A DEATH WORTH DYING: A SURVEY OF THE ROLES AND PRACTICES OF

PSYCHOLOGISTS WORKING IN END-OF-LIFE CARE

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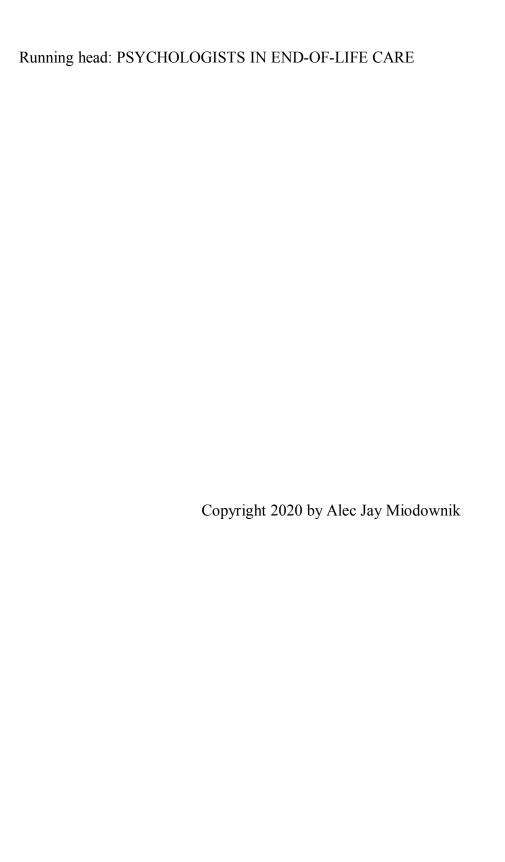THE STATE UNIVERSITY OF NEW JERSEY

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ABSTRACT

As individuals approach end-of-life, they and their families and other caregivers may be especially vulnerable to experiencing psychosocial stressors that can negatively affect psychological wellbeing. A growing body of evidence suggests that there are numerous benefits to providing psychosocial care to all these individuals as they confront end-of-life care and end-of-life. Importantly, clinical psychologists are qualified for, well suited to, and add value to such end-of-life psychosocial care. They can intervene before the onset of illness; after an illness is diagnosed and treatment has been initiated; during advanced illness and the dying process; and after the death of the patient with grieving family and survivors. Despite the ways that clinical psychologists are particularly well-equipped to engage professionally with end-of-life care, they are still relatively rare members of and not generally perceived of as central to end-of-life care treatment teams. In light of this professional gap highlighting clinical psychologists' absence in end-of-life care, the present study seeks (a) to document the valuable roles, practices, and functions of clinical psychologists now actually working in end-of-life care settings, and (b) to understand the ways in which these professionals cultivate meaning in this highly stressful work to sustain themselves. Towards this end, in this dissertation, I first provide a review of the current literature describing psychology's relationship with death and dying, psychology's role at end-of-life, psychosocial treatment at end-of-life, and meaning-making. Then, I describe the qualitative study methodology I used to conduct semi-structured interviews with clinical psychologists now practicing in end-of-life care settings to capture the range and depth of the participants' relevant experiences. The interviews were both (a) analyzed individually as narrative case studies in order to

identify the variety of practices and experiences among the subjects; and (b) compared

and contrasted with each other to highlight common themes found across individual

cases. I end with a discussion of the implications of this study, including directions for

future research and implications for clinical practice.

DEDICATION

This work is dedicated to the memory of my grandparents, Jean and Lou Greenberg, and Meilich and Fela Miodownik. To my *Zaidy*, Meilich Miodownik, I never knew you, but you taught me that life and living do not end after death and dying. To my *Babi*, Fela Miodownik, your ability to renew and will to survive demonstrated to me the healing power of connection and the power of the human spirit to rebuild despite unimaginable loss. To my Grandma, Jean Greenberg, your fierce devotion to your values, unapologetic passion, and commitment to your family modeled for me the virtue of living for something greater than myself. Finally, to my *Apoo*, Lou Greenberg, you showed me from the floor of your living room that youth has no age and that kindness and humility have no limit.

Finally, I would like to dedicate this work to the COVID-19 frontline healthcare workers across the world who are currently working selflessly to protect and promote dignity both in life and in death. Despite every inclination we have to pull away, you have shown us the humanity of leaning in.

ACKNOWLEDGEMENTS

As I complete this final endeavor of my graduate training, I fear that words will fail me as I attempt to express the depth of my gratitude for the army of people who have supported me to this point in my life. I could not have completed this without them.

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this project felt too heavy to bear. Thank you all.

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INTRODUCTION

Psychology's Relationship to Death and Dying

Reflections on and an awareness of death and dying have pervaded both Western and Eastern philosophical and religious alike. Indeed, a human fascination with the power of death as a force of meaningful change is demonstrated throughout recorded human history. The ability to grasp the concept of impending and inevitable death is perhaps what distinguishes humankind from other species (Feifel, 1990). Examples of this awareness of death are demonstrated in the belief in the Abrahamic tradition's belief in a resurrection or an afterlife; Indian and Dharmic religious beliefs of reincarnation or rebirth; and the atheist notion of consciousness stopping to exist in perpetuity.

The role of death and dying as a feature of human life has been addressed, to varying degrees, by psychology's earliest founders. Sigmund Freud famously described an innate human "death drive" (Thanatos) and concluded that people hold an unconscious desire to die and are inhibited by life instincts (Eros), which largely temper this wish (Freud, 1948). In his eight Stages of Psychosocial Development, Erik Erikson describes his final stage, marked by the conflict of "Integrity vs. Despair," in which an individual must reflect on one's life and accepts oneself and comes to terms with the notion of impending death. The inability to do this, Erikson noted, results in an existential feeling of despair (Erikson & Erikson, 1998). Erich Fromm (1964) addressed death in describing the distinction between those who love life (biophilia) and those who love death (necrophilia).

In her pioneering work on stages of grief, Elisabeth Kubler-Ross (1975) advocated for the integration of a death awareness into one's life, noting that only by

"accepting the finiteness of our individual existences can we find the strength and courage to reject extrinsic roles and expectations and to devote each day of our lives—however long they may be—to growing as fully as we are able" (Kubler-Ross, 1975, p. 164). Similarly, Viktor Frankl (1986) noted that an awareness of the finite nature of life is a precondition for drawing upon meaning from life.

Despite psychology's interest in death, some have critiqued psychology for neglecting an *empirical* understanding of an investigation of the role of death and dying (Feifel, 1990). They have argued that academic psychology had all but ignored death altogether until the 1960's. Notably, at that time, efforts stemming from other disciplines to understand death sparked interest from *academic* psychologists to investigate death and dying.

Feifel (1990) details several reasons academic psychology avoided the study of death, including large-scale cultural shifts dating back as far as the Enlightenment. Specifically, he notes "a shift from spiritual mastery over self to physical conquest of nature," resulting in a profound impoverishment of "religious or philosophic conceptual creeds, except nominally, with which to transcend death" (Feifel, 1990, p. 537). Death and grief became cultural taboos as everything associated with death and dying grew gradually more marginalized and isolated from society unless properly sanitized and decontaminated. Additionally, increasingly industrialized societies promoted the steady fragmentation of fairly homogenous family and community units, depriving individuals of the emotional and social supports with which to attenuate the impact of death. Grief became de-ritualized, as Western societies grew increasingly critical of death practices as "being overly expansive, baroque, and exploitive of the mourner's emotions."

As modern society placed increasing value on markers of life—that is, productivity, accomplishment, and the future— reminders of death and the notion of no future at all were viewed as anathema to contemporary ideals. Notably, death had been purged from everyday experience. As recently as one hundred years ago, humanity lived acutely aware of the presence of mortality in everyday life. In the last century, however, most of Western society has lost contact with the reality of dying and death. The experience of death has changed dramatically as pain-reducing medications have significantly diminished the physical discomfort of dying. The dying no longer spend their last days in the familiar surroundings of their home as they are moved to the sterile and shielding walls of hospitals and the medical establishments. Even dead bodies are removed from the family by healthcare professionals and funeral directors as mourning customs changed, and references to death are disguised by euphemisms (Dugdale, 2015). Death has become a mysterious and sanitized experience for many, representing the fearful unknown and has become the domain of the technical professional instead of the human (Feifel, 1990).

Additionally, academic psychology moved away from the study of death and dying as the result of a need to distinguish itself from "mental philosophy and metaphysics." As American psychologists attempted to mark their new field, they grew increasingly interested in the study of that which was measurable and repeatable. Psychological inquiry aligned itself increasingly with logical positivism; the more abstract areas of values, death, love, and free will were rejected in favor of concrete phenomena such as memory, reaction times, and visual perception. While these early

efforts were essential in bringing psychology in line with other scientific fields, it fostered a profound avoidance of "the existential richness" of life (Feifel, 1990).

Attitudes towards death education changed in the 1950s, as pioneers like Herman Feifel (1959), Elisabeth Kübler-Ross (1969), and Cicely Saunders (1967) encouraged scientists, physicians, clinicians, and humanists to investigate death and dying. These early pioneers initiated the death-awareness movement, which prompted a renewed interest in and widespread study of death, dying, and grief. This movement also triggered the development of contemporary interventions for the dying and bereaved, as well as new research on death and dying. This movement mirrored early efforts by psychologists to address the study of death as well. The first organized symposium on death, organized by Herman Feifel in 1956, was called <u>The Concept of Death and Its Relation to Behavior</u>, which was presented at the 1956 annual meeting of the American Psychological Association (APA) in Chicago.

Since then, academic psychology has made significant contributions to the study of death and dying. More recently, clinical psychology has expanded upon the developments made by researchers towards clinical applications of this vital body of knowledge about death and dying towards areas such as suicide, death attitudes, and grief. These growing domains of clinical application have gradually augmented the emergence of clearly defined clinical roles for mental health clinicians in end-of-life care (Neimeyer, 2005).

Psychology's Role in End-of-Life (EOL) Care

Reflecting a growing openness to and reintegration of death awareness into Western culture, the hospice care movement began in earnest with the opening of St.

Christopher's Hospice in England in 1967 by Cicely Saunders. In the same year, the home healthcare portion of the Hospice of New Haven was opened in the United States in 1967. These institutions sparked a cultural shift that provided dying individuals and their families with the notion of choice in their end-of-life care.

While end-of-life care can refer to both palliative and hospice care, the two treatments have key distinctions. Palliative care is a fairly general concept and refers to the holistic management of the physical, psychological, social, spiritual, and existential needs of individuals living with life-altering illness; palliative care does not reference the specified life expectancy of a patient. Palliative care focuses on the treatment of conditions that are life-limiting or cannot be managed by disease-modifying treatment. Palliative care can be provided in addition to curative treatments. By contrast, the term hospice care usually refers to a type of comprehensive palliative care provided during the last six anticipated months of an individual's life and is often linked to specific programs offered under the Medicare hospice benefit. Both palliative care and hospice care conceptualize *both* the patient and their family members as "the patient," and both models of care emphasize addressing the needs of both the individuals anticipating death as well as their families.

The main goal of hospice and palliative care is to promote optimal quality of life for dying individuals and their families. This goal is achieved largely through the following: relieving suffering, appropriate pain management, psychological and social support, maximizing patient functioning, and respect for the patient's agency and decision-making. While palliative care does not mean that a patient must not engage with curative or life-prolonging treatments, patients with a hospice care designation usually

must agree to disengage with life-prolonging or curative interventions (though exceptions can be made for interventions aimed at maximizing quality of life. The goals of hospice include: self-determined life closure, safe and comfortable dying, and effective grieving (National Hospice Organization, 1997).

This holistic approach to care required by hospice and palliative care, which recognizes the complex and multidimensional needs of patients and families, calls for an interdisciplinary team. Team members typically include nurses, physicians, and social workers, though others may be present, including psychologists, chaplains, pharmacists, dietitians, occupational or physical therapists, and volunteers. Conditions for which hospice and palliative care are appropriate include cancer, AIDS, congestive heart failure, chronic obstructive pulmonary disease, end-stage organ disease, and dementia, and other progressive neurological diseases (Haley, Larson, Kasl-Godley, & Neimeyer, 2003).

Patients receiving palliative or hospice care as they approach end-of-life are especially vulnerable to psychosocial stressors. Werth, Gordon, and Johnson (2002) identify some of the most common, impairing, and/or treatable psychosocial concerns that must be assessed and treated for patients at end-of-life care. Specifically, they note diagnosable disorders identified in the DSM (including anxiety and depressive disorders), delirium, dementia, personality disorders, and substance use disorders. Importantly, they also identify "intrapersonal issues," including concerns of autonomy and control, decision-making capacity, dignity, existential issues, spiritual issues, fear, grief, and hopelessness; and "extrapersonal" issues, including interpersonal issues, financial concerns, cultural issues, absence and or presence of significant others, and pressure about end-of-life decisions.

In light of the psychosocial difficulties that patients can experience at end-of-life, there is research that illustrates the ways in which hospice care can improve perceptions of quality of care at end-of-life by patients and families (Baer & Hanson, 2000). There is also research that demonstrates that providing care to the psychosocial needs of the family members of dying individuals may reduce psychological and medical problems in those family members later on (Chentsova-Dutton et al., 2000). In sum, when dealing with patients and families in hospice care, the psychological and social needs of both patients and family members must be met in order to improve the quality of life throughout the dying process (Nydegger, 2009)

Haley et al. (2003) identified four unique times in which psychologists can intervene during the lives of patients and families being treated in end-of-life care: (a) prior to the onset of illness; (b) after illness is formally diagnosed and treatment has started; (c) during advanced illness and the dying process; and finally (d) after the death of the patient with grieving family members and survivors. Psychologists can provide these services in a variety of settings, including community healthcare clinics, independent clinical practice, outpatient medical clinics, hospitals, palliative, and hospice care settings, and nursing homes.

Twenty years ago, APA (2000) created a "Report of the Working Group on Assisted Suicide and End-of-Life Decisions" and noted that "psychologists are particularly suited to carry out clinical roles in assessment, intervention, advocacy, and interdisciplinary service delivery" at end-of-life. Specifically, the Report identified specific activities for which psychologists are well suited, including assessment and "evaluation of mood and anxiety disorders, pain, family and caregiver interactions,

psychological and cognitive functioning, and existential concerns." Additionally, intervention activities with individuals, family members, and providers were identified as key activities for psychologists in end-of-life care treatment teams. Specifically, psychologists can treat problems such as clinical depression if and when it arises in end-of-life contexts, as well as a host of other mental health problems that may arise.

Psychologists can also provide end-of-life counseling, including facilitating emotional expression; assisting caregivers in appreciating the psychological dimensions of the pain involved in dying; and being effective listeners for patients who are dying, their families and caregivers, and even their healthcare providers. Psychologists may reduce survivor vulnerability to complicated grief by promoting healthy anticipatory mourning processes (Rando, 2000) and by normalizing anticipatory mourning among family and caregivers. Psychologists can also work effectively with patients and families confronting difficulties associated with mourning and loss, traumatic stress, and promoting objectives for the care of individuals at end-of-life (Weisman, 1972). Psychologists can also advocate for comprehensive and effective medical treatment alongside other professionals (i.e., nurses, social workers, and chaplains). Finally, psychologists can participate in hospital ethics committees, palliative care, and other multidisciplinary teams.

Despite the numerous ways that clinical psychologists are qualified for, well suited to, and add value to end-of-life care, psychologists are still relatively rare members of end-of-life treatment teams. Nydegger (2009) conducted a study examining the participation of psychologists in hospice programs by sampling programs across the United States. The study compared the results to an earlier study that was conducted in

1990 to examine changes in the participation of psychologists in hospice care between 1990 and 2003. The data collected in 2003 found that of the 94 programs that responded, only seven indicated that a psychologist had been providing some of the mental health care services, and estimated that psychologists only provided about 17% of the total mental health care activities provided in those programs. Other professions more involved than psychologists in the provision of mental health services were Social Workers, Pastoral Counselors, and Nurses.

Notably, *volunteers* were drawn upon more frequently to meet the mental health needs of patients than were psychologists. Additionally, of the 94 programs surveyed, only five said that they would refer to a psychologist, and 71 programs said that they would refer to a social worker when asked about which type of professional a patient or family member would be referred if the hospice program could not meet their needs.

The study also drew comparisons to data extracted from hospice programs in 1990. In the sample from 1990, 13 programs of the 83 that responded to the questionnaire (about 15%) said that psychologists provided some of the psychosocial care for their patients and families; this was compared to the seven out of 94 programs (7.4% of the programs responding) that said that they used psychologists in the 2003 sample. Although the difference was not statistically significant, it certainly suggests that between 1990 and 2003, there was no increase in the utilization of psychologists in hospice care among the programs that responded to the survey. Additionally, in 2003, five programs (5.3%) said they would refer a patient or family member to a psychologist, while in the earlier sample, nine out of 83 programs (10.8%) said they would refer to a psychologist. This difference was not statistically significant either but indicated that between 1990 to

2003, there was no increase in the number of hospice programs that would refer patients or family members to a psychologist who was not on their staff (Nydegger, 2009).

Since psychosocial care has been demonstrated to be a beneficial aspect of end-of-life care, it is especially important that competent and trained professionals be available to meet the needs of this vulnerable population. At the same time, while it is clear that psychologists have much to offer towards end-of-life care, it is also evident that psychologists are rarely included in hospice and end-of-life care treatment settings.

Rationale for Present Study

Given the importance of addressing the psychosocial needs of patients and families experiencing issues related to end-of-life, it is important to understand the roles and functions of psychologists who currently work in end-of-life care settings to understand how they address these issues and add value to treatment teams. By examining the roles of psychologists practicing in end-of-life care, this study ultimately aims to increase an understanding of the ways in which psychologists can continue to increase their presence in these settings

METHODOLOGY OF PRESENT STUDY

This exploratory study employed a qualitative research methodology in order to understand and elucidate the professional roles, practices, and meaning-making processes of psychologists who work in end-of-life care settings with actively dying individuals. This study's approach to data collection and analysis borrows from Fishman's (1999, 2013) narrative analysis approach. This study will seek to clarify the roles of psychologists practicing in end-of-life care as well as the ways that they draw meaning from their clinical work by using the experiences identified in interviews with the research participants as raw data. In this chapter, this study's selection criteria, recruitment procedures, interview protocols, demographic questionnaires, and data analysis and treatment procedures will be outlined.

Selection Criteria

Clinical and counseling psychologists who are or have been employed by or consult to healthcare settings in which actively dying patients are cared for were eligible for this study. In addition, participants must have held a doctoral degree in clinical, counseling, or applied psychology[1] and have been licensed in the state in which they provide or provided clinical services. Those excluded from participation included psychologists who did hold a doctoral degree but who were not licensed. Also excluded were mental health professionals with other certifications (e.g., LMSW, LCSW, LMHC) who were expected to have different training and serve different roles than clinical psychologists in end-of-life care. Additionally, psychologists who practice or practiced in

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[1] One participant listed an Ed.D. Degree in "Applied Psychology" that he had earned in the early 1970s, which was the only exception to degrees in Clinical Psychology or Counseling Psychology.

end-of-life care settings but who did not provide direct clinical services in (e.g.,

supervising interns and postdoctoral fellows; serving in management positions of

consulting groups) were not included; while they may have been able to provide valuable

information about the roles of psychologists in end-of-life care, they may have lacked a

rich set of direct clinical experience in end-of-life care settings from which they can draw

upon when interviewed.

Recruitment

Two female participants were recruited through referrals of personal, professional

contacts I made myself. In addition, one other female participant and five male

participants were recruited through advertisements in the email listservs of special

interest professional psychology organizations, state psychological associations, and

graduate psychology alumni organizations. The advertisement included the study's

intended aim of investigating the roles of psychologists practicing in end-of-life care as

well as the ways in which those psychologists draw meaning from their professional

service in end-of-life care. The advertisement also noted that the study offered no

compensation for participation, that participation in the study was voluntary, and that

participants could terminate their participation at any time (see Appendix A). Interested

participants were instructed to contact me for a phone screening (see Appendix B).

Measures

Demographics questionnaire. I employed a Demographics questionnaire (see

Appendix D) to gather information about participants' age, gender, race/ethnicity,

religious/spiritual background, psychotherapeutic theoretical orientation, professional

background and specialty training, and the number of years in which they have been engaged in professional practice.

Semi-structured interview. I employed a semi-structured interview (see Appendix E), which comprised open-ended, phenomenological questions about how psychologists' work in end-of-life care. More specifically, the participants were asked questions about the nature of their graduate and postgraduate training as it relates to end-of-life issues; the factors that drew them into working in end-of-life care settings; their end-of-life work experiences and practices; brief descriptions of cases in which they described their clinical work with actively dying patients; and the meaning-making processes in which they engaged in their professional practices. The goal of the semi-structured interview was to collect a comprehensive set of data of the individual participants in order to build a full picture of their experiences in end-of-life care and to describe how these participants became interested in, were trained in, and function effectively in end-of-life care. All interviews were audio-recorded and transcribed for subsequent analysis.

Procedures

Interested participants were instructed to contact me via email or phone contact in order to schedule a phone screening, which was used to ensure that the prospective participants met inclusion criteria and to inform that person about the intended aims of the research and what participation would require. Participants were also encouraged during the phone screening to ask me any questions about the study.

Individuals who did not meet inclusion criteria were provided with an explanation as to why they were ineligible to participate in the research and were thanked for their

time and interest. For those prospective participants who were interested and eligible for participation after the phone screening and who were deemed to meet study inclusion criteria, I scheduled an individual interview at a mutually agreed upon time at either (a) the participants' place of work, which was recorded with an audio recorder; or (b) via HIPAA-compliant video conferencing, which was also audio recorded. Three interviews were conducted using option (a), and five, using option (b). At the beginning of each interview, the participant's written informed consent for participation and audio-recording was obtained (see Appendix C). All participants were interviewed using the semi-structured interview protocol (see Appendix E), and all the audio-taped interviews were transcribed. Each interview lasted approximately one and a half to two hours.

Treatment of Data

Before being interviewed, all participants were assigned a case number in order to protect their identity, and no identifying information was attached to the study data or obtained audio recordings. No identifying information was attached to the transcriptions or audio recordings. All data was stored and managed in accordance with IRB rules and regulations to protect participants' confidentiality. Copies of the consent form that participants signed were kept in a locked cabinet. Consent forms were kept in a separate location from hard copies of the interview data, the audio recordings, and the interview transcripts in order to maintain confidentiality. Digital files of the interview were stored on a password-protected computer. Once interviews were transcribed, digital copies of the transcriptions were stored on a password-protected computer.

The Primary Researcher's Background, Experiences, and Biases

In any research process, and in qualitative research inquiries in particular, the primary researcher's identity, subjectivity, bias, and attitude are an integral part of the inquiry process. As a result, it is crucial to continuously examine these aspects of the researcher's identity in order to ascertain how the researcher's perspective may influence the construction and deconstruction of data and theory (Creswell, 2007).

As a relatively young and relatively healthy man, I spent (and likely continue to spend) much of my life unknowingly in the knowledge that I live my everyday life free of concerns and questions about my mortality, limitations, and impending death. I have enjoyed the benefits of and put much faith into contemporary medicine; I can rely upon family support in times of illness; and I have never faced the reality of receiving a potentially life-threatening illness, experienced a medical trauma, or undergone life-altering or life-sustaining medical treatments. Indeed, my interest in death and dying stems not from personal experience but from a growing awareness of the immeasurable void that exists between my life now and what I know I must ultimately face at any moment, not if, but when, health or youth are no longer mine.

Witnessing the stark contrast between the deaths of my maternal grandparents had a profound impact in shaping my understanding of and relationship to death and end-of-life care. My grandmother, a vivacious and youthful woman, grew ill and died quickly in the sterility of a hospital enveloped in tubes and surrounded by machines. The prospect of her death had not occurred to any member of my family and had never been discussed by her treatment teams after she grew ill. My grandfather, by contrast, a quiet and gentle man, progressed into old age and gradual decline over many years surrounded by family

and died in his sleep in the relative comfort of his home, the reality of his finitude infused into every decision made in his final years.

       After the jarring loss of my grandparents, I started to grasp the impossibility of understanding death. Thus, I am aware that I bring a personal and professional commitment to better understanding death and dying and how psychologists can improve and better understand the psychology of death and dying, knowing, however, that while we may grow closer to understanding, it is unknowable. As a part of this process, I also sought to continue uncovering my privilege (as healthy, young, free of life-threatening and chronic illness), and misguided assumptions about end-of-life care and the ways in which an individual's death may be influenced by those who never have, and never will, experience it while they aim to do so. This humbling knowledge impelled me to conduct this research in order to promote the wellbeing of dying individuals and their families, knowing I will never fully "know" the reality of death and dying.

RESULTS[2]

The Case of David[3]

Background Information

David is a 73-year-old Caucasian male who has been a practicing licensed clinical psychologist for 47 years. He graduated with an Ed.D. degree in Applied Psychology and has remained in clinical practice since he completed his doctoral degree in 1973. He described his religious background as Jewish and identified the primary theoretical orientation that guides his clinical practice as psychodynamic/psychoanalytic and received formal training as a psychoanalyst.

Method of Recruitment

David had been recruited to participate in this dissertation research after responding to a dissertation participation recruitment email posted on his state psychological organization's email listserv seeking interviews with psychologists practicing in end-of-life care.

Graduate and Post-Graduate Training in End-of-Life Care

David noted that he experienced difficulty remembering the specific training he may have had in end-of-life care when he was a doctoral student, and stated that there had been "little to none," if any, graduate coursework in death and dying while he was a graduate student.

Despite the dearth of graduate training that he received as a predoctoral psychology student, David reported that he had learned about end-of-life care while

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[2] I did not have the time to ask all of the interview questions to all participants. Areas that were not addressed with the participant in the interview are indicated as such under those sub-headings.
3 Pseudonym: The names and any identifiable information of participants or the patients with whom they provided psychological services have been changed to protect the identity of the participants and their patients.

completing his psychoanalytic training, which had been based inside of an academic

medical center. He stated that his psychoanalytic training institute invited lecturers to

speak "once or twice" about end-of-life care. He noted that his psychoanalytic training

program faculty were "non-traditional," stating "they were not the classical, in-depth,

psychoanalysts," adding that the institute was "somewhat modern and avant-garde." He

noted that his colleagues in some of his courses were nurses, emphasizing the unique

medical environment inside which the training institute was housed. He summarized that

"the result is we were in a medical environment and how can you not talk about end-of-

life? People died in hospitals."

David noted that he was not sure if and how his training as a psychologist

prepared or did not prepare him to work in end-of-life care, adding that he "didn't have

that many cases in [his] training of elderly, dying people… [to] deal with it in a

supervised, supervision setting." He did note, however, that he developed a peer

supervision group with two other geropsychologists, which included readings and

discussion of cases, which he did find to be helpful in working with an aging population

confronting physical and cognitive decline, and death.

Professional Development

David described beginning to work in an assisted living facility about twenty

years ago, at about the time that his mother had entered an assisted living facility. At the

time, he had been working exclusively in private practice. He described becoming

"friendly" with the director of the ALF during visits to his mother in the facility. He

noted that he would engage with other residents of the ALF while he would visit his

mother. During those visits, he described experiencing the thought that he "could do

this," referring to geropsychology and end-of-life care and then mentioned to the director

of the ALF that he was interested in a position at the ALF and the director then invited

him to consult to the ALF as a clinical psychologist.

Professional Roles in End-of-Life Care

David noted that he consults to three assisted living facilities (ALF) in the suburbs

of a major northeastern city, providing psychological services to older adults, including

individual psychotherapy and family psychotherapy. Additionally, David noted that he

provides seminars to staff who work at the assisted living facility on death and dying and

provides informal consultation and "debriefings" to staff following the loss of a patient at

the assisted living facility.

David describes providing individual psychotherapy to older adults at the assisted

living facilities at which he consults. He also noted that he has provided family

psychotherapy and that the frequency at which he provides family therapy has diminished

in "recent years." David said that, often, when he contacts family members to engage

them in treatment, they might respond, "Hey, y'know, what are you calling us for? Go

talk to my dad [the patient] or go talk to my mom [the patient]!" He did note, however,

that if a family member contacts him, he is "extremely responsive and extremely

involved in whatever way I can. I tell them, 'Call me anytime,' and I offer them to come

to my office, and we could have a session in the office, or we could have a session at the

assisted living facility and talk about things."

In addition to conducting psychotherapy, David noted that he has consulted to

ALF staff by providing seminars and "debriefings" to direct care staff following the loss

of a patient. Specifically, he indicated that he confers with management personnel or

direct care staff at the ALF in order to elicit "the most useful" and recent information about his patients' current functioning. He noted that staff "might give me some details about what happened last night… about how they were last week." In addition, he described that "we might discuss the case, and at times, I might make suggestions to them about how they might handle things." He also noted that "very often, they're simply talking to someone about [someone who] sometimes is a difficult patient, [which] is therapeutic for them and helps in their care of the patient." In this way, he described that he provides consultation to staff by providing an opportunity for "catharsis" when working with "difficult" patients.

David also described providing seminars on "Death and Dying" to staff at the ALF to which he consults. He noted that he provides psychoeducation about "death and dying" and discusses the "stages of dying."

Referral Process

David noted that his referrals for patients who may benefit from psychological services come primarily from the nursing staff at the facilities to which he consults.

Psychology at the End-of-Life

David described his work as a psychologist with two patients confronting end-of-life and described the interventions he used while working with them, as well as his rationale for the method and timing of his interventions. Notably, he described the primary goal of his work with dying patients as making the patient "comfortable."

David described conducting individual psychotherapy with a 100-year-old patient who has been diagnosed with a form of dementia. Throughout the time that David had been working with him, this patient's diagnosis of dementia had progressed and included

significant memory impairments. Early in treatment, David noted that the patient had stated that "What I need is... a familiar face." David said that "I've now become a familiar face. I'm not sure if he'd remember my name. But when he sees me, he lights up, smiles, shakes my hand."

David noted that the patient had begun discussing death and dying, noting that the patient was stating that "he's dying, he feels not sure how much longer he can go on." At that point, David decided to pursue the patient's thoughts and feelings about dying, his motivation for wanting to die, what his death means to him, and his perceptions of the "afterlife." Despite these discussions, David noted, however, that the patient continued to "perseverate" on issues related to the fact of dying per se.

At that point, David decided to disclose to the patient that he had a close friend who had the same name as the patient. The patient then revealed his "given name," which had meant "blessing" in another language with which David was familiar. At that point, David noted that he and the patient then conducted a prayer together, after which the patient smiled. David then asked the patient about the origins of his given name, which led to a discussion about the patient's childhood, family of origin, and memories of "playing slap ball in the street" as a young child. David noted that "by the end of this session, this guy was smiling and laughing and felt… feeling much better than the beginning when he was telling me about dying."

David described the decision to "shift" the session away from "death and dying" and towards "something having to do with life" as guided by David's knowledge of Erik Erikson's Psychosocial Stages. David noted that he had hoped to guide the patient through Erikson's final Psychosocial Stage of Development, "Integrity vs. Despair,"

conducting a "life review" in order to promote a sense of satisfaction and integrity about the patient's life. He noted that he achieved this through "reminiscence" of positive memories of this patient's life, guiding the patient away from a sense of despair about his impending death and towards a sense of integrity about the life that he had lived.

David noted that he had used his countertransference" to guide his decision making when intervening with this patient and that his decision making will vary from patient to patient. More specifically, in the case described above, David noted that "I used what psychoanalytically might be called my countertransference: the feeling I was having, the thought, and my own association. Something said, 'Tell him about... your good buddy Ben who died.' He was my first supervisor when I opened my practice, like 40 years ago. And he was a sweet, gentle man. And this [patient] that I was talking to at Assisted Living was also a sweet, gentle man. And somehow there was some association for me to that and, using my countertransference, led me to this kind of discussion where he could tell me about what his name was and playing slap ball and so on."

David described perceiving that he had "helped this guy feel pretty good... better." Notably, he explained that he made this patient feel "comfortable," adding that he believes that when working with patients approaching death, "It's kind of like slow medicine, or hospice care, where you're not gonna make the person better, but... you want to make them comfortable. And I think I made him comfortable with that intervention."

As a part of the treatment, David also described the "frame of reference" that he employs: "as both as a psychologist and particularly as an analyst, I don't think of myself as guiding people, I think of myself as walking with people... through their psyche. And in the case of my demented patients that are dying, whatever is left of their psyche." With

this patient, David noted that what had been "left" of his psyche was "about his playing handball and his name."

In another case in which David worked with a dying patient, he described conducting individual psychotherapy with "Al" [a pseudonym], an artist with a hospice care designation at the ALF in which David consulted. David noted that Al was "in pretty bad shape," both physically and emotionally. David reviewed the final psychotherapy sessions he had conducted with Al, describing how he would discuss Al's "artwork, what it meant to him, how he had evolved as an artist." David added that Al had several works of art hung in his bedroom in the ALF, where the two would meet. David said that the two would "talk about them, what he remembers about them, and [that] he wanted to get back to art."

David also described the workstation that Al had set up in his room in the ALF, which contained the materials he used to create his works of art. In their "last session or two," David said that Al had discussed a wish to create art again, and that "he was talking about getting ready to go back any day." David said he believes that discussions about Al's artwork had been therapeutic, as evidenced by the fact that Al expressed hope about the prospect of returning to his art. David added that Al had never married never nor had children, "so his artwork was literally his life." David noted that he believes that reminiscing with Al about his artwork and career as an artist had been therapeutic, and that he believes that the fact that Al had the thought that he wanted to return to his artwork had been "therapeutic" because, as David stated, "he had hope!"

As a demonstration of the "frame of reference" that David uses in his treatments (described above, in Case 1) of figuratively "walking with people," David noted that he

"walked with [Al] towards the end, hoping that he could still do some artwork and still hold on to life." He added that he did *not* say "Well, you know, there's a possibility that [you] won't do any more artwork," because "he was still holding on and didn't want to give up, so I didn't want to take that away from him." He described the decision to avoid confronting the prospect that the patient may never engage with art again as evidence of "walking with rather than guiding through."

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

David described numerous factors that affect the provision of psychological services to patients confronting the prospect of death and dying. Some of the factors he identified include perceptions of the value of psychological services from patients and family members, financial burdens of care, systemic factors affecting the delivery of care, and David's perception of his professional role.

Specifically, David noted that some patients experience the financial burden of care for psychological services as prohibitive, especially for those who are no longer in control of their finances. Additionally, he noted that when family members or caregivers are managing the patient's finances, they may feel that "talking to someone is not particularly helpful, especially if there is a little bit of cost involved." As a means of circumventing financial barriers, David noted that he has now routinely offered to accept Medicare's reimbursement rates, and for patients who have Medicare Advantage plans in which he does not participate, he offers the option for patients to pay a full fee. Additionally, David noted that he has perceived that because the costs associated with

care provided at an ALF can be financially burdensome for many patients, the additional expense of psychological services at an ALF living facility can be perceived as prohibitive.

David described that the "culture of caring" at the facilities at which he consults could also affect the provision of psychological services. He noted that some facilities are efficient, much "like a well-run business [that] knows what they're doing." He added that these facilities have low staff turnover, and he has experienced that management teams at these facilities are interested in their patient's psychological wellbeing. At these facilities, David noted that he could enjoy his work more by "helping the staff" to engage patients with psychological services. By contrast, he noted that some facilities do not demonstrate the same "culture" of care for patients, and he experiences a sense of frustration when he perceives that clinical staff or facility administrators are focused almost exclusively on "medical treatment, particularly medication." He added that he is "all for" medical treatments, noting that "the great majority of patients are on antidepressants, for example. But you know, every once in a while, I do remind people that [psychological] therapy sometimes is helpful also."

David also noted that he perceives his professional role as "ancillary" and embedded within a larger treatment team. As such, he noted that he has "really never sat with... someone while they're dying. The staff is there for that. And I've come to realize this one of the good things about my job. My services are very often in some way regarded as ancillary, rather than central." He described feelings of frustration earlier in his career, noting that he felt he "was not valued." However, he noted that he has "come to realize that for this person to benefit, they need a whole setting of nurses, of aides, of

their family, of physicians coming in. So, I'm part of the picture. And sometimes not central to the picture, [although]… sometimes I am."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

David described the factors that facilitate his ability to engage with patients confronting death regularly. He noted that he engages in "some denial" and in self-care activities, supportive family relationships, prioritizing the non-professional aspects of his life and identity, and performing his work among interdisciplinary teams.

