient death affects their own grasp on death in general.

One technique implemented in those who are affected by death anxiety is called Terror Management Theory (TMT), developed by Becker (Becker, 1997). TMT suggests that when an individual is reminded of their own mortality, they will rely on cultural and moral values to manage the complex feelings that accompany death anxiety (Solomon et al., 2015). In this research, HCP were asked about their experiences with death anxiety, what factors influence their experience of death anxiety, and what values they rely on to get through that anxiety. Responses have included rituals used to transition HCPs from a

professional mental state to a personal one, or using religious belief to either disengage with the anxiety or to process it.

Another technique used to alleviate death anxiety is Cognitive Behavioral Therapy (CBT). CBT aims to redirect anxiety-inducing thoughts by “distracting and drawing attention away, problem-solving, overcoming or changing problematic behavior and activities, and identifying negative automatic thoughts” (Moradi, 2022, p. 2791). This technique is also used by HCPs when feeling death anxiety or challenging emotions while working with dying patients. In my interviews, HCPs often discuss using exercise or focusing on developing new skills to redirect anxious feelings.

The importance of techniques like TMT and CBT are reflected in the literature. For example, nurses who view death “from a neutral or escape perspective” can provide higher quality care which results in “improved patient outcomes and satisfaction for the patient, family, and nurse providing the EOL care” (Lange et al., 2008, p. 958). Perceptions and attitudes about death can be complex and it can be a natural reaction to want to avoid reminders of death if one experiences negative feelings or attitudes about death. In one study, “...nurses who reported higher fear of death and death avoidance and those who perceived death as an entry point to a better afterlife held less positive attitudes toward caring for dying patients” (Braun et al., 2010, p. E46). Overall, attitudes about death, including death anxiety, influence how nurses feel about caring for dying patients. As HCP death anxiety increases, positive attitudes about caring for dying patients decreases (Peters et al., 2013).

## **Healthcare Communication**

HCP and patient communication rely on a variety of models to navigate the complexity that comes with discussing death with a patient. This is partly due to the need for verbal and non-verbal communication skills. Models exist to guide HCPs through EOL conversations. These include the Bayer Institute for Healthcare Communication E4 Model, the Three-Function Model/Brown Interview Checklist, the Calgary–Cambridge Observation Guide, Patient-Centered Clinical Method, SEGUE Framework for Teaching and Assessing Communication Skills, The Four Habits Model, and SPIKES (Kissane et al., 2017, p. 16). Although each has more descriptive or less descriptive steps, they share the general steps of educating the patient about their illness and treatment options, empathizing with the patient, discussing plans, and engaging in such a way where the patient feels the HCP has their best interest in mind. Each of these implements the understanding of sociolinguistics where communication is affected by an individual's personal background and social upbringing.

These models, and how easily they integrate with medical education, are an important part of patient outcomes and well-being. Communication in EOL care, as previously mentioned, is easily and quickly improved when using emotional training. Part of this training includes acknowledging the importance of empathy, compassion, and spiritual recognition for patient outcomes. When patients feel their physicians empathize with them, they are more likely to follow medical instructions or comply with necessary treatments, and overall satisfaction is improved (Kim et al., 2004). This empathy is shown using active listening skills and an overall awareness of the quality of time spent with each patient. This understanding is acknowledged in this research through inquiring

about education received in EOL communication and active listening. The response has been that although HCPs have received some training on breaking bad news, it did not prepare them to have these conversations with dying patients in the field.

Communication is another discipline that shares models from other disciplines, such as psychology, which are used to develop communication models. These include:

- The Health Belief Model
- Social Cognitive Theory

However, again, it is important to note that a single theory cannot be used in healthcare communication. The Health Belief Model states that the perceived threat of illness or disease along with the perception of a treatment's effectiveness will influence which path of treatment will be taken (LaMorte, 2022). This is incredibly important to my research, as a common cause of miscommunication comes from a patient making healthcare decisions based on a faulty belief that the treatment or action will cure them or put off death. This is also notable in patients making life-sustaining decisions or advanced directive choices. The quality of life experienced, even if these advanced directive actions succeed, only prolong death for several hours (Balaban, 2000). Improved communication techniques can help “allay fears, minimize pain and suffering and enable patients and their families to experience a ‘peaceful death’” (Balaban pg. 195, 2000).

This is a central concept in this research, which explores the overall environment of EOL communication. In the hospital setting, Goals-of-Care (GoC) are used, which detail the EOL goals decided between the HCP and patient. In one study, 53.7% of intervention participants endorsed the statement, “I want to make decisions about my



care with my provider,’’ whereas 29.3% endorsed the statement, ‘‘I want to make my own decisions about my care after considering my provider’s opinion,’’ showing the importance of GoC conversations. GoC intervention training resulted in a significant increase in the frequency of? GoC discussions between patients and HCPs (Doorenbos et al., 2016, p. 357).

Social Cognitive Theory (SCT) explores how an individual’s personal experience, environment, and behaviors affect an individual’s decision making. SCT helps illuminate the delicate nature of discussing EOL options with a patient, as these choices vary on the patient’s cultural, religious, and social belief systems. The importance of cultural and spiritual recognition has been researched, showing improved patient outcomes when these aspects are recognized. Empathy is shown using active listening skills and an overall awareness of the quality of time spent with each patient. Additionally, ‘‘spiritual care is as important as physical care and supporting patients spiritually as they approach the end of life is vital. Appropriately trained nurses and healthcare professionals are better able to assess, explore and meet patients’ spiritual needs’’ (O’Brien et al., 2019, p. 1). As such, education for HCPs to improve EOL patient care and communication must include aspects of emotional sensitivity, spiritual awareness, recognition, and respect.

The topic of death is something that cannot be explored completely, especially through a singular discipline or theory, as it is a unique experience for each individual and comes with associations of one’s culture, religion, personal experiences, and physical health associations (San Filippo, 2006). This is seen in the limitations of Social Cognitive Theory which does not consider biological hormonal reactions, such as the flight or fight response. We experience a biological reaction to the news of impending death, but it is a

stress that we cannot run or fight (though we will try). Additionally, although there are models by which to communicate difficult prognosis to patients, they are limited in that they pose a generic path of communication (Kissane, 2017). The other part of communicating with patients requires the HCP to integrate themselves to facilitate a more nuanced conversation. This does not mean the study of death and the many aspects of human sciences it affects is meaningless. To study death is to study what it is to exist, and the better HCPs understand how death affects them, the closer patients get to being able to experience a good death.

### **Family Involvement**

EOL care and communication also extends beyond the patient to the patient's family. Hospital settings that provide private spaces and support for family member caregivers of dying patients resulted in HCPs reporting higher and more positive family member caregiver bereavement outcomes (Dosser et al., 2014). HCPs are not the only ones responsible for EOL communication. Adult children of older patients in EOL care often become the in-between communicators between HCPs and their parents. This can result in communication issues due to adult children's own death anxiety, which affects their perception of their parent's death anxiety. Adult children perceive their parent's death anxiety as being higher than their own; however, adult children's death anxiety is reported to be higher than the reported death anxiety of the patient. This leads adult children to not fully communicate with their parents the reality of their prognosis (Sinoff, 2017). This communication deficit can impair lasting memories of the relationship after death.

Having to face death daily is an existential battle many of us do not have to address. HCPs must develop healthy coping strategies that integrate personal beliefs and experiences with their healthcare training. In this research, many responses seem to come from the professional version of themselves, and then from their person version. The relationship between their professional and personal identities is complex. It can be a delicate conversation; nearly every interviewee has experienced a patient's death that has affected them deeply, and that they reflect on frequently. It is important that this research explores the psychology behind these actions or feelings, how their personal philosophies drive their interactions, what communication methods they implement, what methods they learned from their education or from more experienced mentors, and the overall healthcare environment, which may limit their options or how deeply they connect with a patient. As death anxiety affects perceptions, so does it affect the willingness to communicate difficult prognoses. Palliative care social workers' reports show "...as the death anxiety scores increased, the communication scores related to disclosure of information and values in living decreased" (Marlys, 2009, p. 55). Most healthcare professionals without training will avoid discussing patient fears or plans because they themselves fear death (Clare et al., 2020). In many of the responses, HCPs will refer to their experiences of death prior to entering the field, resulting in incredibly nuanced interactions that draw from associations the HCP may have about these experiences.

