A CHANGING NARRATIVE: THE IMPACT OF COVID-19 ON THE ROLES OF HEALTHCARE CHAPLAINCY AND ADVANCE CARE PLANNING

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I intend to submit a copy of my Health Science Scholars thesis to the Texas ScholarWorks (TSW) Repository. For more information on the TSW, please visit https://repositories.lib.utexas.edu/.

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Shilpa Rajagopal Date

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Acknowledgments

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Epigraph

“Dear family and friends and whom it may concern

I’m writing this poem to help you discern

The actions to take and the things to refuse

When some terrible day you are faced with the news

That some sudden illness or stroke of bad luck

Has left me unconscious and helpless and stuck

face-up in an ER,

laid out on a stretcher

With chaos around and you’re under pressure

To make some very quick, high-stakes decision

I want you to feel you at least have a vision

Of what you can do, so you’ll know in your soul

That you’ve done what you could with what’s in your control.”

-TIMOTHY BOON, RN from “When Something Has Happened We’d All Prefer Not” (2019)

Abstract

Advance care planning (ACP) is a set of processes designed to help individuals express and document their preferences for future care and treatment interventions in accordance with their unique personal values. Prior research has identified healthcare chaplains as well-suited, yet potentially underutilized, facilitators of ACP given their expertise in spiritual care and healing. While ACP plays an important role in mapping patients' long-term care plans, the physical and emotional strains of the COVID-19 pandemic have disrupted traditional avenues of ACP. As a result, this study analyzed 236 frontline accounts from board-certified healthcare chaplains to identify the ways in which COVID-19 has affected ACP across different clinical settings. Content analysis revealed two major themes: 1) COVID-19 has limited the scope of ACP and completion of advance directives, leading to 2) the emergence of legal, organizational, and technological adaptations in response to these challenges to continue supporting end-of-life care decision-making. Given the severity and progression of COVID-19, such findings suggest that there is heightened urgency for ACP, especially among patients and families who are unprepared or unfamiliar with navigating such conversations. This is further reinforced by the fact that ACP should ideally occur prior to a patient becoming critically ill, necessitating that healthcare professionals approach ACP education from a more proactive stance. Additionally, there may be future opportunities to incorporate the changes in ACP facilitation to foster greater interprofessional collaboration and accessibility through virtual platforms.

Key Terms: advance care planning, COVID-19, goals-of-care conversations, healthcare chaplaincy

"The ventilator's rise and fall.
The ambulance's siren call.
The yellow gown's swish down the hall."
-Rafael Campo (2020)

Introduction

Amid the hospital's fluorescent lights and persistent beeping of the vital signs monitor, a group of physicians evaluate options. The patient is in critical condition, with a failing heart and acute abdomen, leaving surgical intervention as a risky option. A look into the patient's advance directive reveals that the patient has granted medical power of attorney to a loved one. This individual thereby possesses the legal authority to serve as a healthcare proxy and make medical treatment decisions on behalf of the patient who is currently incapable of communicating their preferences. The process of proactively designating medical power of attorney represents an important step in allowing the patient's wishes to be respected, yet this particular situation is further complicated by the fact that the healthcare agent feels overwhelmed and ill-equipped to act as a decision-maker.

While the above scenario is fictional, adopted from a narrative arc in the television series *Grey's Anatomy*, it suggests some of the nuances in carrying out goals-of-care conversations, alternatively known as advance care planning (ACP), in the event of serious or life-threatening illness (Rhimes & Corn, 2013). Deeply personal and intersectional questions that begin with assessing the patient's understanding of the trajectory of their illness and transition to gauging their end-of-life care goals and responses to specific life-sustaining treatments can help guide ACP discussions among patients, healthcare providers, and family members. Examples of such questions may include: "What are you hoping for with your care? What factors matter most to you (independence, quality of life, longevity, comfort at home, etc.)? Who is your support

system? What are your fears about the future? Who do you trust and would like to see involved in discussions about your care?" (The Conversation Project, 2021; University of Utah Health, 2015). The benefits of ACP are manifold: these conversations encourage patients to exert autonomy over their health and well-being, present clinicians with a documented list of preferences to inform future care decisions, offer peace-of-mind, and provide a connectional space for patients and family members to discuss issues of personal significance.

ACP is defined as a collaborative process, involving not only patients and their loved ones, but also different members of the interprofessional care team, including physicians, nurses, social workers, and healthcare chaplains. In particular, healthcare chaplains, whose perspectives are the focus of this study, can serve as useful facilitators of goals-of-care conversations given their role in addressing spiritual and emotional distress through crisis intervention and counseling support. A qualitative study surveying chaplains' participation in shared decision-making between patients and physicians found that chaplains frequently reported engaging in "whole-person/patient-centered care" (Johnson & Wirpsa, 2017). This approach, drawing from Dame Cicely Saunders' comprehensive definition of "total pain" as "a phenomenological connectedness between individual experiences of pain, distress and suffering," helps chaplains view a patient's identities and needs beyond their medical diagnosis, working in tandem with other interprofessional team members to integrate psychosocial, behavioral, and spiritual services as part of the care management plan (Clark, 1999, pg. 734).

In late 2019, the emergence of SARS-CoV-2 and COVID-19 ushered a global pandemic, characterized by high levels of transmissibility and severity of disease complications, which can include pneumonia, pulmonary scarring, respiratory distress, and organ failure (Mayo Clinic, 2021). The escalation of symptoms among acute cases of COVID-19 have resulted in patients

and families grappling with the sudden proximity of death and dying. The urgency in end-of-life care conversations at this time necessitates an understanding of how the pandemic has impacted ACP and the patient experience. This thesis analyzes narratives from frontline healthcare chaplains to portray the challenges and changes in ACP facilitation that have arisen during the COVID-19 era.