Re denial, David stated that "in order to protect my own psyche, I know at times, [I] utilize denial to kind of cope and deal with things," that is, he engages in "healthy denial" to be able to work with dying patients. Specifically, he noted that he had felt "somewhat overwhelmed" earlier in his career when patients would die. At this stage in his professional practice, however, he noted that can engage with "denial" by cultivating a sense of "distance" from the patients in which can work with them professionally and cultivate a meaningful relationship while "not taking it home" with him.

Regarding denial, David said that he is able to maintain a "middle ground," wherein he can cultivate a "connection with the person" but that he is not "so involved" where he may adopt the role of a family member and experience impairing worry and anxiety and burden the patient with this own distress. He said that he wants the patient to "feel free" and that in order to promote that sense of freedom, he needs to develop "a kind of distance there from it, including not taking it home." He summarized his sense of denial about his patient's imminent death as, "It's not that I don't think about it, but I don't think about it at two o'clock in the morning."

David also described cultivating spending time engaged in self-care activities, such as prayer and spending time with family so that he can focus on the patient most optimally when he is with them by ensuring that his own needs are met and attended in "in some optimal way."

Additionally, David said that he draws upon the support of his wife, who is also a psychotherapist, in finding ways to cope with the difficulties associated with his work. He added that "90% of our dinner talk is what happened during the day, what cases we dealt with, and so on. So, she is a wonderful resource in that regard."

David described that he has also grown to prioritize the non-professional aspects of his life and identity in order to cope with the losses he experiences on a regular basis in his work. He noted the knowledge that death is a part of life has led him "to try to enjoy life as much as I can for myself because, you know, one day I'm going to die and I encourage people to do the same [in enjoying life]." He noted, too, that he tries to enjoy time with family and grandchildren as a means of appreciating the value of the time he does have remaining in his life.

Finally, David also noted that being a member of a larger treatment team has been helpful to him in performing his professional responsibilities, describing that patients "need a whole setting of nurses, of aides, of their family, of physicians." He added that knowing that his patients can also rely upon the support and care of an interdisciplinary team of professionals is helpful to him in knowing that that the patient is in the care of "a larger holding environment" and that he is not solely responsible for the wellbeing of his patients.

Interdisciplinary Relationships

This topic was not discussed in this interview.

Professional Meaning-Making in End-of-Life Care

David noted that he "explicit[ly]" makes meaning of his professional role in end-of-life care. He noted that he conceptualizes his professional role as "walking with people," and that he is "doing God's work" and "caring and loving as much as [I] can [for] elderly people in their 80's and the 90's and over 100 [years old], a few of them. And it's my own 'mitzvah' that I can do this in my own life. And it gives tremendous meaning in my own life."

Influence of Personal Experiences with Death

David described his own experiences "being a good son" to his mother as she approached the end of her life as being influential to him in his current work with dying patients. He stated that he provided a great deal of care to his mother as she lived in an ALF near his home, adding that he visited and spoke with her on a regular basis and "was helpful to her also, on an emotional basis, because [I] could talk to her in a way that perhaps others couldn't." He added that "I do think that [in] the work I do … I become somewhat of a good son, of a caring son, to a lot of my elderly patients."

Influence of Religious and Spiritual Beliefs

David stated that his own belief in a "higher power" may facilitate his ability to explore patients' perceptions and beliefs about religion as they face death. He noted that he has prayed with patients and that he prays regularly on his own. As such, he noted that he may encourage patients to engage with prayer as they confront the end of their lives. He also noted that he sometimes inquires about his patients' religious and spiritual

beliefs, noting that he may ask "if the person believes in God and what God is and who God is and what it's about." He added that his "own belief in God...allows [him] to do that with a person;" and that if he did not believe in God, he would not be sure how he could approach those topics with patients, adding that he would "have to deal with it abstractly."

Ethical Considerations in End-of-Life Care

This topic was not discussed in this interview.

Changing Attitudes about Working with Death and Dying

David noted that he increasingly considers his mortality as he ages, noting that as he has "gotten older, it's certainly affected [his] perspective on death and dying." But he did not describe the ways in which a growing awareness of his mortality affects his work.

Additionally, David noted that he had felt overwhelmed and flooded by the prospect of death earlier in his career. Now, he noted that he is able to engage with a sense of "denial" of death as a means of coping with this prospect in order to "distance" himself from the reality that his patients are dying and will die so that he can continue to maximize the time he has remaining in his own life.

Professional Landscape for Psychology in End-of-Life Care

David noted that he was unsure of the current professional landscape for psychologists practicing in end-of-life care. While he is not involved in the American Psychological Association (APA), he said that he suspects that there will be a "Division [of the APA] if there is not yet one."

Vision for the future of End-of-Life Care

David noted that his vision of the future of psychology's role in end-of-life care included healthcare delivery systems cultivating a greater emphasis on interprofessional communication and integrative care as well as a "holding environment" that extends beyond psychotherapy.

David described that he believes that "optimal outcomes" are the result of "everybody getting as many of the parts working together as possible." Specifically, he noted that he thinks patients would benefit most from regular interprofessional communication that would promote patient care from a variety of professional lenses as they face death (i.e., social work, medicine, religious authorities). He noted that he believes that this model of integrative care might attenuate patients' feelings of "being alone" as they die.

Additionally, David said that patients would benefit from great emphasis on "a larger holding environment," which he believes would promote patient wellbeing. Specifically, he noted that his ability to engage with patients effectively and to know that the patient's needs are being attended to (beyond just their psychological needs) is facilitated by the knowledge that all members of a healthcare facility "seem to care about the residents and the patients."

The Case of Amy

Background Information

Amy is a 36-year-old Caucasian female who has been a practicing licensed clinical psychologist for eight years. She graduated with a Psy.D. in Clinical Psychology and has remained in clinical practice since she completed her doctoral degree in 2012.

She describes her religious background as including "some Buddhist principles" and being "generally agnostic," and identified the primary theoretical orientation that guides her clinical practice as a combination of Dialectical Behavioral Therapy and Cognitive Behavioral Therapy.

Method of Recruitment

Amy had been recruited to participate in this dissertation research after responding to a dissertation participation recruitment email posted on her state psychological organization's email listserv seeking interviews with psychologists practicing in end-of-life care.

Graduate and Post-Graduate Training in End-of-Life Care

Amy described receiving extensive training in end-of-life care at both the masters and doctoral levels. For example, she noted that she took a course in "Death and Dying," which she added included discussions of topics "like grief, and stages of grief, and trauma, and things of that nature," as well as discussions about attitudes, beliefs, and responses about end-of-life and end-of-life care. Amy added that the course included discussions of the ways in which psychology can fill a role in end-of-life care. She said that her courses also included discussions about changing trends in end-of-life care, including classes on "medical aid in dying and the various variations" of that. She concluded that the courses were "more general to issues that come up in terminal clients" and that the courses did not include information on "specific interventions, or like 'This is the model.'" Amy noted that she felt that these courses had prepared her for working "with terminal clients."

In terms of postgraduate training, Amy noted that most postgraduate training in end-of-life care is directed towards other disciplines, namely medical professionals such as hospice nurses. As a result, she said that she had pursued more medically oriented training and experiences, having had greater difficulty finding training directed towards psychologists practicing in end-of-life care settings.

Amy also noted that she felt that her intensive training in Dialectical Behavioral Therapy (DBT) prepared her to work effectively in end-of-life care. She elaborated:

> One of the main tenets of DBT is this concept of radical acceptance. And I found a nice segue and transition in the training I've had in DBT and applying it for terminal populations, geriatrics, clients with chronic pain, and complex medical issues because radical acceptance is a key issue that they struggle with. Another component is mindfulness and increasing the joyful moments… And then also… distress tolerance. So, I found after receiving that [DBT] training and having that background, that was a really good complement and really set me up to be able to easily segue into this type of work.

> DBT is uniquely positioned with holding to dialectics [accepting that two opposite entities, experiences, forces, etc. can be true at the same time]. You can be pursuing treatment and also accessing palliative care to improve your moments, your day-to-day life, your pain. Death and faith are not all mutually exclusive, that we can hold these things at this time. And these help people have more options and have better transitions and better deaths.

Additionally, Amy felt that her background in behavioral medicine, including treatments for chronic pain, and her experiences working in hospital settings with individuals with "complex medical issues" have helped prepare her to work with "the pragmatics and the day-to-day experience of working with those [end-of-life] populations." For example, Amy stated that her background training in pain management and conducting "opioid assessments" has helped her to appropriately assess for and advocate for pain management.

Professional Development

Amy stated that she had "always" had an interest in working with medically complex patient populations. Additionally, she described an experience when she was a graduate level psychology extern at a rehabilitation center and nursing facility where she conducted neuropsychological assessments and said that she was seeing a lot of medically complex patients and realized that she "did well with that population." She added that her father was a psychologist who started a mental health services consulting company that served a rural area of a northeastern state. She stated that the company provided psychological services primarily to older adults in rehabilitation centers, skilled nursing facilities, assisted living facilities, and specialized units in hospitals. After she graduated, she started working for him and joined his company in 2015, seeing a high volume of older adult and medically complex patients and, eventually, working with patients who had a hospice designation. Because of her work with this consulting company providing services to medically complex and compromised patients, Amy said she found herself doing a lot work with actively dying patients.

Professional Roles in End-of-Life Care

Amy noted that she consults to skilled nursing facilities, as well as hospitals with specialized nursing, rehabilitation, or memory care units in a rural area of a northeastern state. She noted that the patient population she works are financially under-resourced and include "a lot of farmers, factory workers...people that served in the military." She added that many of her patients also meet criteria for co-occurring substance use disorders. As a consultant psychologist, Amy noted that she provides individual psychotherapy (which includes advocacy and coordination of care for patients); family therapy; and training and psychoeducation for new clinicians working with geriatric, medically complex, and terminally ill patients.

Amy said that because the patients she sees have complex medical profiles and are in the "pre-active dying or active dying" process, the type of work she conducts in an individual psychotherapy session is "really different" than "what we would traditionally think of [in a] …good psychotherapy session." She noted that "when [patients] get close [to death], it's very practical."

Amy described that, as part of her professional role, she provides advocacy for her patients in order to coordinate care to meet their needs and goals prior to their death. She described that a large percentage of the patients she works with "don't actually have family members that come in or are a part of any of this." She added that "outside of the nurses or physicians or medical personnel [or] aides that they're seeing, I'm the only person." Because of this, Amy noted that she provides a great deal of advocacy and "case management" in order to help patients achieve their "specific wishes" because other health care providers, such as aides, may not have the "power or authority to do that, to

be able to make that happen for that patient." Because many of her patients do not have family present, Amy noted that she also serves the function of family advocate for her patients.

In terms of advocacy and case management, Amy noted that she has been able to coordinate with other disciplines in order to help her patients meet their goals for end-of-life. For example, Amy said that if she has identified a patient's wish for end-of-life, she will contact her patient's social worker to help arrange the logistics of her patient's wishes and goals (see Case 3 in the "Psychology at the End-of-Life" section below for an example). Additionally, Amy said that she advocates for appropriate pain management for her patients experiencing pain at the end-of-life.

Notably, Amy stated that she has worked with family members very rarely, adding that "it's less than on one hand, families that have been involved in years of doing this." Despite the relative dearth of actively involved family members available with many of Amy's patients, she noted that she does engage family members when they are available and that the type of family-based interventions that she provides will depend on "how they are struggling." Specifically, Amy described providing psychoeducation to family members about the dying process, providing support to family members struggling with the impending or recent loss, and providing problem-solving support including establishing "final wishes, funeral planning, like very practically oriented things." She said that for family members who "don't have a medical background or experience in this area," they might not understand the dying process, or what might be happening for a dying person in pain, and so she finds it crucial to provide psychoeducation and

cultivating a sense of empowerment for family members to advocate for family members who are dying.

Finally, Amy described providing psychoeducation and training for new clinicians hired through her company, which provides mental health consultation to skilled nursing facilities and hospitals with specialized nursing, rehabilitation, and memory care units. She noted that "not a lot of clinicians of all stripes, whatever their mental health background is, tend to work in this area" of end-of-life care. For them, she provides initial training and guidance about the "ins and outs" of working in medical facilities. She described that "a lot of times, I'll take [the clinicians] around and do a rundown of issues that may come up and provide a lot of upfront support, oftentimes, for the first couple weeks to months that they're doing this type of work, because they do tend to need a lot of support. Because it can be really challenging, and it's stuff that people don't think of or haven't experienced, even if they've had a career." She added that she provides guidance on "the setting, the patient population, and patient issues that come up... [and] institutional aspects to navigate that are different from other settings and patient population issues."

Referral Process

Amy noted that the referrals that she receives for patients who may benefit from psychological services typically come primarily from "the social worker or... the director of nursing" at the facilities to which she consults. She added that the referrals are typically prioritized for patients in the facilities who "have a mental health diagnosis in their patient history, or [are] on psychotropics, or [are] struggling with active mental health or behavioral health symptoms, or have been put on hospice, or usually, a lot of

times when they've recently been given... a terminal diagnosis." Amy added that she will "occasionally" receive self-referrals, noting that patients may see her or have a "friend or roommate" who has seen her, and want to be seen by her as well. Finally, she added that if family is available and involved with the patient's care, she may get a request from family members who wish for her to see family members in the facility.

Psychology at the End-of-Life

Amy reviewed her work as a psychologist working with three patients confronting end-of-life, describing the nature of the interventions she used while working with them. In all three cases, Amy noted that while the goals of intervention frequently "overlap," the interventions can "look different" depending on the length of time during which she is able to work with the patient. Across the treatments that she describes, Amy noted that a primary goal in each case was to "increase joyful moments."

Amy described seeing a 60-year-old female schoolteacher who had been diagnosed with a form of terminal cancer and whom she had seen "once or twice" for individual psychotherapy, after which the patient died. Amy added that she had not expected the patient to die "that quickly" and so had limited time to work with her. When she met with her, she described providing psychoeducation about "the dying process" and addressing the patient's cognitive distortions about the dying process. She also described working with the patient on "letting go of beliefs that [were] ... contributing to her suffering" and increasing the patient's mindfulness and "joyful moments."

Amy also discussed another case in which she saw a male diagnosed with liver failure, who had been living at a skilled nursing facility for "months" as a result of the length of his treatment. She noted that this treatment was "a little bit different, because it

wasn't like we had like [just] two sessions." In describing her work with this patient, Amy said that the goals of the interventions she conducted were "more oriented towards reconnecting with estranged family members and friends that he hasn't seen, being more social in his remaining time, and just increasing joyful moments."

In a third case, Amy described seeing a female in her 60's who had been diagnosed with ovarian cancer. The patient had been living at the facility to which Amy was consulting for four months, while engaging in "last ditch" medical interventions, including chemotherapy and radiation therapy. The patient opted for hospice and told Amy her last dying wish was "to go to Target." Amy reported that the patient's most joyful moments were spent while she was at Target, where she'd "like to gallivant and run errands and shop and like find decorations. And that was just her best self and her happiest time." Amy noted that she was able to coordinate with the patient's social worker in order to arrange medical transportation for the patient to go to Target one last time. After the trip to Target, the patient died "hours later." Amy stated that the goal of her interventions for this patient, too, was to increase "joyful moments."

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

Amy described a variety of forces that affect the provision of psychological services to patients in end-of-life care, including: clinician exposure to working with dying patients; chronic exposure to dying patients; reimbursement structures; access to knowledge about palliative care and hospice; family involvement in care, relative health and age of the patient, family engagement with patients at end-of-life, appropriate pain

management at end-of-life; socioeconomic status of patients; and difference in end-of-life care settings.

Amy described a major barrier to psychologists providing psychological services for patients confronting death was that psychologists who have not had prior exposure or experience with dying may experience a "visceral response" that can be perceived as very disturbing. Specifically, Amy noted that because most Americans die in medical facilities and because most individuals don't have a great deal of exposure to individuals who are dying, most psychologists would not have had a great deal of exposure to seeing their patients in medical facilities as they die.

Amy described that many clinicians that she initially supervises are not prepared to witness "the body decomposition… sights, sounds, smells—things that [the patient is] experiencing." She added that other visually disturbing stimuli may include "different medical devices… catheters or ports. A lot of clients have open, infected wounds. A lot of times they can be very agitated, depending on the circumstances…there can be a lot of moaning, crying, yelling, very delusional, combative, things like that that people may not be aware of." Most notably, Amy stated that "usually, it's the sights, sounds and smells" of someone who is actively dying "that really people have not experienced, they haven't seen." She stated that psychologists who have not had exposure to these realities may need to "desensitize" themselves and conduct "exposure work" about these uncomfortable stimuli.

Additionally, Amy noted that psychologists who have not had prior exposure to working in medical facilities with medically complex, older adult, and terminal patients confront challenges that may affect their ability to provide psychological services to these

patients. Specifically, she described that there is a "very strong need for psychoeducation" for psychologists when they first start this type of work and she will "provide a lot of upfront support, oftentimes, for the first couple weeks to months that they're doing this type of work, because they do tend to need a lot of support." She noted that she provides support to clinicians about institutional challenges, working in medical facilities, and "patient issues."

She also noted that a major challenge for psychologists working in end-of-life care is that

> they do it for a very short periods of time and then they're done. Very short periods of time. I've had a couple friends try to venture into this area, and they're like 'This is not for me.'
>
> People that tend to be psychologists [and] mental health professionals tend to be sensitive, they're very caring and empathetic [sic] types of people. And they can become very emotionally flooded in circumstances like this. Being with someone in the active dying process can be tough. Yeah, or even just the day to day in a skilled nursing facility, or depending on what the medical unit is, I mean it's tough stuff. … It can be really challenging, and it's stuff that people don't think of or haven't experienced, even if they've had a career."

As such, she noted that these clinicians need a lot more support and guidance in the earlier stages of trying to engage with this work. However, she noted that she has

> been able to get older clinicians around more quickly, because, think about it: as we age, we have more experience with death! We have parents, we have

our own medical issues and things like that. So, I think they come around

more quickly.

She emphasized that prior exposure to death and illness may actually help facilitate the

psychologist's transition into end-of-life care.

Amy also described the difficulties associated with chronic exposure to dying

patients. She noted that "when you work with geriatrics or you do death and dying work,

there is an understanding that your patient is going to die probably more quickly than a

younger adult that you're seeing." She also stated that because psychologists are typically

'well connected" to their patients, and are "empathetic and caring," they can occasionally

fail to "realize how impactful that can be. And when you have a caseload of geriatrics,

and also hospice patients, you can have multiple deaths." She noted that in one month,

she remembers experiencing five patients' deaths. Additionally, she remembered that her

father had experienced 12 patient deaths in three weeks "one December where the flu

went around." As such, she noted that the experience of chronic exposure to working

with dying patients can take "a toll" on clinicians.

Amy described how the systems of reimbursement for psychologists also impact

the provision of care, adding that "the reason why a lot of psychologists are not doing a

lot of this work is financial." In line with this, she noted that one of the primary reasons

that she conducts brief individual psychotherapy sessions is because of "the

circumstances: the medications people are on, the medical problems." Thus, "seeing more

people in shorter sessions might be more financially tenable," that is, seeing a greater

volume of patients for shorter periods of time is more incentivized financially than seeing

fewer patients for a transitional 45-minute psychotherapy session.

Amy added that companies that manage hospice and medical facilities expect that "because the reimbursement [rate] is so low, they typically employ master's level, or lower level mental health professionals, to do the work" of providing mental health services. She also stated that "the funding [rates for reimbursement] is through Medicare... and Medicaid, [which are] terrible." She described, too, that because the reimbursements are so low, "hospice nurses or just nurses in general tend to be doing the work of what you would think a psychologist would be doing in terms of... family counseling or counseling of the patient." She concluded that for psychologists who consult to end-of-life care facilities, it's a "very niche part of their practice" since they "have to do a tremendous volume of it to really make it financially feasible," since these psychologists must also be generating enough income to hire medical billing experts to "effectively recover reimbursement for [their] services," and those medical billing services can be "cost prohibitive and very expensive" for most practitioners. As such, Amy noted that psychologists who provide services in end-of-life care must either supplement their incomes and diversify their practices or commit to engaging with a very large patient volume.

Additionally, Amy described the barriers that patients describe in accessing end-of-life care, noting that she sees "the majority" of her referrals that come from hospice "one, two, maybe three times." In fact, she noted that "there are times when I get a referral, and they've died before I can even see them for an intake. Within a day, I mean." As such, Amy noted that a major barrier to engaging patients in end-of-life psychological care is that "people just aren't utilizing hospice early enough that it could really benefit." One of the reasons that Amy believes contributes to patients not accessing end-of-life

care "early enough" is that, for example, "the way cancer is discussed a lot in our country and just the public dialogue is it's very dichotomous: you're either fighting and surviving, or you're 'giving up' kind of thing. And I think that really creates a barrier for clients and families to really access palliative care services or hospice early enough in the process where it can be really beneficial." She said that patients may perceive that engaging with end-of-life care to be "losing" since the national vocabulary about coping with illness appears to be dichotomous as "fighting" and "winning" versus "giving up" and 'losing.'

Additionally, Amy believes that medical professionals tend towards engaging with "more and more interventions." In addition to a desire to "continue fighting" for their patients, medical professionals may also face "liability issues for…giving prognoses" and so these professionals tend to avoid suggesting interventions that may suggest end-of-life is approaching and may then also avoid referring to hospice. As a result, when patients do finally engage with hospice when end-of-life care may be the only available intervention left, "they have like… days, like it's usually less than a week. So, if I'm working with a hospice patient, I may see them once or twice, a new hospice patient."

Amy also described additional factors that would influence the length and nature of sessions, including a patient's age and health status. She noted that "most" of her patients "have some level of cognitive impairment and that, as they approach the active dying process, are either sedated, or have some impairment." As such, her sessions with patients do not resemble "the typical 45-minute outpatient appointment" and are frequently briefer depending on the patient's ability to meaningfully engage with her. One exception is sessions "with a select patient or age group, usually when they're younger,

it's longer." Additionally, she stated that "the complexity of medical issues" may influence the length of sessions. However, she noted that her sessions tend to be "short, brief interventions" and that they are "very practically oriented." However, she will sometimes have "extended longer family sessions" that may include end-of-life care planning or providing psychoeducation to family members about the dying process.

In terms of family involvement, Amy noted that the presence, availability, and willingness of patients' family members will affect the provision of care. Specifically, she noted that family-based interventions will be "mostly geared towards some of these practical things: psychoeducation about what's going on… providing them with support, problem-solving these last final wishes, funeral planning ... very practically oriented things."

However, she can count on "less than one hand" the number of times that she has engaged with family members who were present "at bedside to a person that's actively dying." Many of the patients she sees in nursing homes or "institutionalized settings of that nature" are "estranged from family, they don't have family left, their family doesn't want to be involved or doesn't have the resources to be involved." She also described additional barriers for family members to actively engage with patients and with their treatment as the patients are dying, adding that some family members may experience the presence of a dying person as very disturbing. She described the sensory changes she has witnessed as loved ones are dying:

> the sights, sound, smells… they don't look like their loved one [and] the
>
> rigidity in their muscles, the skin changes, and they won't look like

themselves also, which can be very disturbing. And a lot of times, they will

not recognize family at a certain point, which is disturbing to the family.

Amy also said that the lack of family advocates can inhibit patients getting

effective care, because many medical facilities are "understaffed" and, for those patients

who do not have family available to advocate for their care as they die, they may get

suboptimal care.

In addition, Amy noted that medical professionals avoid giving specific prognoses

or timelines for an individual's anticipated life expectancy because "it can be incredibly

hard to predict when a person is going to die." As a result, family members may

experience difficulty truly "being" with an individual when they are about to die. Amy

concluded that "maybe family has come in, but then they're not there for the moment the

person dies, or they're not there because it's so hard, the final day, hours." She believes

that this difficulty interferes with family engagement in treatment.

Additionally, Amy described that a major barrier that inhibits quality of life at the

end-of-life is pain. Patients who do not receive appropriate pain management can be

"over-sedated," which can interfere with patients spending time with loved ones and

engaging in "pleasurable activities" as they approach death. By contrast, patients who are

not engaging with adequate pain management can be "thrashing; they look like they're in

pain or moaning, screaming, crying," which can also significantly reduce their quality of

life. Thus, there is a "fine line of finding that appropriate level of sedation where a patient

is comfortable and having the best quality of moments."

Additionally, Amy said that, because of the rules and regulations that govern

home-based hospice, family members are forbidden from administering intravenous

sedation at an individual's home as a result of fears that family members may help

patients overdose, or overdose themselves which creates an additional barrier to

providing effective pain management at the end-of-life.

Financial factors such as the socioeconomic status and health coverage of patients

also affects the provision of care at the end-of-life. There is "a high rate of poverty"

among the patient population with whom Amy works, and many of these individuals

"don't actually have family members that come in or are a part of any" of the care. As a

result, patients may engage with end-of-life care in understaffed facilities with little to no

family advocacy or support. She said that

> outside of the nurses or physicians or medical personnel, aides that the
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> patients are seeing, I'm the only person. So if they have these specific wishes
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> [for end-of-life], a lot of times it's important, in terms of advocacy, to have a
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> handle and problem-solve how to make that happen for them because if they
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> share with an aide that they want to go to Target, that may not actually trickle
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> down to anyone of power or authority to do that, to be able to make that
>
> happen for that client.

Amy noted that for patients who are financially under-resourced, she also adopts

the added role of advocacy because their socioeconomic status may affect their ability to

accomplish their end-of-life wishes or engage with optimal care. However, Amy said that

"it may be very different if you were in [another state or geographic situation from me],

where the socioeconomic status is much higher, there's different religious groups, and

people have different cultural backgrounds where family may play a different role. It may

not work in that way or function in that way." Therefore, the knowledge that family

members and financial resources are not as readily available with a population that is largely impoverished influences her professional role.

Another financial consideration that may affect end-of-life care for patients is their insurance coverage and the setting through which they received end of-life care. Amy noted that the setting in which a patient is being treated can determine the frequency and nature of interventions. For example, patients on home-based hospice typically see a nurse every single day, so that their needs are attended to at a relatively high frequency. As such, their pain management and other needs can be adjusted fairly quickly. By contrast, if they have a hospice designation in a medical facility, a hospice nurse may see them three days per week, which would mean that if their needs change rapidly, medical professionals may not be available to attend to their needs as quickly. Thus, the care provided "really varies at times based on their [the patients'] funding and their insurance—what they're covering," and the setting of care. In addition to medical facilities and home-based hospice, some patients engage with end-of-life care at a "hospice facility," which Amy said is "more of a rarity" because "it's very hard to get a room" and because "usually, it's insurance based, and you usually only get a week. It's hard to meet the criteria, and it's very expensive." Because of the cost involved, insurance companies "make the criteria very difficult." As such, "there's really a push for home-based hospice, or most people end up dying in medical facilities."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

When asked about the factors that support her work in end-of-life care, Amy identified specific reasons that help her continue to engage with death and dying, including institutional support that promotes the provision of psychological care to

patients as they approach death, the meaning she derives from engaging with this patient population, the patient characteristics that maintain her continued interest, and increased education and resources for patients and clinicians engaged in end-of-life care.

Amy noted that there are "specific laws and regulations for certain types of medical facilities" based upon accrediting agencies such as The Joint Commission that dictate when patients should automatically be provided with mental health services when seen in a medical facility. Specifically, she noted that medical facilities will usually make a referral for Amy to see patients for psychological services when patients "have a mental health diagnosis in their patient history, or [are] on psychotropics, or [are] struggling with active mental health or behavioral health symptoms, or have been put on hospice, or usually, a lot of times when they've recently been given … a terminal diagnosis." Because the medical facility can get a citation if those patients are not seen by a mental health professional, Amy said that "there's usually a push, there's support… for those clients to be seen." Amy said that this institutional support helps her engage with this work on a regular basis.

Additionally, Amy experiences her work with patients approaching death as "some of the most rewarding patient population or [patient] work I've ever done as a clinician, and that's why I continue to do it." She stated that "there's a tremendous privilege in being present when someone is passing, as well. And that I've been able to help in that way or ease their suffering in any type of way and help them transition." Also, for Amy's older adult patients, she noted that "their outlook on life, the meaning that they've found, their storytelling and narrative about what they've experienced and the insights and perspective they have on life has just been extremely interesting and just

been a tremendous privilege for me to work with them. So, I find that to be really rewarding."

Finally, Amy noted that gradually increasing resources for dying patients and clinicians engaged in end-of-life care has been helpful to her in this work. She described that, when she first started doing this work, she would joke that "Wouldn't it be great if we had a manual for how to die? That was one of my lame psychologist jokes." Soon afterwards, she found that hospice was beginning to provide something akin to a "death manual." In these manuals, Amy said that patients are educated about "how your body decompensates and the [associated] specific processes," and that "even just going through and explaining what they can anticipate is a great relief" to patients and family members. She concluded that for "all my patients where we've done that, it's been very helpful."

Interdisciplinary Relationships

This topic was not discussed in this interview.

Professional Meaning-Making in End-of-Life Care

Amy stated that she like to conceptualize herself "as a death coach" for her patient's "transition" wherein she is "ushering people into this next realm of their… next chapter, whatever that looks like for them." In this role, she feels privileged to serve individuals as they approach the end of their lives and feels like she is "touching lives." She added that she has found that working with patients at the end of their lives is "some of the most rewarding patient population or [patient] work I've ever done as a clinician, and that's why I continue to do it. Yeah, definitely tremendously rewarding."

When asked about the reasons she finds working with patients as they die to be rewarding, Amy said, "I like to think of myself as a coach for their transition. And kind

of ushering people into this next realm of their… their next chapter, whatever that looks like for them." Additionally, she said that "it's a privilege to serve this population" and that she experiences a great deal of "affirmation" and "positive reinforcement," particularly when patients describe the ways in which they believe she has been helpful to them. For example, she stated that patients have said "'You've unburdened me from my worries,' or 'You've helped me with my pain.'" When Amy perceives that her patients value her work, and value seeing her, she feels like she's "touching lives" and experiences gratification that she is "a small part of that journey."

Influence of Personal Experiences with Death

Amy described the experience of witnessing her father's death as an influential experience in her ability to work professionally with actively dying patients. Her father was diagnosed with a terminal cancer diagnosis as he was about to retire and as she was transitioning into his role at the company that he owned. Her family and her father decided to opt into home-based hospice as he was dying and she had "intimate experience" of the realities of home-based hospice for family members. The experience altered her perception of the dying process and influenced how she works since she was able to cultivate an awareness of "things that improve quality of life;" to learn about what death and dying "look like" from an observer's perceptive; and to develop a "more intimate knowledge of the functions of hospice" and "how it can be helpful." That experience changed how she interacts with family members of her patients and it enables her to be a "better clinician in those moments" when she is having discussions with family members about the dying process.

Influence of Religious and Spiritual Beliefs

This topic was not discussed in this interview.

Ethical Considerations in End-of-Life Care

This topic was not discussed in this interview.

Changing Attitudes about Working with Death and Dying

When Amy first started working professionally with dying patients, she noted that she had an "idealized image" about working with individuals as they approached death, "whether they're on hospice, or they're... older geriatrics." Specifically, she had perceived that she would be working with individuals who were "trying to subscribe meaning" to their lives, and that the work would be "more spiritually based." She stated that she has found that with "most dying patients, it's... very mundane, random, practical." However, she has been surprised to find herself helping patients achieve "mundane" and "simple pleasures."

> I can't tell you the amount of times it's just like, "I need a Snickers," or, like, "Let's put on bad reality TV," or... [other] random simple pleasures. That's just increasing joyful moments and it's not super tied up to some type of existential, spiritual, meaning process, and that's very surprising.

Professional Landscape for Psychology in End-of-Life Care

Amy stated that the professional landscape for end-of-life care has been "more so directed towards hospice nurses and medical professionals" than to psychologists, and she acknowledged that there were relatively limited resources for psychologists specifically. As such, she stated that the education and resources that she has pursued in end-of-life care had been found in other, mainly medically oriented disciplines.

Vision for the future of End-of-Life Care

Amy stated that her vision or the future of psychology's role in end-of-life care included changes in the reimbursement structures to increase access to care, increased exposure to end-of-life care at the graduate training level, increasing options for access to end-of-life care, and public education about and destigmatization of palliative care and hospice-based end-of-life interventions.

As a result of the numerous financial barriers to psychologists functioning in end-of-life care, Amy hopes that the reimbursement structures that appear to deter psychologists from engaging in end-of-life care are reorganized to facilitate the presence of psychologists in such care. Amy concluded that "I would hope reimbursement structures would change so people can get the care that they need. Dying is hard; people need support."

Additionally, Amy hopes that graduate students can gain greater access to working with patients confronting death because "in graduate school, there isn't a lot of access to [working with that] patient population..., and I think a lot of people could be interested or could be really good at it if there was more exposure." She added that she believes earlier exposure could draw more psychologists to end-of-life care.

Amy believes that "we're slowly moving away from a lot of last-ditch, intense medical interventions…that really increase pain and make the dying process a lot harder… prolonging it." She believes that interventions such as medical aid in dying may grow in popularity and accessibility as society promotes "options and choices to craft a death that's meaningful to [individuals and] … "what they see for their death."

Amy illustrated her perception of the unique roles that psychologists can fill in promoting end-of-life care and how they can bring their specific skillset to add value to this field. Psychologists can provide palliative care-focused interventions "before it's just a couple days out" of an individual's death. In order to do this, psychologists can provide public education and make coordinated efforts to destigmatize and change the lens through which most of society currently perceives palliative care. Psychologists can advocate for the reality that individuals

can be pursuing treatment and also accessing palliative care to improve your moments, your day-to-day life, your pain… If people started engaging in palliative care to improve their quality [of life] and pain management regardless of their continuing to pursue medical intervention or what have you, it's going to improve the quality of life, which should be one of the major goals here. …

Death and faith are not all mutually exclusive that we can hold these things at this time. And these help people have more options and have better transitions and better deaths…

When treatment teams and families also are unable to think flexibly about it or hold those dialectics, the person can suffer in silence tremendously because they have no outlet to say, "Hey… I want to talk about my death. I want to plan my death. Because it's like, so dichotomous from hope, and, you know, "We're fighting this!" and that kind of thing. It really leaves a person feeling isolated alone. And also, they're not able to tie up loose ends, make

the plans or the death that they want to have, or whatever it is, you end up

running out of time."

As a result of the difficulties that patients, treatment teams, and family members experience engaging in palliative care and end-of-life care interventions that are focused on improving quality of life as individuals die, Amy believes that there is a unique role that psychologists are positioned to fill in educating the public about the benefits of interventions that improve quality of life while still leaning into the reality of death.

The Case of Eric

Background Information

Eric is a 48-year-old Caucasian male who has been a practicing licensed clinical psychologist for 11 years. He graduated with a Psy.D. degree in Clinical Psychology and has remained in clinical practice since he completed his doctoral degree in 2009. He identified the primary theoretical orientation that guides his clinical practice as stemming from principles of Dialectical behavior therapy (DBT).

Method of Recruitment

Eric had been recruited to participate in this dissertation research after responding to a dissertation participation recruitment email posted on his state psychological organization's email listserv seeking interviews with psychologists practicing in end-of-life care.

Graduate and Post-Graduate Training in End-of-Life Care

Eric described taking graduate-level coursework in Lifespan/Developmental Psychology, wherein he describes learning about "older folks" and added that "for the most part, there was no ...specialized discussion or coursework about death and dying."

Additionally, while he was on internship at a Veterans Administration (VA) hospital at a major northeastern city, Erik noted that he rotated through a Palliative Care/Oncology unit, where he worked with patients confronting the prospect of death.

Erik also noted that he received two weeks of training at his current job through the company that he works for, wherein he "shadow[ed]" a psychologist working in a nursing home, learning about the facility requirements and professional expectations. He did not describe the nature of the training as it related specifically to end-of-life care in the facilities.

Eric noted that there were some ways in which his training prepared him to work with actively dying patients but also conveyed that he felt largely unprepared to work with patients facing end-of-life concerns. Specifically, he felt that his training supported his ability to develop an awareness and understanding of "how to quickly report on the overall mental status of the patient" through exposure to psychological and neuropsychological testing.

However, Eric noted that he did not "feel like there was enough focus on processing the death of a patient or preparing for one." While on internship, when he was working on a Palliative Care/Oncology unit, Erik described experiencing difficulty in his relationship with his supervisor, wherein he felt he was not able to adequately address patients' thoughts about their impending deaths because his supervisor directed him to address other psychological concerns. He noted that he reflects on this experience as "a lost opportunity to try to help somebody get some closure with what the patient needed." Despite these concerns on internship, Erik said that he had been able to independently deepen his understanding and ability to have "conversations about pending death, other

patients dying, roommates dying or people down the hall, friends dying, [and] preparing a patient for helping their family process a death" through the provision of direct psychological care to his patients during his internship training.