In this study, the relationship between dying patients and HCPs was explored using semi-structured interviews by way of phenomenological research. Guiding research questions include:

- How comfortable are HCPs when working with dying patients?

- Were HCPs prepared for end-of-life (EOL) interactions by their education and experience received in medical school and residency?
- Whose responsibility is it to tell a patient they're dying?

Questions about work environment and support between HCPs experiencing difficult emotions related to dying patients, as well as personal rituals used to cope with the trauma of experiencing death, were included in the semi-structured interview to allow emerging themes of the relationship between HCP practice and the professional environment of healthcare to be explored. Current research suggests themes including education, experience, and death anxiety affect comfort and confidence in having EOL conversations (Lange et al., 2008, Braun et al., 2010, Peters et al., 2013., Clare et.al, 2020). This project's objectives were to continue investigating the issue and explore emerging themes. Some preliminary emerging themes relate to US cultural perceptions of death affecting healthcare perceptions of death, the availability of emotional/mental support from healthcare administration, and personal philosophical practices, beliefs and rituals, and the quality of a patient's death.

## **Methods**

This research study uses a qualitative design and phenomenological methodology. A semi-structured interview (Appendix B.1) was developed, which is a common data collection method in phenomenological research. 5 healthcare professional participants were recruited using the researcher's connections in healthcare as a hospice volunteer and then used the snowball technique which allows participants to refer other participants. After receiving the signed consent letters from the participants (Appendix A), interviews were conducted via either a virtual environment, such as Zoom, or an in-person interview

in their office. Interviews lasted between an hour and two hours unless a shorter time was requested. Recorded audio was transcribed with time stamps using the built-in transcription service from Zoom. Emerging themes were established using a codebook with definitions (Appendix B.2). The coding program NVIVO was used to code the interviews to identify emerging themes of responsibility, working environment, and local cultural views of death and dying. These have been defined in the codebook.

### **Coding Procedures**

Below are the steps of qualitative hybrid thematic coding being used:

1. Create initial codes
2. Read through transcripts
3. Determine what to code
  - a. Related to initial codes
  - b. Interesting or surprising findings
  - c. Recurring patterns
4. Allow data to show other appropriate codes
5. Collate codes with excerpts
6. Group codes into themes
  - a. Casual conditions and contexts
  - b. Consequences of phenomena
  - c. Broader categories and connections
7. Evaluate and revise
8. Identify themes of the data using quotes

***Table 1: Research Timeline***

<b>Spring and Fall 2021</b>	<ul style="list-style-type: none"> <li>● Connected with HCPs through community service connections (Location of work not mentioned due to confidentiality of interviewees).</li> <li>● Created semi-structured interview - reviewed with advisor and qualitative researcher at institution.</li> <li>● Fall: Requested IRB approval category 2 exempt.</li> </ul>
<b>Spring 2022</b>	<ul style="list-style-type: none"> <li>● Began interviews (three completed by Summer 2022).</li> <li>● January: Received IRB approval category 2 exempt.</li> <li>● Applied to NCHC 2022 with preliminary findings.</li> <li>● February-March: Two interviews conducted and transcribed.</li> <li>● April: Presented orally at UNC Research Day.</li> <li>● May: Third interview conducted and transcribed.</li> </ul>

<b>Fall 2022</b>	<ul style="list-style-type: none"> <li>● October: Applied to present at NCUR in April 2022.</li> <li>● November: Presented Poster at NCHC - awarded first place.</li> <li>● December: Fourth interview conducted, began Portz Proposal, review literature published in last year.</li> </ul>
<b>Spring 2023</b>	<ul style="list-style-type: none"> <li>● January: Met with Dr. Tom Smith (Philosophy) and Dr. Emily Holt (Qualitative Thematic Coding) and continued to contact the Communication department.</li> <li>● February-March: Finish Portz proposal.</li> <li>● April-May: Recruited 1-3 more participants.</li> </ul>
<b>Summer 2023</b>	<ul style="list-style-type: none"> <li>● Analyzed data using NVIVO Qualitative Analysis Software.</li> </ul>
<b>Fall 2023</b>	<ul style="list-style-type: none"> <li>∉ August-October: Continued reading and including recently published literature.</li> <li>∉ November: Completed coding.</li> </ul>
<b>Spring 2024</b>	<ul style="list-style-type: none"> <li>● Finished thesis.</li> <li>● Submitted finalized project to the Honors Program for publication in the Honors Journal.</li> <li>● Submitted thesis for publication in URSIDAE.</li> </ul>

## Participants

The participants interviewed were recruited by professional or academic associations to the researcher and the snowball technique in which participants would recommend other HCPs to participate. Information collected included their healthcare licensure, specialties, and time spent working in healthcare. Licensure acronyms below: MD is a Medical Doctor, DO is an Osteopathic Doctor, PA is a Physician Assistant.

**Table 2: Participants**

Associated Number	Specialty and Experience
1	Oncology: MD working with cancer patients for over 20 years
2	Grief Counseling: Counselor working with dying patients and families in grief processing
3	Palliative Care: DO working with dying patients for nearly 5 years

4	Family Medicine: PA with over 20 years' experience working with all patients
5	Emergency Medicine (EM): DO with over 20 years' experience in EM and nearly 10 years' experience in Medical Education

This research study received UNC IRB approval in January 2022 and was given Category 2 Exempt approval (Appendix C). However, due to the sensitive topic and the traumatic experience that can be associated with patient death, the researcher included a brief and debrief. Due to the limited available time for HCPs to give an interview, a full year and a half was used to obtain the five interviews. Materials used are the professional Zoom account to record and transcribe audio. NVIVO, a qualitative thematic coding program, was used to code interviews and identify themes. Access to NVIVO is provided through the university virtual labs. Access to literature was done through Search Summons through the University of Northern Colorado library's online access page, <https://www.unco.edu/library/>.

Emerging themes were identified using inclusion and exclusion criteria. Aggregated References were used to provide clarity of insignificant parent codes to more significant child codes or a part of a larger theme. Codes which were coded once in one interview were reviewed in connection to the code, however, were excluded if the code had more than one aggregated reference as it was a parent code to a more significant child code.

#### Inclusion Criteria

- Coded ten or more times
- Coded in least four interviews
- Coded once in one interview with one aggregated reference

### Exclusion Criteria

- Coded less than ten times
- Coded in less than four interviews
- Coded once in one interview with more than one aggregated reference

## Results

After coding the five interviews, code references were gathered and totaled using features provided by NVIVO. These features include tabulating the code references which refer to the number of times a code is referenced in total, the number of interviews in which that code was used, and the referenced codes aggregated with parent and child codes. Table 3 displays the codes, the coding references, in how many interviews that code was used, and a reference key for the resulting graph (Figure 1). Aggregated referenced codes can be best visually understood using Figure 2. The importance of coding references and interviews coded, especially when compared, can help identify which codes are most prominent in the interviews and which were less discussed. Codes such as Colleague Inadequacy, Patient Support via Emotion, Supportive Techniques, and Administrative Support were major codes with many references in most interviews. Just as meaningful as the codes most referenced in most interviews are those least referenced in the minority of interviews, such as Education\Sufficient, Mentorship\Positive Availability, Training\Not Useful, Training\Positive Availability, and Positive Patient Provider Communication.

