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The Psychological Impact of Visitor Restrictions on End-of-Life Patients

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Abstract

The Psychological Impact of Visitor Restrictions on End-of-Life Patients
By Pamela L. Boyd

As healthcare facilities instituted restrictive visitation policies, designed to slow the transmission of the Coronavirus, many patients were separated from family, friends, clergy, and loved ones. This was one of the most devastating features of the Coronavirus pandemic: end-of-life patients were left to die without the comforting presence of those who were closest to them. In this project, I explore the psychological impact of visitor restrictions for end-of-life patients, their families, medical staff, and chaplains at Vidant Medical Center, where I serve as a palliative care chaplain. I begin with a description of this setting and the way visitation policies were affected by the COVID-19 pandemic. While my study is focused on my own context, concern about the impact of COVID-era visitor restrictions is widespread. I discuss some of the emerging research in this area in the literature review section. Then, drawing on six interviews conducted in November 2021 with Vidant Medical Center palliative care staff about their experiences during the COVID-19 pandemic, I show that restricted visitation has an impact on patients. I also show that VMC's visitor restrictions affected family members perhaps as much as patients, and that they also affected staff. Understanding the impact of these policies is important for the health and welfare of patients, but has wider implications for healthcare institutions, clinicians, and spiritual care providers, as well. I conclude by discussing some of my recommendations in light of these findings.

The Psychological Impact of Visitor Restrictions on End-of-Life Patients

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Introduction

We were all in our respective places, going about our daily routines, and then the COVID pandemic attacked our work and play like a tidal wave without warning. COVID placed a knee on the necks of the healthy and the sick and suffocated the very life out of families and patients. It was difficult at best to navigate the lack of spiritual and psychological remains of COVID-19.

Not only did the COVID pandemic bring death; it fundamentally reshaped the experience of dying. As healthcare facilities instituted restrictive visitation policies, designed to slow transmission of the virus, many patients were separated from family, friends, clergy, and loved ones. This was one of the most devastating features of the Coronavirus pandemic: end-of-life patients were left to die without the comforting presence of those who were closest to them. Families were forced to allocate limited visitation spots, making heartbreaking choices about who would be at the bedside of a dying parent or child. Both families and healthcare workers navigated new technologies, creating new forms of virtual connection, even as they grieved the suffering of separation. From the time we are born and throughout life, the presence of love is shown in various ways, especially by a touch, whether it be in the form of a hug or a simple holding of the hand. In the context of visitor restrictions, patients were denied the one thing they perhaps needed the most when they were sick and sometimes dying.

When I began this research in March 2020 there were no vaccines, and I anticipated the day that they would be readily available. I assumed that once vaccinations could be administered, the nation's problem would be solved. I was very wrong. The United States muddled through the first wave of COVID with a rapidly mounting number of deaths. With hospital morgues overflowing, refrigerated trailers had to be placed outside of hospitals to accommodate the bodies of the dead. Certainly, after witnessing the atrocity of these deaths, I thought that the help

of a vaccine would be awesome. I was wrong again. The second wave of COVID and the Delta variant came racing to the scene like a tsunami, taking just as many lives if not more than the first time. News media as well as multiple social platforms frenzied in reporting these deaths several times a day. Wave after wave of death and loss was overwhelming.

I remember listening to all the reports, including the reports of innumerable bodies piling up in containers in places like New York, and thinking to myself "if those who died were displaced in such a manner…I wonder how their end-of-life experience was?" I did not encounter many stories at all that talked about how those patients died. As a side bar it is certainly noted that hospital staff were so busy trying to not only care for the influx of COVID patients, but caring for other seriously ill patients as well, that there just was not enough time to take on yet another task. Staying afloat and trying to stay alive seemed to trump anything else going on at the time. As a chaplain, I naturally thought about not just patients who had the COVID virus, but also non-COVID patients who were at end of life and who were affected by almost the same hospital visitor restrictions as a result of a virus that had nothing to do with them. Patients at Vidant Medical Center who died alone, many of whom were too sick to voice their feelings, died with a certain unrest in knowing why they could not have many of their loved ones at bedside. It was a stark realization that this has not only affected patients' health but has forced healthcare institutions to make radical changes in almost every aspect of daily operations.

This research project focuses on one of the most significant and detrimental of these changes, the restriction of visitors in hospital settings. Visitor restrictions have become a matter of broad concern and debate, not only for hospital chaplains and staff, but for the public as well. In the early months of 2022, as I finish this project, a public outcry against these restrictive visitation policies has continued to expand, fueling anger and even legislation. On March 11,

2022, the Florida Legislature passed a bill that allows people to visit their loved ones in health facilities regardless of the pandemic or public health crisis. At least eight other states had passed similar legislation, and several more states were considering similar bills.[1] As Holly Nelson-Becker and Christina Victor show, loneliness at death is one facet of potential suffering and pain, and those who die alone are imagined to have a disturbing death.[2] The question of how to balance "the joy of visits with the risks of infection" has become a major political question in the wake of the COVID pandemic.[3]

In this project, I explore the psychological impact of visitor restrictions for end-of-life patients, their families, medical staff and chaplains at Vidant Medical Center, where I serve as a palliative care chaplain. I begin with a description of this setting and the way visitation policies were affected by the COVID-19 pandemic. While my study is focused on my own context, concern about the impact of COVID-era visitor restrictions is widespread. I discuss some of the emerging research in this area in the literature review section. Then, drawing on interviews with VMC palliative care staff, I show that restricted visitation does have an impact on patients. I also show that VMC's visitor restrictions affected family members perhaps as much as patients, and that they also affected staff. Understanding the impact of these policies is important for the health and welfare of patients, but has wider implications for healthcare institutions, clinicians, and spiritual care providers, as well. I conclude by discussing some of my recommendations in light of these findings.

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[1] Stephanie Colombini, "New laws let visitors see loved ones in health care facilities, even in an outbreak," *National Public Radio* (NPR.org), April 3, 2022, https://www.npr.org/sections/health-shots/2022/04/03/1086216581/visiting-patients-during-covid.

[2] Holly Nelson-Becker and Christina Victor, "Dying alone and lonely dying: Media discourse and pandemic conditions," *J Aging Stud.* (2020), 55:100878. doi: 10.1016/j.jaging.2020.100878.

[3] Colombini, "New laws."

Institutional and Community Context

Vidant Medical Center (VMC) is a 1000-bed hospital in Greenville, North Carolina, and the heart of the Vidant Healthcare System, which serves 1.4 million patients across 29 counties of eastern North Carolina. Vidant Medical Center is also a teaching hospital for the Brody School of Medicine at East Carolina University; the system will soon to be renamed East Carolina Health to reflect this partnership.[4] The Center is recognized nationally for its patient- and family-centered approach to care and is the ultimate regional resource for comprehensive health services and clinical expertise. Additionally, the hospital has particular expertise in several other areas, including neurological surgery, stroke care, and endovascular care.