Eric did, however, feel that his psychological testing rotations and psychological report-writing provided him with valuable awareness of the terminology he now uses to report on his patients' mental status and orientation. However, he noted that he continues to experience difficulty understanding medical terminology and diagnostic implications of illnesses that many of his patients face and felt ill-prepared to work with medically complex, older adult, and terminally ill patients. He said that "it's a confusing thing. I mean, just the amount of different medical diagnoses that I just don't know about, that I'm trying to learn more about a little bit or at least understand how it impacts the patients. I mean, that's a bit bewildering at times. I'm writing down a lot of diagnoses. And I'm like, 'I think that's a heart thing? I think that's a lung thing? That's an infection…skin thing...?' So then understanding how much that impairs them, or how much pain that causes them, or is this a curable thing or not? Like all of that medical stuff, I'm just winging it." He also said that "it really sucks to be there hearing a patient describe their diagnoses… and I'm like, 'I'm not sure what that means. Is that dire? Is that a problem that can be fixed? How is that going to impair their daily life?'" Because he feels underprepared in his understanding of medical terminology, Eric also said that he tries to use restraint when saying things such as "Well, you'll get better!" because he noted that he realizes that the reality is with some of his patients' diagnostic profiles, "some of these things, you don't get better from." He said that he has had to learn what these diagnoses and medical terms mean on his own.

Further, Eric noted that he felt that his training did not prepare him to discuss the nature and limits of his professional roles with his patients. He stated that many of his patients have grown accustomed to "talking about all their medical problems and ailments" while living in nursing facilities, and that "what patients mostly want to talk about is, 'This hurts, and that hurts, and I don't feel good there.'" As such, he stated that he has had to define and provide psychoeducation to his patients about the nature of his role in the nursing facility, noting that he will say to patients, "'Right. I'm a psychologist. Actually, I'm not going to actually help you with those things. I *do* want to know about them, because of how it impacts your life. But I can't fix those. I can help you take some deep breaths and try to relax a bit more or just look at the big picture with you or communicate better to your doctors and nurses.'"

Professional Development

Eric stated that his decision to pursue a job consulting to nursing home facilities came as the result of a combination of "familiarity, experience and the fact that somebody hired" him. He noted that he felt "familiarity" and "experienced" pursuing a job working with older adults as a result of a sense of comfort working with older adult patients that he cultivated during his internship year training. During that year, Eric felt like he was "connecting" and "somewhat helpful" with his patients. Additionally, he noted that the company that hired him to consult to the nursing home facility had been "flexible" with his decision to develop an independent practice concurrently and had been agreeable to his decision to scale back his hours at the nursing home facilities as he built his practice.

Professional Roles in End-of-Life Care

Eric stated that he consults to nursing home facilities, providing psychological services to older adults, including individual psychotherapy and brief cognitive assessments. Eric described that it is "rare" for him to meet with the family members of patients in the nursing home in order to facilitate individual therapy sessions with collateral (i.e., family members) or to conduct couples or family therapy sessions. Eric also stated that he provides brief cognitive assessments for patients in order to provide diagnostic clarity, clarify a patient's level of cognitive functioning, or complete a medical decision-making capacity evaluation. Additionally, Eric described providing advocacy for patients as a part of his professional role as well as providing consultation so that staff in the facilities to promote more effective care for patients in the facilities.

Eric noted that in addition to his 'traditional' role of providing psychological services to patients, he also advocates for their needs to be met by facility staff. For example, he described requesting that a patient's television remote be repaired in order to provide some relief to the patient of the patient's negative experience of the facility. While he described that this falls outside of his traditional role, he believes that he could genuinely promote his patients' wellbeing by problem-solving with staff at the facility, which he believes is a core part of his professional role.

Additionally, Eric said that he provides consultation to staff who are experiencing difficulties providing optimal care to patients. For example, Eric noted that he will occasionally "get complaints about or my referrals seem to be is 'That patient is such a pain' or 'They're always complaining about stuff!'" In order to help staff and patients engage with one another effectively, Eric said that he does "a lot of trying to help each

side act differently, think differently about each other." He said that he will try to reframe an individual's perceptions to provide an alternative lens from which to understand one another's behavior, noting that "They're not always evil, or they got a lot to do, or they're in a lot of pain." He said that he has experienced success providing this type of consultation, adding that part of his work includes "lots of dealing with peoples' needs."

Referral Process

Eric noted that the referrals that he receives for patients who may benefit from psychological services come from the company that hired him, and not *directly* from nursing home facility staff. He noted that, while he was "a little vague" on the process, his perception was that staff in the nursing home facility, including nurses, doctors, and administrators will make a referral to the company that hired him, and then they send a referral to him. He did not describe the rationale for the process or how referrals to the consulting psychologist are typically made, but he did not that he believes that any patient who arrives at the nursing facility with a prior psychiatric diagnosis does prompt a referral for his services.

Psychology at the End-of-Life

Eric illustrated his work as a psychologist working with two patients facing death and described the interventions he used in each of those cases. In both therapeutic encounters, Eric described how his perceptions of a patient's lifespans and expected deaths did not align with the reality of their health and summarized the difficulty in being able to 'know' when a patient will die.

Notably, the first case that Eric described was a case working with an older adult woman whom he perceived as dying imminently, and he stated that she ultimately did not

die when he had expected. He stated that he had been conducting an initial individual psychotherapy session with this patient and that when he first met her, she "was looking very bad, she was vomiting while I was talking to her, some orange juice that she was drinking." He noted that he pivoted his interventions at that moment to discuss her 'apparent' impending death, fearing that the woman's difficulty "keeping food down" may have signaled a dying process. He said that, after the session, he spoke with staff at the facility, whom he said "seemed…kind of confused and surprised" because "they had known her as a very energetic person and saw this as an illness that she would recover from." He noted that, because of the differing nature of his relationship with this woman, he had been perceiving her illness as the signs of an imminent death, whereas other staff felt she did not have to prepare in the same way. He said that staff took the woman to the hospital, where medical personnel were able to effectively treat the woman's illness, and Eric noted that she returned to the facility appearing "better than I've ever seen her, as good as they had seen her before." As a result of this experience, Eric noted that he was reminded that not all older adult patients die as a result of all illness, and that "it's a tricky thing because the level of impairment when [older adults are] ill is so significant" that it was hard for him to know precisely when an impaired older adult is truly declining. He described that "when the 30-year-old gets sick, they're in bed and they're mopey and vomiting or feverish, but when an older person is that ill, they're not able to keep food down, they're delirious at times, they just have compounded problems." This experience also highlighted for Eric the unknowability of knowing with any degree of certainty 'when' a patient is going to die.

In another therapeutic encounter, Eric again confronted the challenge of not knowing when a patient may die. He described being deeply affected while working with an older adult woman who had survived World War II. He noted that in his first and only session with the woman, wherein he was conducting an intake evaluation of the patient, she revealed that as a teenager during the war, she had seen "some really atrocious horrors: a children's hospital that had been bombed, and she was seeing dead babies and children and wounded babies and children." He noted that the woman died "within a week or two after meeting" and that he remembers feeling "a bit frustrated" because he felt as though she had not "received any help" and that he had been "really hoping to be able to try to provide some benefit." As a result of her death, he stated that he felt forced to cope with frustration stemming from the feeling that he had not been able to meaningfully help her after she had disclosed her history of trauma. He concluded that "there's a bit of a frustration and just a 'bad timing' kind of sadness and frustration." In spite of his frustration, Eric noted that the "best" he could do was to "say 'Well, at least I was there to hear the story and reflect in that moment back to her. Like, that's, that's horrible. That's terrible. I'm sorry you had to see that.'" However, he added that "it's funny," but also a reality of the work that he doesn't "wonder if this is the next [or] the last time I'm going to see a patient" but that he can expect that he may never work with a patient again who appears to be in apparently stable health in an older adult care setting.

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

Eric discussed the factors that affect his ability to provide psychological services with patients facing end-of-life. Some of the factors he identified included not knowing when a patient is going to die, posthumous discussion of the death of a patient among staff, staff to patient ratios, interdisciplinary communication deficits, financial reimbursement, and patients' access to psychological care.

As described earlier, Eric described the process that he underwent in learning that there is no way to know when a patient is truly going to die. As such, he noted that he has had to pivot his interventions to honor the patient's current status but has also had to accept the knowledge that there is no meaningful way to know when a patient will die and that his end-of-life focused interventions may not always 'land' at the right time, or at all. However, he did note that he has experienced "a bad-timing kind of sadness and frustration" about his capacity (or incapacity) to help patients who may die at any moment in the treatment, especially when they die before experiencing relief.

When staff at the facility confront the reality of a dying patient or a patient death, Eric stated that "it is kind of funny how there's not much talked about… especially after a patient dies. He noted that his own electronic records may not even reflect the death because the company that hires him to consult to the nursing home facility only records the referral and he is not well connected to the nursing home facility's electronic medical records. For example, Eric noted that he may walk in to the nursing home and inquire about his patient's wellbeing, and a staff member may respond simply that the patient died, and that there is rarely any additional discussion that follows. He said that the conversation that follows is "usually like… 'That person's gone, and now we're having a

new person coming into that room.'" He described feelings of discomfort about the facility's response to a patient's death and feeling as though there was no space to process the loss of a patient for both patients and staff. Notably, Eric added that he has perceived he's not "seeing [staff] get very upset about losses" and that "they seem to steel themselves to 'It's going to happen. Let's try to get not too attached.'"

Eric also described additional institutional challenges that affect the delivery of care, including nursing home facilities being understaffed and overwhelmed with patient's physical and medical concerns which can inhibit staff prioritization of patient's psychological needs. He noted that he remembered discussions while he was on internship that focused on the stress that nursing staff experience while attending to patient medical needs on the one hand, and stresses from supervisors on the other hand. Currently, he noted that he often hears nursing staff "joking about, 'I'm depressed,' or 'I'm stressed out, can you help me?" He said that while they request help in a joking way, that there is "actually some truth to what they're saying" because of "the exhaustion" that they experience and how some of the facilities he has been consulting to have been "cutting down the number of nurses and aides that they have." He said that overburdened staff and understaffed facilities result in poorer standards of care for patients which affects staff ability to attend to patients' psychological needs.

Eric noted that a major barrier to providing effective care is the difficulty he has experienced with consulting with other professionals and staff at the nursing home facility in order to collaborate or discuss patient care. He noted that he does not think that interdisciplinary communication at the facilities at which he consults is "optimal" and that it the nature of the communication is often contingent upon the rapport that he has

established with some of the staff. When he is unfamiliar with staff, or when staff are on vacation or have rotated to another unit or hospital, he has experienced confusion about who he should speak with to discuss his patients. However, he stated that even when he finds a "covering" nurse or staff member, the staff member may not "know that patient that well." He also noted that he often also has the experience that staff are not aware of his shifting caseload, which he stated creates difficulties in his ability to effectively collaborate with staff and "to triage and figure out who are the newest [patients] I've never met and need to meet [and] who are the ones I do want to follow up with on a monthly basis and who are the ones I need to see every other week or every week." Because of this difficulty, Eric noted that he has requested to join team-based meetings, but that he has been instructed not to attend and that he has been told "because you're not going to get paid to go to meetings." He has also heard that "'They're going to talk about all the patients and you only want to hear about a couple, so it doesn't make sense to go into those meetings because their priorities are going to be different from yours.'" He noted that his previous experiences in team-based environments had proven helpful to him in his ability to effectively provide care because he "loved being able to discuss a patient from a couple of different disciplinary viewpoints" and that is was "always helpful for all of us to really be getting everybody's input." Eric concluded that "that's a challenge is… always the communication." To cope with this communication deficit, Eric noted that the "best" he is able to do is "maybe a short brief verbal with [staff]."

Eric also endorsed difficulties associated with reimbursement for his services that affects the provision of care to patients. He noted that the company he currently works for compensates his services on a "per-patient" basis, a payment structure in which he is

incentivized for seeing a greater volume of patients. However, he said that this structure affects his ability to spend additional time with patients who he feels really need the time, and he feels an added pressure to maximize his patient volume at the expense of the necessary time to see patients. He said that it "is crazy, but that's the most efficient use of my time is just to cut people off at 16 minutes and say, 'I'll see you next week." He noted that he tries not to "pay attention" to the duration of sessions as long as he is able to leave in a timely manner each day. However, he noted instances in which he was not compensated for time spent conducting psychotherapy. For example, he said that "I have had some situations where I'm talking to a patient for two hours and I'm only getting paid for, I think, 45 minutes and so it's difficult."

Eric also described barriers to providing psychological services when his patients have difficulties with speech production or language difficulties. He noted that he experiences difficulties accessing interpreters and has to rely upon non-professional interpreters (such as a social worker and a nurse who also work in the facilities). Despite obtaining access to nonprofessional interpreters, he noted that their lack of training has impacted upon his ability to effectively provide psychological assessments, especially when the nonprofessional interpreter had been giving the patients "hints." Additionally, Eric continues to experience difficulty providing services to patients who have difficulties vocalizing and producing speech as a result of "problems with their vocal cords or the muscles involved in speaking."

Finally, Eric described difficulties that he perceives patients experience when trying to access psychological services. He noted that because he is only available to meet with patients once per week at nursing home facilities, patients who may benefit

from more immediate services are unlikely to be able to get them. He added that "it would be nice if a patient, feeling like they're going to die, might be able to have a quick session with a psychologist. For that, we'd have to be more available at the site on an everyday basis, or at least Monday through Friday or more frequently than once a week." However, he noted that "the problem is that some of these places only have four patients, two patients at a time that need any kind of psychological service. So, it's hard to make us get us to be there at the time that's needed."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Eric described that a major factor that has helped him in his ability to engage with patients as they die is an understanding and acceptance of the reality and inevitability of death. He noted that, through his personal experiences with death in his family (described later), he has learned, in part from his training in Dialectical Behavior Therapy, of the importance of the dialectic of accepting that patients may be dying and, at the same time, holding on to the thought that they may remain alive in spite of their illness.

Interdisciplinary Relationships

Eric noted that he perceives that his relationships with other professional staff at the nursing home facilities at which he consults are suboptimal. He described experiencing difficulties communicating with staff because he is a consultant psychologist and not always physically present in the facility. He noted that, because he consults to the facility, he does not know the staff with whom he works well, and that they do not have a good sense of him or his professional roles. He added that he has found it helpful to "educate the staff" about the services he provides and the limits of his professional capacity.

Professional Meaning-Making in End-of-Life Care

This topic was not discussed in this interview.

Influence of Personal Experiences with Death

Eric noted that his experiences dealing with the deaths of his grandparents had an influence on his capacity to work with patients approaching death. Specifically, he noted that when he was about 22 years old, his paternal grandmother had been hospitalized after she had broken a leg and developed pneumonia while recovering in the hospital. He described going to visit his grandmother while she was in the hospital and saying "You're going to get better and go back home. It'll be fine." He said that his grandmother, who had been a nurse, responded, "No, I'm dying." and he said, "No, you're not." He described memories of trying to "push back" which he perceives now as "invalidating her." At the time, he said that she kept saying "No. It's okay, though. I'm dying, but it's okay." He said she ultimately died during that hospitalization. Since then, he said that he had the thought that "That didn't go so well." He noted that he had the wish, too, that he "could be more accepting of it, and somehow still be in a position of, 'It'd be great to be alive. But if you *are* dying, it's important to also accept it and not push it." Following this experience, he said that he has developed a sensitivity and awareness of the ways in which family member and treatment providers may invalidate patients by asserting a will to live. He concluded that he thinks he can now balance patient's thoughts about their own perceptions of their death as a result of his experience with his grandmother.

Additionally, Eric noted that he was seven years old when his grandfather died and that his grandfather was 60 years old when he died. He said that he remembers that his entire family had been "shocked" by his death. At the time, Eric said, his parents

made the decision not to bring him to his grandfather's wake or to his funeral because they were worried about how he would react to seeing his parents "so emotional." As a result, Eric stated that he thinks he had developed "an impulse to avoid death and people who have died."

Influence of Religious and Spiritual Beliefs

This topic was not discussed in this interview.

Ethical Considerations in End-of-Life Care

Eric identified an ethical dilemma that arise in the course of his work with patients who are approaching death and who have died. Notably, he discussed uncertainty about how to respond to "an urge to… take part in [a patient's] wake or funeral or something like that" if he were ever "invited by a family member." He noted that he asks himself, "How does celebrating life afterward and still be a professional who's not going to be revealing too much even by their presence?" He concluded that while he has not had to confront this ethical concern yet, he is not sure how to handle this ethical ambiguity.

Additionally, he noted that he confronts ethical dilemmas in considering if and how he can disclose patient deaths or discharges to the roommates of patients with whom he has worked or his own patients. He said that, typically, staff will only disclose to patients that roommates are "discharged" or that "They're deceased." However, he noted that "roommates who have had roommates die is an issue that has come up at least once or twice. And it can cause some problems for the patient that I'm talking to." He described an instance of "a patient whose roommate died and the staff were in the room checking to make sure that the patient was dead, notifying kin, having people come in to

say their last goodbyes to the body, but the patient feeling like 'It's been hours, and there's this dead body in my room!' and feeling very uncomfortable about that." He also stated that patients "miss" roommates who die and experience anxiety and sadness about the thought that "'Death is in this building…' and 'Is it going to come for me next?'"

Changing Attitudes about Working with Death and Dying

Eric noted that he thinks he has changed in his professional approach towards working with dying patients as a result of his experiences while on internship. He noted that he had the thought that his internship supervisor had been "setting [him] on the wrong path on several occasions" and that he "had to do what she was asking" which he experienced as very frustrating. Since then, Eric said that he thinks he "developed a reaction to that" and that while he will approach his work in the nursing home facilities with "an agenda," he will also maintain a flexible approach so that he can "try to meet the patient where they're at." For example, Eric f noted that he had attempted to meet with a patient to conduct a cognitive assessment, and when he approached the patient, he said that the patient "just really wanted to talk about other things that were really worrying him." As such, he said that he has tried to maintain a flexible approach to "help the patient where they're at."

Professional Landscape for Psychology in End-of-Life Care

This topic was not discussed in this interview.

Vision for the future of End-of-Life Care

Eric noted that he thought "it would be nice" if current systems of care allowed for patients to engage with a psychologist if they experience the "feeling like they're

going to die." However, as noted earlier, he believes that this would have to allow for psychologists to be available more than he is currently at the nursing home.

He also noted that he hoped that communication between disciplines, especially for facility consultants, could be streamlined and improved so that it is not "overburdening the staff… who are already overburdened." Eric said that while medical charts are typically well-updated and that he could view the chart for patient updates, he has perceived that notes are typically medically oriented and that he does not have a good sense of "the concerns and issues and progress of patients" unless he speaks with patients directly or fears "overburdening" staff by inquiring with them. As such, he concluded that "communication would be the best if somebody could figure out a way to [update] - without making them spend too much time updating me - about how patients doing what concerns they have."

The Case of Janet

Background Information

Janet is a 34-year-old, Haitian-Dominican female who has been a practicing licensed clinical psychologist for 4.5 years. She graduated with a Ph.D. degree in Counseling Psychology, with a double concentration in geropsychology and neuropsychology. She has remained engaged in clinical practice since she completed her doctoral degree in 2015. She described her religious background as Catholic and identified the primary theoretical orientation that guides her clinical practice as "Biopsychosocial/CBT."

Method of Recruitment

Janet was recruited to participate in this dissertation research directly by the Principal Investigator (PI), who had been connected to this participant from a friend of the PI who interned at the hospital at which Janet is employed. The former trainee introduced the PI to the participant via email, and the PI and the participant scheduled a brief phone discussion in order to review the goals of the dissertation and ensure that the participant met the selection criteria of the dissertation research.

Graduate and Post-Graduate Training in End-of-Life Care

Janet described receiving training in end-of-life care in her graduate program through her applied clinical experiences as a result of her graduate program's emphasis on a "lifespan approach." While Janet noted that she did not have any didactic coursework in end-of-life specifically, she had opportunities to discuss the loss of patients while she was an extern at a nursing home in seminars or group supervision settings, and added that coursework "would have been nice."

In terms of applied clinical experiences as a part of her graduate training, Janet said that her program required her to spend her first year of "pre-practicum" in a nursing home in order to provide "broad exposure to clinical work." She added that her "first clinical encounter with end-of-life was in my nursing home work in my pre-practicum." In the second year of her graduate training, Janet externed at a children's medical center in a pediatric oncology unit, noting that this was her "first encounter with children diagnosed with cancer and [her] last encounter" since she "realized that as a clinician, that was not the work that [she] could do for a long period of time." Janet also completed a

postdoctoral fellowship in Geropsychology at a VA hospital, during which time she received advanced training in geropsychology and end-of-life care.

Janet noted that her graduate training prepared her to cultivate "flexibility of working with a wide range of people, so I didn't just focus on adults or children." She also noted that she had worked under the supervision of a board-certified geropsychologists" which she noted helped her "to be more in tune with concerns or issues that arise in end-of-life, even with natural aging and natural death, that's not necessarily a result of chronic illness."

Janet also said that there were ways in which her graduate training did not prepare her to work in end-of-life care. Specifically, she described that her perceptions of boundaries of time and setting had to be adjusted. She stated that "as a palliative care psychologist, you have to be very, very flexible with setting." She noted that "There's no such thing as a set session time." For example, she noted that "90% of my patients are inpatient" and, as such, she has grown accustomed to "being open to having brief interactions" with her patients. She added that "you're not necessarily always having 45-minute sessions, and your patient may not be able to have 45-minute sessions." As a result of the altered boundaries of time and place, she said that she has to tailor her interventions to accommodate short-term interventions. Janet also stated that "every time I see a patient, it could be the last time I see them because they might get discharged, or transferred to a unit, or decompensate physically." As a result of this reality, she noted that "we're not focused on a long-term psychotherapy here…" and that she asks herself, "What can we accomplish in each session?" to guide her interventions.

Additionally, Janet noted that she had not been prepared to adjust her perceptions of "privacy" with patients. Specifically, she noted that she has had to adopt a "more open and flexible" approach." Notably, she described that, because she works on medical inpatient units, her patients often have roommates and staff with whom they must share physical space. As such, she discussed the differences between "visible privacy versus…audio privacy" as well as "privacy in terms of family members."

Finally, Janet described that she felt her training had not prepared her to identify and navigate challenges associated with working with numerous, and sometimes conflicting, parties in a family system. For example, she noted that because she is the only palliative care psychologist, she may occasionally see family members in addition to her patients and navigate the boundaries of those numerous relationships as a provider to multiple individuals. She concluded that "those kinds of things you're not really prepared for, you just kind of have to do it."

Professional Development

Janet stated that she knew that "health psychology, or the intersection of mental health and physical health" was always a clinical interest of hers. Before she started her graduate training, Janet volunteered and then worked at a major cancer hospital conducting research as part of "a survivorship project, looking at women who are survivors of colon cancer and men who are survivors of prostate cancer." As she developed familiarity with participants enrolled in the study, she noted that she would speak with them, and started "hearing their stories…and they explained more about their life and how they are living with the diagnosis." She said that these experienced inspired her "to work with these folks in a more clinical way where we're not just doing research,

but I can actually follow up on coping and… anxiety related to recurrence, these kinds of things, and which made me apply for my externships…"

When she started graduate school, Janet continued to cultivate her interest in health psychology through externships and applied clinical training experiences. Upon graduation, she completed a postdoctoral fellowship in geropsychology and stated that a former fellowship supervisor had recommended her for the position of palliative care psychologist at the VA hospital where she currently works. However, she said that she "didn't expect to end up in palliative care… oncology was always an interest, but I didn't expect to end up in palliative care." Therefore, she said, "there's a lot of overlap on the palliative care and oncology teams and that "it was all coincidence that I ended up in specifically palliative care. I mean, I was always interested in psycho-oncology, and then palliative care, you know, just the opportunity kind of presented itself."

Professional Roles in End-of-Life Care

Janet noted that she is the primary psychologist on the Oncology, Palliative Care, and Home-Based Primary Care teams by a Veterans Administration (VA) hospital in a major northeastern city. She noted that she provides psychological services to medically complex and terminally ill patients adult and older adult veterans and family members, and her professional roles and responsibilities include conducting individual psychotherapy, family therapy, and cognitive evaluations. She also described that her roles include advocacy on behalf of her patients, supervision of psychology interns and geropsychology postdoctoral fellows in palliative care and oncology, and providing consultation to medical teams experiencing difficulties with patients experiencing difficulty engaging with treatment.

As a part of her work, Janet described that she provides 'advocacy' on behalf of her patients, adding that she has engaged in nontraditional interventions on behalf of her patients as long as she can conceptualize these interventions as making "sense." For example, she said that "I've sung to patients, I have sat there and held their hands… while they were dying." She also stated that, for patients who are "not necessarily verbal, there's no other family member…or loved one that I'm providing support for, really just kind of coming by and being empathetic or adjusting their blanket, you know, being an advocate." She added that her advocacy is guided by trying to ensure that her patients' needs are attended to or that "sometimes it has nothing to do with your patient, it's being an advocate and being the liaison between your patient and their medical team, or between the patient and social work or, you know, administration. And that can be an intervention itself. That *can* make sense."

She noted that identifying the patient with whom she will engage in psychological services can be "complicated" in a VA hospital since the guidelines that determine "who gets care and who doesn't" can be difficult to determine. She said that "billing-wise, it's easier to delineate" that the identified veteran is her patient. However, she added that she can see family members of veterans or both veterans and family if it is deemed appropriate, but that these decisions are made on a "case-by-case" basis. For example, Janet described seeing a patient who was "nonverbal, history of multiple cerebrovascular accidents (CVA); the only thing he can do is blink, basically. But his one person is a family member… a sibling, *she* is the client. And she's the patient because she's the one that is going through all the distress, and that's needing a lot of support around making decisions, especially around life-sustaining treatments, or discontinuing life-sustaining

treatments – guilt, shame, anger - that she's feeling around that, so she's getting the

support." She added that she could bill for those types of family interventions under

health and behavior codes. Sometimes, she noted that she sees both the veteran and

family members, contingent upon all parties being "on the same page" and the veteran

providing consent for the psychologist to see family members, and then she could see

them jointly as well. For example, she noted that she currently sees a patient "for the first

half-hour with his daughter and his wife. And in the second half-hour, he wants to have

his own session, which is totally okay." Throughout this decision-making process, Janet

noted that she needs "to be flexible." In summary, she said, "So who gets to identify who

the patient is? I think we do. And then make sure that the veteran is okay with that if

they're able to consent."

Janet said that because she is the only palliative care psychologist on her service,

she cannot 'split' the patient and family in treatment and say "Okay, so-and-so will see the

family and I'll see the patient, that way we keep the boundaries clear" since "that's not

always possible." As a result, she said that confronts challenging situations in which she

must provide treatment to different 'stakeholders.' As a means of managing this

challenge, Janet said that she will lay out the reality that she will work with all parties

involved, saying that she must "put it out there on the table like this is what the situation

is, and hope your patient can work with you."

Because Janet described that there is "overlap" between her role and that of other

professionals on the palliative care team such as the chaplain and social worker, she said

that she must regularly evaluate her professional role with her patients. She said that, as

part of her assessment in evaluating whether a patient should be meeting with her or

another professional, she will ask, "Does this patient need a clinical psychologist? Or do they have this really… supportive relationship with the chaplain, and that's really what's appropriate and what they need?" She said that she must evaluate whether or not her patients "need a psychologist or another type of clinician" for each of the patients that are seen in the palliative care service. While she said that she tries to meet with most patients, she must delineate, "What is necessary for the psychologist to do other than testing and dealing with psychosis or clear mental health diagnoses." However, she concluded that in light of the overlap between her professional role and that of other disciplines, "there's no easy answer" to determine which professional will meet with patients when challenges regarding overlapping professional roles arise.

Finally, Janet stated that she consults with the medical teams with whom she works. She noted that she provides "a lot of psychoeducation, de-stigmatizing behaviors, advocating" for patients engaging in behaviors that demonstrate the difficulty they experience while engaging with their treatment. For example, Janet described a case of a 65-year-old male veteran with a psychiatric history of bipolar disorder with psychotic symptoms and a medical diagnosis of metastatic prostate cancer. This patient has been taking psychotropic medications in order to manage his bipolar disorder and was recently started on androgen deprivation therapy (also called ADT, or hormonal therapy) in order to treat his prostate cancer. Janet provided psychoeducation to the medical team that this patient may begin to demonstrate an increase in behavioral symptoms as a result of the ADT, adding that she would request that the medical "don't judge [the patient] by how he's acting now, it's because you guys just started ADT on a 65-year-old with a history of psychosis." In another example, Janet described providing consultation to the medical

team working with "frail" patients diagnosed with a form of dementia in which they engage in "nonsensical movements" that can scare the medical team. In response, Janet noted that the team might decide to restrain the patients, and in these instances, Janet said that she might recommend that the team use "soft mittens" when restraining the patient instead of tying the patient down.

As another example of advocacy and consultation, Janet also described providing education and being able to "call out bias" to medical teams about their perceptions of "a good death." She noted that she has had to discuss with team members that while they believed a patient 'should' engage in a particular decision-making process about their deaths, that "that's not necessarily true" and likely colored by their own biases and backgrounds. In all of these cases, Janet noted that she is cognizant that she remains within her scope of practice when providing consultation.

Referral Process

Janet described the process by which she receives referrals for patients. She said that on her team, she and other professionals are regularly communicating about which patients might be the most appropriate referrals for a psychologist to see. As part of their morning meetings, her team reviews each patient's status as well as new admissions. During this team meeting, Janet said that "there are things that I'm listening for, as you know, as a psychologist that maybe other folks are not listening for. So, if I'm hearing multiple admissions, or patient lives alone, history of non-compliance or non-adherence, some substance use history, history of depression, or any kind of mental health history. So those are things that I would flag and say, 'This is someone I should definitely meet.'" She also said that she screens every single chart to determine "if there is anything that

pops out," then makes sure to meet with that patient. After she decides to see a patient, she conducts a formal assessment in which she meets with the patient to elicit "background information" and conducts "cognitive screens" and then gauges, in collaboration with the patient, "if they could use some support while they're here and maybe after that." She concluded that "it's really a case by case basis in deciding who needs what and when."

She also said that "You might have folks who don't have any of that and are now having resurging symptoms of depression and more feelings of regret. And they just really want to talk to someone about that." For those patients, she also said that she will try to meet with them. Additionally, she described that, for patients who are approaching end-of-life, "there is this emotional shift in folks with things that they weren't prepared to face before, that they are now more willing and prepared to talk about." In those cases, too, Janet said that she will try to meet with those patients who request her services or who might be confronting death.

She said that as part of the referral process, she consults with other disciplines such as the chaplain or the Reiki therapist and may ask patients with whom they "resonate most with" on the team. For patients who describe that they feel more connected to other members of the team, Janet said that "that might be who they need to see" instead of a psychologist. However, she said that "when we're doing capacity evaluations, or any kind of cognitive assessment…that only psychology does. Sometimes they can call psychiatry to do it. But in those instances, we will be the people that are consulted."

In addition to referrals which she receives through team meetings, she said that other referrals for a palliative care psychologist come "almost always through medicine, so either inpatient - the inpatient team - or outpatient team, sometimes through oncology, with some encouragement." She said that she hopes to increase referrals to the palliative care service through the hospital's specialty clinics so that she and her team are "not waiting until someone is in a medical crisis or inpatient" before they could benefit from their services.

Psychology at the End-of-Life

Janet demonstrated her work as a palliative care psychologist working with patients confronting death. In both cases, she described the challenges and supports she has been able to lean on in order to support her work.

Janet said that she had worked with a particularly memorable patient when she first began her career as a palliative care psychologist at the VA hospital that highlighted how she works. At the time, the patient was receiving treatment in the Intensive Care Unit (ICU) of the hospital, and Janet had received a referral to meet with him because he had been experiencing agitation, refusing medical interventions, and refusing consultations from psychiatry. She said that the patient could not leave his bed to engage in aggressive behaviors and was not perceived by staff as physically threatening. Instead, he was wheelchair-bound and connected to numerous monitors. She also said that he had a wife, who had stopped visiting the unit at the request of other medical providers because he would express all of his anger towards her during her visits. Janet said that "it was just not healthy for her to be there."

Each time that Janet would attempt to meet with the patient, she said he would yell at her, saying "I'm not crazy, get the [expletive] out of my room!" and that she would respond, "Okay, sounds like you're upset right now. Are you open to me coming back a different time?" She said the patient would often respond, "Yeah, do whatever you want." When she returned, Janet said that the patient said, "All right, if you're going to be here, then you're going to hear what I have to say" and that he would then go on to curse and berate the staff. Janet said that she perceived that the patient was experiencing a great deal of anger "and in so much pain" and that she thought of her role with that patient at that moment as a "a vessel" to hold everything that he had been angry and in pain about. She said that, at one point, she asked him if he felt that "anyone" listens to him, and he responded, "No, they shut my door." In response, Janet said that because nobody would listen to this patient, she would let him express his anger and share his pain with her. When she returned for an additional session, she discovered that he had been transferred to the hospice care facility affiliated with her VA hospital, where she also worked at the time. The next time she was at the hospice care facility, she went to visit him, at which point he said to her, "'What… you're everywhere! What are you doing here?' And I'm like, 'I'm just here to say hi, and to see how you're doing.' And he just started bawling. And [he] was like, 'I can't believe you actually came and saw me here… I gave you every reason to not ever see me or talk to me again.'" During their conversation, Janet said that the patient articulated that he was angry that he was dying "soon" and that he felt that "it wasn't supposed to be this way." He asked Janet if she could express his thoughts and feelings to his wife (who was not visiting), and so Janet helped him to write down the things he wanted to convey to her and was able to leave for her in a 'legacy project.' After

this, Janet said that the patient "actually hugged" her. The day after that meeting, the patient died after experiencing a fatal cardiac arrest.

As a result of this experience, Janet said that she learned of the value of balancing persistence in her work and attempts to connect with patients while also balancing and respecting patients' wishes for autonomy. She said that, "if you find that you're giving up pretty quickly, 'Oh it looks like they might be eating, or 'It looks like they might be sleeping,'" which can connote health, "to check yourself and wonder if you're avoiding approaching a difficult situation or avoiding engaging in a relationship where you know you might lose that person" because, she concluded, "that's how some people cope with this kind of rotation."

Janet also said that she learned of the importance of maintaining a presence for psychology in inpatient end-of-life care settings, where she felt she was able to have "the opportunity to have constant access" to this patient. In fact, Janet said that she thinks she would not have been able to have this experience with a patient on an outpatient basis since this patient would have likely never returned to pursue mental health treatment. Because she was able to see him in an inpatient setting, she was able to return and continue to advocate for the patient and to provide him with the option to engage with psychological services at a time during which he was "in a lot of pain" and "scared" which had made it more difficult for him to initially engage. She added that "the responsibility is on us to have a presence there and explain how we can be helpful rather than waiting for that person to have insight" or wait for the patient to engage in therapy once they are already experiencing a crisis.

Janet described another instance in which she felt particularly challenged in her professional role as a psychologist working with a medically compromised patient as a result of ethical challenges that arose in the course of treatment.

In this case, Janet described working with a patient whose presenting problems included "severe anxiety and what seemed like true psychosomatic symptoms" of pain, as well as polysubstance abuse. The patient also had a history of multiple medical hospitalizations (almost monthly, Janet said) and a diagnosis of metastatic cancer, which helped to explain the exacerbation of pre-existing symptoms of pain. However, Janet added that "his thoughts and ideas about pain and the location of this pain predate his diagnosis." Janet also said that while experiences of pain are subjective, his subjective rating of pain as a "5 can feel like a 15." She described that the "most challenging" aspect of working with this patient is wondering about how she and other treatment providers can help to "relieve his suffering: his psychological suffering, and his physical suffering" because she feels that the treatment team "really cannot tease those apart for him." While the treatment team has provided the patient with pain medication, they have "maxed" out the medication that they can administer, and he is still in "excruciating pain." She said that the treatment team continues to take his symptoms very seriously and that they have done "CAT scans, PET scans, MRIs, lots of testing to make sure there's nothing" that they may be missing. In this case, Janet thinks this patient would benefit most from an inpatient psychiatric setting but that he cannot engage with that care because he is on a medical unit "so, there is no real place for someone like that." Each time he is discharged from the hospital, she said that "he'll be okay for a few days and then returns to the hospital" for additional pain-relieving medications. The patient is currently on home

hospice care, where he can engage with round-the-clock medical care as well as an on-call service that will come to his home when needed. However, Janet noted that this type of intensive medical care "feeds into his anxiety."

