

Safeguarding the spiritual care of vulnerable inpatients during health crises

Nicholas P. Taylor, BSc¹

¹ Faculty of Medicine, University of Toronto, Medical Sciences Building, 1 King's College Circle, Toronto, Ontario

Abstract

Spiritual care consists of supporting patients to experience meaning and hope in healthcare settings as well as access religious and spiritual services as desired by the patient. Proper spiritual care is associated with improved quality of life, increased functional status, and decreased depressive symptoms. Spiritual considerations are particularly important for inpatients as well as patients facing diagnosis with high levels of uncertainty or poor prognosis. The COVID-19 pandemic has necessitated changes to hospital policies that impair patient access to spiritual care. Policy modifications include elimination of volunteer programs, restriction of family visitations, and reduced access to community faith leaders, though not all patients are affected equally by these changes. Patients of low socioeconomic status and those with low technological literacy struggle to access spiritual care by alternate means (i.e. using communication devices). Additionally, linguistic and cultural bias may contribute to unequal patient access because policy exceptions are highly variable. Furthermore, socially secluded patients bear a disproportionate burden due to previous reliance on discontinued hospital volunteer programs. Suggestions are presented that target building more robust spiritual care systems within hospitals and minimizing the impact of future crises on spiritual care access.

Introduction

Shortly after the COVID-19 pandemic outbreak, I began a new role as a COVID-19 door screener at a hospital in southern Ontario to bridge the summer between my first and second years of medical school. I was stationed at a hospital entrance and charged

with implementing policies that would govern who could enter the hospital. For a medical student, this was a unique opportunity, driven by the unique challenges of the pandemic. I found myself reflecting on issues within the medical field that are not easily captured in medical education curriculum: the spiritual needs of patients and how they are met. While my experiences are certainly not ubiquitous – being confined to an individual experience within an individual hospital network – the learning points are relevant to a broader discussion on spiritual care needs, especially during times of healthcare crisis.

In my interactions as a screener, it became apparent to me that there was a common theme in the experiences of various visitors I interacted with: the COVID-19 pandemic had not only affected patients' medical care but had also resulted in monumental challenges to patients' ability to experience healthcare within a meaningful and safe environment that aligns with personal patient values. The problem was most pronounced among the inpatients, many of whom endured weeks or months of relative isolation while bearing physical pain, psychiatric distress, uncertain diagnosis, unclear prognosis, or terminal illness.

Despite the effect on patients, these policy decisions were largely necessary for the prevention of COVID-19 transmission and hospital outbreaks. Many decisions were made in the early stages of the pandemic under conditions of extreme uncertainty. Over the ensuing months, policies have been modified as the medical community adjusts to both advances in scientific understanding as well as real time epidemiological data. However, previous levels of spiritual care provision will likely not be achieved until the pandemic is effectively ended. Unfortunately, systems for delivering spiritual care to patients under such extreme and unexpected circumstances were not in place.

Spiritual care

The World Health Organization defines palliative care to include "assessment and treatment of pain and other problems, physical, psychosocial, and spiritual".¹ The last element, spiritual care, has gained significant attention in recent years as physicians and researchers grapple with one of the most complex elements of health and wellness: cultivating meaning and hope during events that, for patients, may be the most challenging moments of life. Spiritual care addresses many of these intangible patient needs. Spiritual care providers help patients find meaning in difficult circumstances, maintain hope through suffering, and gain access to religious/spiritual rites and services that are comforting to patients and often viewed as essential elements of life.

Corresponding Author:
Nicholas P Taylor
nicholasp.taylor@mail.utoronto.ca

For patients with life-threatening illness, spiritual well-being is robustly correlated with quality of life. Spiritual well-being impacts not only patient meaning, peace, and faith, but also physical, cognitive, emotional, and social functioning.² Spirituality has been shown to decrease anxiety and depressive symptoms in advanced cancer patients.^{3,4} It improves ability to cope with life-threatening diagnoses by reducing suicidal ideation and hopelessness.⁵ There is evidence that spiritual interventions can decrease pain intensity and increase patient satisfaction with pain control.⁶ The benefits of spiritual care on patient wellness and quality of life are evident,^{7,8} so much so that there have been suggestions to codify “spiritual distress” as a clinical diagnosis.⁹ Recent literature outlines the challenges that the COVID-19 pandemic have posed to healthcare providers’ attempts to meet spiritual needs of patients, including difficulty integrating spiritual care provisions into practice, and the deeply complex moral and ethical decision-making required of healthcare providers when tasked with implementing COVID-19-related policies.^{10,11} While early recommendations have begun to emerge in literature for spiritual care improvements, much theoretical and practical work remains to be done.¹²