Located within the confines of VMC is the Palliative Care Unit. I am a staff chaplain at VMC and my clinical area of responsibility is the East Carolina Heart Institute. The Heart Center is located in its own separate tower and stands adjacent to the Cancer Center tower. The Palliative Care Unit is located within the confines of the Cancer Center. Often my patients who are at end-of-life will transfer to the Palliative Care unit. The Palliative Care Unit at VMC consists of twenty-five beds of which a Palliative Care chaplain is assigned. Admitted patients of Palliative Care are those who have serious illnesses that are terminal; however, this does not

[4] Vidant Health and East Carolina University have announced a joint enterprise which will involve rebranding of the health system, to being May 2022. The new health system will be known as East Carolina University (ECU) Health system. I refer to the hospital and healthcare system as Vidant Medical Center and Vidant Health throughout this project because this was the name of the system for period covered by my research. Vidant Health, "New ECU Health logo revealed; re-branding to begin in May," News & Press Releases, Vidant Health, April 14, 2022, https://www.vidanthealth.com/new-ecu-health-logo-revealed-re-branding-to-begin-in-may/; Vidant Health, "Vidant Health CEO and Brody Dean Dr. Waldrum provides update on ECU Health, rural health care in Edenton," News & Press Releases, Vidant Health, March 17, 2022, https://www.vidanthealth.com/vidant-health-ceo-and-brody-dean-dr-waldrum-provides-update-on-ecu-health-rural-health-care-in-edenton/.

mean that patients are at end-of-life at the time of admittance. What this means is that some patients are able to transition home, some to hospice care on the unit, and some to other places. Usually Palliative Care patients who are hospitalized have a very short life expectancy, but many of them can be discharged to other facilities who have a longer anticipated life, although still at end-of-life. Palliative Care is staffed with a team of doctors, nurses, case managers, social workers, nurse practitioners, and physician assistants who work collectively to make these decisions.

When patients at Vidant Medical Center make the decision to transition to Palliative Care, they are deciding to have their symptoms managed. Managing symptoms means that either the patient or the family member(s) of patients have made the decision not to have their illness aggressively measured or treated. The term often used for this decision is called "comfort care." Once patients are placed in comfort-care, the symptoms they experience such as nausea, vomiting, and shortness of breath are managed with medicine. For example, if a person has been diagnosed with cancer and are at end-of-life, they can make the decision not to undergo any more chemotherapy or radiation, but instead have their pain managed at comfortable levels until death.

Spiritual care is an essential part of palliative care. Palliative care patients and their loved ones are given emotional and spiritual support, usually by family members first, and also by chaplains and the palliative care medical team. For this reason, the presence of families in the unit is important and routine. Although hospital team members — chaplains, physicians and nurses — are able to provide a certain level of intimacy for patients, they cannot provide the long-lasting care and love that have been cultivated between families, spouses, and extended family members, or the comfort of visitation from their own priest or pastor. Virtual visits have

become the norm in the context of COVID, but there is no substitute for the physical presence of family members and loved ones.

Prior to COVID-19, VMC allowed family members, friends, and clergy to visit loved ones seven days a week and 24 hours a day. There were no visitor restrictions except in Intensive Care Units. Family members, friends, and others would come and go all hours of the day and night; and many family members would sleep in rooms with patients, especially those at end-of-life. Patients look forward to seeing their loved ones when they are ill.

Hospital Restrictions in the Context of the COVID-19 Pandemic

Like many hospitals in the U.S., Vidant Health has embraced open and flexible visitation policies as one aspect of patient-centered care. In May 2011, Vidant Health established other policies in an effort "to support the presence and participation of family members and visitors in caring for their loved ones in a safe, compassionate environment that respects the rights as well as the preferences of patients, family members, and visitors. Family members were welcomed at any time and remained flexible and could be customized and personalized to the need of patients and to respond to the diverse and changing needs and preferences of each patient and family." This very relaxed policy was patient- and family-centered, and remained in effect until the COVID-19 pandemic turned the world upside-down.[5]

As the pandemic began, Vidant's relaxed visitor policies immediately became highly restrictive. Visitor restrictions were established to prevent the potential risks to patients and to healthcare workers. A friend dropping of some flowers or a card may serve as a conduit for

[5] Vidant Medical Center, "Family Presence and Visitor Policy and Guidelines, VH-PFE2," *Vidant Health PolicyStat*, http://vidanthealthvmc.policystat.com/policy/10026548/ (internal site), accessed December 2021.

COVID-19, just as a patient's visiting daughter could be at a heightened risk for contracting an illness from the hospital staff. Beginning in mid-March 2020, in response to the spread of COVID-19, Vidant Medical Center began the process of imposing visitor restrictions policies. On Sunday March 15, 2020, Dr. Keith Ramsey, Medical Director of Infection Control at VMC, revised the visitor policy to read, "…only immediate family members over the age of 16 and not exhibiting any symptoms of illness may visit a Vidant hospital." Approximately two weeks later, on March 30, the policy drastically expanded with a notice that the hospital was

> *prohibiting visitors across all Vidant hospitals* and emergency departments effective today. To accommodate special circumstances on a case-by-case basis there were other units in the hospital that allowed ONE healthy adult visitor [emphasis added].[6]

End-of-life patients who were infected with COVID-19 could not have any visitors at all inside the room. Families had to view their loved ones from a glass window.

Within hospitals, including Vidant Health, the physical barriers created by the use of personal protective equipment further limited human contact or communication. At the onset of COVID-19 at Vidant Health, all patients who contracted the virus were in a designated space in the hospital, including palliative care patients. If patients were in Intensive Care Units, COVID-19 restrictions meant that families were not able to touch or be in the same room as patients at all. Indeed, for many palliative patients, the conditions imposed by COVID-19 may have limited patient autonomy, including decisions around place of care and place of death. Such restrictions, while imperative during a pandemic profoundly shaped experiences and relationships between patients, families and clinicians, limiting forms of closeness, intimacy and proximity.

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[6] Vidant Health, "COVID-19 Visitation Restrictions in place at all Vidant Hospitals," *MyVidant News*, https://myvidant.org/news/Pages/COVID-19-visitation-restrictions-in-place-at-all-Vidant-hospitals-.aspx (internal site), accessed April 2021.

As the pandemic wore on, policies shifted slightly, but remained restrictive. On April 27, 2020 the policy expanded for the Maynard Children's Hospital, which is located within Vidant Medical Center, allowed one guardian only in Neonatal ICU and Pediatric ICU; switching of the two designated guardians could occur with only one guardian allowed to be present at the beside at any time. In the event *of palliative or end-of-life care* for children, both guardians were allowed to be present at the bedside together with approval from administration. On May 8, 2020, Vidant updated the policy to allow visitors who were screened and wearing a mask—and now allowed patients who were having procedures that required sedation and/or anesthesia. This policy remained in effect through June 18. Prior to this May 8th update patients who were having any kind of surgical procedure were not allowed. This policy remained in effect through June 18.

As Vidant began to experience some relief in infectious cases over the summer of 2020, the hospital expanded visitation in incremental steps and even reopened Vidant cafes at 50% capacity. Those visitors could visit units between the hours of 11 a.m. and 7 p.m. as opposed to 24-hour visitation. On August 11, 2020, Vidant's policy changed yet again to allow one healthy adult visitor per patient at a time, and one additional healthy adult visitor who would be able to switch out with the first visitor. This meant that the patient could have two visitors, but only one visitor at a time, and once one visitor left and the other came, they could not switch again. The constant shifts in visitor restriction policies welcomed by some, posed as a concern for others, and were utterly confusing to some staff members and families.

Just as employees began to get accustomed to the policy listed above, COVID-19 began to rear its ugly head once again. On November 22, 2020, Vidant reverted back to its earlier "one healthy adult visitor per day" policy. On December 11, another restriction was added in that, visitors could not reenter the building prior to 24 hours. This was difficult to manage, but team

members developed a system that entailed each visitor being given a bracelet at time of visitation. That same visitor was documented in the system, thereby date and time stamping the last visit. If a particular visitor came prior to the 24-hour time period, they were told that they could not visit.