**Table 3: Coding Results**

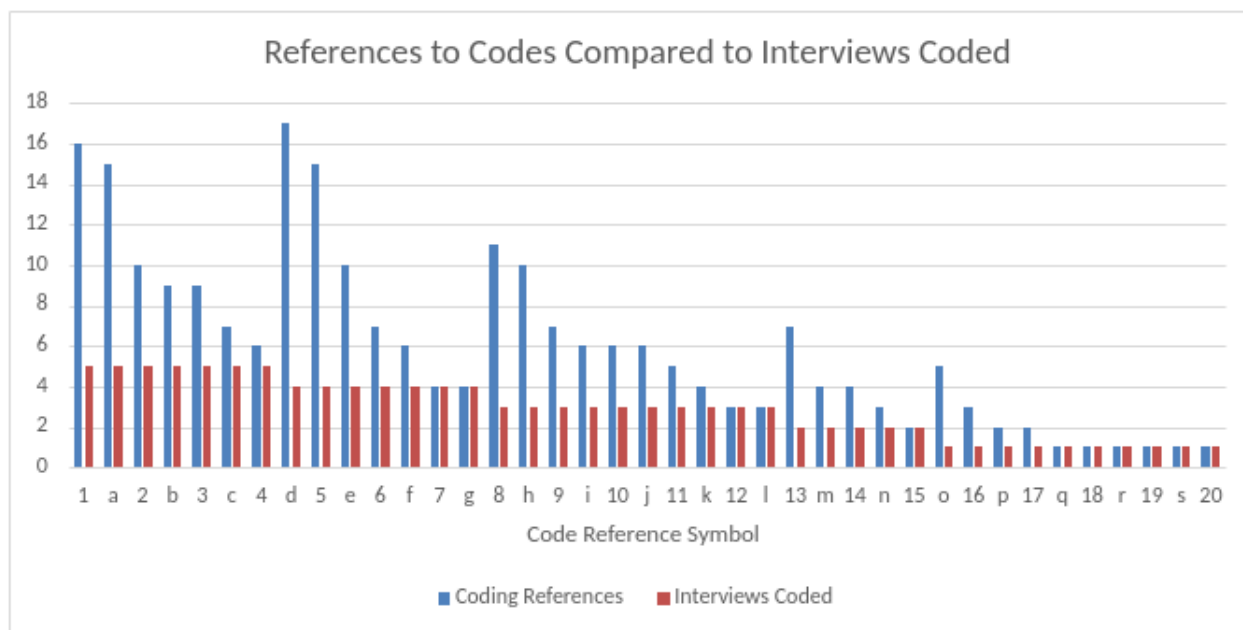
Graph Reference	Codes	Coding References	Interviews Coded	References Aggregated



1	Work Environment\\Patient Support Via Information\\Patient Support via Emotion	16	5	16
a	Cultural Influences\\Personal Culture\\Supportive Techniques	15	5	15
2	Quality of Death\\Good Death	10	5	10
b	Education\\Insufficient	9	5	9
3	Work Environment\\Patient Provider Miscommunication\\EOL Discussion Ambiguity	9	5	9
c	Experience\\Mentorship\\Comfort	7	5	7
4	Education\\Sufficient\\Active Listening	6	5	6
d	Work Environment\\Colleague Inadequacy	17	4	17
5	Work Environment\\Administrative Support	15	4	15
e	Work Environment\\Patient Provider Miscommunication	10	4	22
6	Work Environment\\Reliance Upon EOL Specialties	7	4	7
f	Death Anxiety\\Experience of Death Anxiety	6	4	6
7	Cultural Influences\\Personal Culture\\Mortal Salience	4	4	4
g	Quality of Death\\Medically Aided Death	4	4	4
8	Work Environment\\Concepts of professionalism	11	3	17
h	Patient Relationships	10	3	10
9	Quality of Death\\Provider Philosophical Associations	7	3	7
i	Cultural Influences\\US Culture	6	3	6
10	Experience\\Training\\Insecurity	6	3	6
j	Work Environment\\Concepts of professionalism\\Avoidance due to fear of professional consequence	6	3	6
11	Work Environment\\EOL Discussion Responsibility	5	3	5
k	Experience\\Training\\Negative Availability	4	3	4

12	Work Environment\\Patient Provider Miscommunication\\Religious	3	3	3
1	Work Environment\\Support between colleagues	3	3	3
13	Goals of Care	7	2	7
m	Work Environment\\Patient Support Via Information	4	2	20
14	Quality of Death\\Bad Death	4	2	4
n	Education\\Sufficient\\EOL Specialties	3	2	3
15	Death Anxiety\\Communication Affected by DA	2	2	2
o	Education\\Valuable	5	1	5
16	Experience\\Training\\Comfort	3	1	3
p	Experience\\Mentorship	2	1	12
17	Experience\\Mentorship\\Insecurity	2	1	2
q	Cultural Influences\\Personal Culture	1	1	20
18	Education\\Sufficient	1	1	10
r	Experience\\Mentorship\\Positive Availability	1	1	1
19	Experience\\Training\\Not Useful	1	1	1
s	Experience\\Training\\Positive Availability	1	1	1
20	Work Environment\\Positive Patient Provider Communication	1	1	1

***Figure 1: References to Codes Compared to Interviews Coded***



Additionally, a coded map which can show aggregated code referenced, or the total of parent and child codes, was formatted as a feature of NVIVO (Figure 2). For example, Patient Provider Miscommunication was a parent code with the child code of EOL Discussion Ambiguity representing half of Patient Provider Miscommunications. Additionally, Supportive Techniques were a major topic of discussion within HCP's Personal Culture as compared to Mortal Salience, which although referenced in 4/5 interviews, was an insignificant topic regarding communication with EOL patients. This map provides clarity on what was significant within the parent codes in these discussions, especially when used with Table 3 in understanding the low references to Personal Culture, but high references to Supportive Techniques.

**Figure 2: Aggregated Code References Map**

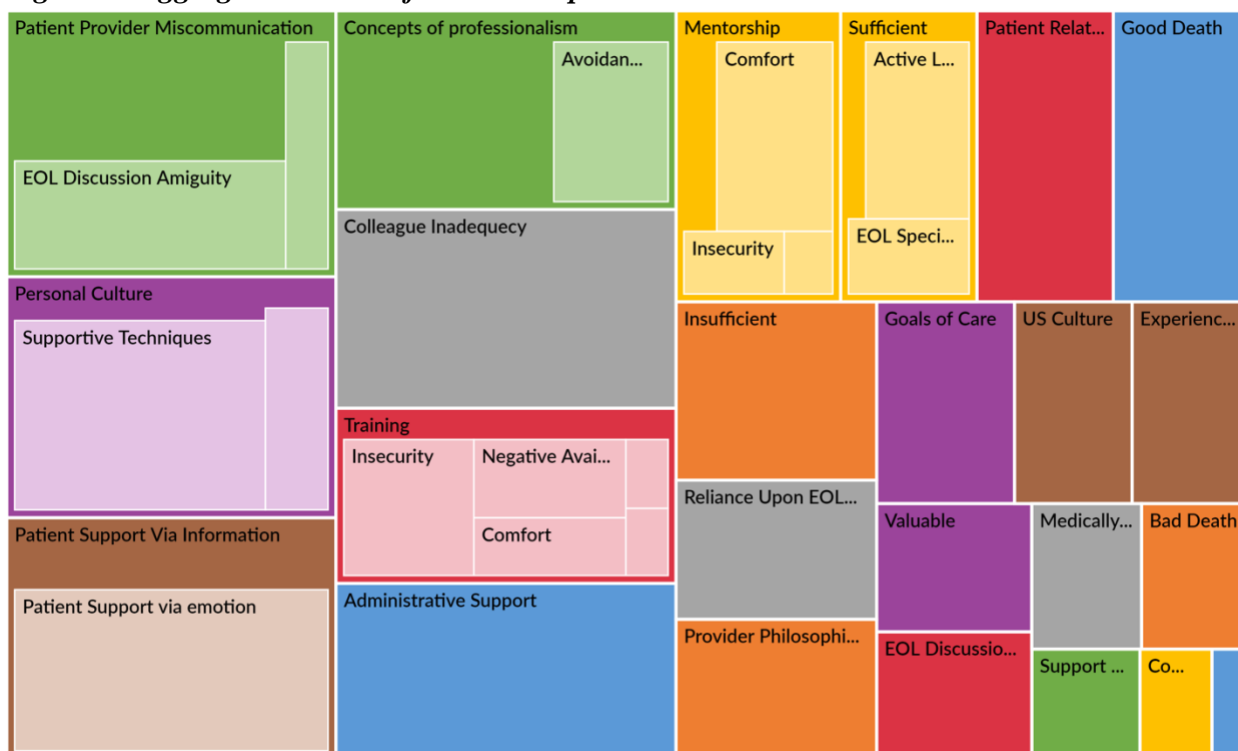


Figure 2 shows the aggregated codes which means the parent and child codes together in addition to codes which did not have child codes. The aggregated parent codes that were the majority are Patient Provider Miscommunication, Personal Culture, Patient Support via Information, Concepts of Professionalism, Colleague Inadequacy, Training, Administrative Support, Mentorship, Sufficient, Patient Relationship, and Good Death. The other codes were represented less than the others in interviews, however this was important when the code itself was reviewed. This is discussed later in the Emerging Themes and Participant Profiles section. Definitions for these codes can be found in the complete codebook (Appendix B.2).