She said that she and other treatment providers have struggled with not knowing "what else we can give" to the patient. She added that while the patient is currently in remission, the treatment team monitors his cancer each time he comes into the hospital. Because the patient has a complex medical history as well as a complex psychological profile with polysubstance abuse, she said that she struggles with balancing her wish to advocate for pain management as well as ensuring that the treatment of his pain will not contribute to a relapse episode in the patient's substance abuse. Currently, the treatment team has agreed to provide the patient with one week's worth of pain medication at a time so that he cannot overdose on the medication, and then he returns to the hospital for prescription refills. Another challenge that Janet is anticipating is that, at a certain point, the patient will be too weak to come into the hospital weekly, and she is concerned that she and the treatment team will then not be able to adequately treat his pain as he approaches end-of-life. She said that this case had prompted her to consider the numerous ethical and conceptual challenges of this work, noting that "part of hospice is comfort care. How do you define comfort? Discomfort can be coming here every week or anticipating that you might run out of meds." In order to manage the complexity of this patient's care, Janet said that she consults with the "in-house ethics team," which is directed by the palliative care physician.

Supervision and Training in End-of-Life Care

As part of her professional roles, Janet provides training and supervision to geropsychology fellows and clinical psychology interns in the Oncology clinic as they provide psychological services to patients approaching end-of-life in order to gain "exposure to what diagnosis, illness and treatment and end-of-life can look like." Janet noted that she perceives "great benefit" in her supervision role, as it provides her with the opportunity to expose students to the palliative care psychology and the roles and benefits of a palliative care psychologist on a multidisciplinary team, "because that's something people are not necessarily exposed to prior to internship." She also said that her supervisory responsibilities provide her with a forum in which she can discuss "bereavement in terms of being the provider and having loss" because "the volume of loss" is much higher in palliative care than in other areas of psychology. She said that she attempts to encourage her students to feel whatever emotions come up for them in working with dying patients and tries to help them explore why those particular emotions come up and what the trainees may be accessing when they feel those emotions. She also facilitates a periodic bereavement processing time for her trainees on the rotation. Finally, she noted that, as a supervisor, she hopes to "broaden people's experiences and thoughts about what palliative care can be" and provide education to rectify misconceptions that students may have about palliative care (and the vulnerability that many students have to conflate palliative care with hospice).

Barriers to the Delivery of Psychological Services in End-of-Life Care

Janet described the barriers that she has perceived in providing psychological services to dying patients, and identified specific challenges that she has encountered in

this work including working with children at end-of-life, chronic exposure to death and dying as a treatment provider, distinguishing psychology's role in end-of-life care, patient perceptions of psychological care in medical settings, defining her professional role, VA-specific regulations that dictate hospice care, and providing bereavement services to patients' loved ones.

Janet noted that she had been a neuropsychology extern at a pediatric oncology facility while she was a graduate trainee, where she conducted neuropsychological assessments for children who had completed chemotherapy, radiation, or hormone treatments. The assessments were conducted in order to provide the children with appropriate academic accommodations for when they planned to return to school as a result of possible changes in cognitive functioning as a result of their treatments. She noted that she confronted death in the pediatric setting when children had a recurrence of cancer or when treatments were not successful, and then "you think you're going to go test your patient, and they're no longer there." She said that "the pediatric work was difficult" and that she "couldn't do it long term." While she described it as "a great experience" and that she had "an amazing and supportive supervisor," she said that that "wouldn't be a career goal" because of the challenges associated with working with dying children.

Additionally, Janet described the challenges associated with providing treatment while experiencing chronic exposure to death and dying. She said that some treatment providers might engage in avoidance of the patient if they perceive that the patient may be approaching death or may collude in denial of the patient's impending death. She said that the patient and providers might also "sort of collude and avoid together; [the] patient

says, 'I'm okay'" and then the treatment provider will say, "'You're okay, all right, great, we're both okay, we don't have to deal with this.'" She noted that she believes this interpersonal dynamic may be the result of "so many losses" and that it is a reaction to cope or defend from the loss, "to keep you going." Janet said that she encourages her trainees to try and fully experience their emotions when working with these patients, including "anger, apathy, avoidance, you know, feeling silly and making inappropriate morbid jokes," adding that "they're all responses to this work." However, she said that does prompt her trainees to "talk about it and find out 'Why is it happening? What is this accessing for you?'"

She also described the challenges associated with distinguishing her professional role on a palliative care team at times when there was "overlap" in her roles and those of other professionals. As described earlier, Janet identified that she must continually evaluate both her professional role as a clinical psychologist as well as the needs of her patients and which treatment providers they identify with most. She noted that while psychological testing or "clear" mental illness would be her professional domain, there are times where a patient may feel more comfortable speaking with other treatment providers. At those times, she said that there is "no easy answer" to determine if and when she, as a psychologist, will meet with the patient to provide psychological services.

Another barrier that Janet identified is the degree of familiarity with and perception of the role of a psychologist in a medical setting. She said that patients do not generally expect to meet with a psychologist in a medical setting, and are frequently surprised or confused when she approaches patients to offer "psychological support." She said that while the VA system is an integrative care model, many patients are not familiar

or accustomed to models of care in which psychologists are "co-located or integrated into specialty care teams." However, she thinks that "it's something that people will get used to over time. But for now, it might still be a stranger concept."

Similarly, Janet noted that she had to define her professional roles and responsibilities for herself, which she said, "can be challenging, depending on what team you're on." Because of the numerous definitions and perceptions of what a palliative care psychologist is, Janet has noted that it can be help to allow for flexibility in her role, but that it presents as a challenge in defining her role.

Additionally, Janet said that, in contrast to the rules and regulations governing hospice care for most individuals, "veterans who get referred to hospice do not have to stop curative treatment." As a result of this difference, Janet said that patients may experience difficulty understanding the implications of hospice care if they are still able to opt-in to potentially curative or life-prolonging intervention. Janet expressed a concern that, in addition to the difficulties that patients experience in understanding this, some hospice care facilities that contract with the VA may also not understand this regulation. As a result, the hospice care facility may unknowingly communicate differing information to the patient and potentially inhibit their ability to engage with life-prolonging treatments. Janet noted that the VA must repeatedly tell hospice care facilities that this is a regulation that is specific to veterans referred from the VA. Additionally, as a psychologist, she noted a specific challenge in conducting "end-of-life work" with a patient while, at the same time, they may also be engaging with curative treatments, which can be a challenging dialectic for patients to understand and engage with.

Finally, Janet described the difficulties she encounters in the VA system providing bereavement support to family and loved ones once the veteran passed away. Some of the barriers that Janet identified in providing bereavement support included concerns about liability, stating that "can the federal government cover your liability if the identified patient is deceased?" She also identified billing concerns, noting that "how do we bill for this, if the patient is deceased, we're not supposed to put notes with encounters in their chart because the person is no longer here" and that she could not "create a collateral chart because it has to be connected to a live person." In the past, Janet was able to provide bereavement support to family members for "15 months post-death and then refer out to the community," but she is no longer able to provide that. She noted that, because she can no longer provide bereavement support at the VA, she refers these individuals to local hospice care facilities that are not affiliated with the VA. At these facilities, family and caregivers can get bereavement support even if the veteran was not on hospice.

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Janet described some of the factors that she perceives help to support her work in end-of-life care. Because she works in an inpatient medical unit, Janet said that she values "having the opportunity to have constant access to that person and access to those feelings." As a result, she said that she can consistently advocate for the role of psychology to help patients cope with difficulties while they are being treated on an inpatient medical unit even if they are not receptive at first.

Janet also noted that she "appreciate[s]… being in contact with other palliative care psychologists" to help cope with the challenges associated with the type of work and

the patient population with whom she works. In addition to contact with professional

psychologists, she said that she is "lucky to have the team, to be on the team that I'm on,

where we find sort of concrete systematic ways of processing situations." She noted that

she has noticed that, on her team, "every death is impactful" and that every death is

acknowledged. Additionally, she said that she sends "bereavement packages" to the

family of the patient one week after the death, six weeks after the death, and one year

after the death. As part of the packages, the entire treatment team signs a card for every

patient that has died while under the care of the team. While she acknowledged that the

care packages take time, she said that preparing the package is a "part of the healing and

part of processing." She also said that she is able to process the loss of patients with other

team members who can check in with one another and provide emotional validation. In

addition, she noted that her team acknowledges that "it's appropriate to grieve for patients

or have a normative way of processing" losses. She said that for other medical

professionals such as the oncologists with whom she works, "if they lose a patient, I don't

really see where or how they have a way of processing that with each other because they

don't necessarily have the same team or, like, understanding of the relationship that they

had with that patient." By contrast, having a team means that "the entire team is caring

for that one person, and you share that loss."

Janet also emphasized the importance of maintaining boundaries for herself in this

type of work, noting that she doesn't "bring work home" or that she would "rather come

here [to the hospital] on a weekend than doing notes at home or anything like that."

Finally, Janet noted that she maintains her continued interest and ability to engage

with death and dying by "purposely" diversifying her caseload and having "a more

balanced schedule, meaning I do have healthier patients who…have a cancer diagnosis, but they're getting treatment. They're most likely going to have remission and be okay. So, there is – I'm not only doing one type of work and only seeing one kind of outcome." She concluded that she "could not do only palliative care 24/7, I would need to have some kind of diversity in the work that I do" so that she knows that not all her patients are dying or "sick all the time."

Interdisciplinary Relationships

Janet described her interdisciplinary relationships as largely positive, noting that she is "lucky" to be a member of her multidisciplinary palliative care treatment team. She described the benefits of being on a supportive treatment team upon which she can draw support. She also discussed how she can effectively provide consultation to medical teams to consider the psychological wellness and factors that may influence patients' medical decision-making and health-influencing behaviors.

Professional Meaning-Making in End-of-Life Care

Janet discussed her perception of the ways in which she is able to cultivate meaning from engaging with patients as they face the reality of their death. She said that, for all of her patients, "one thing that is always a common factor is death, and it's in the room, right? So, we're going to die. That is something that is known, [but] not necessarily talked about." She added that she has learned that for those patients with whom she has worked that *do* want to discuss their death, it can be a "very lonely place because most of the people who love and care about them don't want to talk about it. They'll say, 'You're going to be okay, let's not talk about that.'" However, Janet said that "what's been most meaningful" is that her patients allow her "to be a part of their space in such a pivotal

time in their life." She described that she perceives that when "this person is okay with us engaging in this therapeutic relationship, where they're just meeting you," it is similar to "a crash course in… building rapport in a very short period of time." She noted that she feels "honored" by the prospect that her patients engage in the relationship with her at this stage of their lives.

As a result of the introspection she has engaged with, Janet said that "the meaning is it helps me to reflect a lot. Ask a lot more questions that I wouldn't have asked otherwise." Specifically, she said that regular engagement with death and dying has prompted her to consider her mortality, how she feels about her mortality, the thoughts and feelings she has when working with death and dying, and the knowledge of the finitude of her existence. Because of the ever-present nature of death, Janet has conceptualized her work as "about living. You are alive today…how do you want to spend the time that you're alive? How do you view the rest of your life? It could be a day or ten years; I don't know. But how do you want to live? And that's a question I ask myself; how do I want to be remembered? So, if I were to die tomorrow, what would I want people to say in my obituary, and am I living up to those values? And if not, why not?" Additionally, Janet said that "Being confronted with death really makes you think about the time that you're here, the space that you're taking up, the privilege that you have to have for… I have for working limbs; I can advocate, get up, and go to the bathroom. Right, just looking at all the ways that you're lucky, but things that you might be taking for granted."

Finally, Janet said that she derives meaning from the "understanding that these people have an impact on you; this is impacting how I view death, how I view how I'm

living. You really get to see how fragile… the human body is. Just from the medical perspective, just if you're healthy, and okay, you're kind of not immortal, but not picturing what can go wrong." The ability to reflect upon her mortality and fragility is something she said she would not consider if she were not engaging in this type of work and finds meaning in the ability to meaningfully reflect on that for herself.

Influence of Personal Experiences with Death

Janet noted that her mother had died during her professional training, which she said has impacted upon the ways in which she approaches working with her patients approaching death, stating that it "brought me closer to my work." She noted that her mother had been diagnosed with cancer while Janet was in her postdoctoral fellowship training and that her mother died within one year of her diagnosis. As a result of her mother's death, Janet noted that she has "a lot more empathy and perspective" when she works with families of patients who are dying. For example, she described that she is often called upon by medical teams to work with family members of "clearly" dying patients who "are having a harder time accepting and are asking for more treatments, or treatments that are clearly not going to reverse the process" in order to help the family understand the costs and benefits of these life-prolonging interventions. Additionally, when working with these families, she says that her experiences with her own mother's death have also helped her "to not pathologize those family members and not saying that they're in denial" and that she can normalize and provide a "way of explaining to the team what's happening for these folks, that it's not necessarily denial or not acceptance; this is their family member." Finally, Janet noted that she was concerned that she would not be able to engage in this type of work once her mother was diagnosed, but that she feels

instead that she has grown closer to her patients and their families as a result of her loss

and feels she can "really" empathize with them.

Influence of Religious and Spiritual Beliefs

When asked if and how her religious and spiritual beliefs influence her work,

Janet said: "Yes, and no." She explained that she believed that her religious identity has

impacted her "work in actually a very positive way." Specifically, she said that her

capacity to speak with patients about religion facilitates hope, adding that, "I don't shy

away when patients talk about God or talk about the afterlife or spiritual things that

they're going through. I think, for other providers, it might be not as comfortable for their

medical providers, or sometimes they even pathologize like if people start to have a

stronger faith and are believing in miracles and hope, in ways that we cannot see, like,

there's no practical way of this person being healed, but the patient is feeling like God can

heal me. I think it opens up the ability to have that discussion and not really shutting

down their hope."

She also said that, as part of her "standard questionnaire," she asks patients about

their religious beliefs. If she identifies that patients have different religious beliefs or

identities than she does, Janet will ask the patient "if they're comfortable talking about

that" with her "and if they foresee this as an issue." She believes that the discussion about

religion with her patients "gets people closer together" and that many patients "are not

expecting to be able to talk about this without being deemed as crazy for believing." For

example, she noted that "If someone says, 'I think my grandmother's spirit is going to

come and get me,' like, no, I don't think they're hallucinating or delusional; this is a

belief." As a result, she said her religious beliefs have likely brought her "closer" to most of her patients.

Ethical Considerations in End-of-Life Care

Janet reflected on the numerous ethical questions that arise and which she must regularly consider in the course of her work.

Janet described that she must be cognizant of maintaining the confidentiality of her patients when she is speaking with numerous family members of a patient. For example, she said that, at times when she has a patient's consent to speak with family members, she is certain to discuss with patients what the limits of their comfort are in instances where a patient requests that Janet disclose certain information to one family member and, at the same time requesting that she does not disclose to other family members. However, she noted that she makes explicit her inability to prevent family members from speaking with one another. She summarized that "your loyalty is to your patient" above all else.

Additionally, because of the overlap in her professional roles with that of other treatment providers, she described that she must reflect upon her role in evaluating how she bills for her time. For example, she said she asks herself, "Is this service something that a clinician should be doing? Right? Is this something that a volunteer can do? If I'm just sitting here with the patient, am I doing a clinical intervention that should be reimbursed for a psychologist's time? Or is this something that really the chaplain should be doing or social worker or a volunteer?" Because she is a VA employee, Janet noted that she has "the luxury" of "not necessarily talking to the insurance companies," but that she engages with this self-assessment because "it is the ethical practice." However, Janet

said that she has engaged in non-traditional roles and practices such as singing to patients or holding their hands while they were dying, so long as she perceives that the intervention with which she is engaging makes sense.

She also discussed ethical challenges in the treatment of pain at end-of-life when patients are experienced impairing pain but may also have diagnoses that make the provision of pain management a challenge. In the case described earlier, Janet described the challenges she faced in providing pain medication to a patient experiencing pain and who also has a history of a polysubstance abuse disorder. Additionally, she noted that "part of hospice is comfort care" and that she and the treatment team experience dilemmas in defining the parameters of "comfort" and "comfort care" for patients who are being treated at the end-of-life who may also experience difficulties remaining engaged with interventions. For example, as described earlier, Janet discussed the difficulties of monitoring a patient's pain management medication and requiring that the patient return to the hospital each week to refill his pain medication. However, Janet noted that, while he is engaging in hospice care, "discomfort can be coming here every week, or anticipating that you might run out of meds." In those cases, Janet said that consults with the hospital's ethics team to navigate the nuances and complexities of these dilemmas.

Changing Attitudes about Working with Death and Dying

Janet also discussed her perceptions of changes in the care provided at end-of-life and changes in the ways that she functions as a psychologist. In terms of systemic change, she said that while she does not think she has "been in the field long enough, maybe to experience changes yet," she expects, "changes, because… of health care

reform and increased integration, and also insurance laws are changing. So there probably are going to be just major shifts in how we work, what we can do what we cannot do."

Janet also described the ways in which she has changed in her work, noting that she has grown in her ability to advocate for what she believes "a palliative care psychologist is." For example, she noted that she has had the experience that "medical teams think you are the person that is going to convince a patient to do what the team wants them to do." As a result, she has increased her ability to advocate for patient preferences and patients' abilities to engage in autonomous decision-making. As noted earlier, she has also had to "call out bias" to the teams she works with in order to provide education about their perceptions of "a good death" and how patients may have differing expectations about "a good death."

Professional Landscape for Psychology in End-of-Life Care

Janet noted that she was not very familiar with the professional landscape for psychologists working in end-of-life care, adding that "I don't even think we have conferences that I can think of." However, she noted that she has found a listserv for palliative care psychologists who work in the VA system to be helpful to her.

Vision for the future of End-of-Life Care

Janet described her 'vision' for the future of psychology in end-of-life care. She noted that, because most people conflate palliative care with hospice, she is hopeful that "we can sort of broaden people's experiences and thoughts about what palliative care can be."

She added that she hopes that the field will cultivate more clarity for patients, professionals, and other psychologists in the services provided by palliative care

psychologists, noting that there has been increasing attention paid to defining what a palliative care psychologist is and what they do. She is also hopeful that there will be more training opportunities and education provided about palliative care psychology, noting that "palliative care psychology is really its own entity" and that it is not just the domain of older adulthood; for example, she said that, "40% of my patients are under 65."

The Case of Richard

Background Information

Richard is a 50-year-old Caucasian male who has been a practicing licensed clinical psychologist for seven years. He graduated with a Psy.D. degree in Clinical Psychology and noted that he had had specialty training in psycho-oncology while on internship. Richard has remained in clinical practice since he completed his doctoral degree in 2012. He identified the primary theoretical orientation that guides his clinical practice as psychodynamic. Finally, he noted that he does not identify with any religious or spiritual background.

Method of Recruitment

Richard had been recruited to participate in this dissertation research after responding to a dissertation participation recruitment email posted on a graduate school's alumni organization's email listserv seeking interviews with psychologists practicing in end-of-life care.

Graduate and Post-Graduate Training in End-of-Life Care

Richard stated that issues related to end-of-life had been discussed "very little" while he was in graduate school. However, he noted that he had had discussions about

death related to suicide and suicide attempts while he was a clinical psychology extern training in a psychiatric emergency room. There, he stated that he had been seeing patients who had engaged with "a lot of literal attempts" at suicide; Richard did not detail the nature of these discussions about death.

Richard also had exposure to death and dying as a clinical psychology intern and postdoctoral fellow when he engaged in a cancer hospital rotation and worked with patients diagnosed with cancer and their family members. Richard stated that he worked with patients who had died while he worked with them, providing psychotherapy.

Richard noted that he perceived that the training he received in end-of-life was "inherently theoretical" and that it was "all kind of very remote," existing in an "airtight theoretical space." He said, "it's very hard to train someone to sit in a room with someone who they're suspended over dying" and felt as though his training did not prepare him 'practically' to work with someone approaching death. He also noted that he had never been taught that "dying of cancer, it's like, it's a relational phenomenon," adding that "the biggest thing that happens to a person is every relationship in their life will change." However, he said that "if you see enough people across the spectrum, that's the one thing that certainly stood out to me."

He also noted that he experienced difficulties in discussing prognoses with patients as a possible result of the limitations that his training demonstrated in preparing him to engage with those discussions with patients. He said that "Oncologists will not tell patients that they are at the end of the road, they will always scare up some other bullshit thing to kind of keep the ball afloat. And literally, I've been sitting in many meetings where the oncologists are like, 'We're done here, we're at the end of our road, this is it.'

But they will never tell the patient." As a result, Richard said that he might have to share with the patient that they may be approaching death, adding that "In some cases that actually fell to us to get the patients, sort of, ready. It wasn't our responsibility to tell them. But there's something fucked up about sitting in a room with a human being that you've developed a relationship with knowing this information and not imparting it to them in some way."

Notably, despite these challenges, he noted that he felt additional training in end-of-life care would *not* have better prepared him to work with this patient population. He added that he felt his "readiness" to work with patients as they approach death had more to do with who he was as a person than it had to with "getting the right training." He added that "there were a bunch of variables" more significant than training that prepared him. For example, he noted that engagement in his own psychotherapy was crucial in his development and added that he perceives that his "older" age contributed to him having "had a bunch of experiences that were kind of wrapped in it." When asked about his perceptions about what helps in working with death and dying, Richard stated that, "I don't think it's their training. I think it's something very personal. And in a weird way, I can remember…I haven't thought of this in a long time. But part of me, my thought was like, 'I should do this because I can.' Like there's something about it that doesn't make me super anxious. I don't have any problem talking about death, or someone's death or being there with them, you know. And you know, we could speculate on the why of it, but I don't think it's like a curriculum."

Professional Development

Richard said that he was drawn to pursue a postdoctoral fellowship in psycho-oncology because he wanted to learn more from a supervisor he had respected. He noted that "one of the… probably the most talented supervisors I worked with during my internship year was in charge of the psycho-oncology program. So, part of it was also just a wish to kind of be able to learn more from someone I respect."

Professional Roles in End-of-Life Care

Richard stated that he currently practices exclusively in his independent outpatient practice in a major northeastern city. He has had had experience working with dying patients while on internship and during his postdoctoral training year in an outpatient cancer treatment setting in a major northeastern city.

In his current outpatient independent practice, Richard noted that he provides individual psychotherapy and couples therapy. Notably, he said that he gets referrals to his practice from a major urban cancer center for individuals who have or who have had a cancer diagnosis who have been successfully treated or are in remission.

During his internship training year, Richard noted that he provided individual psychotherapy to individuals who had "somehow been touched by some type of cancer diagnosis," noting that he had "a caseload of people with late-stage cancer" as well as "a handful of people…[who were] family member[s] of someone who had the diagnosis." When he transitioned into his postdoctoral training year, which he completed at the same hospital as his internship, Richard said that he continued to provide individual psychotherapy to individuals who had been "touched by some type of cancer diagnosis" and that his "caseload grew... significantly" because his internship responsibilities were

"behind" him and he was able to cultivate more niche and specialized interests during his postdoctoral training year.

Referral Process

Richard described the process through which patients had been referred to him while he was on internship and as a postdoctoral fellow. He stated that medical personnel provided all patients affiliated with the cancer hospital information about psychology services offered throughout the course of their illness and that patients had been encouraged to engage in psychotherapy if they were experiencing any difficulties. Richard said, "One of the things that was very good about the intake process for the cancer patients, and as people were brought into the system, [is], they were made very well aware of this offering. And they were encouraged to pursue it. And I think at any point during the process, if they hadn't gotten on board with it, and they were struggling, I think people were very, very quick to suggest that they get this kind of support. So, it was really ideal in that respect."

Psychology at the End-of-Life

Richard described his conceptualization of his role of a psychologist working with a patient approaching death, stating that when a psychologist learns of a patient's imminent death, or that "most signs prove the fact that they're" dying, a psychologist can "try and help them open up space" of preparing for death. He added that "by and large, the experience I've had is people are ready to occupy that space of getting ready to die" once a psychologist can provide that space. However, he also said that "you've got to meet the patient where they're at. And if they're in the middle of a big fight, you fight

with them. You prop them up to be able to keep going." In summary, he noted that the psychologist's role is to provide space for a patient in whatever route they choose.

Additionally, Richard said that when he conducts a personal assessment of his role as a psychologist at end-of-life, he perceives that "The one thing that I think falls squarely within the realm of psychology is anything relational." As such, he thinks that issues such as "existential stuff around death" can be addressed by a religious authority such as a rabbi or priest. However, "anything that falls into that camp [of anything relational], I think, not only informs the work you're going to do at the outset but also kind of defines the parameter that, 'Oh this thing makes sense and should be happening with [a psychologist].'"

Richard also described two cases of individuals with whom he worked as they confronted or currently confront their own deaths and articulated how these cases highlighted psychological interventions in the context of end-of-life.

Richard described his work conducting individual psychotherapy with a 52-year-old male patient who is in remission of pancreatic cancer. While he is in remission now, Richard said that there is a "high likelihood that this [cancer] is going to come back." The patient is currently pursuing individual psychotherapy to discuss the transition that has occurred since he was diagnosed with cancer and is looking to talk "about how to live… as a new person, because you're not the same." Because of his diagnosis and despite the remission of his cancer, Richard said that the patient is cognizant of the reality that "he'll never be the same again." However, the patient noted that his friends and family perceive that, because he is in remission, he has been "cured" and that they want him "to get on with it, and they want this chapter closed, they want him to, you know, go back to the guy

he was beforehand." The patient reflects, however, that the prospect of living into older adulthood is likely "not going to happen," and he has articulated that "'I need to do something different now. Like, I've got all the treatments behind me,' and he wants to live life more expansively." However, the patient's wife is "unwilling to accept that. Like she wants the old version of him back." Additionally, the patient's wife "wants them to tuck in as if they're in the, you know, a couple, that'll be around together when they're ninety." Because of her wish, the patient's wife is, in some ways, "preventing him from like, living as kind of expansively as I think he'll want to have lived if that cancer recurs."

Richard discussed this case in order to highlight the challenges he confronts with patients at end-of-life. In this case, he described how he can help patients discuss their deaths when they have no other space in their lives to do so, and that the people upon whom they might generally rely for support (such as a spouse) may not be willing to discuss the end of a relationship with someone who is dying.

In another case, Richard summarized a treatment spanning two years that he had started during his internship year and continued into the end of his postdoctoral fellowship year. In this treatment, he worked with a 62-year-old Caucasian, single female, who had pursued individual psychotherapy after she was diagnosed with ovarian cancer. When they first began working together, Richard said that the treatment team had perceived that this woman's cancer was "treatable." Over the two years of the treatment, however, the woman's prognosis worsened, and Richard said that he was actually "at her house the moment she died" (the reality of which, he added, "would never happen today.") He described the woman as "highly educated" with a "very big personality." She was estranged from her only sibling and had a good relationship with her one niece, but

he added that "everything about her [was] very thorny, like everywhere she went…she somehow managed to get into interpersonal tension." Richard and this patient identified that they had come from very different backgrounds; for example, Richard had been brought up Episcopal, and this woman had been raised Jewish and that parts of her Jewish identity had been "replaced" by his involvement in the "Landmark Forum." He added that their differences "really fascinated her" and that he had "been tested" by the patient in light of their differences. Because of their ability to work through the differences, Richard said that he "became one of the most important figures in her life very quickly." Towards the end of the two-year treatment, during which time, the patient "fought like hell," she had "an eleventh-hour sort of reconciliation with her estranged sister, and then she died."

When reflecting on his work with this patient, Richard said that "sort of having this experience with another human being, the word that I would use to describe it…I remember the word was…it was beautiful" and that "but for the fact that she died," the patient " would have shared the same sentiment." He added that "The whole thing graduated to a different plane of getting to witness somebody's life. She was just a fascinating human being. For all her decades on the planet, [she] had lived, with a capital 'L' in a million different ways. So, it was almost kind of a privilege."

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

Richard described the difficulties he perceives that psychologists face in providing psychological services in end-of-life care.

He noted that "many" of the patients he saw died while he was working with them as an intern and as a postdoctoral fellow. He said, "From the time of diagnosis to death is a very short window. So, we're only talking a matter of weeks or months." He added that "I don't think it was a question of them taking up the service late. I think it was them getting a diagnosis very late." As a result, he noted that one of the primary barriers to engaging with treatment was that many patients did not have a significant amount of time to engage with treatment and died.

He also described "the hardest" challenge as a "heartbreaking" difficulty, which he has confronted while working with patients that are not prepared or willing to discuss the prospect of death. He said that patients who avoid the reality that they may die could "rob" themselves of the ability to "do a lot of things" to prepare for the deaths. For patients who can discuss their deaths, he added that "No, it doesn't change the outcome. But it changes the way they die. It changes the person they leave behind."

Richard also noted that he has perceived that many patients and their families experience financial barriers to accessing psychological services. He said that, after an individual is diagnosed with cancer, they and their family members may pursue psychotherapy as a means of coping with the transition. However, he noted that "money becomes a big issue" when seeking psychological care for many patients.

Another barrier that Richard identified for many clinicians is that "they cannot get themselves out of the room." Specifically, he noted that clinicians who cannot individuate and distance from their patients' suffering "have more difficulty with this work." He summarized that some clinicians "can't help but be like, 'Yeah, but I think…' or 'I like…' Who gives a shit? That's not what we're doing here. We're doing *them*. So, I think you've

got to be able to get yourself entirely out of the room. *My* death, *my* mortality, is not relevant. That's not what we're doing. And I think the people who have more difficulty with this work cannot put that away. So, you've got to leave the room." He noted that "The role we have relative to these people is, you almost go into it boundaried. So, 'I'm going to miss you. I value greatly the time we spent together.' But it's not going to have a profound reverberation in your day-to-day life in the way it would if it were a loved one."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Richard also described the factors that he believes helped him provide care to patients as they die. In terms of individual factors, Richard noted that his "own therapy was a very big deal" in preparing him to work with death and dying on a regular basis. He also said that there are personal characteristics that he thinks make him well-suited to this field, such as the reality that thinking about death and dying does not make him "super anxious" and that he doesn't "have any problem talking about death, or someone's death or being there with them." He identified other characteristics that he thinks are helpful is a clinician's ability to compartmentalize, but did not provide additional detail.

Richard also identified systemic supports that have helped him in providing psychological services at end-of-life. He noted that "I think members of the treatment team could be bigger support than having understanding loved ones on this topic because they're in there with you." He said that the ability "to share [feelings] with other people…who get it, who are in the same space. I do think this is important."

Interdisciplinary Relationships

Richard described positive relationships with the other disciplines with whom he worked while he was on internship and during his postdoctoral fellowship training year.

He worked with oncologists, nurse practitioners, social workers, and psychiatrists and perceived that they had achieved optimal collaboration as a result of shared "beliefs in patient care, the belief of coming at it from every angle." He identified these shared beliefs as the product of a hospital-wide 'culture' of interdisciplinary respect.

Additionally, Richard noted that he could rely upon team members from other disciplines for emotional support as a result of a shared understanding of the challenges associated with their work.

Professional Meaning-Making in End-of-Life Care

Richard stated that he has been able to cultivate meaning for himself in his work with patients approaching death because he can be "in proximity to people doing *work*" as they approach end-of-life. He said that "when people get cancer, contrary to popular belief, they do not jump on a plane to Tahiti. They do not go live big. Nobody does." He described that

> as opposed to being like, 'I'm going to pack it all in and then it's going to slide, and then everything's going to go downhill.' Everyone's mentality is the opposite, which is, 'I'm going to fight like hell to get back to a good place.' Some people it works for. Many people, it does not. And so being able to…watch somebody fighting for something

has proven meaningful for Richard in his work.

Influence of Personal Experiences with Death

Richard said he had not had "any sort of significant losses" until about one year after his postdoctoral fellowship when his father died. Since then, both his mother and father have died. However, he felt that his own experiences with death had *not* influenced

his professional work while he was an intern and a postdoctoral fellow because he had

not experienced "significant" losses at that point in his professional development.

However, he did think that those losses impacted his *current* work as a

psychologist because, after the loss of his parents, he realized that he was "fine" and that

this experience highlighted for him that their death had been a normal "part of the human

experience." He concluded, "It's so sad, but tomorrow's gonna be a normal day for you."

Influence of Religious and Spiritual Beliefs

This topic was not discussed in this interview.

Ethical Considerations in End-of-Life Care

This topic was not discussed in this interview.

Changing Attitudes about Working with Death and Dying

Richard noted that he had grown more "sure" of himself in his work at end-of-life,

adding that he is better able to identify patterns in his work because of increased exposure

of the course of his career.

Professional Landscape for Psychology in End-of-Life Care

Richard stated that he was not familiar with any professional organizations for

psychologists practicing in end-of-life care. He also stated that he noted that he perceived

that "there weren't a lot of opportunities" for psychologists pursuing work in end-of-life

care or psycho-oncology settings.

Vision for the future of End-of-Life Care

Richard described his vision for the future of psychologists practicing in end-of-

life care. He noted that he has perceived that individuals and families experience a great

deal of stress following traumatic medical information or diagnoses and that they are

poorly equipped in those moments to find appropriate psychological care. Richard noted that a system that would increase access and to finding psychotherapists and clarifying the process of psychotherapy to patients could be helpful as they struggle to assimilate a tremendous amount of information about medical diagnoses and treatment.

He also noted that he believes that additional pragmatic training in issues specific to end-of-life care would be helpful for practitioners. He noted that because he has found most of his training in death and dying to be "theoretical," he said he thinks additional resources dedicated to the practical aspects of working with a dying patient would be helpful.

The Case of Rachel

Background Information

Rachel is a 38-year-old Caucasian female who has been a practicing licensed clinical psychologist for 4.5 years. She graduated with a Ph.D. degree in Clinical Psychology with a specialization in Neuropsychology. She completed her doctoral degree in 2011 and has been in clinical practice since 2012. She describes her religious background as a "fairly Protestant, Christian background." Additionally, she noted that while her "formal preparation" for psychotherapeutic intervention was "in the Neo-cognitive world" (including CBT, DBT, and ACT), she described that she is increasingly "drawn to more traditional psychodynamic" interventions. However, she added that she does not feel competent to practice in a psychodynamic framework.

Method of Recruitment

Rachel had been recruited to participate in this dissertation research after responding to a dissertation participation recruitment email posted on a professional

geropsychological organization's email listserv seeking interviews with psychologists practicing in end-of-life care.

Graduate and Post-Graduate Training in End-of-Life Care.

Rachel stated that she did not receive significant training in end-of-life care while she was in graduate school. In one of her graduate school seminars, Rachel noted that she remembers a professor discussing how clinical psychologists must "be comfortable with ambiguity and that the work – that nothing, or very little, was ever cut and dry, or black and white," and that "in our work with people and in our work with ourselves, ambiguity is more the rule rather than the exception." In this respect, Rachel described perceiving that her training prepared her, in some ways, "to be comfortable [with] *not* being an expert." She adds that neuropsychology and "many of the neo-cognitive therapies as well, really position the psychologist as an as an expert, as the doer for, or [adopt the approach] that they [i.e., psychologists] have something special or unique to offer that the client doesn't have." She finds this aspect of her training was not helpful or even appropriate in working with patients who are dying *or* healthy since she has perceived that individuals

> don't generally want a therapist or psychologist to come in and sit in a place of [an] expert, they want somebody who will *be* with them and maybe help provide more insight, or ask them questions that will help them see themselves and their situation differently. But they don't want a lecture, and they don't want somebody who's going to come in and *do* to them.

Rachel also described a training experience that she perceives had been helpful to her in her current work in end-of-life care. She said:

I had a very interesting rotation at a chronic pain clinic. And while that wasn't an assessment rotation, it was a general intervention rotation, [involving] psychoeducation [and] a couple of short-term therapy clients. That rotation introduced me really experientially to this idea of traveling with people, or walking alongside people on their journey, and maybe offering them tools as they want them.

In this role, Rachel described thinking that she could not "be in control," and that was she not "able to necessarily fix the problem." She added that "in the context of chronic pain, it's likely *not* going to go away, or else it wouldn't be chronic pain, right? So that was, in retrospect, helpful for the work that I do with clients at end-of-life, who often also have chronic pain, so there's good crossover there."

With respect to one of her most challenging cases (described in greater detail in Psychology at the End-of-Life, below), Rachel stated that she felt

profoundly unprepared for many things [both] from my own emotional reaction, learning about her death, [and] supporting colleagues who had been with her when she died. And then meeting with them and the broader nursing team, trying to help them make sense of a death like that. And the feelings of guilt, because none of them had liked her.