End-of-Life patients were allowed to have two healthy visitors per patient, if agreed upon by the palliative care team, but visitors still had to adhere to the 24-hour limitation once leaving. Because of lower infection numbers, on March 17, 2021, Vidant Health relaxed some of the stringent policies by allowing one healthy adult visitor at a time during open hours, for most units in hospitals and clinics across the system, including the emergency departments. Visitors were also allowed to leave and re-enter or switch out with one other visitor during a single day. Prior to this change there was no switching of visitors. As I recall, this policy seemed to be a welcome change because it allowed for another person to visit.

The month of August 2021 brought about increased community spread. Therefore, the hospital decided to reinstitute the restriction of all visitors in the emergency department lobby or waiting areas at hospitals across Vidant's system. From August to November of 2021, things seemed to settle down, and just as the institution thought some much-needed relief from the COVID-19 virus and the Delta variant, yet another variant situated itself amidst the United States. As a result of the Omicron variant, on December 10, 2021, Vidant visitor restrictions were revised yet again, stipulating that two healthy adult visitors, screened and masked at all times, could visit between 7 a.m. and 9 p.m. Visitors could not leave the patient's room unless they were visiting the café. On December 29, 2021, Vidant updated this policy and reduced the number of healthy visitors from two to one healthy adult visitor with no switch outs, a policy that included end-of-life patients, as well.

Throughout the pandemic, Vidant encouraged visitors to consider virtual visitation options, such as FaceTime, Zoom, Google Duo or phone calls. Assistance with virtual visits, including iPads for patients without the necessary technology, was available upon request. iPads were purchased by the hospital so that appointments could be scheduled for family member to see their loved ones. I think this made a great impact for those who are familiar with technology, but for the elderly it was more of a handicap than help.

Not only were the policy changes challenging to implement, but they raised fundamental questions for chaplains about their role as chaplains during Covid. This is important because if chaplains did not understand how they were to best practice spiritual care, it could have led to moral distress in many instances.[7] This was certainly not intentional, but things were difficult at best to figure out because during the height of the pandemic, all health care facilities were faced with important decisions as to who were considered essential on-site staff and who could perform their job functions outside the care setting. As a result, for many institutions across the country, the distance imposed for safety developed into deep feelings of disconnection as team members worked together despite a growing social and emotional distance.[8] Chaplains at VMC were deemed essential and worked a full schedule during the entire pandemic and continue to do so.

As Vidant Medical Center monitored the response to the COVID-19 pandemic across North Carolina, the safety of patients, team members, and family members were of primary

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[7] Megan Best, et al. "A Long Way to Go Understanding the Role of Chaplaincy? A Critical Reflection on the Findings of the Survey Examining Chaplaincy Responses to Covid-19," *Journal of Pastoral Care & Counseling*, no. 1S, pp. 46–48.

[8] Katherine Easton, "Alone, Together: Redefining Connectedness in the Age of COVID," *Journal of Social Work in End-of-Life and Palliative Care* 17, no. 2-3 (2021): 91-93, https://doi-org.proxy.library.emory.edu/10.1080/15524256.2020.1811832.

concern. It was the implementation of these new safety measures that led to the institution of multiple policies and procedures regarding visiting restrictions as a result of the COVID-19 pandemic. At times, the visitation policies changed so frequently that both staff and visitors had a difficult time in keeping up with the changes. Vidant Health did eventually relax the visitor restriction policy, but it still had a cost, as isolation and loneliness grew into despair for patients who did not have the privilege of experiencing the remainder of their lives on their own terms.

Literature Review

The purpose of this study is to explore the psychological impact that visitor restriction policies have on end-of-life patients in the hospital setting. In this section, I analyze various articles and studies to determine what the existing research says about the impact of visitation on patients who are dying and their families.

In recent decades, open and flexible visitation policies have been widely embraced as a cornerstone of "patient and family centered care" and an important element in improving patient outcomes as well as patient satisfaction. Trogan cites other studies that have found "positive patient outcomes related to open visitation policies, including rapid recovery times and decreased length of stay." These studies indicate that "Visitors can boost morale, provide comfort and relief for patients in the otherwise cold and sterile environment of the hospital, and supplement the day-to-day care provided by hospital staff."[9] Trogan also mentioned the potentially negative

[9] Brit Trogan, "Do hospital visitors impact patient outcomes?" *Clinical Correlations: The NYU Langone Online Journal of Medicine*, August 3, 2018, https://www.clinicalcorrelations.org/2018/08/03/do-hospital-visitors-impact-patient-outcomes/; Donna Ciufo, Richard Hader, et al, "A comprehensive systematic review of visitation models in adult critical care units within the context of patient-and family-centered care*." International Journal of Evidence Based Healthcare* 9, no. 4 (2011): 362-387, https://www.ncbi.nlm.nih.gov/pubmed/22093387.

impacts of visitation and noted that people coming from the community can be carriers of a virus, thereby transmitting to patients and staff members upon visiting.

The COVID-19 pandemic brought a significant shift in this open and flexible approach. The experience of these new COVID-era visitor restrictions has led to a new wave of research and reflection on the significance of in-person visitation for patients and the impact of the sustained visitor restrictions put into place during the pandemic. Below I explore some key elements of this emerging conversation among health-care providers, chaplains, and researchers.

Impact of Visitor Restrictions on Patients during COVID

In a review of research on the impact of visitor restriction during COVID-19, Karin Hugelius, Nahoko Harada and Miki Marutani found that there are psychological and mental health consequences for patients who experienced visiting restrictions due to COVID-19. The authors denote in their review that there were increased levels of perceived loneliness, depressive symptoms, agitation and aggression. Ultimately, the lack of physical presence for patients in the hospital created worries, anxiety, and sadness. The article states that the long-term effects are unknown but did note that for palliative care patients visiting restrictions were relaxed but those patients still died alone.[10]

Michael Byrne and Daniel Nuzum say that when there is no social and emotional contact with people it can obstruct the benefit of observing communication styles and body language that

[10] Karin Hugelius et al., "Consequences of Visiting Restrictions during the COVID-19 Pandemic: An Integrative Review," *International Journal of Nursing Studies* 121 (2021), 104000, https://doi.org/10.1016/j.ijnurstu.2021.104000.

serve as a barrier to understanding the emotions of patients.[11] Claunei Dutra and Henrique Rocha say that some patients without in-person support have mental distresses of depression, sad feelings, and isolation, and they make the claim that face-to-face support contributes to emotional support. When such support is not possible Dutra and Rocha say that processes must be put in place to promote mental and spiritual health of patients so that psychological damage is minimized.[12]

Julia Frydman and her co-authors agree that the implementation of certain processes should be established to minimize the emotionally challenging work for end-of-life patients and families to say goodbye. They developed a "Video Goodbye Tool" that was to be used by providers in real time to prepare for end-of-life encounters, easing the transition from in-person to virtual goodbyes.[13] Natalie Pattison even mentioned that their institution implemented critical care gardens for patients to have humanizing experiences so that end-of-life care could be provided as best as possible.[14]

These tools and processes are good measures, but in the midst of the COVID-19 pandemic there was no time for the brainstorming of best practices for end-of-life care and

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[11] Michael J. Byrne and Daniel R. Nuzum. "Pastoral Closeness in Physical Distancing: The Use of Technology in Pastoral Ministry during COVID-19," *Health and Social Care Chaplaincy*, 8, no. 2 (September 14, 2020).
[12] Claunei Dutra and Henrique S. Rocha, "Religious Support as a Contribution to Face the Effects of Social Isolation in Mental Health During the Pandemic of COVID-19.*" Journal of Religion and Health,* January 6, 2021, 100–111.
[13] Julia Frydman, MD, Eugene W. Choi, MD, and Elizabeth C. Lindenberger, MD. "Families of COVID-19 Patients Say Goodbye on Video: A Structured Approach to Virtual End-of-Life Conversations," *Journal of Palliative Medicine*, 23, no. 12 (November 12, 2020): 1564–65. https://doi.org/10.1089/jpm.2020.0415.
[14] Natalie Pattison, "End-of-Life Decisions and Care in the Midst of a Global Coronavirus (COVID-10) Pandemic," *National Library of Medicine*, Elsevier Public Health Emergency Collection, no. PMCID: PMC7132475 (October 1, 2020).