Patient Provider Miscommunication was coded to statements that discussed any instance in which information between a patient and their provider was misunderstood. Under this parent code is EOL Discussion Ambiguity, in which uncertainty was

experienced regarding the identification of who should communicate EOL information, such as prognosis or the reality of a diagnosis. When a confident statement identifying an individual responsible for communicating an EOL prognosis was made, the statement was coded as EOL Discussion Responsibility.

Personal Culture is any reference to the HCP personal life outside of healthcare. Most importantly are the Supportive Techniques the HCP used to decompress from the overwhelming emotions that can arise when working with dying patients. Participants discussed techniques they personally used such as exercise, aromatherapy, time spent outdoors, or an effort to leave the emotions behind. Also discussed were less supportive techniques, such as alcoholism.

Patient Support via Information was coded when HCP specifically responded with the provision of information in response to an EOL patient's struggle with their prognosis. Under this is Patient Support via Emotion when empathy or emotion was provided in addition to information. This was a child code as it is the professional duty to provide information by HCP, however only some find it appropriate and necessary to also give empathy or emotion. This feeling of emotion being appropriate compared to their colleagues was explored further in Colleague Inadequacy and Concepts of Professionalism.

Colleague Inadequacy was coded when statements were made regarding the observation of colleagues failing in their duty to EOL patients. This was often regarding the opinion of colleagues not providing emotional support, not asking appropriate questions of a patient's health, or an inability to recognize when a patient should be considered EOL. For example, Participant 3 stated, "I find that sometimes the most

skilled physicians still can't recognize a dying patient when it's right in front of them and so oftentimes part of our job as the palliative care team is to [get them to] look at the big picture, get the, you know, the ICU (Intensive Care Unit) doctor, whoever it is, outside of the numbers and details and look at the whole person.”

Training was a parent code used to identify any statement referring to training with Insecurity, Negative Availability, and Comfort as child codes most represented. Insecurity was the converse to Comfort, which stated that the training did not prepare them for EOL interactions. Insecurity described the majority of experiences shared regarding training. Additionally, Negative Availability was used when participants stated training was unavailable or inaccessible. The definitions are identical to Mentorship, however participants reported more comfort with mentorship than insecurity.

Administrative Support was coded when participants brought up administration when discussing EOL patient interactions. Support provided by administration varied between workplaces, as shown in participant responses:

- Participant 1: “We have a support team who, really just a phone call, that you can get help, support therapy.”
- Participant 2: “More because of COVID but there's always something available as far as counseling goes for people or employee assistance programs.”
- Participant 4: “I wish more clinics would have open discussions and support group for their providers on how to deal with it.”
- Participant 5: “I was fortunate in that we were in an environment where we at least tried to have those support structures. I don't think we were as

well educated in how they could work best, but we did try and build that structure so that you had a sounding board or someone that understood what you're going through and was there to let you talk it through.”

Sufficient was a child code used for Education, with EOL Specialties and Active Listening as child codes. Sufficient was coded when participants reported having received education in Active Listening or in relation to their specialties in EOL care that prepared them for working with EOL patients.

Patient Relationship was coded when the participant discussed the development of a relationship with the patient, such as when Participant 2 stated, “You know some of the best discussions I ever [had], and the best relationships I [had], [they] developed over the 6 or 8 months when people are dying.”

Good Death was coded when a participant defined a good death or mentioned the importance or impact of a good death, as opposed to a bad death. Good deaths were associated with patients who experienced less pain and received more support. Additionally, good deaths were also associated with Medically Aided Dying, in which HCP supports a patient choosing to die rather than suffer a terminal illness. “They may have pain and you're treating that pain, that's, that to me seems more of a, a good death, you know, a death where they're as comfortable as possible and you're not doing all of these heroic measures that will give someone two days, unless that's truly what they want. And there are some people who want that. But yeah, it's being there and having family with you, holding your hand and going peacefully into the night is a much more

pleasant death in my mind than with tubes, whistles, bells and ventilators. Yeah. And I know that's the way I'd prefer to go" (Participant 5).

## **Discussion**

### **Previously Identified Themes Confirmation**

The previously identified themes, those related to education, experience, and death anxiety, were present in the interview data. EOL-focused education outside of EOL specialization training was viewed as "terribly inadequate" (Participant 2). In support of the sentiment shared in Kubler-Ross's book on the attitudes of death and dying in the medical culture, one participant stated, "The medical field, really struggles, with the idea of death and dying because for so much of our training, you know, obviously we are taught all the ways to prevent that from happening. Very little training outside of a palliative medicine fellowship is dedicated to the examination of a dying patient" (Participant 3). Regarding death anxiety, Participant 5 stated, "I think the idea of our mortality comes up [and] is a little bit more present, and especially as [I'm] getting older and, you know, people around the same age as me are diagnosed with illnesses, life threatening illnesses, or they face death, definitely. I think [death] comes into your mind more and your mortality is that much more of a reality." Although the participants had variable experiences in the availability, sufficiency, and comfort in the training, education, or mentorship they received because of their specialty and time of entering the field, all participants shared finding value in and the need for EOL training, education, and mentorship. In teaching future generations of HCP in EOL care and communication, Participant 5 stated, "It's something I definitely want to teach the next generation of physicians about... [and] want to incorporate in our curriculum to teach about and see if



we can have some clinical experiences for our students to start to see how that works and to experience that end of things.”

However, it was recognized that fully preparing HCPs to work with dying patients was complex. How an individual can be prepared for death relies upon personal experience and support to prevent them from being overwhelmed. “Trying to figure out how much to introduce at what level of training is key because how do you do this without overwhelming a budding doctor who maybe has never seen death in their entire being? You know, they've never lost a grandparent, they've never had to face these feelings and they're gonna come up when they see patients die. Um, so what level of support do you have? What level of introduction to these concepts do you have and when is it appropriate to take them into that room is a tough decision” (Participant 5). It can also be challenging teaching these skills to HCPs already in practice who lack those skills. As Participant 4 stated, “We got a huge chip on our shoulder. Prepped our whole life, thinking we got to be the best of the best to get here. We got to think we're 110% right all the time, to be sure. So, it's hard to get them to accept. You gotta get to the core, and that takes a lot of effort. Difficult teaching how to deal with death to the people.” The sentiment that associated HCPs having a fear of being wrong and possibly suffering legal consequences as well as having poor EOL communication and education, was reflected in most interviews and has been identified as an emerging theme.

These themes have been identified and explored in previous literature, as discussed previously. The purpose of this research was to identify emerging themes that could provide clarity on areas of improvement.

## Emerging Themes and Participant Profiles

Codes which were identified as emerging themes using inclusion criteria were:

- Work Environment\\Patient Support Via Information\Patient Support via Emotion
- Cultural Influences\\Personal Culture\Supportive Techniques
- Quality of Death\\Good Death
- Work Environment\\Colleague Inadequacy
- Work Environment\\Administrative Support
- Work Environment\\Patient Provider Miscommunication

Themes include Supportive Techniques used by HCPs to process challenging emotions because of working with EOL patients, the importance placed on patients experiencing a Good Death and subcodes in Work Environment such as Patient Support via emotion, Colleague Inadequacy, Administrative Support, and Patient Provider Miscommunication.

### *Participant 1: Oncologist MD*

- Direct Care
- Most brief interview
- Participates in GoC
- Does not experience as many direct personal discussions
- Feels education was appropriate (20 years ago)

Work Environment\\Patient Support Via Information\Patient Support via Emotion

"...just listening to patients and... to be fair and to show empathy then it's a lot easier to talk about these things. Even though it's a bit more emotionally draining it is easier in the long run."

Cultural Influences\\Personal Culture\Supportive Techniques

"Do some meditation...just try to drop it all and forget about it when I walk away from the office."