Professional Development

Rachel noted that she had been trained as a neuropsychologist and that she accepted the position she currently holds because, she said, "I was newly pregnant, my husband and I were living in a city we didn't like, my parents were living in [the rural location], they [the government organization] posted this job, [and] they said it needed a

neuropsychologist. I didn't ask very many questions at all. I would never have anticipated doing this work. So, this is really… I've kind of stumbled into it." She added that she applied for the job because the organization had "indicated that they wanted a neuropsychologist" for a new position, "and in retrospect, I'm not actually sure that they wanted a psychologist at all. I'm not sure they certainly needed a neuropsychologist or somebody with a neuropsych[ology] background, because that's part of what I do, but certainly not the biggest part of what I do." She added that she had *not* had any initial professional interest in end-of-life care when she accepted the position.

Professional Roles in End-of-Life Care

Rachel currently serves as a government-employed psychologist in a healthcare facility in a rural location outside of the United States in an area with a large indigenous population. Rachel says that most of her professional time is spent doing "a lot of coaching and consultation. I'd say fifty percent of my practice is supporting other professional caregivers; provid[ing] support to clients—often with a brain injury or dementia; or what we call 'response behaviors' within the context of a skilled nursing facility, so challenging or disruptive behavior." Consequently, "at least half of the actual day-to-day practice is working with nurses and other allied health clinicians to help them support clients with challenging behaviors-- with dementia, syndromes, and brain injuries."

Aside from these consultations, Rachel says that "the other part of what I do—the direct client work, I'd say maybe fifteen percent of it, fifteen to twenty percent, would be around assessment. Many of those referrals are around capacity and capability." She noted that her background in neuropsychology "does help inform those assessments. You

know, cognitive impairment isn't synonymous with capacity, but it can inform an opinion on that."

She noted that she perceives that the boundaries between consulting with other staff and intervening with her patients can be difficult to distinguish. For example, she said that, at times, "I'm not sure if the intervention is for the client or if it's for the staff so much." She clarified, "[If] the staff knows that Mrs. Smith is going to be seeing a psychologist, I think it alleviates their distress as much as the work that I do with this specific [patient]." This perception is based on her own feeling; as she says, she is only "measuring outcomes with my direct client. I'm not measuring the distress of the other professional caregivers, but my feeling is that when I do meet with clients for intervention work, that there's a broader effect. It's not just on the person I'm seeing, it's on a broader team, which is really interesting."

Referral Process

While Rachel did not specifically address where referrals to her service come from, she does mention that government policies and guidelines influence the referral process. She explained that since the government pays for her work, they have also "tried to control who I see. Because they don't want public referrals for a service that is not publicly funded. I'm not sure it makes sense myself; I just know my ability to see families for longer follow-up is limited."

Psychology at the End-of-Life

Rachel says that her professional practice intersects with end-of-life care in a variety of her roles. In the legal arena, she said that legislation dictating medical assistance at end-of-life requires her to conduct "capacity assessments to see whether

people are capable of consenting to that [decision]." Her role in end-of-life care also

comes up when Rachel is called upon to

> support caregivers around delirium and client behavior at end-of-life. I've done
>
> debriefing with staff after complex and difficult deaths. And certainly, [in] the
>
> work that I do with some of my clients, we talk about death every week, not in the
>
> context of suicidality, or even dysphoria or low mood… low mood certainly, but
>
> it's more around people who are struggling with feeling they have little value left
>
> and feeling trapped—[that] they can't die; their bodies won't let them die. They're
>
> not technically eligible for assisted suicide, so they're in this waiting period. It's
>
> very interesting work.

Rachel described three examples of individuals she has worked with and the

unique challenges she faced for each of them. She described the first individual she

worked with as an older adult man who

> lived a life according to his values. He was a loner. He lived off the grid as much
>
> as is possible anyways these days. He made a living somehow. He wasn't married,
>
> and he didn't have any social connections. He didn't have a primary care provider;
>
> he didn't seek medical attention. And then he got catastrophically ill and ended up
>
> being hospitalized for a year. Now, [he] has a condition where he will never live
>
> outside of a skilled nursing facility. His nursing care needs are hours and hours
>
> every day. This client will never be able to revert to the life that was meaningful
>
> to him, won't be able to live a happy, to you know, hunt, fish and do all the things
>
> he did to make his life worthwhile. Whereas [before] he wouldn't see a person

[except] once in a couple of weeks, now he's in this nursing facility and

surrounded by [all these people].

In this case, Rachel says that this man talked extensively "about suffering, with me, he

talks about it with everybody." Rachel finds this to be an example of the difficulty she

described regarding the inability to intervene in a concrete way. She elaborates, "What's

the intervention, other than to *be* with someone in their sorrow and suffering?" She says

that he talks about "how much [he] wish[es he] had died, [this] is the thing that [he

wants] most," because "the life that [he wants] to live is actually impossible now based

on [his] medical condition." She added:

> In this case, I can't bring myself to see this necessarily as pathology. Maybe a
>
> complicated bereavement of sorts would be best. But not an adjustment disorder,
>
> not one of the trauma syndromes, [because] it seems proportional to the degree of
>
> loss that this gentleman has experienced.

> She does not feel this was inappropriate for the situation, as "the role of many

things, especially nursing, is [that] we're here to help people… we're here to make them

feel better or wave our magic wands and make people happy."

> Rachel also said that this served an example of a boundary-crossing, adding

"that's an individual who I'm involved with to offer direct support as a therapist, but [I]

also provide support to his other care providers because there's rampant ethical distress

and distress around [him]."

> In another example that highlighted Rachel's role in end-of-life care, she

described working with an older adult indigenous male. She described him as being

"medically unwell" and "living [at] a skilled nursing service." She described a request that he had made of her:

> One of the very first things that this client asked me to do was to perform a ceremonial prayer for them when I left. So, he asked me to buy tobacco, take it to the river, and when I saw a crow, to make an offering to the Creator for him. Of course, I said yes. But how could, only—what would my graduate supervisors have said about that?

She goes on to say that she found a way to fulfill his request and described a feeling of uncertainty about her decision:

> Is that an intervention? Is going to the river and making a tobacco offering to the Creator that the client has asked you to do; is that an intervention? I didn't chart it. I didn't record that I had done [it]. I recorded the request. But I didn't record what I did. Maybe I should have. I don't know.

Rachel's final case example involves numerous professional roles and again highlights boundary crossings in end-of-life care. She describes the client as a woman, "one of those hateful patients. I would say somebody…who had… personality characteristics that made communal living and dependency on others highly difficult for everybody involved." Rachel was asked to "help the care team develop a behavior care plan for her," since the care team felt "that a consistent behavior care plan with appropriate boundaries might help manage the behavior, make the behavior more manageable to the staff." She then conducted a cognitive assessment because she had "picked up on some cognitive deficits that hadn't really been documented or identified

anywhere. So, [I] did a cognitive assessment. And that helped inform a behavioral care plan."

Rachel described this woman as socially isolation, noting that she had "nobody, she had no family. She had no, no family remaining. If she had living relatives, they were long since estranged. No friends; no social connections. She was totally alone in the world."

Rachel then described her final interaction with this client:

I forget what happened, but she declined fairly rapidly, and the team knew she was dying. They sent out a call for staff who wanted to come and vigil her. There's a death vigiling organization in my community where people will come and sit with people who are dying, so they don't have to die alone, but it was hard to find volunteer vigilers over Thanksgiving. I said that I would come, so for a couple of nights, I came in for one or two hours and sat with this woman while she was dying. That was a new, brand-new experience for me. It gave me a lot of time to reflect on what the hell was I doing?

And then, a couple of nights later, after my last vigil assignment, I came into work the next morning and was called to an urgent meeting with a colleague to ask if I could see the two nurses who had been on the night before [when] this woman had died. And she had died what was described as a very hard death. And the two nurses appeared to be in profound mental stress and crisis, and my colleagues within the organization, within the skilled nursing facility, wanted me to see them because they couldn't find them a crisis counselor, and they knew that I was familiar with the patient who had died.

Rachel went to meet with the two nurses and described this meeting as "a really good example of dual roles and multiple roles in a small town, a small organization." She clarified with the nurses that she was not their psychologist and that they weren't her patients, nor was she assessing or diagnosing. She does say that "they were both presenting with really marked symptoms of trauma, like vivid re-experiencing, intrusive thoughts, it was remarkable." She concluded that

> It turned out that this woman who had been dying… I think everybody anticipated she would just kind of fade away. Every sign was [that] death was quite near. And when she actually died, she hemorrhaged, and she hemorrhaged—what I understand is—from just about every orifice she had, I'm not quite sure what happened. And she started coughing at the end-of-life, there was pressure, she started bleeding everywhere, it went all over the staff, [and] the walls of the room, and it was all over her.

She perceives it had been a very hard death for the client, as well as for the caregivers. She also described what actions she took after the death (described in further detail in Interdisciplinary Relationships).

Rachel sums up her approach to her role as a therapist at the end of her patients' lives by saying

> I really do think shit happens as a part of the normal human experience, and there will be tragedy, and there will be grief and sorrow and anger; all of that stuff comes up around end-of-life. It [presents] a good question, what do we offer in an intervention? Is there a formal intervention to offer? In my thinking, like I said, I've landed more on often the relationship itself as the intervention, and being the

person that our client will talk to about anything in confidence to work out their own reasoning and feelings, and express their desires and fears, and not have to worry about my reaction, or whether I'll try and encourage them to take one path or the other, or whether I'll leave them and I won't come back. That's how I see some of the work that I do around this.

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

Rachel described that the primary barriers she encounters providing psychological services in end-of-life care are "the psychological barriers themselves" with confronting the prospect of death. She explained that while many of the clients she has worked with want to discuss death, "I think there are probably just as many who are at the end-of-life, or who are actively dying, who cannot stand, for whatever reason, cannot admit that to themselves." She said that sometimes patients decline meeting with her, which she perceives as a "psychological barrier." Rachel also stated:

I have seen where nursing teams become very, very close. And we have favorite patients or favorite clients, and so nursing teams might become really attached to a particular patient. I've wondered if that attachment becomes a barrier. Because the team or the nurse making the referral (or the primary care provider) would have to acknowledge to themselves that the client was preparing to die and acknowledge that anticipatory grief. A lot of people aren't comfortable—they can't sit with those emotions in a way that's tolerable. So, they spend a lot of time and effort trying not to feel.

Rachel also mentioned that the country in which she works passed legislation that allows people to request physician-assisted suicide if certain criteria are met, one of which is that the individual must be "capable," which she says "automatically makes people living with a major neurocognitive disorder ineligible." She is occasionally involved in that assessment, which can bring her and her client in conflict with family members. She said:

> One of the folks that I have seen is a long-term client. I've been seeing her weekly, maybe biweekly for about two-and-a-half years now. When I first started seeing her, she requested to be assessed [for physician-assisted suicide], and then her family found out, and that request got walked back so lickety-split. It's been interesting to see the effects of relationships and family and the influence that survivors, in this case, this person's adult children, really quickly. I don't know if they changed her mind or if their reaction was just so significant and shocked and angry and sad that she brought that back right away, but she hasn't asked again.

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Rachel says the primary factor that promotes the work she does in end-of-life care is that she is employed by a government agency and can see her patients regardless of their ability to pay for her services. As a consequence, she said that "the people I see don't have to pay to see me. Even if I could refer to another clinician, paying $150 an hour would prohibit that interaction for many people. Instead, Rachel said that her salary is "entirely paid for by the government, so I do no billing. So that, I think, helps. Money is not a barrier to referring people to my service, but it is a barrier to referring elsewhere."

Interdisciplinary Relationships

Rachel described her interactions and relationships with other disciplines as contingent upon the individual with whom she works, regardless of their professional background. She stated that "I have found that it really comes down to the individual in the role." Her observation is that those with less training may experience greater difficulty perceiving or attending to the needs of psychologists and medical professionals, and they are sometimes "perhaps a little bit more reactive [with patients]." When working with multidisciplinary teams, she says that she finds herself "relating to the people who are in those roles rather than the roles themselves." She added, "Some people really facilitate a collaborative relationship and are interested in hearing case conceptualization and engaging in behavior care planning, and some people are decidedly not." The variability in reactions to her work means that interdisciplinary relations are constantly changing and that "they [certain professionals] could be in the same role and on twelve-hour opposite shifts. So, it depends… I never know who's going to be there and what it's going to look like."

Rachel does find that even when working with treatment providers with more training, "there is variance." She said that she perceives that others may perceive her role as, "What can this colleague [i.e., Rachel] do to help me support this patient?" She says that this type of pragmatism does not suit her objectives all of the time.

> Some people are very functional. They want to know, 'What can you do to make
> my shift easier?' And if the answer is actually, 'Well, what I need to do is even
> more behavioral charting for a few days, so we can really trace and understand
> this behavior and its context,' [then] they don't want me to come back. Those

conversations tend to be over the short term. Can you make my day better *today*? [If] I promise in two weeks it will get better, sometimes it doesn't work.

Rachel also descried how her work occasionally requires her to step out of a formal professional role. One such instance was in reaction to the case she had detailed of the patient who had experienced a particularly traumatic death (see Psychology at the End-of-Life), and where the nurses who had been with the patient at the time of death were especially traumatized by the event. She said:

I ended up writing a letter for these two nurses, being really clear and saying that I'm not their psychologist, and I didn't formally assess them, but I want to describe to you the behaviors that I saw from them. It was like I navigated multiple roles and multiple clients, even though the staff members weren't clients of mine.

Professional Meaning-Making in End-of-Life Care

Rachel says she makes meaning of her work in several ways. The first is a meaning she makes with others in what she describes as "fitting one's current experience into the story that one tells themselves about themselves." She thinks of this as more than integration into a life narrative, saying that if she can accomplish this for those she works with, it can "ground that experience" for them.

She considers a second form of meaning-making to be the attempt at "fit[ting] current experience—and again, not just the patient's experience necessarily, but a professional caregivers' experience caring for the patient—if somebody can fit their current experience against the context of their values or moral framework I think those would be the two ways that I see people making meaning around me. Making meaning is

like, how do I make sense of this thing that is happening to me or this thing that I am doing? If it's a caregiver, we're often doing with – or for – clients or patients."

She continues to clarify what an attempt at making meaning through values might look like, and how it may not always be effective in the way she imagines.

C.S. Lewis wrote, and I thought about this a lot, that suffering is kind of like the refiner's fire. Suffering is a way that the Creator, or the deity, shapes a person to be what the deity wants them to be, or brings them closer to the Creator. And sometimes I floated that idea with other Christian patients as a thought balloon, just to see. I'll put it out there and see what they think about it. I don't think I've had a single person say, 'Oh, yeah, absolutely right. This stuff, this thing that I'm currently experiencing is, great. Yep, that makes sense.' It has never worked.

But like for nurses, for example, or other allied health professionals, if they're providing care at the end-of-life for a patient who is still evidencing, let's say, some really challenging behaviors, like every time I go in to see, Mr. Smith he tells me to fuck off and die, and he spits me in the face, but I still have to provide care, right? And I still have to change him, and I still have to make sure, I have to check his vitals you know, like, the work of nursing has to be done, but the patient's behaviors might be really difficult. If that staff member, if that nurse can take that experience and tell themselves about themselves. I'm the type of person who can provide compassion even when somebody's being mean to me, even when a patient is spitting at me. I'm that kind of nurse. Like, that's a type of meaning-making. Like making sense of what's happening and telling it to yourself.

Rachel also discussed personal meaning-making, saying she feels like she makes meaning of her work for *herself* "all the time." She referenced the case she had described of the indigenous man who is unable to live life according to his values (see <u>Psychology at End-of-Life</u>, above) and says that when she thinks of such an individual who "will never again be able to live the type of life that provides meaning [and] value to him," she considers the meaning-making a critical part of the work she does. She explained:

> I don't think I can necessarily help him, but I can help his caregivers understand him better, and maybe cope with their own distress better. So, if I can create meaning for myself, that I can help. I can't fix things. I don't have a magic wand. I can't make things better. But I can help people through some really challenging times. That meaning is important to me; that's part of why I do what I do.

Rachel says that this meaning-making part of her work does not happen as an explicit process. Instead, she finds "that those types of realizations, or that insight, or that reflection, happens when I'm not intending to reflect." She does not think of particular settings as triggering these realizations either, rather that they can happen anywhere or at any time. She said:

> It will happen when I'm driving home from work, or [when] I was riding up in the elevator today. I was like, 'Aha! I never thought about that.' It just came to my mind. So, when I'm out running, and I'm listening to music, or when I'm actively not thinking about my experience, then I feel like I get these moments of insight that help me understand the work that I'm doing for myself.

Rachael finds that this spontaneity helps, rather than hinders, her work. She acknowledges that some people can compartmentalize their work and only think about it "in a much more well-defined way," but she claims, "I can't do that." She concluded:

> I wonder, and maybe I'm just saying this to make myself feel better about myself, if I didn't ask these questions, I don't think I could be who I am with my clients, or that I could be walking alongside them in their path and hearing them, or being fully present with them in our sessions if I then just put it away in a box for the next week.

Influence of Personal Experiences with Death

Rachel did not describe any personal experiences with death that influence the ways she works. She says that she did not have any particular trauma that comes to mind, noting that she had "a regularly messed up but relatively stable childhood." She says that her grandparents both died at an "appropriate age" and the only other close encounter she recalls was when "a friend's sister committed suicide when she [the friend] was fifteen." She does draw slightly upon the dynamic concepts she alluded to earlier, saying, "I'm not aware of it [the influence of these events on her life or work], but I can't see how it wouldn't [do so]. I think that [in] this work, there's probably countertransference that I'm not even aware of, especially because most of my work is with older adults, but it's not at a level I can name."

Influence of Religious and Spiritual Beliefs

Rachel noted that she perceives that the work she does has caused her to "not struggle [with], but question, my own faith experience. As somebody who wishes she had

more faith than she does." She elaborated upon the tension between her religious upbringing and her experiences at work:

> Let's assume for a moment we have a loving and kind Creator. And there is some kind of rational narrative arc to this human experience. I don't know how to make sense of though—how to reconcile those beliefs with the suffering and psychological suffering, and [the] end-of-life legacy. The people wanting to die who haven't died yet, who seem to be in this waiting period. Yeah, it's, it's tricky.
>
> I've talked to another colleague, a friend who is a recreational therapist, and I chatted about it with her once, and she said… 'God has a plan; you just have to trust it.' And I don't know what your faith beliefs are, but I think that's bullshit. That just doesn't… if God's plan is to have people suffering, I don't know how to… So, the work has led me to questions like that.

Rachel said that she also tries to promote discussion about faith her patients "if they have it" and that, "often, they don't," and that it helps "sometimes… and sometimes it doesn't." She said that she was once asked to secretly arrange for a client to meet with a minister (a meeting she had suggested) because "he [the client] didn't want anybody else in the skilled nursing home to know." In that context, she does remember religion coming up (although she was not present for that meeting) even though she finds the more common scenario to be that her clients are largely secular. She also notes that "when I do go to church, I will often find myself praying for clients. And I don't remember necessarily doing that when I had an assessment-based practice."

Ethical Considerations in End-of-Life Care

Rachel described ethical considerations in her work with indigenous patients, noting that some have occasionally requested she engage with nontraditional interventions (see the case of an older adult indigenous man in Psychology at End-of-Life, above). This is particularly relevant to her practice since she deals with many indigenous clients, who have particular cultural rituals associated with death and dying.

Rachel also described ethical questions about prayer, noting, "Is it is a boundary violation to pray for somebody? What does the code of ethics—I don't know if the APA code of ethics specifically mentions prayer anywhere; it doesn't."

Finally, Rachel described ethical considerations that arise in rural treatment settings such as hers. She questioned if it is "better to have somebody who might have some competence and some skills, but certainly not all of the skills, or is it better to have nobody?" Her assertion that her limited interventions are better than none is what helps her to resolve some of the issues she encounters that are not specifically accounted for in standard ethical codes. She said:

> That's kind of how I've tried to make sense of doing these things that feel uncomfortable to me, like making the tobacco offering. There's this tension between doing that and what a psychologist should do, in my mind, and I still think in most situations having somebody—who has some skill, and who can be fully present, and [is] just actively try[ing] not to do harm—can be better than nobody.

Rachel gives an example of the risk involved in her decision with the case of an indigenous client for whom she made what she thought had been

a very standard, evidence-supported suggestion and the family of the client was

horrified and deeply hurt. Because the suggestion I had made—and that the team,

on good faith, started to implement—was deeply culturally inappropriate. And it

was one of those dangerous things, [where] I didn't know that I didn't know it, the

unknown unknowns. I just hope that I don't make mistakes like that, where my

learning has to come at the hurt and expense of other people or their families.

Changing Attitudes about Working with Death and Dying

Rachel does not feel that there have been paradigm shifts yet in the way that

people view death and dying and end-of-life care, but she concedes that it is probably just

"too early" to notice them. She does expect a cultural shift to come, and says, "I think if I

was in a larger jurisdiction where it happened even more frequently, I might have already

started to notice it a shift in culture." She mentions that with respect to people choosing to

die in a way that comports with their values, decisions are still made with secrecy, and

more than is due just to confidentiality. She gets the impression "that there's some stigma

around it [physician-assisted suicide], around accessing it and talking about it, from other

professional caregivers, as well." Despite her country having legislation that makes these

choices legal for her clients, she finds nurses, health care aides, or other professionals

don't always think it is "proper or appropriate" for "people [to] bring their own value

systems to it. Even though they might not be able to stop Mr. Smith [a pseudonym] from

accessing it, they can't not disapprove. I'm not saying people are unprofessional, but I still

very much feel a tone in those discussions."

Additionally, Rachel identified the ways in which she perceives that psychologists

can increasingly fill an additional spiritual role that parallels the roles of religious leaders

in the past. She stated, "There is the space where *we* are care providers. We have power over - in a way - the clients we see, but the things they tell us are, you know, they are akin to us as what would have been shared in a confessional hundreds of years ago."

Professional Landscape for Psychology in End-of-Life Care

This topic was not discussed in this interview.

Vision for the future of End-of-Life Care

This topic was not discussed in this interview.

The Case of Joyce

Background Information

Joyce is a 64-year-old Caucasian female who has been a practicing licensed clinical psychologist for 36 years. She graduated with a Ph.D. degree in Clinical Psychology and has remained in clinical practice since she completed her doctoral degree in 1983, except for one year, during which time she said she took "a year off in the middle." She describes her religious background as Jewish. She also identified that while she initially used "psychodynamic and outgrowths of that theoretical basis" in her psychotherapeutic work, she currently employs "a great many practical and theoretical orientation styles."

Method of Recruitment

Joyce was recruited to participate in this dissertation research through referrals of the principal investigator's professional contacts. Before the principal investigator and Joyce made contact, Joyce was provided with the study's email advertisement seeking interviews with psychologists practicing in end-of-life care by a mutual professional contact.

Graduate and Post-Graduate Training in End-of-Life Care

Joyce noted that she had "pretty much zero" training in issues that come up at end-of-life during her graduate training. She said that "unless we had a client who experienced loss, maybe grief...I would say grief counseling was addressed." However, she added that "end-of-life care, I have no memory of that being addressed at all."

As her children left for college, Joyce stated that she "wanted a new adventure" and joined a friend in a six-week training to become a hospice volunteer, after which she decided to continue her volunteer work for one year. She then pursued training in Clinical Pastoral Education (CPE), which led her to continue cultivating her skills and interest in end-of-life care (see Professional Development for more information, below).

Joyce said she first started getting training in end-of-life care when she pursued chaplaincy training, which she said was the "most helpful." The "second most helpful" training that she pursued was a training workshop called "Practical Aspects of Palliative Care," which she described as "mind-blowing." The "third" most valuable training that Joyce described was an ethics training provided through a major academic medical center, wherein she learned about medical ethics. She said that the "Practical Aspects of Palliative Care" training and the medical ethics training "totally launched" her professional development and skills in palliative care.

Professional Development

Joyce described the factors that led her to pursue a professional role in end-of-life care. For about 18 years after she completed her graduate training, Joyce worked as a child psychologist in outpatient clinics, in her own independent outpatient practice, and as a consultant to private schools. During this time, she described having a clinical focus

working with adolescent girls and their families. She said that she remained in those

settings because they provided flexibility and she could adapt her schedule and the

intensity of her work based on her family needs when her children were living at

home. As her children were going to college, Joyce stated that she "wanted a new

adventure," but she was not sure what she wanted to do. At that point, she decided to

close her independent practice and took a year off from work to consider her next career

move. During that year, a friend of Joyce's asked her to join him in getting training

to become a hospice volunteer. At the time, she said her first response was, "Oh, no, that's

totally creepy. I don't want it." However, she ultimately agreed to have one meeting with

the volunteer coordinator, after which she said she "was hooked." She ultimately agreed

to pursue the six-week hospice volunteer training and then volunteered for one year in

hospice settings. She said that "really liked" the experience. At the same time, she said

she was very involved with her religious community and cultivating her religious identity

and felt impelled to "bring the spiritual aspects of care more centrally into the work that

[she] was doing." Joyce's experiences as a hospice volunteer, and her interest

in bringing spirituality into the work she was doing sparked her interest in pursuing

chaplaincy training. When she articulated her wish to become a chaplain, Joyce said she

faced repeated attempts to discourage her from pursuing chaplaincy and that others would

tell her, "Don't even think about being a chaplain. You can't be a chaplain unless you're a

rabbi." However, she met the head rabbi for the geriatric care organization at which she

currently works, and the rabbi encouraged Joyce to pursue chaplaincy training while

working with her. So, she decided to train at a local academic medical center in

Clinical Pastoral Education (which is chaplaincy training that every priest, minister, and

rabbi must obtain to receive ordination as a clergyperson). She said that the training

involved learning "how to do counseling in the hospitals for people who are sick and

people who are dying" and included coursework and supervision. She said that her

chaplaincy training was "amazing. It was life-altering for me, in part because of the

personal journey that it takes you on, a personal journey really about what is suffering,

what do you believe about God, what do you believe about death, what are some of the

ways that you can talk to a patient about death or pain or saying goodbye?" She added

that the chaplaincy training also helped her to "find language and also to explore my own

personal feelings and experience and history and culture around death and dying and

God's stuff related to physical suffering and emotional suffering." As a result of her CPE

training, Joyce said she "had much more skill and language around really being present

and available in a more clinical way to patients at the end-of-life." As she completed her

CPE coursework, Joyce started an internship at the geriatric care organization at which

she currently works. She volunteered there for one year as a chaplain, and she was then

hired part-time (12 hours a week) as a chaplain at a post-acute setting at the geriatric care

organization. In the post-acute setting, she saw patients who were "very sick" and had

been discharged from the hospital to this sub-acute care setting for short-term

rehabilitation. She said that many of the patients in this setting were dying and either did

not know they were dying or had not "really dealt with it yet." This experience

further promoted Joyce's interest in end-of-life care. While she was working there, the

chief of medicine at the organization, who was also interested in end-of-life care, hired a

palliative care physician. Then, Joyce and the palliative care physician met and "patched

together a team of people interested in end-of-life care, focusing on end-of-life care." She

said that she and the physician were able to find a donor to fund the initial creation

of the palliative care service, and she became the director of the palliative care program at

the geriatric care organization. She noted that the physician with whom she partnered "is

a brilliant but very quiet, unassuming" man "who wanted to focus on the medicine" while

she identifies as an organizer "and making things happen." Therefore, she said she "took

this [project] in hand and grew this program." She said, "I made presentations to the

board, I found money through development, I schmoozed every leadership person in the

organization, I went to – I did some training myself, short conferences, three-day, end-of-

life care training…." As the program developed, she said that she and the physician "put

together a team for palliative care, an interdisciplinary team, and I learned as I went, I

went to conferences I read, and we all did some training together." She also said she went

to a conference to learn how to start a palliative care program. She said, "I was on my

own to learn this stuff. But it was a growing field nationally, so there was a lot. I was able

to attend conferences and lectures and workshops. There was so much stuff going on, that

it was not hard for me to galvanize interest in my leadership and also find places to

continue to learn myself."

Professional Roles in End-of-Life Care

Joyce stated that she identifies as "a chaplain, a psychologist, and the director of

palliative care" at a large geriatric care organization in a major northeastern city. In her

organization, she provides consultation to two continuing care communities, which

includes "independent living, assisted living, long-term care, post-acute care, dementia

care, [and] end-of-life care." She said that her facility has "about 500 patients in it, 400 of

which are long-term care patients. And these are patients who come, usually in the last

year or two of life. They need a lot of care; they can't stay at home anymore. They're sick

with multiple comorbidities, and they're going to die with us." She said that "it's like a

nursing home except we are a chronic care hospital because we have physicians and

specialists."

In her professional role as director of palliative care, she oversees a

multidisciplinary team that includes a psychologist (herself), a physician, a nurse

practitioner, a social worker, a rabbi, and a nurse's aide. She noted that her team acts as "a

roving support team for every unit in the place."

Joyce identified two goals for her team. First, she said that the palliative care

service provides support to patients and families who are struggling with symptoms of

medical illnesses that affect their quality of life, such as "pain, dyspnea, nausea, [and] any

kind of discomfort." Second, her team provides support to patients around their "goals of

care." She defined "goals of care" as the patient's goals for treatment, including those

things that are most important to the patient, including their values, and then developing

a treatment plan that aligns with the patient's values.

As a part of her professional role, Joyce stated that she is called upon by

professional staff to consult to family members "to help them understand that their family

member is dying. Maybe not tomorrow but within the next three to six months or

whatever it is" and Joyce said that part of her work includes "help[ing] them think about

what's important to them during that time so that we can promote their value and help

them imagine" the best possible outcome for their family members.

She also said that there are instances in which family members "get stressed and

distressed and they start yelling at staff, or they yell at each other, or they make poor

decisions on their loved one's behalf" which she perceives is a result of "anticipatory

loss [which] makes a lot of people do strange things." She added that she uses her skills

as a psychologist to assess for extreme distress and trauma in family members, noting

that "a lot of families have been traumatized… by emergency room procedures that were

done to their loved one. And if you've ever been present at a moment where somebody

was being coded or intubated or having a heart attack or anything, it's really stressful on

the families. And it's life and death. It's tubes and things being shoved, and machinery

going into their loved one[s], and it's very chaotic and very stressful." After these

traumatic events, she said that family members are still asked to make decisions about the

care that they want for their loved ones, and so she can help to assess their functioning

and decision-making capacity during stressful times. Similarly, she described "a lot of

times, sometimes the senior, the patient, has not expressed clearly what their wishes

would be so the family is left to guess whether to intubate or not, they're left to guess

whether to put a feeding tube or not." In both of these scenarios, Joyce is called upon to

help de-escalate family members and help clarify values and goals for care to achieve

optimal outcomes.

She said that medical staff regularly request her consultation "in a lot of times for

very crazy behavior, and we have a lot of these crazy behaviors." She said that this

happens most frequently "when family members get worried that they're going to lose

their loved one." When family members demonstrate these behaviors, she said that staff

call upon her service. For example, she said that staff have said to her, "'You've got to

come work with these two daughters because they're driving the staff completely crazy.'

And then I will come in and my 30 years of clinical skills as a psychologist serve me very

well because I am coming to these two daughters to listen to them talk about their mother who's had a stroke, what they're hoping for, and I'm assessing whether I can help them to get accustomed to the idea of losing her, whether I can help them to understand more realistically what their mom is going to be able to do and not do as she recovers from this stroke, because it's been a severe stroke and it's already been eight months, which means the prognosis is very poor." She said that she always approaches these situations with "a very optimistic approach, saying, I'm going to assume that the terrible behavior of this daughter or these daughters is because they're in a lot of distress. And then once we provide good counseling and support to them, they're going to settle down and de-escalate. So, I always start there, and that is true a lot of the time."

Joyce also said that she perceives that "A lot of families have been traumatized - and I think that is something that's underreported nationally - traumatized by emergency room procedures that were done to their loved one." She added that "If you've ever been present at a moment where somebody was being coded or intubated or having a heart attack or anything, it's really stressful on the families. And it's life and death; it's tubes and things being shoved, and machinery going into their loved one, and it's very chaotic and very stressful. And they often come to us having been traumatized. And then they're still having to make decisions, visit their loved one, worrying about losing them. So, it's really [that] they're exhausted and stressed out." As a result of the trauma that she perceives that patients' families have undergone, Joyce added that she is also "assessing" and "trying to help understand where they're at" so that she can support decision-making processes in light of the trauma that family members may have experienced.

As part of her professional role in end-of-life care, Joyce also provides consultation to other disciplines when they are experiencing difficulties with patients or family members confronting issues related to end-of-life care. For example, she said that she provides "consultation to the staff about how to help set limits… about a particular patient who is crazy and needy and always rings the call bell 40 times a day rather than the usual seven times a day." She provides behavioral recommendations to staff about how to manage difficult patients and said that "a lot of these skills have to do with my clinical training as a psychologist."

Joyce also described providing training aimed at educating staff members about the nature of palliative care, information about the palliative care service at her organization and how to engage with it, and promoting "palliative care skills" that organizational staff can use in their interventions with patients.

Joyce also said that she helps to publish and create policies that affect end-of-life care. For example, she described that she and her team "create policy for the organization; we write policy for the organization related to end-of-life care." She said that she has also published, which can have affect policies related to end-of-life care at the organizational, local, and national level[s]."

In describing her professional role, Joyce said that she conceptualized herself as a consultant to the "concentric circle" of levels of care. Joyce details her perception of the "concentric circle," stating that "you've got patient, and then around that is the family, around that is the staff who are working with that patient: the doctor the physical therapist, the social worker, the little cluster of staff working with her. Then there's also the organization. So, we create policy for the organization; we write policy for the

organization related to end-of-life care. And it's not only the organization. Sometimes we *publish*, so we'll have an effect on [the city] or national policy around end-of-life care."

Notably, Joyce stated that she would be unable to function in her various professional roles as a clinical psychologist, exclusively. She described that, despite her clinical psychology training, she was hired at the hospital as a *chaplain*. Joyce noted that she could advocate for this position at the expense of her salary so that she could have more flexibility in devoting time to program development and would not feel burdened by meeting billable hours goals in the ways she perceives that many clinical psychologists do.

Referral Process

Joyce said that she and her palliative care consultation service gets "between maybe three and six new consult requests a day" from staff throughout the facility in which she works in order to help patients and family members understand prognoses, and what choices are available to them while patients prepare for the prospect of death and dying.

Psychology at the End-of-Life

Joyce described four cases of patients for whom she provided psychological services at the end-of-life as a demonstration of the ways in which she adds value to end-of-life care as a psychologist. In each case, she described how her role as a psychologist helped promote and clarify goals of care with patients and staff.

Joyce described currently working with the two adult sons of a 90-year-old male patient that resides at the geriatric care facility. She stated that the two sons "are driving this dad nuts. They're there all day long; they want to get him out of bed." She

said that these two adult sons want their father to be physically active and want staff

to stop administering pain medication so that he won't be sedated and will be able to

move. However, Joyce said that the patient is "suffering" and said that "he doesn't want to

get out of bed." She added that staff in the facility had requested her consultation because

they experienced difficulty managing their reactions to the two sons' assertions that they

should be ensuring their father "moves" and refuse pain management medications. Joyce

said that she arranged to meet with one of the two sons, and in her conversations with

him, she learned that the son had experienced a great deal of anger towards his

father and that it was clear that this adult son wanted "good parenting from this

father." Most notably, Joyce discovered that he doesn't want to "allow" his father to die

"before he says he's sorry, recognizes what he's done, and provides some good caring, 'I

love you' fathering." However, she said that she is aware that the 90-year-old patient "is

never going to do it" but that "the son doesn't know that, and the son can't let go." As a

result, the adult son is insisting that his father 'remain alive' by engaging in physical

activity and ensuring he's not sedated. She said that she doesn't know if she will be able

to help the son achieve acceptance of the fact that his father will never apologize since

this is "a lifelong family dynamic." She said, "For some families, I can help them get

there. For some, I can't." However, Joyce added that she has come to realize that "death

presents a very high drama scenario for certain families because it means that patient will

never say 'I'm sorry' or never be able to be a good" parent.