because of that there may be some collateral damage, according to Alissa Ulanday and Lindsay Minter. Their perspective is that hospital restriction visitation policies caused collateral damage to patients and patients' families by disrupting the support system already place and by leaving patients isolated, and helpless. They note that "81% of patients diagnosed with COVID-19 did not have a family member or loved one physically present during the dying phase." The authors draw on multiple conversations with family members who exhibited emotional distress over not being able to physically visit their loved ones. This information is crucial because it shows that visitor restrictions haves a traumatic impact on patients and on family members of patients, and that this pandemic has already had a detrimental impact on end-of-life transitions and for families experiencing anticipatory and/or complicated grief.[15]

Impact of COVID on Social Isolation

Some of that grief comes from social isolation. There are a number of COVID-era studies looking at the effects of social isolation on individuals, broadly and beyond the hospital context. These studies have various findings and reflect on ongoing conversation between researchers about the impact of the pandemic on different times, places and populations. Because the isolation of patients and families at the end-of-life is the topic I am looking at these studies to provide relevant insights.

Santini et al seem to also agree that visitor restriction policies that force patients to be alone causes long-term effects with the bereavement process. Working prior to COVID, these authors developed a longitudinal study to show the relationship of social disconnectedness and

[15] Alissa A. Ulanday and Lindsay B. Minter, "Collateral Damage of the COVID-19 Pandemic: Isolation, Rapid Decision Making and Multifaceted Distress as Observed by an Inpatient Palliative Care Service," *Journal of Social Work in End-of-Life & Palliative Care*, 2021, 1–8, https://doi.org/10.1080/15524256.2021.

social isolation. This study is important because it demonstrates how a person at end-of-life can suffer psychologically from having no contact with the outside world, primarily loved ones. The study also found that in older adults, social disconnectedness predicted higher amounts of perceived isolation, which in turn predicted higher amounts of depression and anxiety symptoms. These findings show that older adults who experience a lack of support are at a greater risk of depression and anxiety, which in turn may mean that older end-of-life patients may experience the same anguish.[16]

Turkan Guner did not agree with these findings in his study that examined the feelings of loneliness and death anxiety experienced by the elderly during COVID-19. His study determined that the elderly only experienced moderate levels of loneliness when it came to their anxiety about dying as a result of COVID. According to this study it does not appear that loneliness and social and emotional loneliness had any significant effect related to death anxiety of COVID-19.[17] Interesting enough, Ann Riggs quotes psychologist George Everly in her article, countering Guner's position. Everly states that every disaster brings psychological casualties that far outnumber physical ones, including grief, anxiety, guilt, post-traumatic stress and depression, and that he sees all of these psychological problems with the isolation of Covid.[18]

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[16] Ivan Ziggi Santini, Paul E Jose, Erin York Cornwell, Ai Koyanagi, Line Nielsen, Carsten Hinrichsen, Charlotte Meilstrup, Katrine R Madsen, and Vibeke Kousheds, "Social Disconnectedness, Perceived Isolation, and Symptoms of Depression and Anxiety among Older Americans (NSHAP): A Longitudinal Mediation Analysis," *The Lancet Public Health*, Elsevier Ltd. 5 (January 2020): 62–70.

[17] Turkan Akyol Guner, et al., "The Effect of Loneliness on Death Anxiety in the Elderly During the COVID-19 Pandemic," *OMEGA-Journal of Death and Dying* (2021), pp. 1–21, doi:10.1177/003022282 1 1010587.

[18] Ann K. Riggs, "The COVID-19 Context Calls for a Broader Range of Healthcare Chaplaincy Models: An Exploratory Translational Study Utilizing Evolutionary Psychology and Social Neuroscience Loneliness Research," *Journal of Pastoral & Counseling*, vol. 74, no. 4, 2020, pp. 258–64.

In part the lack of having connections between each other shaped the patient experience in more than one way. One study shows how loneliness decreased the meaning of life during coronavirus.[19] It seems evident that if the virus diminishes the meaning of life, then an end-of-life patient whose life is already shortened could mean that the patient will become even more despondent. According to Yildirim et al, the meaning of life is defined by cognitive, affective, and motivation and poses that the experience of feeling that one has is significantly associated with one's purpose in life and thereby causes a variety of mental health crisis and illnesses.[20]

Impact of Visitor Restrictions on Families of Patients

The psychosocial impact not only affects patients but family members as well. Karen Murphy's perspective is that the psychological impact of visitor restriction policies for those who are dying has a grave impact on the family members of end-of-life patients because it leaves family members incapable of sharing their grief with other family members and friends who are closest to the patient. Murphy contends that grieving alone, as a result of COVID is mentally destructive because it creates situations that leave family members with feelings of anger and delayed grief specifically because of COVID related deaths. She believes that people are holding on to grief until such a time when they can get together for an event that reflects on their loved one's life. This article seems to support and highlight the traumatization and guilt of family members who cannot be at the bedside of their loved ones. Murphy notes the thoughts of a daughter whose mother died alone, who expressed a sense of guilt in not being able to be with

[19] Murat Yildirim, et al. "Meaning in Life, Religious Coping, and Loneliness During the Coronavirus Health Crisis in Turkey," *Journal of Religion and Health*, Jan. 2021, p. 23712385.
[20] Ibid.

her mother after all the support in her lifetime that her mother has given to her.[21] The anguish that one feels is a testament to the statistics that state that about 5% of the population are clinically diagnosed with major depression as a result of COVID-19 deaths.[22] When one imagines dying patients with no visitors as some hospitals indicated and even one visitor as Vidant Medical Center initially implemented, it seems implausible that patients and families would not be affected emotionally and psychologically.

Chaplains and Healthcare Workers in the COVID Pandemic

An article written on multinational perspectives of spiritual care also speaks to the area of mental health care, but for chaplains in the United Kingdom. The article provides a personal reflection that describes the effects of COVID-19 on mental health care chaplains, and their practices. It shows that chaplains are adapting to these changes, but at a cost and that the changing healthcare landscape will continue to be affected by this pandemic for many years to come. The authors note five areas of concern: personal loss and questioning; deaths and support; being present without being present; new developments with regard to staff meetings, services of worship, and developing new resources; and returning back to normality by engaging differently.[23] This is important because as one engages the psychological impact for end-of-life patients who die alone, one should also consider the impact it had on the chaplains who served as

[21] Karen Murphy. "Death and Grieving in a Changing Landscape: Facing the Death of a Loved One and Experiencing Grief during COVID-19," *Health and Social Care Chaplaincy*, Equinox Publishing Ltd 2020, n.d., 241–49.
[22] Sandro Galea, MD, et al. "The Mental Health Consequences of COVID-19 and Physical Distancing," *JAMA Internal Medicine*, no. 6, June 2020, pp. 817–18.
[23] Graham Peacock, "Mental Health Chaplaincy in the UK During COVID-19: A Personal Reflection," *Health and Social Care Chaplaincy*, Equinox Publishing, 2020, pp. 223–30, https://doi.org/10.1558/hscc.41803.

frontline responders, but who were also emotionally spent and perhaps experiencing moral distress even as they responded to patients who needed their support the most.