### Quality of Death\\Good Death

“Of course in our job the first one we always hope for better chances of cure, that's always our first one, and unfortunately there are a lot of people who don't have that chance of cure and then the treatment goals are more to control the cancer control the symptoms to hopefully get people more time and quality time. I always tell my patients my job is to squeeze every quality day out of that.”

### Work Environment\\Colleague Inadequacy

“You know there are some physicians who have kind of a more difficult time talking about it and maybe don't have as much, that they feel comfortable saying or talking or have a different demeanor on it, but you know I don't know who's right or who's wrong, we all have different personalities.”

### Work Environment\\Patient Provider Miscommunication

“It's always hard you know where those misperceptions happen and it could be that someone was uncomfortable telling them the truth you know that they sugar coated it... when you have a discussion with the previous physician they say no I told them all of that and that the patients have a great ability to, you know, take those bad bits of information and bury them. And we see it all the time, particularly when they get admitted, the hospitalists always call me up and say this patient was never told that they had [disease]. They were told, it just doesn't sink in.”

### *Participant 2: Grief Counselor*

- Indirect Care
- Does not participate in GoC
- Experiences more EOL discussions and anxiety alleviation
- Strongly feels education is limited and there is a need for more focus in EOL care

- Processes personal emotions related to work openly and utilizes mental and emotional supports

On what death means professionally, the participant stated, "...it's an existential situation realizing that their [the patient's] physical being isn't going to be able to carry on anymore and it's terminal and that they're coming to an existential ending with [their] life and usually trying to find meaning in what it means to die."

Work Environment\\Patient Support Via Information\\Patient Support via Emotion

"We've discussed how it is to love one another, you know to care for one another and know that we're going to mourn them I think those are some very great gifts, you can give someone when you say you know you're going to be missed you're going to be mourned."

Cultural Influences\\Personal Culture\\Supportive Techniques

"My ritual is to really spend some time and I pray but maybe not in the way that people imagined prayer to be to a God and that type of thing it's much more ritual Based on native American teachings and sending up good energy and that type of thing, but I do think about that, I think a lot about their families... I [cry] a lot."

Quality of Death\\Good Death

"And if they've had if they've had a good death, and by that were they able to see the people they wanted to see and were they were they happy with their lives were they did they find meaning in what they're doing or was it a to look backwards and just go gosh I really messed up here and even if they did, can they let go of that so yeah I think a lot about that, I do."

Work Environment\\Administrative Support

“It's a very inhumane work environment, in my opinion, sometimes because we don't allow people to feel so I would worry about that...”

#### Work Environment\\Patient Provider Miscommunication

“I would hope the professionals can slow down a little bit more, but it's hard it's hard for both parties, I think, so I'm very sympathetic to both. With the hope that somewhere along the way, someone will listen... when you go in to a physician and they're typing on a computer, I'm not sure how much they're hearing, because they're trying to engage with the keyboard they're trying to put the information they're just gathering.”

#### *Participant 3: Palliative Care Physician DO*

- Direct Care
- Creates GoC
- Directly works with patient in EOL support
- Felt fellowship education was appropriate but that all specialties would benefit from EOL education

#### Work Environment\\Patient Support Via Information\\Patient Support via Emotion

“Making sure that we are thinking of them as mind body and spirit and supporting them emotionally, and then the last bucket of advanced care planning and making sure as much as possible, that their goals their wishes really align with their medical care.”

"...even if we can't necessarily fix something, that talking about it saying it out loud can help decrease the fear or decrease anxiety, even if we aren't fixing the underlying concern."

#### Cultural Influences\\Personal Culture\\Supportive Techniques

“Part of my coping strategy is still a little bit that magical thinking of. You know it's not going to happen to me. You know not close to my time yet, so I think, because it feels so distant and so outside the realm of possibilities at this time in my life I don't, I don't have a lot of Experience thinking about it, but I guess, even when I have thought about it, I wouldn't say anxiety is an emotion that comes with it...couple of different ways is one leaning on my team members, and you know those debriefing informally and formally the reflections with the condolence cards... [Counseling] has been helpful in teaching us about like a rituals, and so, making sure that prior to going home for the day and leaving your office and figuring out a ritual that that kind of triggers you to leave this space and so, it's been helpful to have like a specific kind of aroma therapy kind of roll on that I can and just put on my wrist and smell and take a few breaths before getting in my car and driving home. You know just that physical exercise and the pieces that overall help your health in general I think are important. And then I would say the final most and one of the most important pieces of advice I received in order to have a career that sustainable in palliative medicine is to not be not get committed to the outcome, and so letting go of the outcome and just being present and supportive through the journey...”

#### Quality of Death\\Good Death

“There's no real good death, you know that that term is thrown around and it's all so personal what is important to someone as they're experiencing death...”

#### Work Environment\\Colleague Inadequacy

“It's just the physician shortcomings, then I think you know, inherently these conversations are emotionally charged, especially depending on the communication skill set of the physician or the provider delivering the news... one of the biggest mistakes of physicians can sometimes make when they're giving a time-based prognosis is not giving a range.”

#### Work Environment\Patient Provider Miscommunication

"...does the patient hear it because of the emotional context of the scenario... the example that happens commonly is the oncologist has said to the patient, you know the chemotherapies not been effective, your disease has gotten worse. And after that sentence patients shuts down completely, doesn't hear, they're thinking about their dogs, are thinking about their finances. Everything else said is not heard, and then the physician goes on to say, you know I'm worried that you have months to live. This patient ends up in the hospital, we asked what they've heard from their doctor and they say chemotherapy is not working, but you know he has other ideas... you know it's a talked about, you know how much time you might have no he's never mentioned it... And so saying, you know, I think you have three months to live and then it's three months and a week later, and the patient is furious and they have anticipated this death, and they've kind of checked off all their things they've said their goodbyes and now they're here and they're okay, and not eminently dying, and so I think that that in itself can be harmful just to the mental health of patients.”

#### ***Participant 4: Family Medicine Physician's Assistant***

- Longest interview conducted
- Direct Care

- Creates GoC
- Directly works with patient in EOL support and connecting patients with EOL support
- Felt education was not adequate and felt strongly about specialties needing EOL education

#### Work Environment\\Patient Support Via Information\\Patient Support via Emotion

“You gotta let them see you feeling the pain. Let them understand that you get their frustration. I will never know how they feel exactly, but I can let him know I feel... we can't be a robot.”

#### Cultural Influences\\Personal Culture\\Supportive Techniques

“You can't drink your way through it. So I had to find alternative... At the end of the day, I reflect on the day, what I could have done different, what I could have done better, and I allow myself 20 min to think about it. What am I going to change in the future? What I could have done differently, and then I let it go... Once a month, I take my sweet little butt backpacking and fishing for a 3 day weekend, and I get out in the middle of nowhere. I don't have to worry about anybody but me, and I take care of me. I let those things go. I realized that though I may have not done the best I could at that particular moment, I did what I could, and that will have to be enough.”

#### Quality of Death\\Good Death

“...to give them the best death possible. That's the ultimate goal.”

#### Work Environment\\Colleague Inadequacy

“I've had many experiences with people less trained and less prepared, dealing with death. For some it was an opportunity to share. For others, they were so dogmatic and set in their own little world, they had no room for learning. And that



was a very sad day. Some people become cold and brutal...as a result, I tried to go back and do what I can to fix it, because it ain't a mistake until we can't fix it... It's just so much harm has been done by that one encounter before me, or 2 sentences before me that it's hard to regroup and address it. Those are very sad days for me. A lot of our colleagues... they want to blow it off to whoever else they can. I've had colleagues that get a pat for a breast biopsy back. Blow the patient off and let somebody else see them to give them the biopsy results. I used to get upset about that. Why are they dumping on me? Why aren't they taking care of their patients?"

"It's very hard to pick your battles with your colleagues, particularly with people that are still learning... it's very difficult to do anything about it because ego is so fragile."

"I know that at least two providers that think that it's losing a fight or a battle...And then there are others that have the same perspective as me. The quality of the life and the way it was led or lived versus the number of years is more important. My goal is to help people have the best quality of life for the time they're given on this earth."

#### Work Environment\Administrative Support

"That's, again, dependent upon the leadership at that facility. If they foster that, if they encourage [team spirit] or are they pitting everybody against each other? Very difficult places to work when they do that, and I do a lot of consulting work trying to fix clinics, and 90% of the time it wasn't the staff. It was the management."

