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Pills, Needles, Support:
Spiritual Care can Improve Communication, and
Compassion in the Healthcare Industry

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Honors Capstone Project
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“I had had no idea of the full scope of human suffering. I was suddenly witness to misery, death, and raw emotion.” The palliative specialist and ICU practitioner, Dr. Jessica Zitter, recalls the first years of her residency as a shock that an understanding of physiology and disease did not prepare her for.⁵⁰

In her book *Extreme Measures*, Zitter digs into the question of what it means to care for a patient.⁵⁰ It is commonly assumed that the ultimate goal of a health care professional is to address a specific physical need of a patient. However, Zitter, highlights the nuance of what it can mean to care for a patient by exposing the reader to the aggressive and invasive procedures that are often used to ensure a patient lives. For example, she presses that when a patient is near the end of their life, once tubes are “cut and sewn into tissue” they risk not being able to die in their home, never tasting food again, and “not being able to take care of your own personal hygiene”. In our current health care institutions “patients are emotionally abandoned”, and suffer as their psychological and emotional experiences are often ignored in favor of finding a diagnosis and cure.⁵⁰

Zitter does not blame fellow doctors for the increasing detachment in doctor patient relationships.⁵⁰ Instead she highlights that the medical industry and national culture often demands the best medicine money can buy and ranks fighting and curing a disease as a more valuable achievement than prevention or learning to cope with a disease.^{16,50} This makes it difficult to find support for the moral dilemma health care professionals often face when deciding if a procedure or treatment plan will reduce suffering and alter the mechanism of disease.^{16,50} Not all procedures result in acquiring meaningful data about a person and not all invasive procedures will make a meaningful difference to someone’s health.^{15,16,50} This puts

doctors in a position of constantly needing to weigh the harm and benefits which may result in decisions that do not accurately address a patient's perspective of what they need and the care they want.^{16,41,50} Zitter writes that "It is uncomfortable to watch people suffer, especially at one's own hands," and found that to cope with the exposure to suffering it's easier to ignore emotional distress than to address it in an effort to protect her own mental health.⁵⁰

Zitter's personal accounts highlight two essential challenges in our current health care institutions: the need for greater connectedness and compassion in a clinician patient relationship, and medicine that provides patient centered treatment plans which focus on coping mechanisms, patient values, and emotional/physical needs.^{7,12,15,16,31,41,50} One practice that can address both of these challenges, yet is often be overlooked by both patients and health care professionals is spiritual care.^{1,37}

Spiritual care is unique because of the emphasis spirituality and spiritual health put on the importance of community, connection, meaning, and relationships. Dr. Gowri Anandarajah, who created the HOPE culturally sensitive spiritual assessments used by the American Medical Association, emphasizes that spirituality "pertains to people's understanding of and beliefs about the meaning of life and their sense of connection to the world around them".² He argues that spiritual needs are an essential component to our mental and emotional health through relationships, purpose, and meaning.^{2,3} Spiritual health and support allows us to become more receptive and compassionate to the people and loved ones in our life, while also allowing us to become more realistic and resilient to hardships such as a medical diagnosis that demands lifestyle changes, invasive procedures that can cause anxiety, and terminal illness.^{2,3,23,27,37}

Ultimately spiritual care is a massive philosophy of holistic care that centers on the significance of spiritual health to the overall health and wellbeing of a person emotionally,

physically, and mentally.^{1,2,3,11,23,27,37} The acts of spiritual care are diverse and largely depend on the perspective of a patient and the tools they need to cope, understand, and find meaning in their illness or current state of health.^{2,3,9,5,25,45} Modern medicine places a large amount of focus on rationalizing the mechanism of a disease and places less worth on understanding patient's conceptualization, coping, and developed perception of a disease or illness.^{11,16,42,50} This paper will examine the ways in which spiritual care promotes the compassionate acknowledgment of a patient's subjective experience, flexibility of treatment plans, and breaks down communication barriers to address the specific values and emotional/physical needs of a patient.