Background

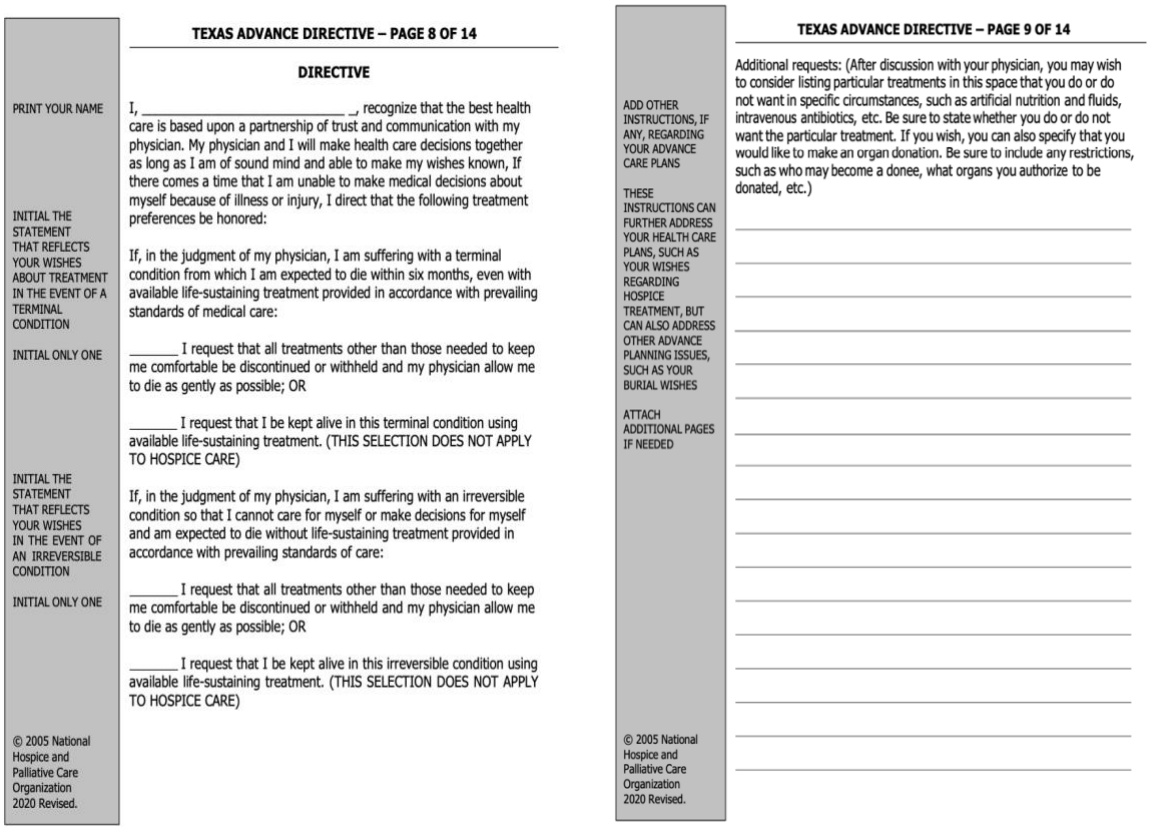
Advance Care Planning

Advance care planning (ACP) is a set of practices enabling patients to decide on future treatment based on their values in the event that they are unable to make such decisions for themselves. These include contemplating and communicating to providers and loved ones about the use of life-sustaining treatment options, resuscitation, artificial nutrition and hydration, dialysis, and ventilation, among other quality-of-life moderators (National Institute of Aging, 2018). Additionally, ACP usually involves completing an advance directive (AD), a legal document that can be periodically updated and outlines these decision pathways for patients, families, and providers (see *Figure 1*, National Hospice and Palliative Care Organization, 2020). Examples of advance directives include living wills, written statements that express these medical treatment preferences, and healthcare powers of attorney (HCPOA), which name another trusted individual to serve as a healthcare decision-making agent on behalf of the patient when necessary (American Cancer Society, 2019). When designating such a healthcare proxy, many individuals may choose their partner, spouse, or close relative; the intent is to select an agent who will adhere to the patient's wishes while remaining calm in the face of critical illness.

ACP discussions serve as an integral component of personalized patient-centric care, ensuring that the types of medical treatments or interventions received are "aligned with the patient's goals and preferences" (Dingfield & Kayser, 2017, pg. 1387). While ACP can theoretically occur at any stage during a person's lifetime, it is most commonly placed under the umbrellas of palliative and end-of-life care. Previous studies have already documented the importance of ACP in healthcare settings including improved quality of care and care concurrent with patients' preferences (Bischoff et al., 2013). However, despite evidence that demonstrates the need for high-quality ACP discussions, such conversations occur with limited frequency; a systematic review by Yadav et al. (2017, pg. 1244) found that approximately "only one-third of American adults completed advance directives" between 2011 to 2016. Notable among major barriers to ACP are training gaps, time constraints, and lack of coordination among healthcare team members to facilitate different processes of ACP (Lee et al., 2018; Blackwood et al., 2019). Moreover, current ACP practices remain disjointed across disciplines, with issues regarding documentation and role clarity among different interprofessional team members cited as concerns (Arnett et al., 2017).

There has been some criticism with regards to the efficacy of ACP, namely due to a perceived lack of communication between patients and their designated healthcare proxy as well as the belief that patients may be unable to understand or articulate their preferences ahead of time in a clear-cut manner (Fagerlin & Schneider, 2004; Sean Morrison, 2020). Yet, such arguments fail to recognize ACP as a dynamic collection of processes, with the goal of helping patients contextualize their care in light of individual and complex life experiences. An excerpt from a response written by Montgomery and colleagues (2020) in defense of ACP outlines part of these considerations from an organizational and structural standpoint:

"One reason there are so many negative ACP studies is that they are conducted within health care systems oriented toward treatment (and often paid more for more treatment or penalized when patients die). ACP is right for patients and clinicians, but health systems have to do their part for it to have real impact. Health care systems need to develop a system-wide infrastructure that promotes quality ACP for all individuals as a standard of care" (Montgomery et al., 2020, pg. 1).



TEXAS ADVANCE DIRECTIVE – PAGE 8 OF 14

DIRECTIVE

PRINT YOUR NAME

I, _____ _, recognize that the best health care is based upon a partnership of trust and communication with my physician. My physician and I will make health care decisions together as long as I am of sound mind and able to make my wishes known, If there comes a time that I am unable to make medical decisions about myself because of illness or injury, I direct that the following treatment preferences be honored:

INITIAL THE STATEMENT THAT REFLECTS YOUR WISHES ABOUT TREATMENT IN THE EVENT OF A TERMINAL CONDITION

INITIAL ONLY ONE

If, in the judgment of my physician, I am suffering with a terminal condition from which I am expected to die within six months, even with available life-sustaining treatment provided in accordance with prevailing standards of medical care:

_____ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; OR

_____ I request that I be kept alive in this terminal condition using available life-sustaining treatment. (THIS SELECTION DOES NOT APPLY TO HOSPICE CARE)

INITIAL THE STATEMENT THAT REFLECTS YOUR WISHES IN THE EVENT OF AN IRREVERSIBLE CONDITION

INITIAL ONLY ONE

If, in the judgment of my physician, I am suffering with an irreversible condition so that I cannot care for myself or make decisions for myself and am expected to die without life-sustaining treatment provided in accordance with prevailing standards of care:

_____ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; OR

_____ I request that I be kept alive in this irreversible condition using available life-sustaining treatment. (THIS SELECTION DOES NOT APPLY TO HOSPICE CARE)

TEXAS ADVANCE DIRECTIVE – PAGE 9 OF 14

ADD OTHER INSTRUCTIONS, IF ANY, REGARDING YOUR ADVANCE CARE PLANS

THESE INSTRUCTIONS CAN FURTHER ADDRESS YOUR HEALTH CARE PLANS, SUCH AS YOUR WISHES REGARDING HOSPICE TREATMENT, BUT CAN ALSO ADDRESS OTHER ADVANCE PLANNING ISSUES, SUCH AS YOUR BURIAL WISHES

ATTACH ADDITIONAL PAGES IF NEEDED

Additional requests: (After discussion with your physician, you may wish to consider listing particular treatments in this space that you do or do not want in specific circumstances, such as artificial nutrition and fluids, intravenous antibiotics, etc. Be sure to state whether you do or do not want the particular treatment. If you wish, you can also specify that you would like to make an organ donation. Be sure to include any restrictions, such as who may become a donee, what organs you authorize to be donated, etc.)