Beyond the scholarly literature, an ethical obligation exists to provide, as possible, the familial and spiritual environment that will best bolster health – or, where health is failing, that will allow for a meaningful end-of-life experience for patient and family that aligns with the patient’s and family’s espoused values. This obligation consists, in its most basic form, of surrounding an ill patient with loved ones. Those who share common life experience and strong social bonds with a patient can catalyze that patient’s ability to see meaning in their life. Furthermore, the impact and importance of faith communities must not be understated. Patients draw on connections with faith communities and community faith leaders as they contemplate life’s meaning and strive to achieve mental and emotional contentment during times of pain, challenge, and uncertainty. For dying patients, great value is derived by taking part in religious rites which mark the transition from life to death with religious significance. Stifling these religious opportunities severely decreases in the provision of holistic healthcare.

COVID-19 and spiritual care resources

Under normal operation, my hospital network has designated resources to support the spiritual well-being of their patients. This includes a small team of full-time Spiritual Care Practitioners (Healthcare Chaplains) charged with directing spiritual care within the hospital and trained to lead end-of-life discussions with patients and families. Prior to the pandemic, a team of twenty spiritual care volunteers would visit inpatients at the bedside. These volunteers often had ministerial backgrounds and received an additional five weeks of training in spiritual care before beginning their service. While spiritual care volunteers are not the only personnel to offer spiritual care services, they make up a large portion of the hospital’s designated spiritual care team, outnumbering the hospital chaplains.

In addition to these volunteers, multiple local religious and faith organizations were active in the hospital. Among the most active groups were a local Muslim ministry and a Roman Catholic ministry. Both groups were represented on-site multiple times each week to provide spiritual counseling and religious rites. Patients of any faith community could request ministerial services from a faith leader of their choice. The chaplaincy office was responsible for organizing these services.

At the onset of the COVID-19 pandemic, immediate steps were taken to restrict vectors of transmission into the hospital. As hospital employees, the Healthcare Chaplains remained in their roles, but the hospital suspended volunteer programs including the spiritual care volunteers, reducing the patients’ access to hospital-provided spiritual care professionals. Patients were compelled to rely more on primary care providers (e.g. nurses and physicians) to fulfill spiritual care needs. However, with pandemic-induced strain on healthcare providers, time available for spiritual care discussions was increasingly limited. These compounding factors put patients at greater risk of retaining unmet spiritual needs.

Policies were also enacted to curtail visits from family and community religious leaders. These visitation restrictions arguably caused the most detrimental change to the patient experience, cutting off inpatients from nearly all in-person contact from outside the hospital. Family visits and religion-specific ministry were each halted. This eliminated patients’ access to spiritual support through family members and, for religious patients, entirely removed the ability to receive faith-specific ministerial visits and religious rites prior to death.

Throughout April and May, patients at end-of-life – defined as less than 48 hours of expected life – were afforded two designated visitors plus a spiritual leader each day. The “two designated visitors” could not change, meaning that only two family members would be permitted to spend time in the hospital with their dying loved one. Patients in critical care were also allowed to designate two visitors, though only one would be permitted to visit each day. No children under the age of 18 were permitted as visitors. Obviously, these policies posed great barriers for families and caused great distress for immediate family members who were not one of the two designated visitors. If a young mother was dying, her husband and sister might become the designated visitors, meaning that her children and parents were not able to visit with her in the final moments of life. For patients with adult children, it was not uncommon that siblings were required to choose one from among them to see a dying parent, while the rest remained outside the hospital.

During the summer months, policy updates afforded visitation allowances to other inpatient units. These patients also designated two visitors for the duration of their stay. The visitors would be allowed a combined two visits per week – they could not be on the same day – and visitors were required to schedule their visit in advance. Inpatients who requested a community faith leader were required to forego one of their normal family visits. This was a major disincentive for patients to request access to spiritual leaders as visitors were forced to choose between family and faith leaders.

Patient vulnerabilities

While all patients certainly felt the impact of increased isolation on hospital wards, there are many ways in which the impact was asymmetric. For example, technological communications enable partial reduction of the pandemic-induced isolation for patients with access to such devices. Not all patients, however, can supply their own resources to connect with support systems outside the hospital. The Canadian Radio-Television and Telecommunications Commission reports that 12.1% of Canadians do not own a cellular device and 15.9% do not own a computer, with the lowest income Canadians constituting a disproportionate share of both figures.¹³ Many hospitals offer land-line services to patients; however, the number

of landlines is limited, and they are located in public spaces – not conducive to hosting deeply personal and emotional conversations on spiritual topics. Even where hospitals provide personal communication devices for patients, such as iPads, manpower is often required to initiate their use. For example, my hospital requires that formal consent be obtained by both the patient and the family member they wish to contact before such devices can be used. In my experience, already over-burdened healthcare workers often do not have capacity to troubleshoot communication barriers in addition to their other responsibilities. These combined constraints risk leaving these patient subsets isolated without recourse.