“Your problem isn't your staff. It's you and a pizza party is not going to fix it.”

***Participant 5: Emergency Medicine DO and Medical Educator***

- Direct Care/Now working in education
- Worked to connect hospice with patients in emergency medicine
- Directly works with patient in EOL support
- Feels education is getting better but still insufficient

Work Environment\\Patient Support Via Information\\Patient Support via Emotion

“I've cried with a patient here and there. It feels very uncomfortable afterwards.

But yes, I have cried along with a patient.”

“I think a lot of it is just trying to put yourself in that person's shoes and truly be empathetic as to what would they need, what would you need if you were in their shoes, giving them that.”

Cultural Influences\\Personal Culture\\Supportive Techniques

“Sometimes it's just you go out and exercise like anything, you know, you feel really stressed about this and there's nothing that's gonna make you feel better. So, you go out and you do a two rough hour at the gym, you know, or for me, I'm a musician, I'll go play music and that, you know, is one way I decompress my stress.”

Quality of Death\\Good Death

“I know this is me projecting some of this on, but when I've seen patients who've come in and have died peacefully, not in a lot of pain, not having multiple painful procedures performed, when you knew they were dying, you know, it's different.”

Work Environment\\Colleague Inadequacy

“Just as there are physicians who make some rather unsound judgements and you can report them, it's still not necessarily, they're not gonna listen to you if you say, wow, you really miscalled that one, didn't you?”

#### Work Environment\\Administrative Support

“I was fortunate in that we were in an environment where we at least tried to have those support structures. I don't think we were as well educated in how they could work best, but we did try and build that structure so that you had a sounding board or someone that understood what you're going through and was there to let you talk it through.

Researcher: Do you think that that support is available to every healthcare professional?

Participant 5: I would say probably not. Although I'm hopeful that as we're continuing to do these wellness initiatives and looking at the wellness of our healthcare providers, that it will improve.”

#### Work Environment\\Patient Provider Miscommunication

"...it can bring back some of the feelings that you have with your own family...with my dad, it was an unexpected death. He was shaving and dropped over, and I was notified while I was working in the emergency department that my father had a cardiac arrest. And they didn't tell me he had died. They said he had a cardiac arrest. And I said, well, what hospital is he going to? And then they said he didn't survive. And that was actually a local physician who called me."

Emerging themes identified due to poor representation include:

- Experience\\Mentorship\\Positive Availability
- Experience\\Training\\Not Useful
- Experience\\Training\\Positive Availability
- Work Environment\\Positive Patient Provider Communication

The poor representation of these codes when associated with the meaning of that code is possibly significant. The overall theme shows a minority of opinions on availability of mentorship and training, training not being useful, and a single instance of observing positive patient provider communication in the work environment outside of EOL specialties. This code excluded EOL specialties as there was an overwhelming representation of appropriate communication from and within these specialties. This is due to the specialized education, training, and expected treatment of EOL specialties compared to those outside of EOL specialties from which these specific codes are derived.

Cultural Influences\\Personal Culture and Education\\Sufficient is excluded due to the high number of child code references. Personal Culture is the parent code to Supportive Techniques which was coded fifteen times in all five interviews and identified as a significant code due to the inclusion criteria, and Sufficient was the parent code for Active Listening and EOL Specialties which were not identified as significant codes due to the exclusion criteria.

The challenge of identifying emerging themes in these interviews was the vast network of codes and subcodes which could have been identified. Additionally, the interview length ranged from roughly thirty minutes for Participant 1 (Oncologist) and

over two hours for Participant 4 (Family Medicine PA). These interview times could also be considered significant, but that was not considered in this paper.

### **Future Direction**

EOL research investigating relationships between patients and providers shines a light on a larger issue: the lack of empathy in healthcare. In EOL care, often the only thing providers can give is empathy, so when empathy is absent it is very clear. However, this is true in every healthcare setting and interaction. Physicians need to spend more time getting to know their patients and facilitating more individualized care, however with the restrictions on time and availability, this can be a challenging goal to meet. Finding a solution requires a systemic change within healthcare. The researcher is enrolled in a Master of Public Health program where she will continue research into empathy-based healthcare and implementation.

## APPENDICES

### Appendix A: Informed Consent Form



#### Informed Consent Form for Participation in Research

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Title of Research Study Comfort of Healthcare Professionals With End-of-Life Patient Communication

**Researcher(s):** Madison Gremillion, University of Northern Colorado College of Biology  
Phone Number: (530) 575-1972 email: [grem5599@bears.unco.edu](mailto:grem5599@bears.unco.edu)

**Research Advisor:** Rosann Ross, Department of Psychological Sciences  
Phone Number: (970)-351-2485 email: [rosann.ross@unco.edu](mailto:rosann.ross@unco.edu)

**Procedures:** This research is for healthcare professionals only. If you are not a healthcare professional such as a registered nurse (RN), social worker, Physician Assistant/Nurse Practitioner/Doctor of Medicine/Doctor of Osteopathic Medicine (PA/NP/MD/DO), certified nursing assistant/medical assistant/licensed practical or vocational nurse (CNA/MA/LPN/LVN), please notify the researcher requesting this consent form. If you participate in this study, you will be interviewed on topics involving your comfort and experiences when working and communicating with dying patients as well as any education you may have received involving end-of-life patient communication. These questions will NOT ask you to disclose personal information about your patients and will respect patient confidentiality. The interview will in most cases be an hour long but can take up to two hours, and you may be asked to clarify any responses with follow-up questions. Interviews will be conducted in private either in a place of your choosing such as your office, or can be done at the University of Northern Colorado's (UNC) library in a private room. Interviews can also be conducted through phone or virtual video. In this case, the researcher will be in a private room and confirm prior to conducting the interview that you are in a space where you feel comfortable being interviewed. The interview will be scheduled at your most convenient time and if it must be rescheduled you will be contacted at least 48 hours prior. The interview will be recorded through notes and with an audio recorder. Interviews will be analyzed using thematic coding to identify common themes. The only personal information published will be your professional credentials and your specialty. Your name and place of work will be kept confidential. At any time after the interview you may request the project proposal, the semi-structured interview questions, ask any questions, or request your interview be removed from the study prior to the completion date of May 6th, 2024.

**Questions:** If you have any questions about this research project, please feel free to contact Madison Gremillion at (530) 575-1972 and [grem5599@bears.unco.edu](mailto:grem5599@bears.unco.edu). If you have any concerns about your selection or treatment as a research participant, please contact Nicole Morse, Research Compliance Manager, University of Northern Colorado at [nicole.morse@unco.edu](mailto:nicole.morse@unco.edu) or 970-351-1910.

Voluntary Participation: Please understand that your participation is voluntary. You may decide not to participate in this study and if you begin participation, you may still decide to stop and withdraw at any time. Your decision will be respected.

**Please take all the time you need to read through this document and decide whether you would like to participate in this research study.**

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

\_\_\_\_\_

Participant Signature

\_\_\_\_\_

Date

\_\_\_\_\_

Investigator Signature

\_\_\_\_\_

Date

## **Appendix B:**

### ***B.1: Semi-Structured Interview:***

1. Do you feel comfortable talking about death and feelings about working or interacting with dying patients?
2. Do you feel that we are doing this interview in a space where you have confidentiality and privacy?
3. Do you understand that you may request to not answer any questions during this interview?
4. Do you have any questions or concerns prior to beginning this interview?
5. What is your professional credential/license?
6. What is your specialty if applicable?
7. Do you or have you ever experienced anxiety relating to death or dying?
  - a. If so, when do you usually experience death anxiety?
  - b. If not, what would you attribute to not having death anxiety?
8. What does end-of-life/dying mean to you professionally?
9. How do you feel your working environment views death and dying patients?
10. How would you describe hospice and palliative care?
11. Have you ever had experience in hospice or palliative care?