The same article also spoke of Catholic priests across Italy who were fulfilling their pastoral duties of providing support, counseling, guidance, and various rituals to care for others, only to contract the virus themselves and lose their lives.[24] As we are well aware this did not only happen in Italy but across the country including the United States. This example demonstrates the varied levels of what 'psychological impact' at end-of-life looks like. Numerous members of the medical staff, chaplains included died alone as well.

When we think of individuals who die alone at end-of-life it is easy to think of patients, but what about my fellow chaplain colleagues, police officers, firefighters, preachers, doctors, nurses, etc.? Holly Nelson-Becker and Christina Victor write that an accompanied death at the end-of-life or a death given for the welfare of others is considered a good death, a heroic death. They say that heroism is often associated with those whose death is identified with a cause, or by those who use battle or struggle metaphors to describe their resistance to disease. The authors ask an important question: "can heroism also be applied to health care staff in protecting the family from risk of infection, or the families who permitted their loved ones to die alone in the hospital to protect staff from risk of COVID-19 from their (the family's) presence?"[25] Whether a heroic death or not, the authors conclude that in the time of the pandemic, many of the world's heroes died alone without choice. A physician who perhaps fought tirelessly to save the lives of

[24] Ibid.
[25] Holly Nelson-Becker and Christina Victor, "Dying Alone and Lonely Dying: Media Discourse and Pandemic Conditions," *Journal of Aging Studies*, vol. 55, no. 100878, Sept. 2020.

others had family members who weren't permitted to be present because of substantial health risks for others.

Impact of Isolation and Visitor Restrictions on End-of-Life Patients

Emma Kirby and her colleagues argue that COVID-19 has made experiences of dying in isolation, or separated from loved ones, more visible. The pandemic has revealed the ways that families are kept apart through forced restrictions on visitors, closed borders, and other public health directives aimed at safety by limiting infection—with profound implications for end-of-life care experiences, including grief and bereavement.[26]

Peter Strang corroborated the feelings of loneliness and isolation by actually interviewing a dying patient. His article used a national study to compare palliative care patients and nursing home patients to determine if dying alone had an impact on all end-of-life patients. The dying person said, "Death and loneliness are in a way associated. Maybe one is scared of death, just because one is afraid of that death, it will mean that you will become totally alone." From the patient's perspective, the presence of others is especially important while still being conscious, whereas being present for the final hour might be symbolically important for family members.[27]

Ayodele Odutayo and Laveena Munshi performed a mixed methods study to understand the impact of visitor restriction perspectives on end-of-life patients. The study is congruent with Yildirum's study showing that the effects of COVID-19 diminish life and are psychologically

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[26] Ema Kirby, Rebecca McLaughlan, Lynette Wallworth, Louise Chappell, Frances Bellemore, and Richard Chye, "Connection, Comfort and COVID-19 in Palliative Care," *Palliative Care and Social Practice*, 15 (April 12, 2021), https://doi.org/10.1177/26323524211001389.
[27] Peter Strang, MD, PhD, et al, "Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study," *Journal of Pain and Symptom Management*, vol. 60, no. 4, Oct. 2020, pp. 12–13.

distressing to patients and morally distressing to staff members. They also noted that dying alone can lead to substantial emotional distress to not only patients but to family members.[28] According to Melanie Smith, some of the distresses came from end-of life patients who had to be disconnected from life support as an only means of seeing their loved ones. Meaning that the only way a dying person could have a family member present in ICU was for a family member to consent for the patient to be taken off the ventilator or other life saving devices.[29] Of course there are grave ethical issues here, but this level of distress is exemplary of the impact that Coronavirus has had on those at end-of-life.

Angelika Zollfrank observed a different kind of psychological impact of visitor restrictions on patients in a psychiatric hospital. Although the patients Zollfrank wrote about were not at end-of-life, the article is still important because there have been many patients at end-of-life who had an altered mental status. The article notes a retired professional woman who had bouts of depression and anxiety. She lost her brother and siter-in-law to COVID-19. The couple had been the patient's familial, social, financial, and legal support system, and with their death, the patient concluded that she had no one in the world anymore. Consequently, she felt the same loneliness and isolation of those who died alone from COVID-19 without the presence of family and friends.[30]

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[28] Ayodele Odutaye and Laveena Munshi, "Impact of Hospital Visitor Restrictions during the COVID-19 Pandemic," *Science Briefs of the Ontario COVID-19 Science Advisory Tabl*e, May 2021, pp. 1–14, https://doi.org/10.47326/ocsat.2021.02.31.1.0.

[29] Melanie Smith, et al. "You Can See Your Loved One Now: Can Visitor Restrictions During Covid Unduly Influence End-of-Life Decisions?" *Covid-19 Resource Center, End-Of-Life Care, Hastings Bioethics Forum*, June 2020.

[30] Angelika A. Zollfrank, "Chaplaincy in a Free-Standing Psychiatric Hospital During the COVID-19 Pandemic," *The Journal of Pastoral Care & Counseling*, no. 2021, pp. 49–52.

In juxtaposition Emmanuel Philor, a chaplain, wrote about his own experience with COVID and the loneliness he felt with the "unbearable sense of fear and loneliness of his patients." He recalled his quest of asking God to "remember me." Philor serves as a reminder of how he was in a similar psychological state as many of his end-of-life patients and stated that he felt as though he was dying and had done everything but plan his funeral.[31]

The direct and indirect impacts of visitor restrictions for end-of-life patients must be changed in light of the emotional agony patients and families face. When someone we love dies, we gain a sense of closure when we can be present with them. It is difficult at best to say good-bye to those when we are far removed and detached from the bond of a simple but meaningful touch. Saying and being present to say good-bye helps us understand the reality of the loss in a way that is meaningful to both the patient(s) and family member(s). Things are further compounded when we are unable to express our feelings and wishes reciprocally. Grief is already isolating and when coupled with the emotional numbness leaves us with the inability to be present we leave ourselves in a state that we sometimes cannot recover.

Methodology

I conducted a quantitative study aimed at learning how the visitor restrictions implemented during COVID-19 impacted end-of-life patients. I interviewed six team members from Vidant Medical Center who were directly involved in the care of end-of-life patients: two Palliative Care physicians, a Palliative Care Nurse Practitioner, a Palliative Care Physician Assistant, and two hospital chaplains. Each of these individuals provides compassionate care to

[31] Philor, Emmanuel. "Remembering," *Journal of Pastoral & Counseling*, vol. 75, no. 1, 2021, pp. 72–73.

end-of-life patients. Palliative Care team members and chaplains were chosen because they could offer significant insight in real time as to the activity surrounding the visitor restrictions policies at Vidant Medical Center. I also interviewed these participants because they all have experience in direct care to end-of-life patients, and I wanted to gain their views on how patients experienced dying from a psychological perspective.

Initially, I sent each participant a separate email inviting them to participate in my research. Each participant who agreed to participate was emailed a "Consent to be a Research Participant" agreement. After receiving the Consent form, I scheduled an interview with the participant in the format of their choice. I circulated the interview questions to participants in advance. (Interview questions appear in Appendix A.) Three interviews were conducted via Zoom, two were conducted in person, and one participant chose to respond to the interview questions by email. Each interview was consistent in that I asked the same questions and allowed each participant to answer without any prompting or persuasion in answers. The interviews varied in length, but none lasted more than about 20 minutes. For each interview, I listened carefully during the interview and took notes. The Zoom interviews were recorded, with participants' permission. I followed up with one participant by email after the interview to request additional information about an incident we had discussed, and included the information provided in that email as part of my research materials.