Another incongruence in spiritual care was the existence of “exceptions” to hospital policy – such as receiving additional visitors – which were granted by unit managers on a case-by-case basis. While exceptions to policy may be warranted in many cases, the localized nature of decision-making puts patient equity at risk. Exception-making has potential to vary widely between units and managers, leaving patient access to family and spiritual care resources up to chance. More concerning is the potential for unconscious bias leading to discrimination based on any number of social factors – racial, cultural, linguistic, etc. This is especially relevant in the Toronto metropolitan area, where 47% of the population belongs to a visible minority and only 52% of individuals consider English to be their mother tongue.^{14,15} Patients who are better able to advocate for themselves or who fit certain perceived cultural stereotypes may be more likely to be granted exceptions.

Perhaps the most deeply affected inpatient population are those who do not have strong social ties to family, close friends, or a religious/spiritual community at all. Without such social supports, these patients have increased reliance on healthcare providers and hospital-provided spiritual care services for meaning-making during their hospital stay. While healthcare providers make significant contributions to spiritual care of their patients, visits with chaplaincy and spiritual care volunteers are among the only conversations solely designated to bring meaning and spiritual contentment to patients. With volunteers removed from the hospital, and chaplains’ and healthcare providers’ time stretched thin, these socially secluded patients risk spending weeks or months on the hospital floor without opportunity to vocalize their spiritual needs, discuss the meaning of life experiences, or contemplate aloud the end of life.

Improving spiritual care systems for future crises

How can hospitals simultaneously protect patients from communicable disease and satiate the spiritual care needs of its patients? There is no clear and obvious solution. I offer suggestions based on personal experience within my capacity as a hospital screener, with the goal of stimulating discussion on this important topic. Based on knowledge gained during the COVID-19 pandemic, further conversation is necessary to make spiritual care systems more robust and protect spiritual care access in the future.

1. *Timely end-of-life notice:* Healthcare workers commonly notify the spiritual care department when patients are approaching end-of-life, often within a few days of expected death. A system might be devised in which the chaplain is given earlier notice for patients nearing end-of-life. While it is true that predicting life expectancy of a patient is nearly impossible, there are many clinical scenarios in which it becomes apparent that a patient’s

remaining life is better measured in weeks than months or years. During times of systemic healthcare strain, when spiritual care resources are restricted, it is critical that hospital chaplaincy can identify patients with the most critical spiritual need. In addition, this categorization of patients allows hospital decision-makers to make policies tailored to this patient group, allowing greater access to visitation or other spiritual care resources to dying patients.

2. *Spiritual distress diagnosis:* Allow physicians or other healthcare workers to identify and diagnose patients in “spiritual distress” as suggested by Puchalski.⁹ The diagnosis may trigger a clinical checklist which includes: (1) a direct visit from a hospital chaplain, (2) ensuring access to family and other social supports, and (3) inclusion of community faith leaders according to patient preference. The diagnosis and checklist system helps clinicians prioritize limited spiritual care resources around patients with the most urgent need. These additional resources need not necessarily include exceptions to in-person visitation policies. For example, consenting patients to use hospital-provided communication devices could be included in checklist item 2, and the chaplain may be involved in facilitating video-calling from a relevant community faith leader under checklist item 3.
3. *Range limits for spiritual care providers:* Rather than spiritual care volunteers visiting patients throughout the hospital, dedicate the service of each volunteer to a small number of units or patients. This decreases risk of transmission between patients or units. The policy may be permanent or may be implemented only in times of high communicable disease risk (e.g. during influenza season or following a C. difficile outbreak). During a pandemic with a novel pathogen, such as SARS-CoV-2, it may be difficult to implement proper range limits immediately before communicability of the pathogen is known. A conservative approach is necessary; however, in a pandemic setting, retaining spiritual care volunteer services with strict range limits may be a reasonable, risk-mitigating alternative to cancelling the programs altogether.
4. *Diverse volunteers:* Increase the diversity of spiritual care volunteers. As risk factors for COVID-19 were identified, many volunteers fell into high-risk categories due to age. This contributed to blanket removal of volunteers.
5. *Formalized access for faith leaders:* Formalize the relationship between community faith leaders (priests, imams, rabbis, and other religion-specific leaders) and the hospital. This may include training on infection control, PPE, and handwashing for faith leaders who frequent the hospital. Formal relationships streamline the process of allowing vetted and trained faith leaders into the hospital during health crises. Not only does this allow religious ministry to continue during crises, but also provides a vector for administering the end-of-life rites and rituals that are vital for the spiritual well-being of religious patients who are facing death.