12. How often if ever do you work with end-of-life/dying patients?
  - a. If you do, in what general capacity do you work with dying patients?
  - b. If not, describe why you have few or no interactions with dying patients.
13. Does working with or the thought of working with end-of-life/dying patients make you uncomfortable?
  - a. Describe your comfort/discomfort.
  - b. If you feel uncomfortable/comfortable, what are some of the reasons why?
14. Have you ever had to discuss dying or end-of-life care with a patient?
  - a. If so, what were some feelings that you experienced?
    - i. How did you manage your own emotions during this conversation?
  - b. If not, do you feel confident in being able to have this discussion? Why or why not?
15. Has a dying patient ever shared being afraid of death or dying with you?
  - a. If so, how did that make you feel?
    - i. How did you respond to this?
    - ii. Do or have you reflected on this conversation or conversations afterward?
  - b. If not, do you feel comfortable with the thought of this situation? Why or why not?
16. Have you ever shared your feelings with a patient, whether it be sadness in their situation, uncertainty, or other emotions? Would or do you feel comfortable crying in front of a patient?
17. Whose responsibility should it be to make it known to a patient that they are dying?
  - a. Why?
18. What do “goals of care” mean to you?
19. Have you ever had to develop goals of care with an end-of-life patient?
  - a. If so, what were some goals you came up with?
    - i. What is the focus of the goals you’ve developed?
  - b. If not, what do you believe would be a focus for goals of care for an end-of-life patient?



20. Have you ever, in your professional training, had a class or course in working with dying patients?
  - a. If so, did this course prepare you for working/communicating with dying patients in practice?
    - i. Was this course included in your education or was it supplemental?
    - ii. Compared to the rest of your education, did you receive little or a lot of training in end-of-life care?
  - b. If not, would you be interested in learning more about working with/communicating with dying patients?
21. Have you ever been present while a patient is actively dying?
22. What are your feelings around medically aided dying?
23. What does active listening mean to you?
24. Have you ever had a course on active listening?
25. Do you feel that you were prepared to work with dying patients upon entering your field?
26. Have you ever worked with others with more experience working with end-of-life/dying patients?
  - a. If so, what are your thoughts/feelings on this difference in experience?
27. Have you ever worked with others who have had less experience in working with end-of-life/dying patients?
  - a. If so, what are your thoughts/feelings on this difference?
28. Overall, do you feel like you build or could build a strong professional relationship with dying patients?
  - a. Why or why not?
29. In what ways do you process the stress and emotions from your interactions or those resulting from a patient dying?
30. Are there any hobbies or activities that you do to maintain your emotional well-being?
31. Do you feel that the environment you work in supports professionals expressing anxiety, grief, or other emotions that might result from working with dying patients?

32. Are there any questions, concerns, comments, or feelings you want to share?
33. Do you feel like we've thoroughly discussed the topics of working with end-of-life/dying patients in the amount of time available?
34. Was there any point during this interview at which you felt uncomfortable?
35. Are there any questions you expected or hoped I would ask?
36. Do you understand that at any point from now until May 6th of 2024, you may ask for your interview to be removed from the study?
37. Do you feel comfortable reaching out after this interview for any additional questions or concerns?

### ***B.2: Complete Codebook***

Name	Description
Goals of Care	Reference to or defining the development of a plan with the patient to identify goals of the patient to achieve before death
Patient Relationships	HCP describes the importance of developing a relationship with the patient as being a central aspect of health

#### Theme: Cultural Influences

Reflections on cultural perceptions of death related to working with dying patients

Name	Description
Personal Culture	Perception of death relating to personal practices or beliefs
Mortal Salience	Reflecting on one's own death
Supportive Techniques	Techniques used to support trauma processing. Includes rituals, therapy, exercise, etc. Can also be references to substance abuse.
US Culture	Reflections on the culture of death regarding the United States, the primary location of the participants

#### Theme: Death Anxiety

Related to the experience of death anxiety or discomfort related to the thought of or reminder of death

Name	Description
Communication Affected by DA	Mentions of communication affected by death anxiety either self or other
Experience of Death Anxiety	Mentions death anxiety either self or other

## Theme: Education

Relating to any reference towards education

Name	Description
Insufficient	Education was reflected on as being insufficient for working with dying patients
Sufficient	Education prepared participants for working with dying patients
Active Listening	Participant discusses active listening
EOL Specialties	Participant mentions working with EOL specialties or specializes in EOL care
Valuable	Participant applies value to EOL education

## Theme: Mentorship, Experience &amp; Training

Related to any mention of mentoring, experience, and/or training, either self or observed

Name	Description
Mentorship	Participant experienced mentorship and relied on this experience for future interactions or was a mentor
Comfort	Did prepare participant for working with dying patients/Confidence with mentor's ability and performance/Feels mentorship is supportive
Insecurity	Did not prepare participant for working with dying patients/Lack of confidence with mentor's ability and performance/feels mentorship was not supportive
Negative Availability	Experience & Training was not available
Positive Availability	Experience & Training was available
Not Useful	Experience & Training is not useful

## Theme: Quality of Death

HCP discusses the quality of a death

Name	Description
Bad Death	Positive experiences relating to a 'bad' death
Good Death	Positive experiences relating to a 'good' death
Medically Aided Death	Discusses experience with MAD
Provider Philosophical Associations	Participant responds with personal philosophical viewpoint outside of medical education

## Theme: Work Environment

Relating to reflections on the working environment, specifically in a hospital or clinical setting

Name	Description
Administrative Support	Participant discusses support and intervention offered by administration, either present or lacking
Colleague Inadequacy	Participant responds with colleagues' inability to communicate or respond appropriately to a EOL patient
Avoidance due to fear of professional consequence	Participant mentions avoidant behavior or action due to fears of legal or professional consequence such as being sued, or being wrong either self or observed
EOL Discussion Responsibility	Participant identifies who should communicate to the patient of their terminal prognosis
Patient Provider Miscommunication	Participant mentions miscommunication that occurs between the healthcare professional and their patient, either self or observed, outside of EOL specialties
EOL Discussion Ambiguity	Participant discusses
Religious	Any mention of religion
Patient Support Via Information	Participant discusses supporting and EOL patient with providing information as valuable
Patient Support via emotion	Participant discusses supporting and EOL patient with providing emotion and empathy as valuable
Positive Patient Provider Communication	Participant reflects on positive communication and interactions with patients, self or observed, outside of EOL specialties
Reliance Upon EOL Specialties	Mentions of EOL specialties as being needed to facilitate or execute EOL interactions
Support between colleagues	Participant discusses support offered by and between colleagues

## Appendix C: IRB Approval



Date: 01/14/2022

Principal Investigator: Madison Gremillion

Committee Action: **IRB EXEMPT DETERMINATION – New Protocol**

Action Date: 01/14/2022

Protocol Number: [2201034298](#)

Protocol Title: Comfort of Healthcare Professionals With End-of-Life Patient Communication: Exploring Comfort, Communication and Education of Healthcare Professionals for End-of-Life Care

Expiration Date:

The University of Northern Colorado Institutional Review Board has reviewed your protocol and determined your project to be exempt under 45 CFR 46.104(d)(702) for research involving

Category 2 (2018): EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS OF PUBLIC BEHAVIOR. Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

You may begin conducting your research as outlined in your protocol. Your study does not require further review from the IRB, unless changes need to be made to your approved protocol.

**As the Principal Investigator (PI), you are still responsible for contacting the UNC IRB office if and when:**



- You wish to deviate from the described protocol and would like to formally submit a modification request. Prior IRB approval must be obtained before any changes can be implemented (except to eliminate an immediate hazard to research participants).
- You make changes to the research personnel working on this study (add or drop research staff on this protocol).
- At the end of the study or before you leave The University of Northern Colorado and are no longer a student or employee, to request your protocol be closed. \*You cannot continue to reference UNC on any documents (including the informed consent form) or conduct the study under the auspices of UNC if you are no longer a student/employee of this university.
- You have received or have been made aware of any complaints, problems, or adverse events that are related or possibly related to participation in the research.

If you have any questions, please contact the Research Compliance Manager, Nicole Morse, at 970-351-1910 or via e-mail at [nicole.morse@unco.edu](mailto:nicole.morse@unco.edu). Additional information concerning the requirements for the protection of human subjects may be found at the Office of Human Research Protection website - <http://hhs.gov/ohrp/> and <https://www.unco.edu/research/research-integrity-and-compliance/institutional-review-board/>.