Once I interviewed all participants, I reviewed the data by looking for common themes and listening for details that were not so common, but described an emotional impact on an end-of-life patient. In the case of recorded interviews, I reviewed the recordings listening for specific material that focused on the experiences of dying patients. I re-read email responses to the questions, as well, and reviewed my notes from the in-person interviews. Based on these

reviews, I identified key themes and insights that emerged across my conversations with Palliative Care colleagues who participated in this study.

Findings from Interviews

Just as Chaplain Philor wrote from his own experience of isolation in the pandemic, research methodology allowed me to glean first-hand from healthcare workers who had daily encounters and experiences with patients and patients' families. I found that the lack of visitation does have an impact on patients. I also learned that VMC's visitor restrictions affected family members perhaps as equally as some patients.

Several themes are evident throughout the participants' interviews. Interviewees confirmed the importance of psychosocial and spiritual care for palliative care patients and the key role that both family members and clergy visitors play in providing this care. They described the negative impact of visitor restriction policies on both patients and family members, including the longer-term impact of these policies on the grieving process for families. They also described the psychological toll these policies took on clinical team members and staff. A range of innovations were developed during the pandemic to allow for virtual visitation with family and caregivers, but my interviewees ultimately felt that these virtual practices fell short of the ideal care for end-of-life patients and their families, something that became especially clear as visitation policies were relaxed. Finally, while participants were unable to make definitive comments about whether restrictive visitation policies shortened patients' lives, they shared observations about how these policies impacting patients' trajectories as well as their quality of life.

Interviewees confirmed the important role that visitors play in the psychosocial and spiritual care of patients at the end of life. A Palliative Care Nurse Practitioner noted that

spiritual support is a key component of palliative care, along with managing symptoms and psychosocial support. "Spiritual support is extremely important for patients at the end of life," she said.[32] Other participants made similar points throughout my interviews with them.

Impact of Visitor Restrictions on Families

Another primary theme that appeared across the interview was the psychological impact of visitor restrictions not only for patients, but for family members as well. Palliative care patients that were hospitalized on the unit were allowed to have two visitors per 24-hour time period; those two people could not change during the course of the hospital stay, and only one person could visit at a time. End-of-life patients who were infected with COVID-19 could not have any visitors at all inside the room. Families had to view their loved ones from a glass window. The Physician Assistant recalled families making the difficult decisions of which two family members would be chosen to see their loved one. He stated that initially families were accepting of the policy restrictions, but soon became intolerable and protested. He recalled the daughter of a patient in the Intensive Care Unit viewing her mother through the glass window who became so emotionally overwhelmed that she forced her way in the room and laid across her mother body as her mother lay there sick.[33]

A doctor said that family members became extremely distressed by not being able to see their loved ones, especially at the end of life. He further notes that even when the visitor restrictions relaxed a bit, it still created painful situations because there were still populations of family members who were not allowed to visit i.e. those 16 years of age and younger.[34]

[32] Interview with palliative care Nurse Practitioner, November 2021.
[33] Interview with Physician Assistant, November 2021.
[34] Interview with palliative care Physician, November 2021.

A palliative care chaplain said that meeting the end-of-life needs of our patients during the most restrictive visitor policies at the onset of the COVID-19 pandemic was exhausting, yet meaningful. It was a difficult time and caused a lot of emotional and moral distress for patients, their families, and team members. One of the factors end-of-life patients consider most important is having family present with them. The impact of the pandemic lockdown robbed dying patients and their grieving families of this meaningful opportunity; leaving it to team members to be the ones to stand in the gap.[35]

In an email following our interview, Chaplain 1 described one of the most traumatic incidents of family distress that she witnessed during the pandemic. Here, I quote at length:

> "Chaplain 1 account of an emotional and psychological breakdown of a patient's family…while on-call one Sunday afternoon, I received a page from Palliative Care. It was the Nurse Manager (NM). She stated that she needed support with a large family who had gathered outside the hospital demanding to see a patient. After meeting the NM in the lobby, she further explained the dynamics: a mother is actively dying and nearing the end, two children are at bedside, 12 other children, are outside, along with a few of their friends, demanding to come in. As soon as the doors opened the family rushed towards us. I sensed NM was a bit nervous by their animated gestures and expressive language. With a background in Mental Health, I made sure NM and I never got enclosed by the crowd…and that we were always closest to the door. We each introduced ourselves and the role with the care of their mother. They zeroed in on her being the manager and vigorously argued their case. Finally, NM asked the family to walk with her over to the side of the building where the Palliative Care was located. She said, "The best I can do is to have your mother bed brought to the window on the second floor so that you can see her." That calmed them down somewhat as they listened to her call the unit to arrange for this to happen. Soon thereafter we could see the nursing team wheeling their mother's bed up to the large window. The siblings were at the bedside and waved.
>
> NM, myself and nurses on the floor used our phones so that they could FaceTime. Each child talked with their mother with one singing a song and another asking for forgiveness. Unknown to the family at the time, their mother had died before all of the children had time with her. Finally, the NM said, "Your mother's nurse just informed me that she has passed." Well, when you say things went South real fast… in this moment, it got bad fast. People started screaming and yelling, running around the parking lot, falling on the ground and wallowing around. People were cursing at the "system" and fussing with each other. The demands to go inside became louder and louder. Based on some of the things I heard them say about their mother, I admonished them to honor their love for her by calming down because it would not honor their mother to have the police get involved. They lowered their voices but the aggressive cursing remained. In fact, one of them said, "I'm going to run right through those doors to see my ---- mother!" I quickly replied, "That would be a terrible thing for you to do. The police will come, and you will be taken away." The young man turned to me and said, "I'm going anyway!" Some family members tried to talk him down, others egged him on. Soon, they all started to charge toward the doors. NM and I ran to get ahead of them. I arrived at the door first, turned and yelled, "Stop! Stop! This will not turn out good for you!" The young man stopped. They all just stood there. NM had already called the Patient Coordinator (PC). I could see her on the inside running toward the entrance. She came out and further

[35] Interview with Vidant chaplain, November 2021.

> explained to them that there was no way for them to see their mother. They cursed and fussed – we will stay here until they take her body to the funeral home. We will follow them there!" PC told them that was not how their mother's body was going to be released from the hospital. She stated that we have some water for them and asked that they get in your cars and leave the area. The family took the water and slowly began to walk towards their cars which were parked near the window where they had been standing. By this time, the male sibling who was at the bedside had come down to talk to them. Just when you thought things could get worst, well it did. He got to cussing, fussing and pushing the others around. Next thing, police cars were coming from all directions. Several officers ran toward us and escorted us to the front entrance of the hospital. There NM and I stood watching the commotion. After a while we went inside. I visited with the nursing team on the unit who were distressed by it all. They had been watching from the same window their mother had just die at –the same window we were trying to offer an alternative means for them to say their good-byes. It was heartbreaking for the team. I listened and held sacred space for them to vent, weep, process, etc. When I sense they were as well as they could be –especially since they had other patients that had to care for, I turned my attention to NM. I walked up to her and asked, "How you holding up?" She reached out and grabbed me…tears pouring from her face. I stood there holding her… I could feel my top becoming wet with her tears. With a faint voice she asked, "What could all of this honor their mother? Didn't she deserve better?" I replied, NM one of things I learned from my CPE Supervisor was, "The way families experience each other in life, you often see that at the time of death." We walked over to a bench and talked. This was a long and exhausting experience. I can't imagine what things would have been like if there had not been visitor restrictions. This demonstration of love or grief may be extreme to most, but it was there painful reality.[36]

The events described by the doctor and chaplain above are just two of multiple events mentioned by participants that highlighted the importance of visitation and of how visitor restrictions on the family members of patients. The strict guidelines were understandable to the head and intellect; however, oftentimes the hearts of the family and team members could hardly embrace them.