The COVID-19 pandemic has strained healthcare systems in unprecedented ways. However, for patients who are medically unwell and facing medical uncertainty, spiritual care is crucial to both quality of life and emotional contentment in the contemplation of death. And, more than in any other aspect of care, the human

element is indispensable. Through connection with others, patients are enabled to discover meaning outside of themselves. As healthcare practitioners, administrators, and decision-makers, protecting a patient's access to visitation by family and spiritual guides is paramount to achieving ethical patient environments and holistic health. This is especially true for the most vulnerable patients, during the most vulnerable episodes of life. By leveraging lessons learned during the COVID-19 pandemic, durable systems can be built that will protect the spiritual well-being of patients during times of both personal disaster and systemic crisis.

References

1. Sepúlveda C, Marlin A, Yoshida T, et al. Palliative care: the world health organization's global perspective. *J Pain Symptom Manage.* 2002 Aug;24(2):91-6. doi: 10.1016/s0885-3924(02)00440-2
2. Jafari N, Farajzadegan Z, Zamani A, et al. Spiritual therapy to improve the spiritual well-being of Iranian women with breast cancer: a randomized controlled trial. *Evid Based Complement Alternat Med.* 2013;353262. doi: 10.1155/2013/353262
3. McCoubrie RC, Davies AN. Is there a correlation between spirituality and anxiety and depression in patients with advanced cancer? *Support Care Cancer.* 2006 Apr;14(4): 379-85. doi: 10.1007/s00520-005-0892-6
4. Pearce MJ, Coan AD, Herndon JE II, et al. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer.* 2012 Oct;20(10):2269-76. doi: 10.1007/s00520-011-1335-1
5. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet.* 2003 May;361(9369):1603-7. doi: 10.1016/S0140-6736(03)13310-7
6. Keivan N, Daryabeigi R, Alimohammadi N. Effects of religious and spiritual care on burn patients' pain intensity and satisfaction with pain control during dressing changes. *Burns.* 2019 Nov;45(7):1605-13. doi: 10.1016/j.burns.2019.07.001

7. Chen J, Lin Y, Yan J, et al. The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: a systematic review. *Palliat Med.* 2018 Jul;32(7):1167-79. doi: 10.1177/0269216318772267
8. Ho JQ, Nguyen CD, Lopes R, et al. Spiritual care in the intensive care unit: a narrative review. *J Intensive Care Med.* 2018 May;33(5):279-87. doi: 10.1177/0885066617712677
9. Puchalski CM. Spirituality in the cancer trajectory. *Ann Oncol.* 2012 Apr;23(Suppl 3):iii49-55. doi: 10.1093/annonc/mds088
10. Ferrell BR, Handzo G, Picchi T, et al. The urgency of spiritual care: COVID-19 and the critical need for whole-person palliation. *J Pain Symptom Manage.* 2020 Sep;60(3):e7-e11. doi: 10.1016/j.jpainsymman.2020.06.034
11. Chaturvedi SK. Spiritual, moral and ethical dilemmata for healthcare professionals during COVID-19 times. *J Psychosoc Rehabil Ment Health.* 2020 Oct;1-2. doi: 10.1007/s40737-020-00205-5
12. Pierce A, Hoffer M, Marcinkowski B, et al. Emergency department approach to spirituality care in the era of COVID-19. 2020 Sep;[ePub ahead of print]. doi: 10.1016/j.ajem.2020.09.026
13. Canadian radio-television and telecommunications commission (CRTC). Communications monitoring report 2018 [internet]. Ottawa (ON): Canadian radio-television and telecommunications commission (CRTC); 2019 [accessed 2020 Nov 16]. 270p. Report no.: BC9-9-1019. Available from: <http://publications.gc.ca/pub?id=9.506067&ssl=1>
14. Statistics Canada. National household survey profile: Toronto, CMA, Ontario (code 535) (table). Ottawa (ON). 2013 [accessed 2020 Dec 26]. Catalogue no.: 99-004-XWE. Available from: <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/prof/index.cfm?Lang=E>
15. Statistics Canada. 2016 Census profile: Toronto census metropolitan area (table). Ottawa (ON). 2016. [Accessed 2020 Dec 26]. Catalogue no.: 98-316-X2016001. Available from: <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E>