Figure 1. Example of an advance directive document for the state of Texas (National Hospice and Palliative Care Organization, Revised 2020).

Role of Healthcare Chaplains

Healthcare chaplains are trained to provide spiritual and faith-based counseling support to patients, family members, and other interprofessional care team staff. Notably, professional

chaplains display “sensitivity to multi-cultural and multi-faith realities,” acting in an advocative capacity by discussing patients’ values and addressing their emotional and existential needs during times of health crises (VandeCreek & Burton, 2001, pg. 85). One proposed conceptual framework for understanding the roles of chaplains in healthcare settings is the Spiritual Assessment and Intervention Model (AIM). Spiritual AIM (see *Figure 2*) discusses the intervention strategies and approaches adopted by professional chaplains based on three primary spiritual needs: “meaning and direction, sense of community, and ability to love and be loved” (Shields et al., 2013, pg. 78). Observations of patients’ attitudes and behaviors thus enable chaplains to identify the spiritual concern(s) of patients, families, and/or co-workers and build relationships to affirm, support, and reflect with their clients.

Among these responsibilities, healthcare chaplains are seen as facilitators of advance care planning (Kwak et al., 2021). Their skillsets in engaging in difficult, nuanced conversations with patients and families are well-suited to the broader purpose of ACP, designed to identify patients’ hopes and fears to inform future care plans. The duties of chaplains in coordinating ACP processes can range from in-depth discussions to family care conferences and assistance with advance directive completion. Additionally, given their close ties to patients and families, chaplains can be viewed as liaisons for the healthcare provider team by collecting and communicating key information between groups (Teague et al., 2019). In this capacity, the involvement of healthcare chaplains also represents increased opportunities for interprofessional collaboration in the workforce.

Plan for Embodiment of the Chaplain—"to Be"		
Guide	**Valuer and Community**	**Prophet and Truthteller**
Intervention—"to Do"		
• Name and reflect back emotions (especially anger) as a source of clarity. • Surface what decisions need to be made or questions need to be answered. • Ask patient how he/she has coped with similar crises and circumstances or made decisions in the past. • Help patient to name resources to help make decisions, answer questions, or achieve clarity about their heart's desire. • Demonstrate support and guidance, as if walking along side patient on a path.	• Surface anger as source of energy; accompany him/her as they feel it. • Surface old, unhealthy, unkind beliefs about self. • Create a "community of two" by keeping patient company and listening to his/her story of illness/suffering. • Make specific, genuine statements of affirmation about attributes, role, and behavior of patient. • Listen attentively while valuing patient's story. • Empower patient to identify what is loveable about them.	• Demonstrate ability to tolerate patient's anger. • Surface and explore sadness, fear, grief, loss of sense of control beneath the anger. • Acknowledge brokenness, tension, or estrangement in the relationships patient discusses. • Remind patient of own internal resources/abilities to advocate appropriately for self. • Hold patient accountable for creating safety for self and choosing to trust others. • Remind patient to say what they need rather than expect others to intuit it.

Figure 2. Excerpt of Spiritual AIM framework describing the roles of chaplains as guides, valuers, and truthtellers based on patient needs (Shields et al., 2013, pg. 79).

COVID-19 and Spiritual Care

Examining health through a multi-dimensional lens often involves acknowledging and addressing the "totality of the patient's relational existence," a combination of "physical, psychological, social, and spiritual" factors (Sulmasy, 2002, pg. 24). The bio-psycho-social-spiritual model of health (see *Figure 3*) thus encompasses patients' "current circumstances, needs, risk and protective factors, and the environmental context within which these elements exist" (Gale & Therivel, 2019, pg. 1). Specifically, spirituality is rooted in finding a sense of purpose through one's life by means of "connectedness to others, self, nature, and the significant or sacred" (Puchalski et al., 2014, pg. 643). This focus on the individual through self-exploration helps distinguish spirituality from religion, which is centered on a set of organizational practices and beliefs.

In essence, spirituality encompasses facets that bring fulfillment and peace to a person. For patients with serious or life-threatening illnesses, spiritual concerns may often feature heavily in deeply personal questions related to life's meaning, death, gratitude, hope, and the

aspects that constitute a life well-lived. Moreover, at a time of loss and despair, spiritual and psychosocial care can also act as a source of community support to foster belonging, which can act as protective factor when coping with stress (Wickham, 2019). These themes run in parallel to the goals-of-care conversations that occur during ACP; as such, spirituality is an intrinsic dimension to ACP. Guiding patients through the process of articulating their hopes, fears, and needs can be translated to tangible medical care decisions and provide patients with a feeling of agency and control over their health.

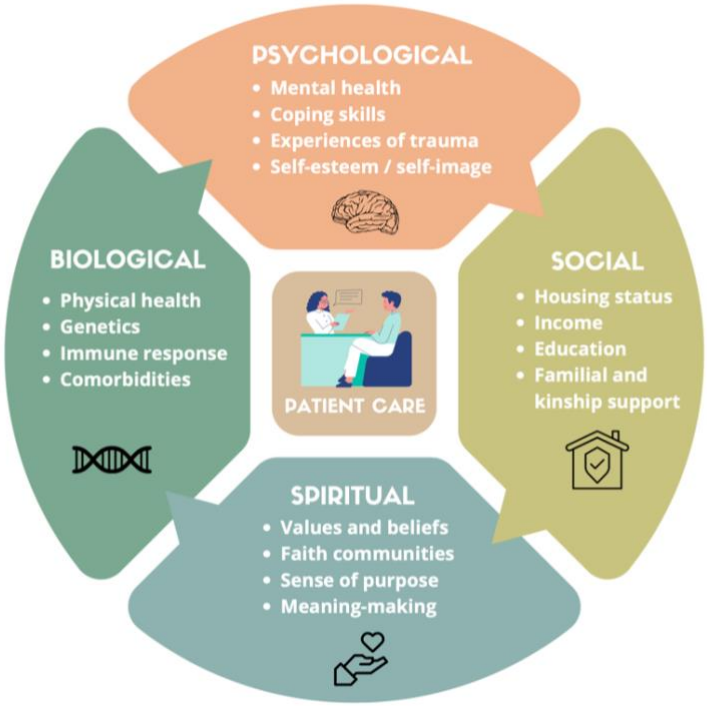


Figure 3. Components of the bio-psycho-social-spiritual model in promoting whole-person care.