Impact of Visitor Restrictions on Patients

End-of-life patients were obviously also affected by visitor restriction policies, and many of them inquired about the absence of their families and had to receive the same explanation about the hospital restriction policy, as did their family members. The participants I interviewed talked about their responsibility in providing quality of care to end-of-life patients and how they took the time to use technology, especially for video calling to connect patients with their families. One doctor found it heartbreaking to see patients trying to talk with their families electronically as they were often so tearful and sad about not being able to physically touch each other in the

[36] Email to the author from palliative care chaplain, November 2021.

same room. The Physician Assistant found it equally heartbreaking, but from a slightly different perspective. He says that the elderly especially has a difficult time with technology, and it was challenging to inform elderly family members about the conditions of their loved ones.[37]

A palliative care Nurse Practitioner spoke intricately about *presence* and how a familiar touch or voice can impact the psychosocial trajectory of patients. She stated that a dying patient may not be able to respond but they can still hear and feel the presence of their loved ones. She spoke with great intention about the *presence of support* in that it was met with insurmountable challenges with visiting restrictions. Additionally, the nurse practitioner mentioned how the impact of *presence* can affect how a dying person may struggle to release when loved ones are not present and by the same token if they are not able to fulfill their spiritual needs through certain rituals and other spiritual practices.[38]

Dr. Y could not attest to any despondency for end-of-life patients, but stated that she did notice other patients on other units do better if family members were present. This could in part be due to the fact that her patients were already so sick it would be difficult to measure. Dr. Y speculated that although she did not witness a change in affect for her patients, if she were a patient herself, she certainly would feel more at ease and comfortable if her family members were present.[39] Dr. X noted that many patients who are at the end of life not only grieve their loss of health and control in life, but also grieve not being able to spend with their families with whatever precious moments they may have.[40] The nurse practitioner also spoke of a personal experience when she was a patient in the hospital at Vidant Medical Center just a few months

[37] Interview with doctor, November 2021; interview with Physician Assistant, November 2021.
[38] Interview with palliative care nurse practitioner, November 2021.
[39] Interview with palliative care doctor, November 2021.
[40] Interview with palliative care doctor, November 2021.

ago and stated that although she is a nurse she would have certainly been less anxious if at the least her husband could have been present.[41]

Often-times when we think of end-of-life we think of adults, but the lives of children were affected as well. Chaplain 2 stated that the Children's Hospital allowed both parents to be present during the end of life stage for children, but no siblings, grandparents, aunts or uncles. It is probably more difficult for a child to understand the precautions centered around visitor restrictions than the average adult. An eight-year-old child that may fully comprehend the fact that they are dying, may not in fact understand why her brother and sister cannot be at bedside at end-of-life.[42]

Impact of Visitation Policies on Staff

In addition to the impact on patients and families, a third theme that seemed apparent in this study was the psychological toll that visitor restrictions imposed on the participants and other clinical team members. Dr. Y spoke very deliberately about the compassionate level of care she and her team provide. Providing the best care for patients at end-of-life can sometimes take long hours. During the pandemic only two visitors were allowed at a time, and during periods when more than two visitors could rotate through the unit, some patients with large families had visitors rotating in over four or more hours. Not only does this negatively affect an end-of-life patient, who for example, may be on a ventilator, but it affects the doctor's own psychological and emotional state of being.[43]

[41] Interview with Nurse Practitioner, November 2021.
[42] Interview with Vidant chaplain, November 2021.
[43] Interview with palliative care doctor, November 2021.

Communicating about visitor restrictions, negotiating with families, and supporting alternative forms of connection between patients and families was often time-consuming for clinical staff. Nurse practitioner described patients who sometimes wanted or needed to have lengthy conversations during visitor restrictions. Without family members or clergy present, they often turned to her. Dr. Y noted that she often took the time to oblige her patients, but there were multiple occasions when she was so overwhelmed with numerous end-of-life patients that she just did not have the time to listen. This also created a certain amount of distress and stress for Nurse Y because she wanted to fulfill all the needs of her patients, especially at the end of life, but it was not humanly possible. The desire is there but the emotional and physical stamina is not.[44]

A Physician Assistant also noted that time was not on his side. He said that there were occasions when he would facilitate family meetings and after beginning the process, another family member would come late to the meeting and he would have to restart and repeat all of what was previously said. This was difficult because during the pandemic of strict visitation policies, end-of-life patients who were infected by COVID-19 *and* were at end-of-life were not in the Palliative Care Unit, which meant that the doctors had to travel a significant distance to the opposite side of Vidant Medical Center's large campus.[45]

Dr. Y referenced another aspect of time as it related to the enormous amount of time she sometimes spent talking with nurses who advocated for multiple family members to visit patients during the rotation at end-of-life. Each family circumstance and dynamic was different, but in some instances, Dr. Y had to decline excessive family visitation. Dr. X pointed out that too many

[44] Interview with palliative care Physician Assistant, November 2021.
[45] Interview with palliative care doctor, November 2021.

family members could jeopardize the safety of staff as well as their ability to practice and protect patients. She said that it was torture to have to make these kinds of decision amidst all the other tasks associated with end-of-life care. I responded to her stating that 'torture' was a very good and descriptive word that expressed how she felt.[46]

Contrasts Between Virtual and In-Person Visits at the End of Life

Another theme that emerged in this study was the contrast that participants noticed as visitor restrictions were relaxed. Participants often mentioned this shift as a way to highlight the importance of the physical presence of loved ones for patients at the end of life. The eventual relaxing of visitor restriction policies was a welcoming change, said Dr. X. When policies became less restrictive, the burden lightened for patients, families, and staff members. He said that once families and friends were able to have some limited visitor access, it did relieve anxiety, loneliness, and distress. Patients were able to receive peace and comfort from the *presence* of their loved ones. Dr. X said that this is not something that can be achieved with medications. Although pain medications and other comfort medications can relieve the physical symptoms, holding hands, talking to patients, playing music, reading from the Bible, etc, were so comforting for the patients, but also very important for the family members to be able provide these comforts at the end of life.[47]

The Physician Assistant was also elated when the policies were relaxed. said, it is one thing to talk about liver failure over an electronic device, but to see, talk, and connect with families as details are being presented is another. More importantly Physician Assistant welcomed the opportunity of family members being present to hold the hands of their loved ones and to begin

[46] Interview with palliative care doctor, November 2021.
[47] Interview with palliative care doctor, November 2021.

the grieving process. The grieving process is paramount for families and can become complicated grief when loved ones are not able to say final good-byes. Physician Assistant said that to provide comfort during the time of a pandemic when families are facing loss of loved ones really was heartbreaking.[48]

Impact on Length and Quality of Life for Patients

A final question that I explored with participants was centered around the issue of whether patients' lives were shortened because of the inability to see loved ones at the end of life. Did participants think patients who experienced the lack of visitation could have lived longer, if more visitation had been possible? While the medical I spoke with admitted that they did not have evidence to show that such restrictions shortened the lives of end-of-life patients, a Physician Assistant, for example, believed that the visitor restrictions probably did shorten the lives of many patients. He said that diseases like dementia and failure to thrive were magnified, and patients lost motivation for physical therapy. He also heard from family members of patients in hospice nursing homes, including former Vidant patients, who stated that their loved ones would not eat because family members were not present to encourage them.[49]

Nurse Practitioner shared some of the same sentiments. She felt that patients became more despondent without visitors, but could not say if that hastened death or not. She said that when support was lacking it played a role in the trajectory of the patient, and patients who were able to have at least one visitor had a different trajectory.[50]

[48] Interview with Physician Assistant, November 2021.
[49] Interview with Physician Assistant, November 2021.
[50] Interview with Nurse Practitioner, November 2021.