In another case, Joyce described working with an older adult woman who had

been struggling with the decision to engage with dialysis or not, since the patient had

been determined not to engage with life-prolonging treatments. One day, this patient went

into acute renal failure very unexpectedly, and Joyce received an urgent request to come to her unit immediately. When Joyce arrived, she said that she observed that the patient was in visible distress while interacting with her physician and medical team, who "love her." Joyce said that the medical team had been urging the patient to go on dialysis to prolong her life, but the patient seemed uneasy about the decision. Joyce said that she and the palliative care physician with whom she works then approached the patient and had a conversation with the patient, providing information about the reality that "she would die probably within the week if she doesn't go to dialysis," trying to understand the patient's wish to avoid life-prolonging treatments and help her clarify her goals for care. During the conversation, Joyce learned that the patient wanted to remain alive for the anticipated birth of her great-granddaughter. About one or two days after the conversation in which Joyce and the palliative care physician helped the patient understand her options and goals for end-of-life care, the patient made the decision to engage with dialysis. The patient remained alive for an additional two years on dialysis. Joyce said that while "it was time-consuming and everything... she [the patient] was glad for it" and "got to see this grandbaby being born, and [spend] more time with her son." After those two years, the patient developed pneumonia and had been hospitalized a "couple of times" and "got really sick." At that point, Joyce met with the patient, who articulated to Joyce that she was prepared to die and was no longer interested in engaging with life-prolonging interventions. The patient requested Joyce's help in discussing her wishes for end-of-life care to her family, noting that she did not know what or how to say that she was looking to terminate the use of additional medical interventions. Joyce said that she was then able to help facilitate a conversation between the patient, the patient's son, and the patient's

granddaughter, wherein she was able to articulate her wishes to engage with "comfort measures." She said that this was "a long, emotional, laborious process," during which time she also "provided a lot of support to her son individually on the side." At the end of these discussions, the patient was able to engage with comfort measures successfully and died at the facility. Joyce perceived that this case "went really well" because she felt that the patient was able to make her own decisions about her end-of-life care, which she said is "ideal."

Joyce also described how she is able to provide consultation with other staff in order to help them work more effectively with patients. For example, she described the interventions she used with a patient with whom staff reported experiencing difficulty and who they perceived as "driving everybody crazy" and "unbelievably rude." Joyce said that the patient demonstrates unrealistic thoughts about her current levels of illness and perceives that she is fit to return to her home. While the patient refuses to engage in individual psychotherapy, Joyce was able to use her skills as a clinical psychologist to engage the patient in a conversation in order to understand the patient's current experience and family dynamics. Joyce said that the patient articulated that "her daughter's husband just had brain surgery, her daughter is not available to really be there for her and help her figure out her next move and she's mad and upset about it." Joyce said that she and the patient "were able to get to a place where [the patient] could elaborate on the family dynamic" and that she could determine that the patient was feeling "agitated and frightened and angry." After this conversation, Joyce was able to "go to the physical therapist, occupational therapist, social worker, and case manager and say, 'This is what's going on with [the patient], this is the story she told me, this is

why she's so cranky and nasty all the time. This is why she's refusing therapy.' And so

there, that will inform how they approach her, how they work with her."

Finally, Joyce described another incident in which she was able to speak with

family members of patients in order to understand their reactions to staff and help them to

de-escalate when they are experiencing distress and demonstrating "bizarre

behavior." When she witnesses "bizarre" behaviors, Joyce said that she attempts to ask

herself, "Okay, what's going on here? What's underneath this? What's the

story?" There's got to be a backstory." For example, Joyce said that she had been paged

to the Medical Acute Care Unit (MACU) along with the facility's security team in order

to help de-escalate the daughter of a patient who had been yelling uncontrollably at staff.

When Joyce got to the MACU, the patient's daughter was "red in the face and

vibrating." When Joyce approached the patient's daughter, she said: "Okay, tell me what's

going on." At that point, the patient's daughter articulated her dissatisfaction with the

nursing staff. Joyce responded, "Well, my understanding is you were taking care of your

mom at home the last five years…you were doing it differently?" The patient's

daughter said, "Yeah, I was doing–." Joyce immediately intervened at that point and said,

"Wow, I can't believe you took care of her by yourself." After that, the patient's daughter

began to sob and said, "Oh my God, it was so hard. But now I can't give it up. You know,

I don't want her in an old age home. She has to be home with me." Joyce said that she had

then been able to segue into understanding the patient's daughter's "emotional story" and

could then provide empathy. She added that the "woman de-escalated within 15 minutes.

And she was fine. I mean, we were best buddies by the end of that session." The patient's

daughter "allowed her brother to make good decisions, send this mom to a nursing home.

And she wasn't that crazy. She was just ill-equipped, very sort of primitive, not so bright, and very well-meaning and loving woman, who just was ill-equipped to deal with this emotional situation." When reflecting on that incident, Joyce said, "You know, a lot of smart people were in that room, but they didn't know what to do with her. I knew what to do with her because I bring those skills. So, a psychologist is good to have around."

Supervision and Training in End-of-Life Care

This topic was not discussed in this interview.

Barriers to the Delivery of Psychological Services in End-of-Life Care

Joyce described the barriers that she perceives in providing psychological services to patients in end-of-life care. Specifically, she discussed major barriers to the provision of psychological services by clinical psychologists, including difficulties with lack of training, difficulties with insurance reimbursement, hospital-based and national policies that provide guidance on hospice and palliative care teams, and difficulties with practicing in independent practice. Notably, she said that she thinks that these barriers are far more salient barriers for psychologists to provide care at end-of-life than "whether psychologists are equipped or interested in end-of-life care."

One of the primary barriers that Joyce perceives in delivering care as a psychologist is that graduate programs do not provide adequate training in end-of-life care and so students do not get sufficient training from the start of their careers. For psychologists who are interested in end-of-life care, Joyce said that "you have to sort of figure it out on your own if you're interested in end-of-life care. There's a lot out there, but you've got to look it up and go get it. You can't just get into a program. You've got to go get little pieces here and there. It's available, it's there, but nobody's going to come to

you. It's not in graduate programs. Even in medical school, I mean, there's more than there used to be, but physicians aren't good at this."

A major barrier that Joyce experienced when she first developed the palliative care service was that she had been experiencing pressure to practice as a clinical psychologist as a result of insurance reimbursement. She explained the rationale for the pressure she received from hospital administration, noting that "because as a psychologist, I could bill for my time, and I would not be such an expensive investment." However, she said that if she had practiced and billed as a clinical psychologist, she "would be held accountable for doing testing if needed" and she "would have to bill for every single minute of [her] time" and that she would experience "a tremendous amount of pressure to fit in [as] a billable medical professional." Because of the expense of hiring clinical psychologists, and the need to code each of her hours at the hospital as "billable," she thinks that she would not have been able to apply her expertise as effectively as director of the palliative care service because she would be concerned with meeting billable hour quotas. She is currently compensated as a chaplain, and not as a psychologist since hospital administration allowed her to stay on as a chaplain and her salary "was considerably less." She noted that she "ended up with…two thirds, in the beginning, maybe even half of the salary that a psychologist would have had." She added that because of this major barrier to providing services in end-of-life care as a psychologist that individuals must be creative, and that "if you want to get a job in palliative care as a psychologist, you have to wiggle your way in somewhere."

Joyce also described additional systemic barriers that inhibit psychologists' abilities to function on palliative care teams. For example, she stated that the guidelines

developed by The Hospice and Palliative Care Organization of the United States, which

dictates the core members of a hospice team does not include a clinical psychologist. She

said, "There's a chaplain and a social worker, a nurse, a nurse's aide, and a physician,

period. And the same thing for palliative care." However, she said, "You won't find

psychologists anywhere, and it's a total bummer because we're really good at this." She

added that "hospice is a Medicare and insurance benefit that's guaranteed to every

patient." However, she noted that Medicare has developed very strict regulations about

what a hospice team "can, should, and must include." As part of their hospice team

criteria, she said that "they've decided that a social worker is the person who needs to be

on that team. And there are a lot of good social workers, but I really feel like, especially

early on, psychologists are even better equipped than social workers to handle the very

complex clinical difficulties" that patients face as they approach the end of their

lives. She described similar barriers to providing care in palliative care settings, noting

that "You won't find psychologists in palliative care because their standards are very

similar to hospice, they encourage the same model." In fact, she described that palliative

care teams include "a physician and nurse practitioner, and almost always a social

worker, sometimes a chaplain, never a psychologist. It's just the model."

Joyce added that while she knows psychologists who "who do grief counseling in

private practice" and "geriatrics" as well as a growing number of "people who specialize

in support around dementia, either for the patient or for the family, and that has aspects of

end-of-life care in it," she was not familiar with any "private practitioners who specialize

in end-of-life care." Some of the barriers that Joyce identified for psychologists who

would hypothetically specialize in end-of-life care in independent practice

include mobility and transportation concerns. She summarized that "most people in end-of-life care can't get in the car and come to your office. So, you kind of have to be in an inpatient setting. There are outpatient clinics, as I said, in hospitals doing palliative care, but it's hard for people to get there."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Joyce described the factors that she perceives to be most helpful to her in her provision of psychological services in end-of-life care. The most salient factors that she described were the ability to engage with work that she finds interesting, the support she receives from her team, maintaining work-life balance and boundaries, the autonomy she experiences as a chaplain in order to direct the program in the ways that she perceives would be ideal, and when patients and family are able to agree upon end-of-life care goals.

Joyce said that she loves the field of end-of-life care as a result of the complexity that she perceives in the cases on which she consults. She said that, instead of burnout, she feels invigorated by the complexity and that she feels the work is "always interesting." She finds the intellectual rigor to be nurturing, adding that "being involved in the ethics committee and other sort of gritty, intellectually interesting aspects of this work, has been really good for me." Additionally, "continuing to attend the spiritual care meetings where all the rabbis are talking about spiritual issues, or in geriatric care, being amongst smart, compassionate people doing this work, learning with each other and providing support to each other, that's really a privilege" and something Joyce described as "very important to my self-care." She concluded that "That's why I love this work. It's just fantastically interesting every day."

Joyce described her multidisciplinary palliative care team as a "very, very close-knit, cohesive team." As part of her weekly, ninety-minute team meetings, she said that she and her staff are able to support one another and engage in self-care. She described herself as "very bossy about a sort of self-care" and that during her team meetings, "we provide a lot of mutual support to each other." She said that she and her team have "been doing this for 15 years, and I think it's one of the reasons there's longevity. People stay on this team doing end-of-life care, which is so grueling because there's really good support." She summarized that:

I would say, for me, the most important thing is that team. This is really, really grueling work. You are keeping people company; you are accompanying patients and families at some of the most intensely sad, difficult, and troubling moments of their life. And if you're doing it well, your heart's in it. You're thinking every minute. You're watching the body language of everybody in the room. You're feeling compassion for these people. You're thinking about what are the stories underlying their words today? It's hard work. And it's sad sometimes. And for me, I can continue to do this because I have colleagues who are joining me. Nobody ever takes a case alone. Every single case has at least two people from the team assigned to it. Because I just feel, I think one of the things that makes me a good director is because I'm a psychologist, and I understand what it takes to provide this care and what self-care looks like. I'm very careful about confidentiality at these team meetings, and we often have fellows or interns or students who join us for a few weeks at a time or sometimes a few months. And I'm very careful; what goes on in this room never leaves this room. So, we are able to provide support to

each other, like "Oh my God, you wouldn't believe what so-and-so said to me the

other day, he was so rude, what do I do about this? And I've been trying such-and-

such." Or just sharing the sadness or sharing how difficult things are, or just

providing support to each other, saying, "You were amazing in that meeting the

other day." And I'll tell you that on occasion when everybody's on vacation, or

people are at conferences, and I'm the only one in the building and nobody, like

on a Monday, nobody else from my team is there, I'm not happy. I need my

people there. And I do a lot of good work on my own, but knowing they're in the

building is really important."

Notably, Joyce said that "there are a lot of people who, they just don't want to hear about

this stuff," referring to her work in end-of-life care. Because of that, she said, "It's not

always easy to get some really good support. And the best I have found is my team."

Additionally, Joyce noted that "The other self-care is just doing the best I can to

leave it at the office." She noted that it was "easier" to do this at her current job than

when she had been in private practice, noting that "I walk out of that building, my patient

is still in that building, there's a full team of nurses and everybody taking care of them. I

don't have to worry about anything. So, in some ways, even though it's a very intense

thing, I can leave it there." In a similar vein, Joyce described how she has positive aspects

of her own life, which she describes as "having something coming back in." She said that

it is important to have "a good life, like friends, and spiritual practice, or exercise, or

whatever floats your boat" in order to continue engaging in this type of work.

Finally, Joyce said that being hired as a chaplain instead of as a psychologist

allowed her the flexibility to develop the palliative care service in the ways she wanted

to. She noted that, had she been hired as a psychologist, she would have experienced

pressure to meet "billable hour" quotas. Because her role does not rely upon the

generation of financial reimbursement, she can attend to other aspects of the program's

development. She summarized that, as a chaplain, "I'm more fluid the way I am, more

available to go where the fires are."

Finally, Joyce said that when patients have conversations with family members

about their end-of-life care wishes, "it's a lot easier." She said that "the best situation is

when the patient has had conversations with a family to say, 'Don't ever put me on a

ventilator, but if I can still sit on the couch and have a beer and watch the game, you

know, keep pushing. But I don't want any machinery breathing for me.'"

Interdisciplinary Relationships

The palliative care team that Joyce directs consists of herself (a clinical

psychologist and chaplain), one physician, one nurse practitioner, one social worker, one

rabbi, and one nurse's aide. She said that the team with whom she works is "a very, very

close-knit, cohesive team." In order to facilitate their cohesion and optimize their

communication, they meet once weekly for ninety minutes. Joyce said that these weekly

team meetings start "with poetry or a blessing," and then they have a discussion of the

previous week's events and recite a blessing and name all of the names of patients who

have died, and then they de-brief about each of those cases. Afterward, they

discuss ethical dilemmas they are confronting or difficulties that they are currently

experiencing. Finally, they run through their patient census and talk about each of

the patients they are seeing.

Professional Meaning-Making in End-of-Life Care

Joyce noted that "there are a few different angles" from which she makes meaning out of her professional roles in end-of-life care. She said that she has "always felt a mandate or an urgency and a desire to be of use in this world" and that she has found that "coming into a crisis is something" that she perceives that she "can do well" since she is "unafraid…calm, I have good judgment, I can think on my feet, and I can help promote resolution and provide support so people can find their wits about them and make good decisions." She said that she feels "there's meaning in the world because she has found something that she is "good at," and the work is "very gratifying to help people find their way and promote healing, promote resolution of conflict." She added that "it feels good to get something done, it feels good to be effective in a time when people are very vulnerable."

She added that she thinks that "we've really lost our way nationally in terms of death and dying. People…we all feel like you can put it off. People have this idea that if you keep going to the hospital, you're never going to die. Because of this, she finds meaning in her ability to be a "part of a national dialogue around" bringing "death and dying back to the family and back to day-to-day conversation and back to physicians being healers *even* in the dying process, rather than always feeling like death is the ultimate failure." She concluded that "meaning comes when you see the faces of family members coming together around something and agreeing about a treatment plan and saying goodbye… having the courage to say goodbye to each other, and allowing a focus on comfort measures so a patient finally gets good pain management and stops having

procedures. When something good happens, you feel like there's meaning there. And if I've been a part of it, then that's very gratifying."

Influence of Personal Experiences with Death

This topic was not discussed in this interview.

Influence of Religious and Spiritual Beliefs

Joyce noted that her religious and spiritual beliefs were one of the primary motivators for her to pursue a career in end-of-life care. When she closed her private practice, Joyce said that she was looking to "bring the spiritual aspects of care more centrally into the work that [she] was doing." This motivated her to pursue volunteer training in hospice, followed by chaplaincy training, and then, ultimately, a career as the director of palliative care at the hospital in which she currently works.

Ethical Considerations in End-of-Life Care

Joyce described that ethical dilemmas are something that she confronts every day as a part of her job and that her work is "an area of medicine that has this amazing combination of medical ethics, emotional distress or emotional complexity, family dynamics, and spiritual issues, as well as possible disagreements between caring professionals and the family." She noted that she has frequently consulted with staff, patients, and family members about goals of care when "there is disagreement about what's right to do" for patients and that, oftentimes, members of a family may argue with one another about the optimal outcome or course of treatment and end-of-life care. For example, she said that "there might be a son and a daughter fighting about whether to keep pushing and put the feeding tube in and keep [the patient] alive, or whether to stop now because he's suffering too much and the quality of his life is so poor that maybe we

should make a shift towards hospice style care." Sometimes, she said that staff such as nurses intervene as well, saying, "'Oh my God, he's suffering so much every time I change his wound bandages, and every time we're trying to give him these shots, it's horrible. We're torturing him. You've got to talk to this family!'" At that point, she said she might speak with family members who might say that "'No, life is life. You have to choose life. We've got to keep pushing, no matter how much he's suffering and look, he's not really suffering!'" She said that the difficulties arise, in part, because there is "a lot at stake because of patient suffering, and also because after this patient dies, this daughter and son and husband have to live with the decisions they made. And they want to be sure that they're making the best decisions possible." She concluded that "there's a lot of complexity in these cases."

Joyce described that "the more intense ones are the ones that are ethical dilemmas." She illustrated the complexity of the ethical dilemmas she faces with a patient with whom she is currently working. The identified patient, an older adult married female, is reporting that she is "not competent…too sick and too sedated to make decisions on her own behalf." As a result, she has requested that her health care proxy, her husband, make medical decisions on her behalf. Joyce noted that this woman's husband is "pushing, pushing, pushing, pushing" and that he "spends about six hours a day, eight hours a day in her room, and he's making us do a lot of aggressive care for her even though she keeps saying she doesn't really want to live this way." The ethical dilemma Joyce articulated lies within the patient's assertion that she is not competent to engage with medical decision-making. On the other hand, the patient has also expressed that she no longer wants to pursue life-prolonging treatments, despite the advocacy

efforts of her husband to engage with these treatments. Because of the ethical dilemma she faces, Joyce is also consulting with the facility's ethics committee while she is also trying to engage the patient's children in the decision-making process in order to clarify the goals of care or arrive at a treatment plan upon which the entire family can begin to agree. She said that "We may end up having to tell this husband that we won't resuscitate her because it's harmful; the physician takes an oath to do no harm. But at the same time, we want to honor families." She concluded that "There's a lot of ethical dilemmas around…Are we treating the family, or are we treating the patient? And who's calling the shots? And who do we owe honor and respect to?" However, she added that "there are no easy answers" in these ethical dilemmas, and the way that she confronts these challenges is to wrestle "with what is the *best* thing to do in these situations," knowing that there may be no absolute ideal solution.

Changing Attitudes about Working with Death and Dying

Joyce discussed the changes that she has observed in the field of palliative care in the last fifteen years while she had been growing her palliative care service. She noticed that staff at her facility had cultivated awareness and understanding of the palliative care service and its offerings, how to partner with a and use the palliative care service, and how to use their own palliative care skills.

Additionally, she noticed that the professional landscape has grown for professionals in end-of-life care. For example, Joyce stated that, at one of the first training seminars she went to, she was the "only one [who] was not a physician there." However, she said that training opportunities in palliative care are "really well known. And there are chaplains and social workers, and all kinds of people go."

One of the major changes Joyce noted was that "the specialty of palliative care is more and more needed, but we can't keep up with it." For example, she said that when she first started working at the facility about fifteen years ago, the majority of her patients "were playing mahjong, going out for trips to the mall in buses, in vans together, and there was a great big dining room on the main floor where everybody came to eat. Now people are so frail. Almost everybody's in wheelchairs. There are no more big dining rooms; no trips to the mall. Everybody's much sicker." As her patients grow sicker, the need for planning around end-of-life grows increasingly important, and she is perceiving that it has grown increasingly difficult to keep up given the growing demand and aging population.

Professional Landscape for Psychology in End-of-Life Care

Joyce described her view of the current professional landscape for psychologists working in end-of-life care, noting that she has found that the most helpful training to be in multidisciplinary training seminars in end-of-life care. Notably, she said that "my professional home is not in psychology; my professional homes are with the multidisciplinary teams that form around palliative care…[with] physicians, nurses' aides, physical therapists, social workers, speech and language people who are dealing with swallowing problems, it's all interdisciplinary, it's fantastically interesting and lively. Again, I'm learning things every day. But I am not part of a hub of psychologists."

She said that palliative care is "a growing field…but if you want to get a job in palliative care as a psychologist, you have to wiggle your way in somewhere" since she perceives that the field is not currently very receptive or structured in favor of the addition of psychologists to end-of-life care treatment teams. She added that

psychologists might "have to be more creative, more patient, more persistent in your professional development, and to… step lightly" in order to find ways to demonstrate added value to end-of-life care.

Vision for the future of End-of-Life Care

Joyce said that she perceives that the United States has cultivated a culture of death avoidance. She stated that "we've really lost our way nationally in terms of death and dying…we all feel like you can put it off. People have this idea that if you keep going to the hospital, you're never going to die." She also said that her vision for end-of-life care includes "bring[ing] death and dying back to the family and back to day-to-day conversation and back to physicians being healers even in the dying process, rather than always feeling like death is the ultimate failure." Joyce summarized that her hope is that death and dying become a normal part of conversations once again so that individuals can experience a sense of agency in their death, instead of feeling "like the ultimate failure."

The Case of Anna

Background Information

Anna is a 32-year-old Caucasian female who has been a practicing licensed clinical psychologist for six years. She graduated with a Ph.D. degree in Clinical Psychology. She has remained engaged in clinical practice since she completed her doctoral degree in 2014. She describes her religious background as "technically Jewish" and noted that she identifies "very loosely with Judaism," stating that "a lot of the beliefs I really don't subscribe to." She identified the primary theoretical orientation that guides her clinical practice as "truly integrative." She added that, because she works with children and families, she believes that "it really makes a lot more sense to use CBT-

oriented behavioral interventions." However, she described that when she conceptualizes cases, she tends "to go in sort of both camps," and described drawing upon theories of attachment and object relations "where it seems appropriate." When working with patients approaching death, she said that she might "go in a number of different directions, some very practically oriented and others in the more humanistic-existential realm" but that the decision on how she works with the patient would depend on the patient's age.

Method of Recruitment

Anna had been recruited to participate in this dissertation research directly by the Principal Investigator (PI), who had been connected to this participant from a professional colleague of the PI. The PI and the participant scheduled a brief phone discussion in order to review the goals of the dissertation and ensure that the participant met the selection criteria of the dissertation research.

Graduate and Post-Graduate Training in End-of-Life Care

Anna stated that she did not perceive that issues related to end-of-life or death and dying were integrated into the coursework of her graduate program. She noted in courses that had been taught by psychodynamically-identified faculty, "there were discussions about it, more so than with I think more of the behavioral, CBT-oriented folks." However, even when these discussions were invited, she noted that "it sort of feels like it was sort of a secondary issue that if it was in the context of a case discussion or someone presenting a patient or sort of an add-on when thinking about conceptualization issues and someone with a medical condition," but that it was "not really ever a primary focus."

She added, "if you looked at the syllabus, it was not one of the weeks of discussion or even integrated in that way that I remember into our core curriculum."

Anna did describe exposure to the roles of psychologists at the end-of-life during her applied clinical experiences in her externship, internship, and fellowship years. She noted that she had been an extern in the department in which she currently works, and had been hired after her previous supervisor had left. During that year, she said that none of her patients had died but that she had heard about patient deaths and that it was discussed as part of her training in supervision and in didactic seminars. During her internship and fellowship years, which she completed at a VA hospital, Anna said that she had gained "a lot" of exposure to death and dying. Anna said that she had cultivated interests in "integrative care and health psychology," so she chose rotations during her internship year in oncology, where she says her supervisors addressed issues related to end-of-life. Additionally, Anna described her fellowship in geropsychology "with a health psychology component," where she worked with older adults. During her fellowship year, she worked with patients who died while she was engaged in treatment with them. Notably, Anna said about her ability to work with dying patients that, "If I had gone through the standard training and then tried to go work in this population without having had any practicum experience, I would not know what to do based on the curriculum alone, it just wasn't addressed in real detail."

Anna said that her training prepared her to be able to have conversations with patients, families, and medical staff about death and dying. In particular, she speaks more with staff about patient death than she does with patients and families, noting, "I find even I'm more involved in that; the conversations in supporting other staff around

patients dying, than I'm even involved sometimes with the patients themselves." She believes that because patients and families must elect to engage with psychological services, she does not necessarily work with all patients. However, all patients interact with physicians and nurses, and so staff members are much more frequently involved with death by virtue of the fact that they cannot avoid it. Anna thought that her graduate training prepared her to confront issues like death and dying "that typically would be scary to someone who's not knowing or trained, and how to address it."

Because she completed much of her clinical training working with adult and older adult populations at private hospitals and VA medical centers, she had extensive exposure and training in working with these populations and their adult families. This training helped Anna to address "issues of capacity and dying with dignity and *when* wishes are communicated and *how* to have a conversation with an adult prior to a loss of whatever functioning, and those kinds of things that then can translate to teenagers and young adults. However, Anna felt that her graduate training did not prepare her to work with pediatric populations and families of young children. While Anna had had training working with children, she had not had exposure to working with children confronting end-of-life issues, and she was forced to learn about navigating death in pediatric populations "on the job."

Anna acknowledged that conversations about "choices" at end-of-life look "totally different" than adult populations when working with children. She highlighted that children are:

> people who can't make decisions for themselves and have legal guardians for a
> reason, but still are independent beings that should probably be included in certain

aspects of their care, if not *all* aspects of their care. And the line about what they should and shouldn't know about their end-of-life experience is very gray and really individualized, based on the parent's preference and comfort. Whereas when someone is 18, it's very clear what you should be doing, how you go about it, and who the primary decision-maker is on all their care unless you're incapacitated in some way. So, it's very nuanced and gets very complicated.

Professional Development

While in graduate school, Anna developed a clinical interest in working with patients experiencing comorbid psychiatric and medical difficulties as well as patients who experienced traumatic life events. As a result, she was drawn to pursuing training opportunities that highlighted the psychological impact of traumatic medical diagnoses. She said that she felt her current role in end-of-life care was "incredibly valuable and satisfying" as a result of her ability to help patients navigate the difficulties associated with "medical trauma." However, she added that "I do think that there is a lot of joy and fulfillment and satisfaction that I get from so much of the work here *because* it is not all end-of-life, it is not all palliative care. But even when you're doing that work, there's so much that you can get as a provider in terms of your own meaning-making that otherwise, I'm not sure I would get working in my general outpatient facility."

Professional Roles in End-of-Life Care

Anna is a full-time staff psychologist in the Pediatric Hematology/Oncology department of a children's academic medical center in a major northeastern city. She described her current professional roles, noting that she provides individual therapy, group therapy, family therapy, parent management training, "parent-child dyadic work,"

consultation and support to staff, and supervision of psychology trainees at the extern, intern, and postdoctoral levels.

Anna oversees all psychology services provided for those who are being treated in her department and who voluntarily opt in to engage with psychology services. Her department has a pediatric treatment focus, and she primarily sees patients ranging in age "basically from birth through… mid-twenties," since her department may also treat patients with specific pediatric diagnoses who must engage with treatment beyond 18 years of age. Her department also has a survivorship program for survivors of childhood cancer, so she also sees patients who are "way into their adulthood." In addition to providing individual therapy to patients, she provides family therapy and other models of systems-oriented psychotherapy to families who are experiencing difficulty as a result of a cancer diagnosis.

Notably, Anna said that "I find even I'm more involved in… conversations in supporting other staff around patients dying than I'm even involved sometimes with the patients themselves." For example, she is one of the "program lead[s]" for her department's "critical incident stress management team," which is a team built specifically for her department that responds to "critical incidents" that affect staff, such as the death of a patient.

Additionally, Anna provides consultation to staff in facilitating conversations with patients and their families or other caregivers to help them understand diagnoses and medical treatments. Anna said, "so many of our families, for a variety of reasons, whether it's emotional barriers or healthcare literacy issues, or a number of other things, they don't comprehend how serious something is." She described the difficulties that some

individuals experience in understanding the implications of certain end-of-life treatments as "supportive interventions only, [and] *not* curative at end-of-life." Some patients, families, and caregivers experience "defenses… that get in the way" of meaningfully engaging with treatments at end-of-life to promote quality of life (and death). However, Anna added that, for some of these individuals, they simply do not understand the sophisticated information that is conveyed by treatment providers about their options. She said, "sometimes it's really just about a real understanding because the information is sophisticated. And sometimes, our providers are not the best at explaining it in a way. They're trying to be sensitive, perhaps, to the person's feelings, and they end up tiptoeing around things that make it harder to understand."

Sometimes, Anna said that she is able to provide psychoeducation for staff about patients and their decision-making processes. For example, she has had the experience that some treatment providers experience negative attitudes towards individuals who opt out of treatments to promote quality of life at end-of-life (palliative care treatments) or who continue to opt-in to life-prolonging treatments. However, she has found that some of these individuals make these decisions because of a lack of awareness or understanding of the treatments. As a result, she can convey important information to patients to help de-pathologize their decisions to treatment providers. She can also provide education about cultural differences in grieving. For example, she said

> I think culturally, also, it's different how people respond to bad news if you want
> to call it that. [The] end-of-life, active dying phase is so different culturally. And
> we've had cases where families have had… the adults have had codes called on
> them because they are passing out in the room while the child is actively dying

and screaming and hollering, and we've had families that can't bear to be there.

But the more extreme case culturally, I can't remember which group it is, which is

totally insensitive, but there was a particular group of people where we had

several cases from that country, and the reaction was the same in terms of grief.

And the blood-curdling screams that came out of the moms associated with those

groups was not like anywhere else. And that was obviously consistent across

different families. And it's just *how* they emote in that moment of such suffering

and pain, whereas other families and other cultural backgrounds would not

necessarily do that. And that's not pathological necessarily, but it's culturally

based, and then that just takes a little bit of understanding and education. But the

first time it happens, no one really was expecting that.

Similarly, Anna can "serve as a little bit of a liaison between a family and staff" by

providing psychoeducation to staff during case discussions and interdisciplinary meetings

in order to clarify differing attitudes and goals of care between patients, family members,

loved ones, and staff members. She said:

There's very rarely consistency across everyone's level of acceptance about their

loved one's fate and wishes, and what things will look like, for the next however

long they should live. And so…people very quickly, not necessarily in this

context, but I think some members of our interdisciplinary team will throw out the

word "denial" very loosely."

In her role as a psychologist, Anna said that she can provide clarity about these

differences in order to avoid "over- and under-pathologizing" those involved in the care.

She added:

The family might share with me some of the things that they won't share with the staff, not because they don't trust them, they have usually beautiful relationships with our nursing staff and our physicians. But because there's a level of emotional honesty that they can establish in a therapeutic relationship that they might otherwise not be able to.

Referral Process

Anna said, "Psychology is very well received in this department" and feels that the physicians and social workers with whom she works look to psychology in order to help "manage those very difficult situations and difficult conversations and support them." While the team social workers also provide "general emotional support," their primary responsibilities include "disposition planning, insurance, financial needs, and general emotional support, not any real psychotherapy." As such, psychology is called in by physicians when difficulties in treatment escalate in order to help "guide these kinds of conversations, discussions, and how to improve the patient relationship and patient experience."

Anna said she is not always called upon for patients at end-of-life, and that her services will only be called upon by some providers. While some providers "are really very hands-on with their patients at end-of-life and walk them through the whole process, very open and blunt. And I say blunt because that's sometimes how it is. It's not just, like the opposite of the tiptoeing around, it's really very direct. And…others tend to be a little bit more hesitant and then look for psychosocial support to come in and kind of corral a little bit." However, there are times during which providers perceive that "clergy is honestly the better source of support for them or intervention and that the combination of

that and social work, and some of those concrete services is really what they need, and they have a large family support or something like that, and psychotherapy is not appropriate."

However, there are certain diagnoses for whom Anna is called upon to join in on family meetings to make families aware of her services. Those diagnoses typically include those which have "a very poor outcome" or which indicate a very rapid decline or "a particularly traumatic end-of-life." While the treatment team does try to alleviate pain, the "loss of functioning" and the "advancement and how fast the disease actually progresses, for the patient themselves and their family, it's very challenging." Given the complexity and associated with these diagnoses, the Psychology service is usually introduced to patients as a service with which they can engage.

Anna noted that while she perceives that "communication is solid, in terms of the desire to bring in referrals and to seek support from us," she feels that "it's just not consistent." Some of the inconsistencies in communication can be attributed to the fact that there are so many providers with whom Anna works. Additionally, communication can be influenced by providers' willingness to "push" patients to engage with a psychologist around conflict or decision-making difficulties. Others, however, may respect a family or patient's wishes to avoid challenging conversations and not make a referral to Anna.

Psychology at the End-of-Life

Anna described the numerous professional roles that she fills as a clinical psychologist in a pediatric Hematology/Oncology department working with dying patients, including the provision of direct psychological services with children

approaching end-of-life and/or their families, as well as being one of the program leads for her department's critical incident stress management team.

Anna described her work providing critical incident stress management, which steps in to provide services "rooted in psychological first aid" to department staff after a "critical incident," like the death of a patient in both group and individual formats. The program is designed to help staff to begin

> "talking about the experience, your [the provider's] role in it, the relationship to the patient, how you're doing in this moment, and then recovery efforts to return to baseline… more like psychoeducation and coping strategies; how to get you back to work and prevent any kind of a traumatic response or acute stress reaction to this experience, with the recognition that we can't get ahead of all of those things, but at least if the person has an awareness about what they're feeling and when they might seek extra support and then we might be able to guide them in the right direction."

The program was developed after staff in Anna's department developed a recognition that "these awful things happen in our workplace" and experienced difficulty continuing to perform in their professional roles. Staff members and health care providers in Anna's department developed relationships with their patients and families of those patients, and soon learned that they were "not immune from grieving [the loss of a patient]." Because of that, the program expanded to include other stressful incidents beyond the death of a patient, such as "relapses of patients or bad news or other events that affect staff and that impact on them in such a way that they can't perform their job at the level that they'd like to, or that they're having some emotional distress in their workplace." After these events

occurred, providers felt that they could not "just go into the next patient's room and pretend like that didn't happen, or that it didn't affect us [the providers]." Anna added that the program was established with the recognition that "certainly at some point down the road, we know what happens as psychologists when we just avoid addressing those kinds of issues." In her role as program lead, Anna facilitates more than half of all of the interventions for providers by conducting groups and providing one-on-one interventions. In her team of fifteen providers, Anna supervises more than half of the team providers as well.

Anna also described treatments she conducted with two families confronting end-of-life, and the unique challenges and successes she had in providing psychological services with these families.

Anna first described a case in which she felt "most challenged and the most successful" in that she had "learned the most, but definitely [felt] the most challenged." In this case, the patient Anna first described working with was "a young teen [female], about 13" years old who had been diagnosed with a rapidly progressing brain tumor and with whom Anna had a relationship for "about ten months." She was initially referred to Anna for psychotherapy as a result of anxiety that she was experiencing anxiety "associated with being in the hospital…for chemotherapy, [and] her medi-port being accessed." When she first started working with this patient, Anna conceptualized that the patient would benefit from "strategies to manage the very practical aspects of her care and adjusting to a relatively new diagnosis." The patient's family was "on board" with the goals of treatment. Anna met with the patient for a "couple of sessions" before the patient's disease progressed, her prognosis worsened, and she started to experience

multiple seizures which resulted in her developing blindness. The onset of blindness, in addition to the realization for the patient "that most likely my [the patient's] disease is getting worse," elevated the patient's anxiety dramatically. Anna felt that the patient's blindness "just shut her down" and that the experience of having to "navigate the world, blind, as a young teen having never had that challenge before, that is an incredibly scary place to be." At that point, Anna's ability to engage with the patient became increasingly challenging, as the patient began to withdraw, developed symptoms of depression, and began to experience "cognitive changes" as a result of increased seizure activity and so Anna's role "shifted to supporting the parents and the family." Anna added that she knew that she was likely working with a family at end-of-life once the treatment team understood why the patient developed blindness and that the "likelihood of cure was really slim…we actually didn't know if she would make it out of the hospital at that point." Additionally, after the patient went blind, the treatment team advocated for starting to have conversations about supportive interventions and hospice care. While the patient did end up living for another six months in gradually declining health, Anna began working more closely with the patient's mother and father.

Anna's initial treatment goal in her work with the patient's family including completing the Families Overcoming Under Stress (FOCUS) protocol, in order to "capitalize on the strengths of the family and do what we can to enhance resiliency, which then when potentially facing a death of a patient [family member] is something that, if you have done that kind of intervention from the start, then the hope is that the family will be able to come together, support each other, and sort of unite around a loss like that." Anna said she thought that she "would help them [the parents] construct

narratives, and then bring in the siblings and have her [the patient] involved in the conversation and really create a timeline with them about this experience and what they had been through, and create an opportunity for them to have a dialogue about it as a family." However, Anna noted that the intervention did not pan out because the patient's parents were "in totally different places" and that they "flip-flopped a bunch of times."