The COVID-19 pandemic, which began in December 2019, has been defined as an unprecedented outbreak, a "combination of a new microbe that has a spectacular degree of capability of transmitting, and has a considerable degree of morbidity and mortality" (Fauci, 2020). According to data from the Centers for Disease Control and Prevention (2021), total deaths in the United States from COVID-19 have amounted to approximately 550,000, while

total cases have surpassed 30,000,000 as of April 2021. Yet, for many, the pandemic has led to "an incalculable loss," its precarity creating substantial strains on existing healthcare systems as the lives of patients and families are upended by the human costs of the disease (New York Times, 2020). Specifically, hospitals have found themselves overburdened by the demand for intensive care unit (ICU) beds, personal protective equipment, and healthcare personnel on-call, with facilities in rural areas disproportionately affected by the scarcity and inequitable access of medical resources. An example of such circumstances can be seen with the regional Avera Health system in South Dakota, "a network of 37 hospitals [that] reported sending more than 150 people home with oxygen tanks to keep beds open for even sicker patients" (Meyer & Madrigal, 2020). This overwhelming state of affairs has intensified the pandemic's emotional toll on local communities. The ensuing suffering and grief experienced by patients, family members, and healthcare staff have highlighted a need for re-imagined spiritual and psychosocial support, especially when considering the pandemic-imposed boundaries placed around gatherings, funerals, and other avenues of "traditional pastoral care to the dying and the bereaved" (Hospice Foundation of America, 2020).

As an infectious disease requiring extensive social distancing and masking protocols due to high rates of respiratory transmission, COVID-19 has presented unique difficulties in maintaining face-to-face relationships with patients. Restrictions placed on visitors have prevented family members from seeing their ill or dying loved ones in-person, creating conditions that not only impair patients' and families' sense of community, but also compound psychosocial challenges given the aforementioned constraints on bereavement rituals. These concerns about patient isolation and distress highlight the importance of social networks in the care delivery process, with chaplains more frequently needing to assume the role of a "valuer" or

"intermediary" to validate and affirm patient and caregiver experiences during the pandemic (Shields et al., 2013, pg. 81). Moreover, the health of patients with COVID-19 can deteriorate quickly compared to certain chronic or long-term diseases; the difference underscores the urgency for ACP-related conversations to occur prior to severe illness and may be associated with a potential increase in demand for chaplains' services in the inpatient setting. These conclusions are substantiated by several studies conducted during the early stages of the pandemic, including observations from the University of Colorado Health, which found that use of an online ACP tool through patients' electronic health record portal increased among patients by about 148% during January to April 2020 (Portz, 2020). On a similar note, the West Virginia Center for End-of-Life Care documented a "77.18% increase in DNR [do-not-resuscitate] cards (1933 vs. 1091) received in the first six months of 2020" compared to the initial six months of 2019 (Funk et al., 2020, pg. e7).

Public Health Significance

In light of COVID-19, ethical and moral strains regarding scarce medical resources such as a shortage of ICU space, supplemental oxygen, and ventilators have led to patients and providers alike grappling with the inevitable inequities of allocation. These issues, which encompass emotional and social dimensions alongside the purely medical considerations, are often addressed through the lens of interprofessional care teams, including chaplains. Additionally, the mental and emotional fatigue of COVID-19 has further demonstrated the need for healthcare professionals who are equipped in providing holistic counseling and spiritual care services.

Amid the pandemic, there has been little research published to date on the intersecting roles of healthcare chaplaincy and advance care planning within the United States. This qualitative study analyzes over 200 written survey responses from chaplains to explore 1) the changes in

advance care planning as a result of COVID-19 and 2) the impact of such challenges on chaplaincy practices and delivery of spiritual care. This work investigates trends in advance care planning due to the pandemic and highlights some essential policies and practices that may guide spiritual care services in meaningful ways for patients and families facing the potentially life-threatening implications of COVID-19.

Methods

Data Collection

From March to July 2020, an online survey of 585 board-certified healthcare chaplains was conducted by the UT Gerontology Lab. These chaplains were recruited from three major chaplaincy organizations in the United States: the Association of Professional Chaplains, the National Association of Catholic Chaplains, and the Spiritual Care Association. An open-ended question asking how COVID-19 impacted chaplaincy practices was incorporated in the survey, eliciting written responses from 236 participants in the sample. This question connected the perceived experiences of the pandemic with the diverse responsibilities of healthcare chaplains, including advance care planning and end-of-life care concerns. The overall research study received Institutional Review Board approval (protocol number 2020-01-0024).

Data Analysis

Qualitative data collected from the survey were analyzed through content analysis, a process of examining textual responses to discern common conceptual trends and key words. Using Excel, responses were initially summarized, coded, and categorized via a two-tier coding system featuring broad thematic groupings under which several sub-themes were housed.

Specifically, drawing from an abstraction process, the text was condensed and labeled based on the methods outlined by Graneheim & Lundman (2004) as part of a line-by-line coding approach. To help establish credibility and trustworthiness of the data analysis, approximately 10% of the codes were verified by a second individual. Moreover, these codes were discussed in collaboration with Jung Kwak, PhD, MSW to achieve clarity and consensus across the primary results. Example quotations delineated by sub-theme are embedded as part of this thesis.

Responses were organized into dichotomized variables to indicate the presence or absence of a particular theme and sub-theme. This format allowed for supplementary cross-tabulation across demographic variables via Statistical Package for the Social Sciences (SPSS) analysis and yielded data on the frequency of a given theme/sub-theme. Among these demographic variables were the chaplains' race/ethnicity, gender, religious affiliation, employment status, work setting, service line designation, and information about the patient populations served.

Results

Descriptive Statistics

The majority of chaplains included in the full coding analysis were white (n=208, 88.9%), female (n=139, 58.9%), identified religiously as Protestant (n=123, 52.6%), and were employed full-time (n=201, 85.5%). A total of 99 chaplains reported that over 60% of the patients whom they served were experiencing a serious or life-threatening illness. The most common work setting for surveyed chaplains was a community hospital (n=101), followed by an academic medical center (n=41) and inpatient or home hospice (n=25) (see *Figure 4* for

classification of different work settings). Additionally, about 48% of chaplains were designated to palliative care, ICUs, and/or oncology.