Sincerely,

Nicole Morse  
Research Compliance Manager

University of Northern Colorado: FWA00000784

## Appendix D: Funding Award Letter

### *OUR Grant Funding*



*Office of Undergraduate Research*

Congratulations Madison Gremillion!

You have been awarded a Spring 2022 Office of Undergraduate Research Grant.

Project title: Comfort of Healthcare Professionals With End-of-Life Patient Communication: Exploring Comfort, Communication, and Education of Healthcare Professionals for End-of-Life Care.

Faculty Sponsor: Dr. Rosann Ross

Grant Period: Spring 2022; January 6, 2022 – May 20, 2022

Final Grant Report Due: May 20, 2022, to [our@unco.edu](mailto:our@unco.edu)

All required payment paperwork due: March 22, 2022

You have been awarded an Undergraduate Research Spring 2022 Grant award based on the proposal you submitted.

The amount of your award is as follows:

Stipend Salary Awarded \$ **300**

- This stipend will be paid as student salary in April, if all paperwork is completed on time.
- If the required paperwork is not completed in a timely manner, then the stipend will be forfeited.
- Student Employment Status **Yes, I am currently a UNC student employee.**
- *Margaret McKeown-Kelley will be sending you all required hiring paperwork to set up a salary job for your payment.*
- *You must respond and complete all paperwork by March 22. Please contact Margaret directly at [margaret.kelley@unco.edu](mailto:margaret.kelley@unco.edu) with any specific questions.*

**GRANT ACTIVITY PERIOD**

Grants may cover activities and purchases that happen between January 6, 2022, and May 20, 2022.

**All grant activities for which you are being compensated must be completed by May 20, 2022.**

Except conference fees may be used to pay for a conference that happens after May 20, as long as the payment is made prior to May 20. (If this is not possible, you may need to reapply for a Fall OUR grant)

**FINAL GRANT REPORTS:**

**A final grant report will be due May 20.** The final grant report will include a synopsis of all activities completed and summary of all supplies purchased or travel/conference/professional development expenses using grant funds. Reports must be emailed to [our@unco.edu](mailto:our@unco.edu).



If you did not receive your full amount requested, we encourage you to apply again in Summer or Fall 2022. OUR will have additional funds available for Summer and Fall allocations. We received more proposals for Spring 2022 than funds were available.

Congratulations again!

Best,

**OUR Staff**

*Office of Undergraduate Research*

Office of Honors, Scholars, and Leadership

**University of Northern Colorado**

Michener Lower Level L-98

Campus Box 13

Greeley, CO 80639

[www.unco.edu/our](http://www.unco.edu/our)

[our@unco.edu](mailto:our@unco.edu)

## *Portz Interdisciplinary Fellowship Award Letter*



May 9, 2023

Madison Gremillion  
University of Northern Colorado  
[grem5599@bears.unco.edu](mailto:grem5599@bears.unco.edu)

Dear Madison,

On behalf of the National Collegiate Honors Council and the members of the Portz Interdisciplinary Fellowship review committee, we are pleased to confirm that you have been selected as a 2023 Portz Fellowship recipient \$5,000 award.

Congratulations!

Your project "End of Life Patient Communication about Death and Dying: Exploring Comfort, Communication and Education of Healthcare Professionals with End-of-Life Care" reflects a thoughtful and relevant purpose, clear research methods, and utilizes an interdisciplinary approach. The members of the committee were impressed with your preparation, your engagement in honors, and evident enthusiasm for your project.

The initial disbursement of your award will be posted this May. **As soon as possible, please reply to [nchc@unl.edu](mailto:nchc@unl.edu) with the following, to ensure you receive your payment.**

- **Your permanent mailing address** (all 3 disbursements of your award will be sent to this address over the next 12 months.)

In order to receive the remainder of your fellowship award, progress reports must be submitted periodically for the committee's review. The schedule is as follows:

- November 1, 2023      Interim Progress Report Due
- December 1, 2023      Second Payment Disbursement Scheduled
- April 1, 2024            Final Progress Report Due
- May 1, 2024             Third/Final Payment Disbursement Scheduled

Please upload your completed progress reports at the following link by the date required:  
<https://survey.alchemer.com/s3/7336989/NCHC-Portz-Interdisciplinary-Fellowship-Progress-Report>

Again, congratulations for your fine work, and best wishes for success in your research. We look forward to reports of your progress.

Kerry Wynn and Betsy Yarrison  
Co-chairs, NCHC Awards and Grants Committee

CC: Rosann M Ross [rosann.ross@unco.edu](mailto:rosann.ross@unco.edu)  
Loree Crow [loree.crow@unco.edu](mailto:loree.crow@unco.edu)

### ***Portz Interdisciplinary Questions***

#### INTERDISCIPLINARY RESEARCH COMPONENTS

*a) State the complex question that drives this proposal. Identify two (or more) disciplines involved in the project, and note why these disciplines are necessary to address that question.*

Death is an experience that cannot be researched with only a single discipline. It is a process that the physical body undergoes, the mind processes, and the spirit embraces. In fact, the foundation of research surrounding healthcare and death formed from Dr. Elisabeth Kübler-Ross's interdisciplinary seminar, which resulted in the psychology study published titled *On Death and Dying*. I've chosen to principally explore the disciplines psychology, philosophy, and healthcare communication as my interview questions are based on models and frameworks of those disciplines. Those questions include how HCPs process their own emotions (psychology), their personal views and opinions on how to support patients and other HCPs, which lead to personal views on death and the dying experience (philosophy), and how they approach EOL discussions (healthcare communications).

*b) Note disciplinary competency of the researcher(s) and awareness of differences in shared or key concepts.*

As a biomedical sciences student, death and dying has not been a subject covered in any of my coursework, with the exception of how cells die. This is reflected in medical education, as well as the responses in my current interviews. The major source of my competency is the training I've received as a Hospice volunteer, having the direct experience of seeing these conversations occur or not occur, and the experience of being a confidant for patients who feel unsupported by HCPs. Additionally, my own struggle with death anxiety has led me to pursuing the literature and theories in the field of Psychology and Philosophy in my coursework as well in my personal life, which I've done so since beginning my academic path nearly six years ago in my mid-twenties. I've spoken about death and death anxiety over the years in my various courses and most recently at a speaking event held by the Honors Program at my university. I've also been an active member within the EOL support community, discussing and working closely with death doulas whose job it is to guide dying individuals and their family through the active dying experience. These interactions have led to hundreds of hours of conversation which include dying philosophies, the psychology behind our reactions to death, appropriate or inappropriate ways of communicating with grieving individuals, and observations as a whole on the healthcare industry's response to dying patients.

Having an awareness of Psychology, Philosophy, Communications, and Biomedicine has been important when framing questions within the semi-structured interview protocol as well as being able to understand the complexity of HCPs' relationship to dying patients and the reality of death overall. HCPs will often respond to

patients as a healthcare professional and explain the protocols set by their specialty and the biological/physiology of death. However, participants will then respond emotionally as an individual having to experience death and grief on a daily basis. HCP experiences with EOL patients include reflections on death, such as family members dying, having affected interactions with dying patients.

In three cases, participants reflected on how their behavior changed when a patient resembled themselves or their family members. This is often the story that accompanies the question on whether they feel comfortable crying in front of patients. These responses require me to be familiar with psychology, and frame my questions to explore these responses. Participants will also reflect on their spirituality, personal beliefs, or activities/rituals that they use to process the existential challenge they face when interacting with dying patients. I have implemented and become familiar with philosophical models and views to better interpret and respond to these reflections. Existential conversations can be challenging and require great sensitivity as these beliefs are incredibly personal. These beliefs are also a major form of processing death anxiety in healthcare professionals (Solomon et al., 2015).

Understanding communication models is key to exploring the relationship between HCPs and dying patients. A physician's duty is to communicate concepts that can be challenging for people who do not have the knowledge to properly understand the severity or reality of medical problems (Balaban, 2000). I experienced this challenge when I tutored Biology and Chemistry; using language that both communicates information without requiring a level of understanding can be extremely difficult making it easy to have miscommunications. Communication is a major part of being a physician, however it becomes more challenging when it comes to communicating death. I've worked to better understand this discipline as it the foundational aspect of interactions between HCPs and EOL patients.

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