The patient's parents experienced a great deal of guilt and anger as a result of the cancer diagnosis. Anna said, "there was so much anger about why the disease had progressed, and what were the signs, and how did we [as parents] not know, and how things could have improved for her, for them, and if we…potentially had any indications, then could we have gotten ahead of that and prevented the blindness and also gotten her some additional treatment that would have been curative." The patient's parents also developed anger at the treatment team. Anna said, "They were so upset and wanting to blame someone so badly, that they fell into the camp of 'We're questioning the team because we don't know who else to question, and we can't make sense of something' [like this].'" However, they did not express their anger directly at the treatment team and instead shared their emotions with Anna because they did not want to make the team "defensive and angry" in turn. Anna's role became "to some degree, their punching bag some days, if you want to call it that, their container other days, and the liaison, certainly, between the team and them."

Despite the treatment team's "clear" suggestion that the family begin to consider end-of-life interventions, the patient's parents did not initially agree to that for the patient since "they didn't feel that she was there." Initially, the patient's parents disagreed about goals for care. The father attempted to find "his own way to figure out how to engage in

self-care" during this process while the mother "was very focused on these basic needs" such as making sure that the patient was eating and drinking and maintained a very 'here and now' focus to the patient's care.

The patient's health stabilized enough to return home with home care assistance, but her overall physical wellbeing continued to decline; Anna continued to work with the patient's parents during this time. The patient's mother continued to engage actively with the patient's home care while the patient's father returned to work. Prior to the patient's eventual death, the patient's mother

> was home with her so much of the time that mom was seeing her decompensate. And the dad, who had initially been much more accepting about her fate and her prognosis and was at work and really not witnessing all of this, which made it then much harder for him to see that she was deteriorating. And in the end, they were so not - I want to say - connected, joined. And he was so, so angry, and she was a little bit relieved and felt incredibly guilty about that. Because she had seen so much more suffering, and I don't think he really even witnessed it.

Anna added, "We see that a lot with two-parent households where one of them has to be working to support the family and is not necessarily bearing witness to a lot of the suffering."

The patient's parents felt that the team could have done more in order to help their daughter. Anna said that the medical team advocated as much as possible for the patient's treatments, and ultimately, there was no "miracle" for this patient when she did die. The parents responded by disengaging from many of the medical team members. After the patient's ultimate death, Anna said that she had become the only staff member from her

department with whom the family could speak. Anna felt that this could have been a

result of the fact that she perceived the family felt there was "safety" when speaking with

her, adding, "I had maintained their confidentiality and trust. There was nothing that I had

to go to the team to tell these very personal and innermost thoughts about their

experience." Because of the connection that she maintained with them, she said that she

encouraged the parents to go to bereavement counseling after "months of talking to them

on the phone, and having the equivalent of sessions by phone until I felt like they would

actually follow through on that [recommendation]."

Anna described this experience as particularly challenging for her because she

"felt very alone in that experience, that they pushed so many of the other staff members

away." While Anna would normally have fellow team members with whom she could

speak and draw support,

even if she is "the only one that's getting some of that emotional content and processing

with them [the family]," she did not have that with this family. She said that "it was a

heavy burden to bear at the time." However, she also felt particularly successful in her

work with this family because:

> I do think that had I not maintained the relationship that we had, I don't think they
>
> would have gotten to the place that they did in being able to then go on to have
>
> bereavement group counseling and be open to that. And knowing that someone
>
> could actually contain all of the intense feelings that they have.

Anna described another case working with a family confronting the death of a

child and the reality of the intensely challenging nature of this work. While the patient is

about "ten, eleven years old" female, Anna is primarily working with the patient's parents

with the aim of eventually working with the entire family. The patient has a brain tumor

and has experienced two recurrences (implying that there is likely no cure) already. The

patient has undergone numerous treatments with little to no improvement and so the

treatment team is currently looking to pursue interventions aimed at "improving or

maintaining quality of life, [and] stability of the tumor."

Anna said that "the two parents are in really different positions" with regard to

pursuing uncertain and possibly risky, life-prolonging treatments. The patient's mother

related to Anna that she would prefer to "forego all treatment options, and I would rather

her just pass away from this disease" instead of choosing a "risky enough surgery that it

could cause significant cognitive deficits and would maybe make my child not be the

person that she is and not have the personality that she does and not be able to function in

the way she does" adding that "I don't think she [the patient] would want that." The

patient's mother "has very much accepted that this child will probably die of this disease.

She has already talked about and planned for funeral arrangements and discussion of

where she'll be buried and what that will look like." By contrast, the patient's father

maintains a different position for this child and is advocating for engagement with drug

trials and novel treatments in order to prolong her life. Anna said that "he's waiting for

that miracle. And he's waiting for the *thing* that's out there. And why wouldn't you [a

parent] do everything and anything that could possibly remove the disease, who knows,

permanently, until the next major drug trial comes through or miracle clinical trial cure,

whatever it is, and that we could figure out a medical miracle for these deficits. And he

doesn't see those things as being such a sacrifice for their child." Additionally, he

redid the ramp in the yard so that he understands that she may at some point be

debilitated and require a wheelchair, and he wanted that accessibility for her. And

it took two years to get there. But he also, upon initial relapses, was so devastated

and anticipating she could die any day that he couldn't go to work for six months.

So, you see the extremes. And now he's sort of in this if you want to call it

'denial,' you could, but it's not. He's just waiting for that miracle because he's

accepted that somehow, she didn't die during that six months, and so she might

actually have [a] life to live. We don't know how long, but now he wants to

believe that it's going to be as long as any one of his other kids, and why shouldn't

he believe that?

Anna said that the patient's parents have separately articulated their thoughts

about the treatments that they'd like to pursue to her, and have abstained from discussing

this with the patient's medical providers. Anna explained this behavior:

What I've heard from families is that they feel safety with their medical team, but

they also never want to seem as if they're challenging their providers. Because

you'll see this in adult care too, but I think you see it even more in your kid's care,

pediatric care, that if there's any sense that they are undermining the authority of

that team, then will they take that out on my [the parent's] child. And there's

paranoia there, not realistic, that doesn't happen here.

Anna said that the patient ultimately died and that the two parents were ultimately

left profoundly split in their reaction to the child's death. The patient's father was

"incredibly angry," and the patient's mother "was in a totally different space." Anna

described the challenges associated with working with this family, in which there was disagreement about the goals of care:

> It was heartbreaking because it would have been wonderful to have seen them
> [the parents] come together and support each other. And that's the best-case
> scenario, but it doesn't always happen. And so, I think that the reality for the two
> of them about the severity of their child's condition and the fact that she was
> going to pass away was not something that they really ever came together on and
> accepted in the same way until their emotional experiences until the very end
> were really separate.

Supervision and Training in End-of-Life Care

Anna also described her professional role as a supervisor to clinical psychology externs, interns, and postdoctoral fellows. While Anna practices in a Pediatric Hematology/Oncology department, which treats a small percentage of children with poor prognoses who ultimately die while in their care, she said that she is mindful *not* to assign her trainees those patients and families where the reality of end-of-life is salient and imminent. She said that

> although it's a good learning experience for a clinician-in-training, it's also *not* a
> great experience because of a number of factors, mostly logistical. I mean, when
> we're talking about patients here, who have a disease with a poor prognosis from
> the get-go, we may say that they have a certain life expectancy and then they far
> exceed that. And we've had so many patients that had that experience. And then
> we have trainees who are here for six-month rotations or a year, and they develop
> these beautiful relationships, and then the patient still lives. And when they do

end up passing away, that person [the trainee] is no longer there. And so, I don't think that's fair to the trainee or to the patient. And so, either I will co-lead those cases with them, and we will have a shared therapeutic relationship. And they'll sit in. Like if it's family work, we'll co-lead those sessions. And that way, we're sort of interchangeable and I'm still knowledgeable about all the work that's being done, and the relationship is established with both of us, or they'll be a part of conversations and case discussions and interdisciplinary meetings, but not actually lead any kind of therapeutic intervention with them, for those reasons.

However, Anna realized that some families and patients might not want a trainee "visitor" in their care, so she tries to prioritize patient preferences in those scenarios.

Anna also described how supervising students has opened her "eyes to how much this [end-of-life] isn't talked about in training." Because of what she perceives as a training deficit, Anna said she will invite her trainees into discussions about death and dying and said she has found that students are "eager to understand and learn about it." While most of the patients who are treated in her department have a high likelihood of survival, Anna noted that "the reality is they're all fragile, anything could happen at any point that could totally alter the course of that person's life or end their life. And I think that most of our trainees don't work in an environment where that's the reality." Because of this, a significant part of Anna's supervision with her trainees focuses on discussing ways in which clinical psychology doctoral students can learn to "maintain an emotional distance that's appropriate, and boundaries that's [sic] appropriate when you are also afraid that your patient could pass away and that you don't know what could happen to them. And when things sound very serious, they are actually quite serious." Anna

discusses with her students the complexity associated with learning to navigate the difficulties that arise when working within a family system. She noted that students may struggle to understand a child's intrinsic fragility when these children "want to… live and be kids." At the same time, however, student clinicians are also balancing the needs of the child's parents who may perceive the severity of the diagnosis and who "may be very appropriately emotional about the fact that they're going through this very serious treatment."

Anna described a challenge that arises for her trainees working with patients at end-of-life:

> I did assign a case to a trainee who did have likely a poor prognosis and was really only here for a short time before going off to a clinical trial. And so, it felt very safe to assign that person at that time because it was really very time-limited, and the likelihood of something catastrophic happening to that person at that time was pretty unlikely. And what I learned from it, though, was that the hopelessness of a student in that moment was very challenging. And it was a great opportunity for supervision. But I think that the student did not know what to do, how to truly *just* be supportive without offering an intervention, because that's where that family was at, and that's where a lot of our families are at when it comes to making decisions around palliative care and supportive care when there aren't curative options.

Anna said the supervision for this case focused on addressing questions such as, "What are we [as trainees or providers] doing here [in this treatment]? Because our goal from a traditional psychology standpoint is, 'What is the treatment plan? What are the targets?

What are the goals? What are the behavioral indicators? What are the outcome measures?' And we have all of these beautiful points that we'd like to make about measuring our effectiveness. But in *this* work, it's not so clear, and it is much more loose. And sometimes, it's just sitting and being with a family." She said that while she perceived that "sitting and being" was a "much more unusual role for a student to be in and was a very good learning experience," she added that, "I think [it was] very frustrating [for the student]."

Barriers to the Delivery of Psychological Services in End-of-Life Care

Anna described the barriers that she perceives in providing psychological services at end-of-life. She reviewed institutional barriers, including limitations in being able to make psychological services accessible to all patients as a result of limitations in staffing and finances, the difficulties she thinks psychologists would face when working exclusively with dying patients, facing the prospect of having her own children while working with sick and dying children, and difficulties associated with feelings of helplessness.

Anna noted a primary concern that there are not enough psychologists on staff to provide adequate end-of-life psychological care and that the larger system within which she works may not recognize the benefit of the addition of psychologists. She noted that her department has a palliative care team which is responsible for overseeing any palliative care treatments provided to patients experiencing a life-threatening illness. However, her department's palliative care team does not include a psychologist. Anna described perceiving that "there hasn't necessarily been a recognition from an institutional level that a psychologist on that team in our *hospital* would be important, and that there

probably could be a psychologist in our department who could just address these kinds of

issues." Additionally, because Anna is the only psychologist in her department, she is not

able to see all patients from the start of their treatment and is not able to be involved with

some of the cases when a patient and/or family is confronting end-of-life. While she

could meet with the family once the patient is confronting end-of-life, Anna said that "by

the time they're dying, or even close to end-of-life, to then meet a new person sometimes

is very off-putting for family and for a patient." She believes that she believes that

institutions may benefit from "a recognition of what psychology offers," which is often

difficult to advocate for because of an institution's cultural attitudes about the perceived

need for a psychologist and the financial cost associated with a psychologist.

Anna also felt that a major barrier to providing end-of-life care is that, given "the

issues that come up here and the longevity of the relationships and the dynamics that

exist, I think it would be way too draining to only do this [end-of-life care]." She

described the difficulties associated with working with death and dying exclusively, and

noted that "because what drives me is to also see the kids that do well, and even the ones

that are on treatment, that just there's joy in their experiences and living their lives, and

promoting you know, quality of life for them is I think a really important part of my job."

Additionally, Anna described the difficulties associated with "just be[ing]

supportive, without offering an intervention" to patients and their families. She noted that

this can be particularly difficult since some psychologists tend to perceive their roles

from the lenses of treatment goals, treatment plans, targets for intervention, behavioral

indicators, outcome measures, etc. However, "in this work, it's not so clear, and it is much

more loose. And sometimes it's just sitting and being with a family."

Similarly, Anna described other examples of things that psychologists cannot change that might promote feelings of helplessness. For example, she said:

When you see a psychiatric patient, we have a list of presenting issues and some of the things you *can't* address. Like family dysfunction, you can try to address, but their [a patient's] mom is going to be their mom. And so, you're not going to be able to remove the mom from the situation, but they're going to present with primary issues that *are* addressable. The primary issue here, cancer, or blood disorder, or a reason for transplant, post-transplant patient, we *can't* address, and that can make you feel really helpless.

Anna copes with this feeling of helplessness by redefining the notion of what she hopes to accomplish with patients:

You can redefine the work that you can do in the same way that you would with any patient that has a serious or chronic condition to help them live with that experience. And I think that when people think about it and say, '*How* do you do this [type of work as a psychologist]?' or '*Why* do you do this?' I don't think they can see it that way. Because there's so much that you can get from helping patients to live with the experience that they have, knowing you can't take away this big, traumatic medical issue that is in their life.

Finally, Anna noted that while she has not personally experienced this challenge, she has heard that psychologists who have children experience difficulty working with sick and dying children at the same time. She said that some psychologists who are also parents struggle in this type of work since, "every time you see the child suffering, you see *your* child suffering."

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Anna described the factors that promote her ability to provide psychological services at end-of-life. Some of the factors that she described include diversifying the patients that she works with to include children who survive (the majority of the patients she works with), eliciting support from colleagues, and engaging in self-care activities.

As described earlier (see Barriers to the Delivery of Psychological Services in End-of-Life Care), Anna noted that one of the difficulties in engaging with patients at the end-of-life can be emotionally "draining." As such, she noted that she values the ability to provide services at end-of-life *because* of the fact that she is able to see children survive and continue to live as well.

Anna also said that the support of her colleagues in other professions has proven helpful to her. For example, while Anna described feeling underprepared for the "emotionality" involved in this work, she said that "my social work colleagues probably helped me here" in navigating the things she had not felt prepared her for the work.

Finally, Anna described the value of self-care, noting that "separating as much as possible is wonderful, [but] not always doable." She added that

I have certain activities and experiences that are truly what I would consider mindful experiences that remove me from this. So, enjoying cooking and music and things that I really can stay in that experience and savor what it is I'm doing. And it takes me entirely away from the emotional experience of this. And so, I really try to do those things and prioritize them. So yes, I do work on the weekends sometimes. It just happens with a number of different things that I am doing. But I also try to do things entirely mind-numbingly dumb on the weekends,

like watch bad TV shows and cooking and things that don't require any thinking at all or energy. And that helps to sort of recovering, rebuild.

Interdisciplinary Relationships

Anna stated that her department has several "teams that have different specializations, like [the] hematology team, the oncology team, the BMT team, which is the transplant team, bone marrow transplant team… And each of those has their physicians and their social workers in there." As the only psychologist in her department, she consults with each of these teams and has opportunities to speak with other professionals during meetings such as Tumor Board and daily morning reports and interdisciplinary rounds. Anna also established Psychology Rounds, "which is basically where staff can come… to talk about a particular patient and consult on a case and figure out if this patient would benefit from psychology services, psychiatry services, or if we need to think about any kind of behavioral plans to put in place and how to help the staff manage whatever their issue is, and concern is for the patient."

Anna also said that she has drawn upon the support of her "social work colleagues" in order to learn to manage the "emotionality" associated with working with patients and families at end-of-life, highlighting the collegial nature of her interdisciplinary relationships.

Professional Meaning-Making in End-of-Life Care

Anna described the ways in which she cultivates meaning in working with dying patients and their families as considering "What is it that I offer this family? And what is within my scope? What are my limits? What is it that I can do to lessen the burden or suffering?" She elaborated:

When I think about meaning-making, I think about my intentions, my goals, and

what I'm able to achieve with any given family and what realistically can lead to a

satisfactory outcome even if the larger outcome is negative or poor. Because I

don't think you can do the work in this context if every time there's a poor

outcome, and a patient passes away, you are seeing that as a failure. And so, if

you are not necessarily able to find an area where there's light, or there is some

opportunity for change or progress, then I don't think you could probably do this.

So that's I think that's what I mean when I talk about meaning-making, it really

depends. But it's usually defined by what I needed to achieve with a patient.

Influence of Personal Experiences with Death

This topic was not discussed in this interview.

Influence of Religious and Spiritual Beliefs

This topic was not discussed in this interview.

Ethical Considerations in End-of-Life Care

Anna described numerous ethical challenges that arise when working in pediatric

end-of-life care settings. Most significantly, she noted that she and her fellow treatment

team members may not always be able to disclose the reality of sickness and dying with

children with whom they are providing care and who may be approaching end-of-life. In

instances where a child's parents may not want a child to know about their diagnosis or

prognosis, Anna said:

It puts our team in a really bad spot because the emotional agony of knowing that

you're probably dying or that something's happening to your body and not having

an answer for that, in my mind, is so much more suffering than anyone should

ever experience. But we don't always have the ability to override a parent who says 'No, I think I'm sparing them.' A lot of times, parents will understand; I'll have a conversation with them and explain that most of our kids, even the youngest ones, understand that *something* is changing. And the *not* knowing is more anxiety-provoking than the knowing. And the not knowing doesn't mean that they're [actually] not knowing. They're respecting and seeing your [the parent's] cues, whatever you're modeling, which is the 'not talking.' They [the child] are then responding to, and not asking [about the illness]. But not because they don't want to ask, or because they don't know.

Anna said that the decision to engage a child in discussions about their own treatment and end-of-life decision-making "depends on the parents and…the kid's requests and intellect and developmental stage, and how open the parents are to including them in those things." She added that

"Parents go in one extreme and the other. Sometimes they'll say 'Absolutely not, we want to spare them from this information. We don't want them to know until we've decided that they have to know, or until the very end.' We've had kids that, in a sense, don't [officially] know that they're dying, even though they probably know that they're dying [without being told]. And they haven't asked, and there's been this unspoken conversation about how 'If my parents aren't telling me then I probably shouldn't ask,' but we probably know that they [the children] know."

The reality that children may not always have the autonomy, agency, knowledge, or understanding about their own death highlights the unique challenges of working with children at end-of-life. Anna said that children are

people who can't make decisions for themselves and have legal guardians for a reason, but still are independent beings that should probably be included in certain aspects of their care, if not all aspects of their care. And the line about what they should and shouldn't know about their end-of-life experience is very gray and really individualized, based on the parent's preference and comfort. Whereas when someone is 18, it's very clear what you should be doing, how you go about it, and who the primary decision-maker is on all their care. Unless you're incapacitated in some way.

Changing Attitudes about Working with Death and Dying

This topic was not discussed in this interview.

Professional Landscape for Psychology in End-of-Life Care

This topic was not discussed in this interview.

Vision for the future of End-of-Life Care

Anna said that she would like to see medical settings continue to integrate psychologists into medical treatment settings. Already, she has perceived that "there has been a greater understanding about the role that psychologists can play in those teams in mitigating distress and getting ahead of some of these issues and preparing patients for major medical procedures or understanding the mind/body connection and how they exacerbate one another and all sorts of conditions that evolve from that." She believes that psychologists could be able to evaluate all patients and families "at some point" during their treatment, adding that there is value "even if it's upon an initial diagnosis, doing an initial screener or some kind of an inventory of how they're doing then some

sort of a follow-up and referrals as needed." However, as described earlier, she noted that

"it's just not something that is, at this point, financially incentivized enough to support."

CASE COMPARISON AND DISCUSSION
Background Information

All eight participants interviewed were clinical or counseling psychologists who had been licensed in the state or province in which they practiced. There was variability in participants' demographics, including but not limited to age, gender, racial/ethnic background, religious/spiritual background and identity, psychological practice orientation, areas of specialization, and years in practice. As a result of the heterogeneity within this small sample, common themes found across participants will be compared and contrasted in order to highlight major similarities and differences across the roles, practices, and functions of psychologists working in end-of-life care.

The differences found across participants' demographics in this sample demonstrates that the role of psychology in end-of-life care is not solely the domain of one particular demographic of psychologists. In this sample, participants ranged in age from 32 to 73, highlighting that psychologists at a variety of ages practice in end-of-life care. This also demonstrated to me the ways in which professional interests in end-of-life are not solely limited to individuals in older adulthood, as had been my perception prior to this study. While psychologists appear to report perceiving that they had benefited from prior experience with death and dying in their personal lives, this sentiment was shared by psychologists at all ages, not just older adults.

This sample also demonstrated that psychologists in this sub-field draw upon numerous theories of human behavior, personality, and behavior change in their professional practice, including psychodynamic and psychoanalytic theories, DBT, CBT, ACT. This finding provides support to the notion that foundational principles of these

theories may be easily applied to teaching, instruction, and practice in psychological practice in end-of-life care.

Notably, however, seven out of eight psychologists interviewed were Caucasian. While this may demonstrate limitations with the study's selection procedures or issues with diversity in psychology as a whole, it may also highlight the ways in which diversity is limited, even in the sub-field of psychological care at end-of-life.

Method of Recruitment

Of the eight participants interviewed, three participants were recruited through referrals of professional contacts I made myself (Janet, Anna, and Joyce). The remaining five participants were recruited through advertisements in the email listservs of special interest professional psychology organizations, state psychological associations, and graduate psychology alumni organizations.

Early recruitment efforts proved difficult since no special interest professional psychology organization for psychologists practicing in end-of-life care exists. Similarly, unlike many other specialty areas of professional psychology, no APA division exists to serve as a home for those psychologists whose primary role is found in end-of-life care. Most of the psychologists I interviewed relied upon the professional homes of other areas of professional psychology, such as geropsychology, health psychology, and psychoanalysis. Additionally, some psychologists relied upon the professional landscape of other disciplines, such as nursing, medicine, and social work. Moreover, while I was recruiting, psychologists referenced relying upon multidisciplinary end-of-life care professional organizations, such as the Association of Death Education and Counseling (ADEC) and the American Psycho-oncology Society (APOS) as professional homes.

Only one participant who was employed at a VA hospital noted that she had access to a national email listserv hosted by the VA for all VA-employed psychologists who were designated as the palliative care psychologist at their VA hospital; she described this as a helpful resource at times, but the breadth of the listserv was limited.

The relative difficulty I experienced in recruiting for this dissertation research may highlight the professional void that exists for psychologists who work in end-of-life care face. I discuss this deficit further in "Professional Landscape for Psychology in End-of-Life Care."

Finally, while I was screening participants for this dissertation, I noted that prospective participants had a variety of definitions about what exactly end-of-life care meant, and prospective participants working in long-term care or nursing home facilities with older adults felt most capable about discussing end-of-life. While it is true, indeed, that psychologists working in these facilities do confront end-of-life on a regular basis, as evidenced by the cases of David, Eric, and Joyce, psychologists may confront death and dying at any age, as demonstrated by the cases of Alex, Janet, Richard, Rachel, and Amy who work with patients across the lifespan.

Graduate and Post-Graduate Training in End-of-Life Care

With the exception of Alex and Janet, who received some academic coursework directly related to end-of-life while in graduate school, all the psychologists interviewed described obtaining either little or no formal *academic* training in psychological care at end-of-life. This highlights an important gap in the provision of training for psychologists at the earliest stages of training. As the field of psychology (or perhaps contemporary Western culture more broadly) demonstrates a recent history of discomfort with death

and dying and discussions about its inevitability, psychology training seems to be limited

to applied experiences at the externship, internship, and postdoctoral levels. However, the

unique challenges associated with providing care at end-of-life does not, on the whole,

seem to be addressed in graduate coursework. When death is discussed, as Richard

described, it is often within the context of suicide, or as Eric described, within the context

of older adulthood. Anna also described her experiences providing supervision to

psychology trainees who have not had any exposure to discussions about death and dying

by the point at which they pursue applied training experiences in pediatric psycho-

oncology.

Those psychologists who were able to pursue training in end-of-life care at the

predoctoral level included Eric, Alex, Janet, Richard, and Anna. Each of these

psychologists engaged with applied clinical experiences working with patients at end-of-

life at the externship or internship level. Notably, none of them described having any

interest in working with death and dying at this stage of their careers. Instead, many

described interests in health psychology or trauma, which may provide valuable insight

into the ways in which health psychology and trauma studies and end-of-life care can

learn from one another, and may provide a platform from which psychology students can

cultivate a long-term professional interest in end-of-life care.

At the postdoctoral level, David, Janet, Richard, Joyce, and Anna received formal

training in end-of-life care. David received this training through his broader

psychoanalytic training (affiliated with a medical center) while Janet, Richard, and Anna

pursued postdoctoral fellowships in health psychology (Anna), geropsychology (Janet),

or psycho-oncology (Richard), and Joyce got training as a chaplain. Each of these

psychologists noted that they worked with patients at end-of-life and got training in death and dying. Even at the postdoctoral level, none of the psychologists interviewed demonstrated a specific interest in end-of-life.

However, none of the psychologists interviewed received specialized postdoctoral training in issues related to end-of-life in pediatrics. Anna, who had experience working professionally with adults and children, noted that "choices" at end-of-life look "totally different" for adult populations than pediatric populations, and highlighted how "nuanced" and "complicated" the specialized field of pediatric end-of-life work is. However, this may be a sampling limitation of this study, as postdoctoral fellowships in pediatric psycho-oncology (with applied training opportunities that include end-of-life psychological care) appear to exist after a brief search on the Association of Psychology Postdoctoral and Internship Centers' (APPIC) Universal Psychology Postdoctoral Directory (UPPD).

Notably, Rachel emailed me after the interview had been conducted in order to convey some final thoughts. In her email, she wrote:

Much of the time in work with clients at end-of-life, I feel like I don't know what I'm doing.

It is a lot like the imposter syndrome they warned us about in graduate school. I may have presented last night [during the interview] as self-confident, self-aware, and confident. My internal experience is often the opposite. I muddle through – try and do the "right" thing – but I don't have an internal sense of certainty. That has led me to do a lot of reflecting and consideration on the work that I do.

It would be so helpful to have access to coursework (through post-grad CE) or

several well-known, experienced clinicians who would be willing to provide

supervision or consultation to others. I would certainly pay out of pocket for

supervision – or consultation- in this area of practice.

Rachel's email highlighted for me the need for psychology to advocate for additional

training in and access to resources for psychologists practicing with patients at end-of-

life.

Professional Development

None of the participants interviewed described an initial or early-career interest in

end-of-life care. In fact, most found themselves initially interested in other areas of

professional psychology, such as health psychology (Anna and Janet), neuropsychology

(Rachel), trauma psychology (Anna), or child and adolescent psychology (Joyce),

highlighting the numerous routes through which a psychologist may find themselves

practicing in end-of-life care, as well as the significant overlap in training and clinical

competencies between psychology at end-of-life and other areas of professional

psychology.

Notably, the psychologists aged 60+ (Joyce and David) who had been interviewed

described early or first careers in other areas or settings of professional psychology (such

as private practice with adults and children).

Some psychologists were drawn to and remain engaged in working with patients

at end-of-life because of the fact that they are also able to see patients who survive. For

example, Janet and Anna noted that part of what helps them to remain in this work is the

fact that they do not see death exclusively.

Only Joyce demonstrated an actual interest in working professionally at end-of-life as a result of her chaplaincy experiences, and not because of her professional training in clinical psychology. Notably, her responsibilities as director palliative care do not reflect the experiences of other geriatric care psychologists (such as David, Eric, and Amy) in that she does not need to attend to "billable hours." She attributes this professional flexibility to the fact that she was not hired as a psychologist.

Some psychologists, such as Richard and Eric, pursued experiences in end-of-life care primarily because of training and professional opportunities and not as a result of an interest in end-of-life. For example, Richard described pursuing a postdoctoral fellowship in a cancer hospital because he wanted supervision from a mentor, and Eric pursued a career in a nursing home because of flexibility in hours. Eric ultimately plans to transition to private practice while Richard has already established an outpatient private practice working with couples and cancer survivors.

Professional Roles in End-of-Life Care

Psychologists working in end-of-life care provide a variety of services and fill many professional roles. Many psychologists provide some of the more 'traditional' roles of psychologists, such as providing individual therapy, family therapy, interprofessional consultation, supervision, and assessment. These psychologists can also provide these services in a variety of settings, including nursing homes, assisted living and skilled nursing facilities, hospital-based specialized care units, hospitals (including VA hospitals, academic medical centers, and specialty cancer hospitals).

Psychologists also provide valuable services beyond those of the traditional roles of psychologists. For example, Joyce was the director of an entire palliative care

program, overseeing the functioning of an entire multidisciplinary team in issues related

to death and dying in a geriatric care organization. She noted that she was able to draw

upon her skills as a clinical psychologist in working with "difficult" patients and families,

and used the sophistication of thought that she had cultivated from years of practice to

consider clinically challenging and ethical dilemmas from numerous lenses.

Similarly, both Alex and Janet described the unique ways that they were able to

draw upon their skills as psychologists in order to fill additional professional roles. Alex

noted that she provided "advocacy" on behalf of her patients. While advocacy does not

appear to have a specific definition, Alex noted that she strives to "increase moments of

joy" for her patients as they confront death. Similarly, Janet noted that she has been able

to advocate for her patients repeatedly and across settings as their illness advance. The

case she described

working with a man who agreed to speak with her on the last day of his life

illustrates the importance for psychologists to provide care across the timeline of illness.

Janet, Amy, Eric, David, Joyce, Rachel, and Anna were also able to use their

skills as psychologists to cultivate empathy for team members experiencing difficulty

working with some patients with whom they had interpersonal conflict or disagreements

about medical decision-making. This unique consultation role that psychologists can play

in any setting, but in end-of-life care settings in particular, can promote patient wellbeing

by increasing treatment providers' capacities to work effectively with patients, increase

empathy, and likely improve outcomes for patient and provider alike.

Additionally, psychologists demonstrated their value in providing care for patients

but *also* for the staff who provide direct care for patients. David, Eric, Joyce, Amy, and

Rachel discussed the ways in which they have been able to "debrief" or check-in or provide care or seminars for the staff who work with death and dying on a regular basis, and who may have no formal training or professional vocabulary upon which they can draw when experiencing the stress of such profoundly physically and existentially draining work. This can be an incredibly important and challenging aspect of a psychologist's functioning in an end-of-life care setting. Psychologists can provide valuable services to professionals who may not have ongoing access to or support with the loss of patients. While some participants reported that some staff may choose to "disengage" from the patients with whom they work, patients at end-of-life can receive more optimal care from staff who know that they do not need to disengage and have adequate support for the eventuality that they will lose relationships with people they work with.

Psychologists such as Rachel describe the challenges associated with providing consultation to other professionals as a part of their professional roles. When describing a particularly traumatic death of a patient in the setting in which she works, Rachel noted that she had noticed staff members who responded to the death began to experience what appeared to be symptoms of trauma. She described navigating multiple roles in providing care for these nurses:

> I ended up writing a letter for these two nurses, being really clear and saying that I'm not their psychologist, and I didn't formally assess them, but I want to describe to you the behaviors that I saw from them. It was like I navigated multiple roles and multiple clients, even though the staff members weren't clients of mine.

An especially important part of this work, then, is the ways in which psychologists must learn to navigate the numerous roles in which they might find themselves in at any given moment, as they provide care to patients and then also "helping the helpers."

Importantly, I did not interview psychologists who provided end-of-life care in an independent practice setting. While Alex described some of the difficulties associated with providing care at end-of-life as an independent practitioner, it may also be the case that psychologists in medical settings are better equipped to meet the needs of patients in settings where many individuals continue to die (as David highlighted when describing his psychoanalytic training institute which had been based in a hospital).

The variation in professional roles may be better explained by the capacity in which some psychologists were hired. For example, Joyce described being hired as a chaplain, and that if she were hired as a psychologist, she would experience additional pressure to meet quotas for billable hours. She has managed to expand her professional capacity by accepting a lower salary and marking herself as a psychologist and chaplain. She also advocated for flexibility for those psychologists looking to pursue this type of work. By contrast, David, Eric, and Amy are psychologists who consult to their care settings, and their work is marked by the need to meet certain goals and consider financial realities when providing psychological services. None of these three are compensated for attending team meetings or engaging in other non-billable activities, which may promote patient care but which may result in lesser reimbursement.

Referral Process

With the exception of Eric, all of the psychologists interviewed received referrals from other healthcare providers, such as physicians, nurses, and social workers. Eric

received referrals from the company through which he was hired, but he described not being entirely familiar with who made referrals and on what basis they were made.

Notably, most of the psychologists interviewed maintained positive relationships with their referral sources. In nursing home settings, where David and Amy consulted, most of their referrals came from the nursing staff. In medical settings, such as where Anna, Janet, Joyce, and Rachel worked, their referrals came from physicians, nurses, and other medical staff.

Notably, Rachel described feeling as though she demonstrated her value as a psychologist by making other professionals' jobs easier. Anna described a similar experience, wherein she was drawn upon to help physicians discuss treatment options or clarify values. Finally, Joyce described being called upon almost daily by other medical staff to manage crisis situations, aggression, and/or family conflicts at her geriatric care organization.

Overall, the sources of referrals seemed to demonstrate the need for psychologists to continue to demonstrate their value in medical settings and expand beyond traditional psychiatric settings while drawing upon psychologists' unique and in-depth training and expertise to provide more optimal care for patients in these settings.

Psychology at the End-of-Life

The question of what psychologists actually do at end-of-life cannot be answered simply. There are many ways in which psychologists can engage with end-of-life in much the same ways that they would work with patients who do not expect to die with any immediacy; they provide therapy, assessment consultation, advocacy, psychoeducation, and support to other professionals. End-of-life is, some might say, another stage of life.

However, psychologists also shepherd individuals (and their survivors) to an end, knowing they themselves will confront the end of a relationship as well. Rachel described the work when she asked, "What's the intervention, other than to *be* with someone in their sorrow and suffering?" While not all patients experience sorrow and suffering as they die, this highlights the ways in which psychologists can *be* with patients as they die in solitude (a dialectic in and of itself). Joyce noted that she believes that our culture has lost its way of confronting death as individuals believe they can put it off to a later day. Psychologists can demonstrate courage and in promoting a death worth dying for patients, support families and loved ones in leaning into the death, and providing support to those professionals who lose relationships when patients die as well.

Additionally, psychologists like David, Rachel, and Richard appeared to conceptualize their work at end-of-life as "walking with" or "being" with their patients. Notably, these three clinicians approach the work from psychodynamic backgrounds (or, in Rachel's case, psychodynamic interests). David described "walking" with his patients, Richard described "fighting with them," and Rachel described as "be[ing] with" patients. This shift in focus of "doing" something for patients versus simply "being" with them highlights the challenges that Anna documents in her work with trainees, who experience difficulties simply being supportive and present with patients, and the extreme challenges and difficulties associated with being with someone as they ultimately leave you.

Rachel describes how she learned in her training that, as a psychologist, she would need to learn to be comfortable with ambiguity. This could not be truer at end-of-life, where psychologists confront and balance closeness with distance, life with death, sadness with joy, professionalism with humanity.

Supervision and Training in End-of-Life Care

Joyce, Amy, Anna, and Rachel also felt there was not enough supervision and training in issues related to end-of-life across training levels. Anna noted, for example, that she tries to cultivate conversations about death and dying with her trainees when they extern or intern under her supervision in a pediatric oncology setting, but that many demonstrate discomfort with discussions about death and have not had these conversations or substantive training in their graduate programs. However, she noted that she tries to ensure that patients confronting end-of-life not work exclusively with trainees since she is concerned about the duration of time during which a patient can realistically see a trainee. Amy also said that she provides training to mental health professionals in her company when they first start working with her to provide guidance about working in medical settings broadly, as well as to provide psychoeducation about the realities of death and dying and the "sights, sounds, and smells" which they can expect to see with dying patients. She noted that many clinicians have never had exposure to this, and it can be traumatic and a reason many clinicians do not remain in this work for long. Janet noted that psychologists who do go into end-of-life care work settings have to learn and figure out much on their own, as she did. Rachel expressed a similar sentiment in an email she sent to me after the interview (highlighted above, in Graduate and Post-Graduate Training in End-of-Life Care). While Janet did not discuss the deficits in supervision and training opportunities, she noted that she does supervise interns and postdoctoral fellows, and described the ways in which she tries to provide exposure to those trainees, noting that they often have not had that training experience.