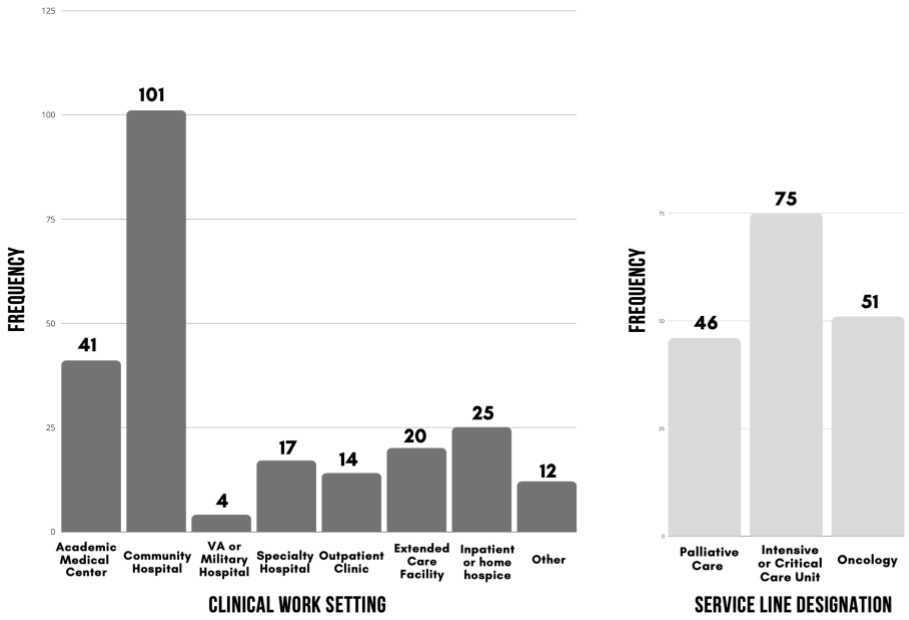


Figure 4. Overview of work settings and service line designations for surveyed chaplains.

Major Themes

The results presented in this thesis are part of a more comprehensive study on healthcare chaplaincy and spiritual care conducted by the UT Gerontology Lab under the direction of Jung Kwak, PhD, MSW. Upon examining responses to the survey question about COVID-19 implications, several themes were identified using content analysis. These included 1) various risk mitigation efforts reported by chaplains, such as visitor restrictions and limitations on in-person patient rounding; 2) depersonalized spiritual care delivery methods adopted by chaplains because of social distancing mandates; and 3) greater need for psychosocial support in response to the stress experienced by patients, families, and healthcare staff (Kwak et al., 2021, Unpublished manuscript). Additionally, a subset of the responses specifically discussed ACP

practices from the perspective of healthcare chaplains; these findings with a focus on ACP serve as the basis of this thesis paper and are discussed in detail below.

When analyzing the impact of COVID-19 on ACP, two major themes emerged from the analysis: 1) limited ACP and completion of advance directives (including legal barriers impacting witnessing, patients' severe illness status, and difficulties communicating with patients' families), which have shaped 2) responses to ACP facilitation challenges. These changes encompass modifications to witnessing processes, greater incorporation of technology and telechaplaincy tools, increased recognition among chaplains for the need to proactively approach ACP, increased focus on discussions centered on code status concerns and orders, ethical concerns over limited resource allocations due to scarcity, and expanded avenues for interprofessional collaboration.

Limited Advance Care Planning and Completion of Advance Directives

Chaplains reported various constraints in carrying out ACP conversations and documenting patient wishes through advance directives (ADs) (see *Table 1*). Among these limitations were legal barriers to fully completing ACP-related documents due to the social distancing guidelines and visitor restrictions posed by the pandemic. The signing of ADs must typically be witnessed by two qualified individuals; by law, qualified witnesses generally cannot be direct family members or healthcare representatives. As such, the lack of available witnesses in light of hospitals' and clinics' COVID-19 risk mitigation efforts has prevented AD forms from being finalized. The responses listed below from several chaplains offer examples that point to the prevalence of witnessing barriers and its implications for "sub-optimal" ACP documentation (Response ID: R_10TAv).

- "HCPOA/LW [Health Care Power of Attorney/Living Wills] are no longer executed at my hospital. Due to visitor restrictions witnesses and notary are not available." (Response ID: R_1pM5b)
- "ACP pretty much came to a stop at my institution since we couldn't have a patient sign or have witnesses." (Response ID: R_3KUCh)
- "We are currently not offering ADs at our hospital because of COVID. Our state (NC) requires 2 witnesses, who cannot be Hospital employees and we are currently not allowing Patient visitors except in a few circumstances. It is literally impossible to execute an AD." (Response ID: R_tRkH5)

Beyond the legal challenges associated with AD completion, chaplains noted difficulties in facilitating meaningful ACP discussions with COVID-19 patients and their families, attributing them to both the narrow use of virtual platforms and health conditions of the patients themselves. The inability to be physically present alongside patients was perceived as a barrier to carrying out conversations that are intimate and reflective in nature, contributing to a depersonalized ACP process with family members and loved ones. As one healthcare chaplain indicated, "Family conferences and decision-making [were] challenged because of holding more conversations on phones…family members couldn't see and visit patients" (Response ID: R_1IT7h). Another chaplain stated that COVID-19 has made it "harder to glean patient wishes or have direct conversations, since I'm doing fewer home visits & my patient population is older, less capable in video or phone communications" (Response ID: R_2UXip). While COVID-19 has increased the use of technology to delivery healthcare services, issues surrounding accessibility and usability of technological resources continue to persist when considering who such platforms are intended to serve and support.

Moreover, the physical health state of COVID-19 patients contributed to the difficulty in conducting ACP conversations. Several chaplains indicated that patients were too ill to engage in discussions related to ACP and documentation of care plan preferences. The fear among patients that engaging in ACP conversations means they are actively dying has previously been cited as a barrier to ACP facilitation from the patient perspective (Bernard et al., 2020). As such, disinterest and miscommunication in the purpose of ACP, to elucidate and document goals of care, tend to cause individuals to postpone or ignore ACP-related topics until it may be too late. This has become especially true with the suddenness and complicated progression of COVID-19, leaving those who had unexpectedly become severely ill with few options to formally document their wishes. One chaplain described the concern as follows: "The often rapid on-set of life-threatening symptoms often precludes ACP considerations and conversations. Without hard evidence, my sense is that the number of severely ill or dying persons without advance directives is proportionately much higher" than prior to the pandemic (Response ID: R_2V8FF). This was echoed by another chaplain who responded that "the very sick COVID-19 patients they [sic] may be unable to participate in a discussion of Advance Planning for their own wishes. This conversation would be better discussed prior to the patient being admitted to a nursing home and/or a hospital setting" (Response ID: R_OOvIY). Moreover, social distancing protocols dictated by COVID-19 have limited the often intimate and individualized care environment that chaplains rely on when consulting with patients. As one chaplain reflected, "I depend on eye contact and body language to assess patient's readiness for conversation and their confidence in the decisions they make. Often with COVID -19 patients, they were so sick they were not capable of even having the conversation" (Response ID: R_YWRL2).