Dr. X noted that it is extremely difficult to answer this question of whether lives were shortened due to lack of visitation and psychosocial support. He said, "most of our patients who died in the hospital were in critical condition, so I am not sure that having a family in the room would have made a big difference from their life expectancy, but the quality of their life during that time would have been much better."[51]

The results of this study showed that there is a significant psychological impact of the visitor restriction policies on patients, patients' families, and team members. While palliative care staff worked hard to make virtual visitations and other forms of connection possible during the pandemic, they felt that these alternatives were not a fully satisfactory substitute for the fully embodied presence of family, friends, and clergy or spiritual companions at the bed of someone nearing the end of life.

Biblical and Theological Assessment

The main building blocks of my faith and culture were hued from the stone of the Christian Church. My core beliefs are grounded within the Black church and Black community. Highly influenced by the faith and practices of my parents, I embrace a theology that led me into education, ministry, and public service. I understand God to be a loving God who has no respect of person, a God of hope, and a God of divine presence. I believe God's presence in the world was revealed by his love of Jesus Christ and the indwelling of the Holy Spirit as recorded in the biblical text. I also believe my body–*presence in the world*– to be a God-given instrument for doing sacred work in the world. My theology provides space for me to practice my faith in a manner that respects the diverse belief systems and spiritual boundaries of others. Additionally, I

[51] Interview with doctor, November 2021.

understand that my theology is not authored as an end in itself, but to produce good works in and through my interpretative practice and work as a minister, educator, chaplain, etc. To this end, the integration of my beliefs are embedded within my personal definition of pastoral care – "Pastoral care is to be authentically *present* with others in ways that allow them to rest – to find some comforting strength both from and in their burdensome experience." My way of being present with others allows me to join them where they are and demonstrate capacity to embrace the many belief systems I encounter. I see physical presence as central to my work as a chaplain.

The COVID-19 pandemic changed many things; and providing spiritual care during a time of physical distancing has been challenging. At best it seems like an oxymoron. I mean, how could I be caring, comforting, compassionate and supportive to families at a distance? Therefore changing the way I show up in a room was difficult as best. This calamity became even more evident for me during an end-of-life visit in Palliative Care. I offer this vignette to showing how important physical presence is for patients and family members.

I arrived to find Ms. V's daughter and granddaughter at her bedside singing gospel songs. I stood by quietly as they finished. Upon introducing myself, Ms. V's daughter, Ms. WV, turned quickly, rushed toward me, and wrapped her arms around me. Burying her head on my shoulder, she cried. I was momentarily stunned as I stood in my yellow PPE gown, blue and white mask, and matching blue gloves. I was holding the actions of a grieving woman in tension with a mandate to practice social (physical) distancing.

What was I to do? How did I attend to this grieving family, was I to push her away? I simply returned the embrace and allowed Ms. WV to weep. Then, I walked with her to the bedside and joined them in song and prayer until their mother and grandmother took her last breath. It was clear. The theology of this family was reflected in their singing and moments of

brief testimonies. By connecting with them at a place that was familiar to them, I demonstrated the capacity to support them in the reflection of their personal beliefs and help them to find solace and peace in the process. I entered the space within the context of my theology that was able to provide a place of revered temporary rest. My shoulder was a symbolism of eternal rest for her mother and temporary rest for the daughter. This encounter demonstrated how my personal definition of pastoral care is reflected in my provision of spiritual care - "…to be authentically present with others in ways that allow them to rest – to find some comforting strength both from and in their burdensome experience.

This particular patient had not been stricken with the infectious virus and was allowed at the time to have one visitor, but those who were infected did not have the support of a loved one to sing, read, pray, or just to hold their hand—presence.

Sacraments in many Christian traditions, and especially in the Catholic faith, could have presented a major concern at the end-of-life because most sacraments involve the chaplain or clergy touching the patient in some manner. Vidant Medical Center has one Roman Catholic chaplain who expended himself from the time COVID began until present. Fortunately receiving a sacrament directly was not required as long as the patient had the intention to receive or participate. In cases of which the patient could not make the request, which was most often, family members would request the various practices for them.

What's at stake? This study demonstrates that visitor restrictions do have an impact on patients who are at end-of-life. What that impact is definitively I think is still unknown. However, from the research articles and interviewees we can say that patients' affects are better when family members are present versus dying alone. The Nurse Practitioner stated that for palliative care, spirituality is one of the ways they measure an end-of-life patient's quality of

care. She stated that "end-of-life patients can still hear, feel a touch, and most importantly experience the *presence* of a loved one. Since the senses are still present at end-of-life, patients may be waiting to hear the last voice from those they love.[52]

There have been hundreds of reported instances when patients hang on until they receive a visit from that one particular person, and other instances when patients wait until family members have said their final good-byes and left the room and then take their last breath. I can personally reflect on times when a family member waits tirelessly for their loved one to die while in their company, and as soon as they go get a cup of coffee, the patient expires.

For families and loved ones, what is at stake is complicated grief that extends from loved ones not able to be present. When one is not present to express the last words they will ever have or give the final hug that may be long awaited, the grieving process is hindered at best. How can family members of the deceased begin the grieving process without the closure of being physically present to offer a hug or a touch?

As a chaplain, I too lament that the lack of human contact leads to the loss of spiritually healing significance of touch, the hands-on approach to spiritual care, the physical aspect of journeying with, and the feeling of being alongside the medical staff.

Implications and Recommendations

I believe that end-of-life patients should continue to have the same level of visitation no matter what. However, that visitation should come with some restrictions. In the context of the current pandemic, for example, those who want to visit patients could perhaps be required to submit a negative COVID test within the last 24-48 and submit it upon arrival, in addition to

[52] Interview with Nurse Practitioner, November 2021.

having a health screening and temperature check at the door. In this way, at least there would be an option in place for family members, including children and grandchildren, to say their final good-byes. Children and teens are often forgotten when it comes to mourning because there is misconception that children do not understand what is going on. If you are a sixteen-year-old child whose parent is dying in the hospital, and you cannot see your parent, it is psychologically challenging at best.

I think we have to really work hard in the healthcare system to brainstorm ways that will ensure the that we take seriously the importance of the human touch or embrace at end-of-life. There are ways to ensure the safety and protection of healthcare staff members and still offer end-of-life patients dignity of dying. As mentioned earlier, in the crush of this pandemic, there was not much time to devise well thought out plans of implementation for a virus that seemed to change every few weeks — much less an intentional protocol that focused on the particular needs of end-of-life patients and their families. Vidant Health did the best job it could at the time and tried to be proactive with every measure. Now that we can take a look back over the course of the pandemic, however, we can confront some of the issues we had with these policies and focus on resolving these issues with the future in mind. This learning is important for healthcare institutions as they make decisions that affect the welfare of patients, their families, congregations, and communities.

Appendix A

Title: The Psychological Impact of Visitor Restrictions at End of Life
Principle Investigator: Pamela L. Boyd, MDiv, BCCI

Interview Questions

1. What is your role and responsibility with EOL patients?
2. During the pandemic, was there a time when EOL patients could have no visitors? If so, how did this policy affect patient's health?
3. During the pandemic was there a time when EOL patients could have a limited number of visitors? If so, what did you notice in the patient's affect?
4. If clergy were not allowed to visit, what impact do you think this had on patients?
5. Do you think a dying person become more despondent when not allowed to have visitors?
6. What signs did you notice in patients who had to die alone?
7. If patients were able to speak, did they ask you about visitation policies?
8. Do you think patients who experienced the lack of visitation could have lived longer?

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