Importantly, Anna described a significant challenge in supervising trainees at end-of-life, noting that trainees want to "do" something and that oftentimes, she described she provides supervision in "being" with the patient and accepting the limitations of what we are able to do as psychologists-in-training with someone who is dying.

Very few training programs (at the graduate, extern, intern, or postdoctoral levels) offer supervision and training in end-of-life care, highlighting the experiences shared by the psychologists interviewed. Psychology training programs at every level of training may look to expand upon opportunities for trainees to work with patients at end-of-life to advocate for our role as valuable members of end-of-life care teams.

Barriers to Delivery of Psychological Services in EOL Care

The psychologists I interviewed described numerous personal and systemic barriers to providing care at end-of-life. While these psychologists appeared to have each found their own ways to navigate these barriers, the limitations and difficulties that they may experience may have implications for the field of psychology as a whole.

In nearly every single interview, psychologists discussed the difficulties associated with reimbursement and the finances associated with the provision of care at end-of-life. For those psychologists who consulted to end-of-life care settings, reimbursement appeared to be a major force in the ways in which these psychologists worked. For example, David noted that while he is a Medicare provider, he has adjusted his financial policies to allow patients with certain plans to pay him directly at the Medicare rate, which is lower than what he may normally charge for these patients. He also noted that patients may experience difficulty accessing care at end-of-life in geriatric care settings because these settings can be so expensive, and patients and their families

may not want to pay for an "additional" service. Cultural perceptions of what is most important at end-of-life, such as prolonging life at the expense of quality of life, may influence how these individuals perceive psychological care as individuals age.

Amy, too, noted how she structures sessions to be shorter and "pragmatic" so that she may see more patients. While she noted that she sees patients for longer sessions when it seems appropriate, she must consider her own compensation and financial wellbeing as well. Eric described similar experiences, where he is compensated for the number of patients he sees. David, Eric, and Amy are all inhibited in their ability to attend team meetings and consult with other staff since they are not able to receive compensation for that time.

Anna also described financial barriers. She noted that her department likely needs additional psychologists, but that hiring more psychologists is not "financially incentivized," so that she may have to prioritize which patients she sees and is unable to see all patients who may benefit from care.

Rachel, too, is hired by a governmental organization, and her ability to see patients is dictated by what this organization will ultimately pay for. Similarly, Janet who works at a VA hospital noted that she has to engage thoughtfully with whether or not her work should be conducted by a psychologist or if she should be referring to other professionals, even though she does not experience the same type of financial pressures that other psychologists in end-of-life care settings do.

Additionally, while the psychologists interviewed advocate for the presence of a psychologist at end-of-life, some also noted that there are difficulties in distinguishing their roles in their care settings. For example, Janet noted that because of the overlap in

her role with that of social worker or chaplain (for example), she must constantly ask herself about whether or not she is the most appropriate professional to make a particular intervention (noting that she is the only one to conduct assessments as a psychologist). Similarly, Amy noted how some of her sessions include "advocacy," such as ensuring that her patients can obtain "simple pleasures" and not necessarily a "traditional" psychotherapy intervention. This has important implications for the training of psychologists in end-of-life care since the relative dearth of psychologists in this field also means that well-defined roles of practice may also be hard to find and will vary across settings. Similarly, Joyce is a psychologist but had been hired as a chaplain. While she described using her skills as a psychologist regularly, she felt that she would not have been able to maintain her job if she was compensated the way a psychologist would normally be.

Additionally, Joyce described difficulties with conducting end-of-life psychological work in an outpatient practice setting, noting that as patients are dying, they do not typically have the ability and mobility to travel to an outpatient practice setting with ease. While Richard does currently have an outpatient practice, he noted that he was able to see patients with flexibility (such as making home visits) while he was an intern and postdoctoral fellow working with patients at end-of-life, a reality of which he said would be unrealistic now. This highlights the ways in which psychologists may benefit from adopting innovative ways to work with patients at end-of-life, including telehealth and increasing access to care for patients in end-of-life care settings.

Importantly, the prospect that psychologists do not have enough time with patients as they approach death was discussed repeatedly. While this may reflect some

unspoken wish for patients to remain living, it also demonstrates the time-limited nature

that psychologists must confront at this stage of life. Indeed, Amy, Richard, and Eric also

describe difficulties with patients who died within a few weeks or sessions or before they

could even see them a second time. Broadly, this highlights difficulties with patients

accessing end-of-life care sooner in life. It also marks a reality that psychologists may

need to consider short-term or even single-session interventions for patients.

Psychotherapies to address patients at end-of-life include Meaning-Centered-

Psychotherapy, though even short forms of this therapy are six to eight sessions, a

timespan that may not be realistic for many of the patients seen by psychologists at end-

of-life.

In a similar vein, Rachel discusses how attachment to patients can serve as a

barrier to providing effective care when a patient is dying. In most treatments, an

emphasis on a strong therapeutic alliance permeates effective treatment. Indeed, the focus

of treatment in some orientations is the therapeutic relationship itself. Rachel described

how the attachment may prove a barrier to acceptance on the part of the treatment

provider than an end may be coming, and a mutual denial of death (on the part of the

therapist and the patient) may occur. This is an especially important reality that

psychologists must pursue training and supervision in, as psychologists must learn to

navigate a therapeutic (and real) relationship while acknowledging the inevitability of the

loss of the patient.

Finally, Amy and Janet described difficulties in providing care to dying children.

While Janet noted that she had completed an externship in pediatric psycho-oncology,

which reaffirmed the notion that she could not work with dying children, Amy too

described difficulties she foresaw with being able to work with dying children when she herself may have children, noting that she fears she would see her own children when working with others. By contrast, others noted that personal experiences with death actually promoted their work (such as Janet, Richard, Eric, and Amy). This also highlights a distinct difference for providers in engaging in end-of-life care in a pediatric versus adult or older adult treatment setting and may speak to cultural attitudes about when is an "acceptable" age to die.

Factors that Promote Delivery of Psychological Services in End-of-Life Care

Psychologists identify numerous factors that help promote their ability to work with patients at end-of-life.

Psychologists interviewed described (in a variety of ways) the need to "diversify" their work or to allow themselves to consider those ways in which their work is not limited to death and dying exclusively. None of the psychologists interviewed work exclusively with dying patients, however, and they may not consider how they would cope with working with dying patients only. David described the ways in which he engages in self-care and thinks about his own children and grandchildren and establishes work boundaries. Janet also said that she is able to do this work because she also works with patients who have a life-threatening or life-changing diagnosis and go on to live afterward. Similarly, Joyce and Amy noted that they maintain a work-life balance, which is crucial to their ability to engage in this type of work. David is an independent consultant, while Joyce and Amy work as part of multidisciplinary teams, highlighting the reality that psychologists in a variety of work settings at end-of-life can balance their work and personal lives.

Psychologists also describe the crucial importance of the support that they elicit from and share with friends, family, and, most commonly, fellow team members. Richard noted that he felt team members were most helpful since they understood his loss best. Similarly, Janet, Anna, and Joyce described similar sentiments as they lean on their team for support when experiencing loss. Janet even created a group for her trainees to discuss the losses of their patients. David also noted that he has found that a greater "holding environment" that some nursing homes offer to patients to be helpful to him. This crucial factor highlights the ways in which psychologists face their own loss as patients die and benefit from support. This also marks the differences between the ways in which this type of work is not exclusively professional, and that patients really do affect their practitioners, and that psychologists may not realistically be expected to approach this loss with stoicism.

Importantly, Eric described the single factor that helps him in this work is the understanding and acceptance of the reality and inevitability of death. He described this within the context of his training in DBT that accepting that patients may be dying and, at the same time, holding on to the thought that they may remain alive in spite of their illness. Holding on to the complexity of this thought can be a crucial element for psychologists to effectively engage with patients; to hold on to hope and lean into a relationship and strong attachment, while balancing reality and not denying and avoiding death and the end of the relationships as psychologist and patient know it.

Interdisciplinary Relationships

Psychologists interviewed described largely positive relationships with their colleagues in other disciplines. Richard described some discontent about physicians'

abilities to be honest with patients about their prognosis, and this might highlight a way in which psychologists can consult with other professions about their abilities to discuss death and dying with patients.

Professional Meaning-Making in End-of-Life

All of the psychologists interviewed described infusing meaning into their work and varied greatly in terms of the ways in which they drew meaning.

Across all psychologists interviewed about meaning-making, the notion that there is a meaning in providing help and bearing witness to challenges appears universal. Rachel described how she is able to find meaning in being able to help patients, but also their caregivers (for example, nurses) reconceptualize their roles as providing effective care to someone who makes it difficult to provide care during a profoundly challenging moment of their lives. Similarly, Janet noted that she derives meaning from the ability to be present with patients during this moment in their lives. She also finds that the reality that she confronts death on an ongoing basis has prompted her to reflect on her values and reaffirms her desire to live according to her values. David, too, noted that he finds his work to be a "mitzvah," drawing upon his Jewish religious identity to help ground his work in his religious values. Amy, too, finds meaning and "privilege" in the ability to provide help and be a "guide" to patients as they approach their death.

By contrast, Joyce described an approach to meaning-making that draws upon a global conceptualization of her work. She described the meaning she makes for herself as being able to be a part of a "conversation" about death and dying that can influence how our culture thinks about death and dying.

There was no universal theme I could draw upon to elucidate how psychologists make meaning at end-of-life. This variety in meaning-making illustrates the uniquely personal ways in which psychologists extract purpose and make sense of this work. It also demonstrates the crucial value of drawing meaning in providing care to patients as they inevitably depart.

Influence of Personal Experiences with Death

David, Amy, Eric, Janet, Richard all described ways in which they felt that their clinical work with dying patients had been influenced by their own experiences with death. For most of the psychologists interviewed, close exposure to death had proven helpful in cultivating empathy and a shared understanding of what patients' families may be experiencing, as well as an increased capacity to avoid under- or over-pathologizing.

For example, Amy and Janet both described how their parents' deaths influenced their ability to work with patients; for Amy, she is able to speak to the realities of home-based hospice as she witnessed it for her father's death; for Janet, she felt she could better empathize with patients and their families as a result of the experience of her own loss of her mother and avoids under- or over-pathologizing families experiencing loss. Similarly, David said he had been able to be the "good son" for many of his patients while he filled a similar role as his mother was dying. Eric, too, described the ways in which he felt he had learned as a young child to avoid death, and had been able to lean in to an acceptance of the reality of death after the loss of his grandmother. Finally, Richard said that the loss of his parents allowed him to truly believe that he would be able to survive a loss after it finally occurred to him.

Overall, personal experiences with death seemed to be helpful to clinicians working in end-of-life care in increasing psychologists' abilities to empathize and understand their patients and patients' families.

Influence of Religious and Spiritual Beliefs

David, Janet, Rachel, and Joyce all described the ways in which their own religious beliefs and attitudes have influenced their work with patients at end-of-life. David, Rachel, and Janet described themselves as religious and noted that they had used their own religious backgrounds to cultivate discussions about death, dying, end-of-life, and religious. David and Janet also felt that their capacity to speak about religion with patients helped cultivate the therapeutic relationship and provide a forum through which patients can discuss how religion influences their perceptions of death. While Rachel noted that she had discussed religion with her patients, she said most of the patients with whom she works are "secular."

Joyce, too, felt that her religious background helped cultivate and sustain her interest in her work at end-of-life since she was able to infuse her own religious and spiritual beliefs into her work as a psychologist and chaplain when she began to direct a palliative care service at a geriatric care organization.

Rachel did note that she has found herself "praying" for her patients, which she said makes her wonder about the ways in which praying may cross ethical boundaries, especially if patients have not asked a provider to pray for them.

Finally, Rachel noted that her work at end-of-life had influenced her *own* religious beliefs in that she has questioned her "faith experience." She noted that her belief in a "loving and kind Creator" has contributed to difficulties reconciling "those

beliefs with the suffering, and psychological suffering, and [the] end-of-life legacy. The

people wanting to die who haven't died yet, who seem to be in this waiting period."

While she described this conflict as "tricky," it may highlight the reality that chronic

exposure to death and dying may prompt psychologists to deeply consider the nature of

their religious and spiritual beliefs and that psychologists practicing in this field would

benefit from consultation with professional and religious colleagues when faced with

difficulties reconciling their practice with their professional work. Additionally,

psychologists practicing in end-of-life care should strive to make known to themselves

their own religious and spiritual beliefs and how that may bias or impact upon their work

when working with patients of differing faiths.

Ethical Considerations

The psychologists interviewed in this study highlighted the complex and nuanced

ethical considerations that they must consider when working with patients at end-of-life

across the lifespan.

The situations in which psychologists had to apply their ethical decision-making

skills demonstrated some of the difficulties that remain with any type of decision-making

around death and dying. These decisions included difficult questions, including whether

or not a person has the agency to know they are dying and who gets to make decisions

about death and dying.

Joyce described numerous ethical difficulties as a regular part of her job. She

draws upon her skills as a psychologist to clarify the goals and attitudes of the various

stakeholders with whom she is working but noted that there are really no easy answers to

some of these questions. Similarly, Anna described the difficulty associated with

knowing that a child may be dying, and not being able to disclose that information as a professional if the child's parents did not consent to that disclosure. This highlights the ways in which we determine who "gets to know" about their own death process. Richard discussed similar difficulties working with adult patients, but noted that he had the agency to be able to disclose that information to his patients, and often struggled instead with difficulties associated with other treatment providers not disclosing this information.

Changing Attitudes about Working with Death and Dying

Psychologists interviewed described the ways in which they have changed as professionals as they work in end-of-life care, or how they have observed changing trends in the field broadly. David and Richard described increased confidence in their ability to work with dying patients. Janet also described increased confidence in her ability to work, as well an in her ability to "call out" team members, demonstrating bias about patient's wishes for end-of-life care. David also considered his own mortality more, as he himself ages, and this may be a result of his own identification with older adulthood (and which also highlights the ways in which end-of-life may be conflated with older adulthood). Amy also has grown to accept the more "mundane" aspects of end-of-life work, such as getting a candy bar for her patients to increase "joyful moments," though this may vary based upon a psychologist's perceptions of their role with patients. Finally, Joyce has noted increasing opportunities and awareness about the benefits of end-of-life care.

Professional Landscape for Psychology in End-of-Life Care

As described earlier, there does not appear to be any centralized organization dedicated solely to the professional practice of psychologists working in end-of-life care.

While the American Psychological Association includes specialized divisions dedicated to Health Psychology, Clinical Psychology (including a special interest group in Geropsychology), and Adult Development and Aging, no divisions represent the special interest or practice area of end-of-life care.

Many of the psychologists interviewed have found training, support, and education in end-of-life care from organizations targeted at other professionals, including social work, chaplains, physicians, and nurses. However, the reality is that these psychologists do not have specialized professional "homes" from which they can draw upon the consultation, supervision, and training from psychologists who have expertise in end-of-life care.

Rachel's email (described earlier) reaffirms the need for psychologists to be able to access a professional home as they confront the growing practice area for psychologists in end-of-life care.

Vision for the future of End-of-Life Care

The psychologists interviewed demonstrated hope in psychology's ability to expand its presence in end-of-life care. They described the factors that they envision would promote the growth of psychology in this area of care, including more funding, more access to care, and more training programs. They also described the hope for public education about and destigmatization of palliative care and hospice-based end-of-life interventions.

Limitations

The reader should consider several limitations in the application and interpretation of the results of this study. The first limitation relates to selection bias and sample size

(n=8). The relatively small sample size may not reflect the experiences of psychologists broadly who work in end-of-life care settings.

As a result of the exploratory nature of this study, participant selection was not fully randomized. All participants opted-in to the study through professional contacts or in response to a posting on email listservs.

In addition to participant selection, this study's utilization of exploratory qualitative research design with non-random sampling and no control group may further reduce the generalizability of results, and other interview approaches may have elicited different results.

Additionally, I realized that this study does not explore aspects of diversity in-depth, despite issues of diversity being discussed by participants in numerous interviews.

Finally, some of my own perspectives on death, dying, end-of-life care, and the other topics discussed may have influenced my choice of follow up questions. All of these factors should be considered when exploring the generalizability of this current study.

Concluding Recommendations

The findings from the above eight interviews with psychologists working with end-of-life patients support the following recommendations:

For Practitioners:

- Psychologists must demonstrate creativity and flexibility in their work with dying patients.

- We must also learn to balance dialectics inherent in this work, learning to lean in to closeness with our patients while maintaining one foot in the "land of the living."

- Psychologists must consider their own religious, spiritual attitudes about death and dying, and their own comfort in discussing end-of-life with their patients so as not to reinforce a client's avoidance of death and a client's avoidance of experiencing the loss of a relationship.

- Psychologist engaging with this work should establish supportive professional and personal networks upon which they can rely as a result of the difficulty associated with working with dying patients.

- Psychologists may benefit from pursuing additional training in end-of-life care from other professions, such as from professionals in medicine, chaplaincy, social work, and nursing.

- Psychologists can support medical professionals involved in providing care at end-of-life who may not have access to care in dealing with their own grief and loss.

For the Profession:

- Psychology as a field must confront the field's history of apparent discomfort with death and dying as it works to promote a presence in the growing field of palliative and hospice care.

- Psychology should establish ethical guidelines about working with death and dying as conversations and options for death and dying change, and as attitudes about death change with it.

- Psychology would benefit from increased efforts to provide institutional support, training, supervision, and guidance to individual practitioners in end-of-life care, such as by the creation of a new Division of the American Psychological Association or a new section in the established Division 20, Adult Development and Aging.

- Psychology should provide psychoeducation and advocacy to the community about the mental-health-related aspects of death and dying and provides access to resources for individuals and families as they approach this stage of life.

- Psychology should reframe the public discourse about death and dying away from death as a process of "fighting" and "losing" or "winning."

- Psychology must advocate for its value (conceptually, politically, and financially) in end-of-life care so as to optimize patient and provider care and wellbeing.

- Psychology should develop shorter-term and flexible interventions for end-of-life psychological care.

- Psychology must develop diagnostic codes for patients at end-of-life to be able to discuss end-of-life issues without requiring a mental-health-related diagnosis.

    For Individual Training Programs:

- Psychology training programs should develop more coursework and attention in end-of-life services, including attention to exploring and discussing a trainee's own attitudes, perceptions, and comfort with death and dying.

Reflections

As I reflect on the aims of this study, as well as the potential reach of its implications during a quickly changing global pandemic, I have attempted to highlight

the major findings in order to distill in simple terms what can be learned and applied now.

"Knowing" when a patient will die

Across the interviews I conducted, psychologists articulated the difficulties associated with never "knowing" when a patient will die. While many psychologists work within a framework that presumes that patients and providers alike will have the privilege of time, psychologists working in end-of-life care must radically alter perceptions of time in their work. A psychologist may realistically see a patient one time before the death of a patient. As a result, psychologists may seek to flexibly adapt their interventions and develop short-term interventions that can be applied in end-of-life care settings and in work with dying patients. The prospect of short-term interventions may alleviate some of the distress that psychologists and patients alike may experience in "not having enough time." In almost all interviews, notably, psychologists alluded to the importance of "being with" or "walking alongside" their patients as they approach death. As a result, it would be crucial to emphasize the importance of the therapeutic relationship as essential in any type of effective and therapeutic intervention at end-of-life, especially as patients may feel profound existential isolation as they die.

Psychologists should be intervening earlier

In a similar vein, psychologists interviewed perceive that patients do not engage with end-of-life care early enough to effectively engage with psychology. While individual psychologists may choose to intervene with abbreviated, shorter-term interventions for those patients, psychology as a profession has the opportunity to educate the community about, promote the benefits of and advocate for increased access to end-

of-life care. Psychology has historically demonstrated a commitment to advocacy for underserved communities. In light of the difficulties that psychologists perceive that patients experience in accessing psychological care at end-of-life, psychologists have an opportunity to help promote greater access to care for a potentially underserved community—that of a group of dying patients.

"Changing the narrative" around death and dying

In addition to advocating for greater access to psychological care at end-of-life, psychologists can "change the narrative" that many individuals experience around death and dying. In this study, participants such as Amy and Joyce identified cultural challenges that we face as a society in discussing death and dying, as well as accepting death. Amy even highlighted the language that patients use to describe engaging in treatment for a life-threatening illness as "fighting," and that patients "lose" when they ultimately die or stop "fighting" (by engaging in end-of-life care). Psychologists are well-positioned to adjust the ways in which communities discuss death and dying, and psychologists can provide individuals with an alternative lens from which to view death and an acceptance of mortality. In addition, as evidenced by the COVID-19 pandemic, psychologists can advocate for a shift in thinking, that is, promote thought about *when*, not *if*, life-threatening illness will affect individuals and communities. Psychologists can provide education about the process of death and dying, demystify death, and renew awareness of the ever-present nature of death in life. Similarly, psychologists can advocate for a reduction in existential and death anxiety in communities by promoting the psychological benefits of gratitude for and pride in the life that has been lived, which may

help promote further acceptance of mortality and change our discourse on death as "losing."

"Helping the Helpers"

In addition to promoting greater access to care and adjusting the narrative around death and dying, psychologists can provide care for those professionals who are supporting patients at end-of-life. By "helping the helpers," psychologists may be well-positioned to promote quality of care at end-of-life by attending to the needs of professionals who may lack the training or vocabulary to cope with ever-present death, or who may be experiencing traumatic stress from chronic exposure to death. Participants identified that some professionals may cope with dying patients by "distancing" themselves from patients and disengaging, while others may feel overwhelmed by the loss of relationships. As such, psychologists can provide support and psychological care to these professionals to promote optimal quality of care.

Professionals may experience a reduction in disengagement knowing that they can feel supported by psychologists in their provision of care at end-of-life. During the COVID-19 pandemic, there have been numerous anecdotal reports of the difficulty that frontline healthcare workers are experiencing in providing care under difficult circumstances to dying patients. In moments like these, psychologists can offer a great deal to "help the helpers" cope with this extreme and unusual stress as they work with dying patients.

Advocating for the psychologists' role in end-of-life care teams

In order to promote psychology at end-of-life, however, there is a crucial need for psychology to advocate for its *role* in end-of-life care teams. Because psychologists can

fill a wide variety of roles on multidisciplinary teams, psychologists may benefit from flexibility and openness when considering how they can promote their increased presence on these teams. At the same time, psychologists must be aware of their own limits and areas of competence in this field and pursue additional training and supervision to ensure they are practicing within the scope of their expertise.

Promoting awareness of death and dying in training programs

Finally, psychology as a field must be doing more to promote an awareness of death and dying in training programs. Psychology has done so much to promote life and can do so much more to promote end-of-life. Graduate training programs can promote education and training about death and dying, and highlight the ways in which psychologists can add value at end-of-life. Training programs can also provide training in assessment and intervention at end-of-life in order to cultivate competent professionals prepared to provide care with this underserved population.

Appendix A: Recruitment Email

My name is Alec Miodownik and I am a clinical psychology doctoral student at the Graduate School for Applied and Professional Psychology at Rutgers University. For my dissertation, I would like to interview psychologists who are currently or have previously been employed by or consult to end-of-life healthcare settings including palliative care and hospice care settings.

The purpose of the research is to capture how psychologists draw upon their professional training, clinical skills and knowledge, personal attitudes and beliefs, and their clinical experience to add value to end-of-life care and make meaning of their work. Specifically, this research aims to clarify the practices and roles of psychologists practicing in end-of-life care, determine the nature and training of psychologists practicing in end-of-life care, and evaluate the role and significance of models of meaning for psychologists practicing in end-of-life care.

If you are interested in participating or you know anyone who may be interested in participating, or if you have any questions pertaining to this study, please contact me via email at ajm381@gsapp.rutgers.edu. Interviews are expected to take from 60 to 120 minutes and will be audio-recorded. Although in-person interviews are preferred, videoconference interviews are welcomed as an alternative.

Please note, your participation in this study is completely voluntary and you can terminate your participation at any time. This study offers no compensation for participating. Additionally, all personal, identifying information that is collected will be kept confidential.

If you have any questions about this study, please do not hesitate to contact me.

Thank you for your time and consideration,
Alec Miodownik, Psy.M.
Graduate School of Applied and Professional Psychology
Rutgers, The State University of New Jersey

Appendix B: Phone Screening Script

"Thank you for considering participating in my study. I have a few questions to ask to confirm that you meet the criteria for the study, okay?"

1)   "Do you hold a doctoral degree in clinical or counseling psychology or a respecialization in clinical and or clinical psychology?"
       Inclusion: Holds a doctoral degree or respecialization in clinical and or counseling psychology.

2)   "Do you provide direct clinical services (including psychotherapy and assessment) in end-of-life care?"
       Inclusion: Job responsibilities include the provision of direct clinical services (including psychotherapy and assessment) in end-of-life care.

3)   "Are you licensed to practice psychology in the state in which you are currently employed?"
       Inclusion: Yes.

       If the prospective participant does meet inclusion criteria, the researcher will say, "Great, you meet the criteria for the study. Let me tell you a little bit about what to expect if you decide to participate. The purpose of this research study is to explore the roles and practices of psychologists working end-of-life care settings. You will participate in an individual interview that will last anywhere between 60-120 minutes, plus a few minutes to fill out some brief forms. Your participation is voluntary and you may stop participating at any time. Please note that you will not receive any compensation except for your knowledge that you are contributing to the knowledge of psychologists working in end-of-life care settings. The interviews will be audio recorded so that I can transcribe what is said later. All identifying information will be removed from these transcripts before they are analyzed. None of your identifying information will be recorded or used in the study. Do you have any questions? Are you interested in participating?"
If participant expresses interest, the researcher will say, "Great, let's schedule a convenient time to conduct the interview."

       If the prospective participant does not meet the inclusion criteria, the researcher will state: "I'm sorry, but you do not meet criteria to participate in this study. Thank you for your time and interest."

Appendix C: Consent Form

CONSENT TO TAKE PART IN CONFIDENTIAL RESEARCH

TITLE OF STUDY: A Death worth Dying: A Survey of the Roles and Practices of Psychologists Practicing in End-of-Life Care

Principal Investigator: Alec Miodownik, Psy.M.

This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. After all of your questions have been answered and you wish to take part in the research study, you will be asked to sign this consent form. You will be given a copy of the signed form to keep. Your alternative to taking part in the research is not to take part in it.

You are invited to take part in a research study that is being conducted by Alec Miodownik, who is a student in the Department of Clinical Psychology at the Graduate School of Applied and Professional Psychology at Rutgers University. The purpose of the research is to capture how clinical psychologists draw upon their professional training, clinical skills and knowledge, personal attitudes and beliefs, and their clinical experience to add value to end-of-life care and make meaning of their work. Specifically, this study aims clarify the practices and roles of psychologists practicing in end-of-life care, determine the nature and training of psychologists practicing in end-of-life care, and evaluate the role and significance of models of meaning for psychologists practicing in end-of-life care.

Alec Miodownik may be reached by phone at (917) 683-8664. His email address is ajm381@gsapp.rutgers.edu.

We anticipate approximately 8-10 subjects will take part in the research. You will be asked to participate in an interview which will be conducted either in-person or over a HIPAA-compliant video conferencing website. Your participation in the study will be about 60 to 120 minutes. In-person interviews will be audio recorded using a voice recorder. In instances where subjects will be interviewed via videoconference, interviews will be conducted over HIPAA compliant video conferencing and recorded as well.

Because the interview focuses on the experiences of psychologists working in end-of-life care settings, the risks and discomforts you might experience by taking part in this research include the possibility of unpleasant feelings as a result of recalling some experiences about your work and the possibility of experiencing some discomfort when answering questions.

The benefits of taking part in this study may be that the knowledge that is obtained from your participation and the participation of other subjects may help create a more comprehensive understanding of the roles and practices of psychologists working in end-

of-life care settings. However, it is possible that you may receive no direct benefit from taking part in this study.

You will not be paid to take part in this study.

The research plans to collect the following types of information about or from you: your age, gender, race/ethnicity, religious/spiritual background, and professional background, training, as well as current and previous employment settings. This information will be stored in such a manner that no link between your identity and the data collected will exist. We have plans in place to secure the data in ways that minimize the risk of a data breach, such as being assigned a case number in place of identifying information. Additionally, no identifying information listed above will be recorded or transcribed. Interviews will last from sixty to one hundred and twenty minutes. All data will be stored and managed in accordance with IRB rules and regulation in order to protect participants' confidentiality. All interview transcriptions and audio recordings will be stored in a locked file cabinet accessible only to the PI. Study data will be kept until the study is complete and dissertation is approved. After that, all information will be destroyed.

After the study is over the information collected for this research will not be used or distributed to investigators for other research.

The research team and the Institutional Review Board at Rutgers University are the only parties that may see the data, except as may be required by law. If the findings of this research are professionally presented or published, only group results will be stated.

It is your choice whether you take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time. If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to Alec Miodownik at ajm381@gsapp.rutgers.edu.

If you have questions about your rights as a research subject, you can call the IRB Director at: New Brunswick/Piscataway ArtSci IRB at (832)235-2866 or the Rutgers Human Subjects Protection Program at (973) 972-1149.

AGREEMENT TO PARTICIPATE

1. Subject consent:

I have read this entire consent form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form and this study have been answered. I agree to take part in this study.

Subject Name:_____

Subject Signature:_____ Date:_____

2. Signature of Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed all the important details about the study including all of the information contained in this consent form.

Investigator/Person Obtaining Consent (printed name):_____

Signature:_____ Date: _____

CONSENT TO AUDIO-/VISUALLY RECORD OR PHOTOGRAPH SUBJECTS ADDENDUM

You have already agreed to take part in a research study entitled: A Death worth Dying: A Survey of the Roles and Practices of Psychologists Practicing in End-of-Life Care conducted by Alec Miodownik, Psy.M. We are asking your consent to allow us to audio record you as part of the research. Your consent for audio recording is required in order to take part in the main research.

The recordings will be used so that the PI can transcribe and code interviews once they are complete.

The recordings may include the following information that can identify you: your places of employment and/or work experiences as a clinical psychologist working in end-of-life care settings. In order to protect you from being identified, the recordings will only be made accessible to the PI and the audio recorder and transcribed interviews will be stored in a locked file cabinet accessible only to the PI.

The recordings and interviews will be stored in a locked file cabinet and linked with a code to subjects' identity and will be stored until the dissertation is approved, after which all recordings and interview transcriptions will be destroyed.

Your signature on this form permits the investigator named above to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written consent.

Subject Name _____

Subject Signature _____ Date_____

Principal   Investigator   Signature   _____   Date
_____

Appendix D: Demographic Questionnaire

Participant Code: _____

To be stored separately:
Demographic Information
1. Age:
2. Gender:
3. Race/Ethnicity:
4. Religious/Spiritual Background:
5. Theoretical Orientation:
    a. Psychodynamic
    b. Cognitive Behavioral
    c. Family/Systems
    d. Integrative
    e. IPT
    f. Other: _____
6. Professional Background:
    a. Ph.D./Psy.D./Ed.D.
    b. Clinical/Counseling/School/Combined/Organizational/Applied/Other:_____
7. Specialty Training:
    a. Child
    b. Adult
    c. General
    d. Health
    e. Community
    f. Neuropsychology
    g. Geropsychology
    h. Other (please specify):
8. Years in Practice:

Appendix E: Semi-Structured Interview

Participant Code: _____

Graduate Training
1. How much were issues specifically relating to EOL integrated into your graduate coursework?
2. What kind of training did you receive in EOL care?
    a. How much training was provided in appropriate assessment methods in EOL care?
    b. How much training was provided in the diagnosis of psychological or behavioral disorder in EOL populations?
    c. How much training was provided in psychotherapy as an intervention for EOL populations?
    d. How much discussion was facilitated to address your attitudes, responses, and beliefs about appropriate EOL care?
    e. In your Developmental Psychology course(s) (for example), to what degree was a section on EOL addressed?
    f. Were EOL issues addressed in your Professional Development/Ethical issues course(s)?

Professional Development
3. What led you/inspired you to work in EOL care?
    a. Why did you go into this field?
    b. Trajectory of career
    c. How long have you been doing this work?
    d. Did you expect to be involved in EOL care when you began your career?
    e. How did you become affiliated with the group/practice/facilities/department in which you currently work?
4. In what ways did your training prepare you to work in EOL care?
5. In what ways did your training NOT prepare you to work in EOL care?
6. What kind of training did you/have you pursued towards EOL care?
7. What kind of supervision did you receive in EOL care?
    a. How did this supervision influence your work?
8. Do/Have you supervise(d) other young clinicians?
    a. If yes: Do/Have, how does/has that that influenced your own work?
    b. If yes: What do you think young clinicians need to focus on in starting out working in this field?

Current Work Experiences
9. Describe your work in EOL care settings:
    a. Typical week
    b. Type of facilities
    c. Type of practice
    d. Caseload
10. How does EOL work fit in with your practice as a psychologist
11. Describe your interactions with other disciplines within the facility (nursing staff, physicians, social work, administration etc.):

a. Is it optimal?
b. Why or why not?
c. What would be an optimal collaboration?
12. If you work in different types of facilities, describe how you perceive the differences (between, for example, different patient populations or EOL conditions).
13. Describe your experiences with patients:
14. What are the types of patients you work with? Who is the IP?
    a. Ex: Individual/Families/Couples/Staff/etc.
15. How do you approach working with a new patient?
16. Where do your referrals come from?
17. What are the systems that inform policy for psychologists in EOL care?
    a. Ex: Reimbursement for advance care planning?
18. Does reimbursement work for (or against) the practitioner?
19. Describe a time in which you felt most effective.
20. Describe a challenge you faced:
    a. Ex: Balancing different family interests - Pt. wanting to die versus family wishes to stay alive longer.
    b. Ex: Working with interdisciplinary teams led by medical professionals.
21. What do you see as the most important function you serve in this capacity?
22. How do you choose to intervene when they do?
23. How do you balance the challenges of timing for these weighty topics?
24. How do you conduct a personal assessment of your role(s) based upon your capabilities and institutional support?
    a. Ex: In private practice VS. hospital VS. outpatient clinic.
    b. Not religious leader, not medical doctor, not academic/social worker/nurse (aka "neither fish nor fowl")
25. What barriers do you experience in your effort to provide mental health services in EOL Care?
26. What is your vision for the future (cultural attitudes, changes in EOL care, training etc.)?
27. How has your experience in this work changed through the years?
    a. What is different about the way you practice now versus how you practiced in the beginning?
    b. Ex: Changing policies and attitudes towards death (Physician Assisted Suicide/"Death with dignity")
28. The Report of the APA Working Group on Assisted Suicide and End-of-Life Decisions (2000) noted "The intensity of working with people who are dying makes it essential for such professionals to have a strong support system to handle issues of loss, grief, vulnerability, and traumatization from working so closely with dying and death."
    a. What are the occupational hazards you have identified in EOL work, if any?
    b. What are the support systems you have drawn upon in doing this work?

Meaning-Making

29. How would you define the notion of "making meaning?"
30. Have you found yourself making meaning of the work you do/narratives that you hear?
31. How often/In what types of cases are you looking to do that?
32. If you do find yourself making meaning, how do you make meaning of the work you do, if at all?
33. Does meaning-making look to smooth over dissonance confirming pain? Or does it help to make sense of a situation (i.e. a more acceptance-based approach.)
34. What are the costs and benefits to either approach?
35. How does making meaning of your work inform your clinical practice?
36. What fuels your continued interest in this work?
37. What has been most helpful to you in making meaning of your experience working in this field?
38. What has been a challenge?
39. Process versus Outcome: What informs how you make meaning? Is it knowing that you improved Quality of Life (Outcome) or is it the process of trying to do that (Process)? Or perhaps something else entirely?
40. Personal experiences with end-of-life
    a. Family member?
    b. Did that color their perception of their work?
    c. Or make them prepared?
    d. Or did it draw them to the work?
41. What models guide your decision-making processes in EOL care?
42. What is the role of your own religious/spiritual beliefs in your work, if at all?
43. As EOL issues are considered to be a normal part of life, how do you make sure not to "overpathologize?" Or not?
44. Can you describe a case/individual/family that you have worked with through which you feel that you learned something critically important that may have transformed your practice?
45. Can you give a case example that illustrates how you work?
46. Thoughts/memories/images that stay with you?

Conclusion

47. What has been your experience participating in this interview?
48. Is there anything else you would like to add or think would be worth investigating?
49. Is there anything I did not ask you about your experience that would be helpful to know or consider?
50. If this study could be used toward transforming a particular aspect of EOL care, what would that be?
51. This interview asked you to identify aspects of your professional work as well as the ways in which you do or do not draw meaning from your work in EOL care. Can you comment on why/how both aspects of this interview may be relevant and or critical to EOL work, or do you feel that aspect of this is more important?

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