THEME 1: LIMITED ADVANCE CARE PLANNING AND COMPLETION OF ADVANCE DIRECTIVES	
Sub-theme	**Sample Quote**
1A. Legal issues impacting witness protocol and/or completion of documents (n=9)	*"It has been more difficult to fulfill state's requirements for notarization with two witness (not family or hospital employees) as there are less volunteers available."* (Response ID: R_1rBOd)
1B. Patients too ill to engage in ACP conversations (n=3)	*"From what I am learning re: the very sick COVID-19 patients they may be unable to participate in a discussion of Advance Planning for their own wishes. This conversation would be better discussed prior to the patient being admitted to a nursing home and/or a hospital setting."* (Response ID: R_OOvIY)
1C. Difficulties in communicating with COVID-19 patients' families (n=10)	"*During time of visitor restrictions, family conferences and decision-making was challenged because of holding more conversations on phones, that family members couldn't see and visit patients. There was also uncertainty of doing goals of care for COVID-19 patients themselves, given multiple factors*." (Response ID: R_1IT7h)

Table 1. Salient quotes for theme 1 and associated sub-themes based on coding methods.

Responses to Advance Care Planning Facilitation Challenges

The aforementioned limitations with ACP during the COVID-19 era have resulted in adaptations to existing ACP facilitation processes. These include the implementation of new laws that have modified the criteria for witnessing, increased reliance on telechaplaincy and virtual tools to engage in ACP-related discussions, greater interprofessional collaboration, increased focus on discussions centered on code status concerns/orders with patients and families, and ethical concerns over limited resource allocations due to scarcity (see *Table 2*). Additionally, COVID-19 has created greater recognition and awareness for ACP among chaplains and other healthcare staff members, signaling potential opportunities to expand the scope and accessibility of ACP in the future.

In response to witnessing barriers posed by limited in-person visitors in hospital and clinic settings, several chaplains reported changes in institutional and state-wide laws to offer a

workaround. These modifications to AD completion have provided an outlet for certain facilities to continue coordinating ACP at a time of need. Two example responses from chaplains describing new legal proceedings as a result of COVID-19 are included below:

- "By state law, two non-hospital staff witnesses were required to complete the documents with our inpatients. We were unable to complete ADs because of a lack of available witnesses for two months. Then, the state legislature passed a temporary rule to allow for the completion of documents with only a notary required. Thus we were able to resume completing ADs with patients. Also, more of our staff members were interested in completing ADs." (Response ID: R_2qgVo).
- "The witness/notarization process has significantly impaired our ability to complete documents. Fortunately our state has incorporated new rules around this process at this time and we can now complete them without witnesses." (Response ID: R_3gTbV)

Reliance on telechaplaincy also increased among chaplains, who indicated using a variety of technological platforms, from video conferencing sites to patient intercoms, to connect with patients despite restrictions in place for in-person patient rounding. One chaplain recognized that while these "organization-imposed regulations for the protections of patients, staff and family members" have "limited the ability to have in-person family conferences and some in-person patient visits…ACP has continued" (Response ID: R_28NSz). It was noted, however, that "in-person engagement [for ACP] has been limited to phone and computer conferencing technology" (Response ID: R_28NSz). Technology has also offered additional avenues to chart patient wishes following goals-of-care conversations. For example, one survey respondent indicated that "we [chaplains] have a lot of patient and family conversation over the telephone. If the

quarantined patient doesn't have an Advance Directive, we will at least try to document their verbal preferences in the medical record" (Response ID: R_2eVgx).

Chaplains also reported more frequent incidences of interprofessional support, especially with nurses and social workers, to care for patients and families. This is especially important given that COVID-19 has made it "crucial that ACP occur as early as possible and that it is a collaborative, team effort" (Response ID: R_1OP65). Given the increased demand placed on physicians and other healthcare workers due to high rates of COVID-19 hospitalization, instances of team-based care can potentially decrease time constraint barriers associated with ACP by engaging more qualified staff members such as chaplains in the process.

While several of the changes in witnessing, use of technology, and recognition of more interprofessional processes can act as facilitators of ACP amid the pandemic, infrastructure and capacity limitations within the hospital have presented conditions such that when ACP does occur, these conversations are often narrower in scope, typically restricted to discussions about code status concerns and orders. This was emphasized by one chaplain who stated that "we are now having specific conversations with patients/families around 4 key areas: hospitalization, decision maker, ventilation, and code status. We guide patients to their physicians on many of these key areas…simply plant[ing] seeds to start thinking about wishes" (Response ID: R_1rpi3). Additionally, concerns regarding ethical decision-making have emerged due to the distribution of scarce resources in the hospital. A chaplain respondent juxtaposed the "greater awareness of the need for ADs" with the "greater awareness [among patients and loved ones] that they [ADs] may not be able to be honored, given worst-case allocation of resources situations" (Response ID: R_1FQ9T).

In light of these changes, the external conditions and urgency of the pandemic have contributed to an increased recognition among surveyed chaplains of the necessity for proactive ACP. The many limitations and difficulties highlighted by respondents suggest that ACP is an essential part of care delivery; proper documentation not only streamlines healthcare decisions, but also promotes quality of life due to an alignment with patient preferences. As one chaplain explained, the COVID-19 pandemic has served as "an example of the need for ACP for any situation - not just end-of-life. We never know what is 'around the bend.'" (Response ID: R_XBvrM).

THEME 2: RESPONSES TO ACP FACILITATION CHALLENGES	
Sub-theme	**Sample Quote**
2A. Changes to witnessing process for ACP document completion (n=8)	*"More often than previously, we do video or phone facilitation of ACP and have ACP RN sign patient name on forms per their permission and then 2 chaplains witness instead of in person facilitation. We are also only trying to complete Power of Attorney forms in person for hospitalized patients instead of completing Advance Directive."* (Response ID: R_3Faca)
2B. Increased reliance on technology and telechaplaincy (n=12)	*"Major changes - doing ACP during COVID - no paper docs in the room, oral directives witnessed via phone or video call, etc."* (Response ID: R_3FIr0)
2C. Increased recognition for the need to proactively engage in ACP (n=20)	*"It has added a sense of urgency in completing updated Advance Directives and in identifying funeral and burial plans. In our Home for Veterans, we have increased use of PPEs, Virtual Communication, have restricted staff to a primary unit to avoid cross-contamination and essentially quarantined members (patients) to rooms with no group activities."* (Response ID: R_25uUM)
2D. Increased focus on discussions centered on code status concerns and orders (n=6)	*"We are specifically and in detail addressing the desire for ventilation and CPR for any patient who may have COVID."* (Response ID: R_2Cwjg)
2E. Ethical concerns over limited resource allocations due to scarcity (n=8)	*"During the peak of COVID, there was much conversation regarding allocation of resources and chaplains within our region sought to support COVID + and Patients Under Investigation (both end of life and not end of life) through virtual visitations."* (Response ID: R_1LYvg)

2F. Greater interprofessional collaboration (n=8)	*The facility "was hit hard by COVID…I am not allowed to work on the Isolation Unit (but rather provide resources/rituals via nurses). I continue to work with non-covid residents, 1x1 in their rooms (those confined to their rooms/staying in place). I have found that there are more instances of residents sharing about/pondering/talking about death, end of life questions…The SW [social worker] has worked with families to update POLST [Physician Orders for Life-Sustaining Treatment], in light of covid, if felt appropriate.*" (Response ID: R_1ISN3)

Table 2. Salient quotes for theme 2 and associated sub-themes based on coding methods

Discussion

Key Findings

Healthcare chaplains surveyed in this study indicated that COVID-19 limited the general capacity and space for goals-of-care conversations with patients and families. Legal obstacles posed by a lack of external visitors who could serve as witnesses to advance directives reduced the completion of ACP documents that outline patient preferences. Furthermore, medical complications due to the rapid progression of COVID-19 left certain patients too ill or frail to effectively engage in much-needed ACP discussions. In these instances, treatment decisions would likely be delegated to family members and clinical staff who may experience heightened moral distress or feel otherwise unprepared to handle the magnitude of issues pertaining to end-of-life care.

As a response to general sentiments of reduced ACP in-person because of COVID-19 restrictions, healthcare chaplains have turned to novel approaches in the facilitation of ACP and spiritual care services. Among these are organizational and state policies that have modified the process of witnessing and securing signatures for advance care directives. In some areas, laws that previously required a set number of non-hospital staff witnesses for the completion of ADs

were changed to account for visitor restrictions in place. Other chaplains relied on technological resources, including video conferencing applications like ZOOM® and FaceTime®, to continue conducting virtual ACP visits and patient-family consultations in a safe manner.

Significantly, when looking at the changes in ACP brought about by the pandemic, chaplains reported greater recognition among healthcare professionals with regard to the importance that ACP holds in promoting shared medical decision-making. This finding in particular underscores the necessity of beginning ACP-related discussions earlier in the caregiving process. By definition, ACP is weighty and sensitive, and it requires that individuals contemplate and confront difficult questions before they become real. Educating patients earlier about the importance of beginning goals-of-care conversations prior to the event of hospitalization can serve as one possible avenue to encourage ACP. In these instances, ACP may be branded as a security measure to prepare for future life events, an act of compassion that reduces families' decisional burden, and a preservation of patients' relational autonomy. Ideally, ACP education should be done in a coordinated fashion that involves primary care providers and other interprofessional team members, including healthcare chaplains, to fully address patients' concerns. Moreover, online tools designed to streamline and increase comfort around ACP conversations (e.g., VitalTalk, an educational platform focused on developing clinicians' skills to engage in serious illness conversations) can serve as useful resources in training healthcare professionals about the importance of patient-centered ACP.

Intersections with Health Policy

While legal barriers preventing advance directive completion due to a lack of qualified witnesses were cited as limitations to ACP in this study, some chaplains reported the implementation of alternate policies to adapt to COVID-19 conditions. These policies tend to be

passed at the state level and are often considered temporary. For example, in May 2020, North Carolina included language in NC S704, the state's COVID-19 Response and Aid Act, pertaining to witnessing. The legislation states "the requirement of G.S. 321-16(3) that a health care power of attorney be executed in the presence of two qualified [disinterested] witnesses shall be waived for all instruments" in light of the declared "state of emergency" until August 2020 (S.B. 704, 2019 Session). Additionally, Texas' Health and Safety Codes under Sections 166.032b-1 and 166.154b include provisions that the declarant (in the case of an advance directive) or principal (in the case of a medical power of attorney), "in lieu of signing in the presence of witnesses, may sign the directive [or other ACP document] and have the signature acknowledged before a notary public" (Advance Directives Act, Texas Health and Safety Codes). Due to in-person gathering restrictions enforced to mitigate the spread of COVID-19, the Office of the Governor (2020) invoked a suspension of these criteria to permit meeting with a notary public through a two-way videoconferencing platform in the state of Texas. Such health policy measures, centered mainly on remote notarization, are significant because they broaden the accessibility of ACP, providing an avenue for more individuals to take action and complete these legally binding documents in a safe, socially distanced manner.

Strengths and Limitations

The large sample size serves as one strength of this study. Although many written responses to the open-ended question were shorter in length compared to those from traditional qualitative study forms (e.g., in-depth interviews), the overall number of participant responses ultimately allowed for more perspectives to be included in the theme/sub-theme identification process. Furthermore, this research is unique as it is centered around healthcare chaplains, a generally under-studied population of the broader interprofessional care team. Providing a space

and platform for healthcare chaplains to discuss their views on the intersection of ACP and COVID-19 thus not only offers a novel lens to examine the pandemic's impact on the patient and caregiver experience, but also lends greater visibility to the nuanced roles occupied by chaplains in a clinical context.

Since this thesis generally discusses implications of COVID-19 on ACP, there is potential for the data to be further analyzed across time, geographic location, and workplace setting through cross-tabulation to chart how differential rates of COVID-19 incidence and mortality have affected chaplaincy practices. The study is also limited in terms of its sample characteristics. Respondent demographics indicated that a majority of the chaplains surveyed are white; moreover, few reported largely seeing patients from racial/ethnic minority groups. Given the "disproportionate impacts" of COVID-19 on historically marginalized communities, there may be greater disparities in the accessibility of culturally competent spiritual care services in inpatient environments (Gracia, 2020, pg. 518). Moreover, racial inequities in ACP education, access, and document completion rates may be rooted in systemic issues associated with medical mistrust, which can decrease use of healthcare services or otherwise create delays in seeking care (Vossel, 2021). Additionally, the inclusion of the chaplains' perspective alone provides only a partial view of spiritual care delivery. Surveying patients and family members, the recipients of spiritual care and other support services, may help researchers understand how chaplaincy practices can positively impact the clinical outcomes that matter most to these groups.

Future Directions

Given the sudden nature of changes surrounding COVID-19, there is an ongoing dialogue about the permanence of the new approaches outlined above. These questions include how long such measures should remain in place, their sustainability, and ways in which they compare to

existing systems in offering high-quality support and care for patients and their loved ones. A predominant sub-theme that emerged via content analysis was increased recognition among the surveyed chaplains for the need of ACP. One of the major barriers in ACP facilitation is the erroneous belief among both patients and physicians that ACP conversations are relevant only for the terminally ill and that completing an advance directive may restrict the type of care a patient were to receive. Yet, the pandemic has clearly demonstrated that the unexpected can occur. In such cases, preparing ahead can provide a profound sense of security for patients and families, and ACP offers one validated approach of doing so. Through ACP, patients are able to exert more control over their heath decisions while bringing reassurance to family members. As such, engaging in ACP early can help patients receive the type of care and medical treatments that align closely with their personal values without placing the onus of these emotionally difficult, complex decisions on loved ones.

Moreover, from the vantage of healthcare organizations, there is a need to better understand how electronic health records (EHRs) and patient portals can be effectively utilized to document, store, and share end-of-life care preferences across different hospitals and agencies. These care choices, along with contextualization, should be centrally filed and easily locatable in emergency situations. An example can be seen with the recent collaboration announced by the Louisiana Health Care Quality Forum and Vynca, an ACP solutions company, to embed the state's Physician Orders for Scope of Treatment (LaPOST) forms within the Ochsner Health System's EHR, thus permitting "healthcare providers in all care settings across Louisiana to electronically complete and access patients' LaPOST forms" (Raths, 2021). It is important to note that POST forms are applicable for patients with serious illness; integrating other planning documents such as advance directives and living wills that can be completed by all adult patient

populations into electronic platforms will be an essential step in continuing to increase the accessibility of ACP.

With the advent of COVID-19, the question now becomes how ACP conversations can occur proactively, at earlier stages in life with greater frequency, to increase patient empowerment. One important way, reflected in the survey responses, is a broader use of interprofessional collaboration. Prior research surveying a sample of 118 interprofessional team members found that "while 71% of respondents strongly or somewhat agreed that it is the responsibility of the physician to have ACP discussions with patients or family members, a larger number of respondents (85%) responded that they strongly or somewhat agree that *nonphysician health care team members* can have ACP conversations with appropriate training" (Arnett et al., 2016, pg. 5). Board-certified healthcare chaplains have demonstrated competencies in facilitating individualized ACP discussions with patients that delve into issues of connection, to self and to others, through spiritual care delivery. Individuals are more likely to engage in ACP if the process is advocated by someone they trust, and chaplains, along with other spiritual care and faith-based community leaders, are often perceived as close confidants and providers of relationship-centered support. Accordingly, collective reliance on staff members such as chaplains can help increase the reach of ACP and schedule sessions with a greater number of patients. Moreover, for patients with chronic or advanced stage illness, invoking palliative medicine early in line with patients' wishes may also promote ACP since multidisciplinary palliative care teams tend to be composed of physicians trained in ACP conversations as well as nurses, chaplains, and social workers.

There is additional interest in understanding how ACP can be made more readily available and accessible by means of telehealth and/or telechaplaincy. This can include

discovering supplemental avenues to leverage ACP through technology with interactive applications that encourage people to start reading and reflecting about their long-term goals and values in relation to health, i.e., ACP made easy. There are several examples of this already being implemented, including Five Wishes (a program affiliated with the organization Aging with Dignity), The Conversation Project, and ACP Decisions. Such services, especially as they more widely embed telehealth translation support to cater to the needs of non-English-speaking patients, may also ultimately help increase the number of individuals who meaningfully participate in voluntary ACP discussions irrespective of their current health status.

Conclusion

Delivery of health and social care involves identifying and empathetically responding to the multi-dimensional, complex, and quintessentially *human* needs of patients. Often, when navigating the difficult and painful realities that accompany serious illness, advance care planning (ACP) can ameliorate some of these stressors by identifying patients' values, reducing the potential financial and emotional burden associated with unwanted and unnecessary care, and clarifying decision-making processes. Given their expertise in spiritual care assessment, healthcare chaplains have been, and should continue to be, recognized as facilitators of ACP.

The COVID-19 outbreak has contributed to unprecedented physical, social, and emotional challenges. This paper serves as a preliminary exploration of the pandemic's impact on the ACP practices carried out by chaplains. The findings were two-fold. Barriers to ACP included an inability to legally execute or complete advance directives due to patients' deteriorating health status and the difficulties of communicating effectively and intimately with patients and families without in-person visits. Nevertheless, the accounts from chaplains also

spoke to flexibility and resilience on several fronts. Emergent responses included temporary state-wide measures enacted to assist with document completion, use of telechaplaincy to virtually visit with patients and families, and increased opportunities for interprofessional collaboration among healthcare staff.

Perhaps most pressingly, chaplains reported that the losses incurred due to the pandemic have compelled more people to make urgent healthcare decisions that directly contextualize issues of mortality, providing insight as to why ACP matters. The responses suggest that ACP conversations can occur too late. When patients become too ill to discuss their care preferences, loved ones are tasked with making sudden and weighty decisions, and this is when the preemptive value of ACP is realized. As the world begins to recover from the pandemic, this recognition of ACP, especially as a safeguard against the unexpected, will hopefully continue to persist, encouraging individuals to exercise greater autonomy over their health and well-being.

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Shilpa Rajagopal (she/her) is a fourth-year biology and marketing major at the University of Texas at Austin. Guided by Audre Lorde's belief that people "do not lead single-issue lives," she seeks to understand health and social care delivery at both an individual and population level, drawn to addressing the ways by which identity, culture, and the built environment all affect well-being. During her time at UT, Shilpa served as the President of Natural Sciences Council, a Healthyhorns Peer Educator, a patient support volunteer with New Century Hospice, and an undergraduate research assistant at the Wright Lab in the School of Nursing. She is passionate about expanding the scope of campus resources through service and advocacy and has been actively involved in leading various college/university-wide DEI initiatives to improve the student experience. In her free time, Shilpa enjoys performing as a member of the UT Nritya Sangam Indian classical dance team, reading memoirs, and watching stand-up comedy. Following graduation, she is looking forward to pursuing a Community Health Fellowship with Project Horseshoe Farm in Pomona, CA and helping develop sustainable, community-centered programming to promote health equity.