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The potential benefits of spiritual care centers on the theory behind all holistic care models: all forms of health whether it be spiritual health, mental health, emotional health, or physical health are interconnected and impact the other.^{1,7,13,16,22,36,41}

Biochemically this model makes sense because no part of the body works in complete isolation from the rest of the body, despite the current spike in doctors that specialize and the emphasis insurance companies and hospitals put in assessing patients with rigid anatomical categories.^{16,50} For example the central nervous system of the brain and the enteric nervous system that lines the wall of gut are in constant communication but each “regulates autonomously”.⁸ This means that quit literally our gut can regulate the immune system, consumption of energy, and stimulus from stress.^{8,28,30} In fact current research has even found that the impact of chronic stress and particularly early life adversity can directly affect the enteric nervous system and have significant impacts that range from depression to “functional gut diseases”.²⁸ This is a concept that may run counter to many immediate assumptions that our brain, alone, is specialized in regulating and initiating the body's functions and behavior. This

example and many similar ones highlight that multiple dimensions of health impact our human experiences.

The voices of the psychiatrist Dr. George Engle in the 1970's and the internist Dr. Eric Cassell in the 1980's, to this day stand out as articulating the significance of health care models that address the patient's whole person.^{7,19} Both doctors emphasize that a patient's needs are multifaceted and exist on social, spiritual, emotional, and physical levels that are all interdependent and interconnected. Engle proposed that care for a patient's illness should follow what he called the bio-psycho-social model.⁷ This model argues that an illness is not an isolated event that only impacts the physical body but is an experience that has social, psychological, *and* physical ramifications or causes.^{7,14,16} His model emphasizes that "to understand and respond adequately to patient's suffering – and to give them a sense of being understood – clinicians must attend simultaneously to the biological, psychological, and social dimensions of illness."⁷ Engle's model has since inspired a philosophy of care that seeks to empower patients by engaging with their understanding of a disease; it acknowledges the identity of the patient, a need to be heard, and has a tolerance for uncertainty.^{7,16} In this way champions of Engle's work, hope to move away from strategies of care that "focus on the disease to the exclusion of the person who is suffering."⁷

Similar to Engle's work, Dr. Cassell places weight on the importance of the multiple dimensions of an illness. Instead of emphasizing health he draws his argument from a perspective of suffering.¹⁹ He argues that if the spiritual, social, emotional, and physical facets of an individual's life interconnect, then suffering must be understood more broadly as an experience that threatens a patient's sense of self on all or any of these dimensions.¹⁹ He describes that suffering is "experienced by persons, not merely bodies, and has its source in

challenges that threaten the intactness of the person as a complex social and psychological entity”.¹⁹ He argues that the role of any health care professional should focus on addressing suffering and because suffering is multidimensional and threatens an individual’s sense of self, then acknowledgement of the patient’s humanity is essential to health care.

The perspectives of Engle and Cassell are echoed in various research on health and health care policy. On an institutional level the idea of integrated care has increased in popularity. One recent paper addresses the need for more integrated primary care in which mental health care professionals along with primary care physicians collaborate to address patient’s health needs.⁶ By integrating mental health and primary care professionals, the actual goals primary care seeks to address such as preventative care could be more easily accomplished. Another research group lead by Peral-Moreno et al. shows a strong correlation between “physical and mental comorbid illnesses” and ability to make preventative lifestyle changes.³³ This suggests that encouraging lifestyle changes requires some form of support for a patient’s mental health to have future physical benefits.^{6,33}

Other research papers depict the significance of holistic care models on an individual patient care level. A study conducted by authors Pitkala *et al.*, conveys the interconnection between mental and social health to physical health.³⁶ The study specifically explores the effects of psychosocial group rehabilitation on loneliness and health among patients greater than 75 years of age.³⁶ Loneliness is a “subjective experience of a lack of satisfying human relationships” and the paper argues that loneliness is particularly impactful among older patients with an “impaired quality of life”.³⁶ To underscore the significance of social connection the authors point out that the “feeling of loneliness was an independent predictor of death among coronary bypass surgery patients both in a 30-day and in a 5-year follow up.” The study’s results

found that the participant group that experienced group intervention had lower mortality rates than the control patient group, which did not receive group intervention sessions.³⁶ Furthermore, the intervention group was found to have a significantly improved perception of their health. This study demonstrates how treatment options that include social, psychological, and physical health by being attentive to patient's needs and values, can result in physical health benefits without actually targeting to improve a patient's body function.^{7,18,23,36} In this case participants that experienced a severe sense of loneliness were able to experience health benefits through an intervention that sought to improve the patient's sense of wellbeing and sense of connection.³⁶

This follows closely with results found in a study that looked at how flexible treatment plans that considered psychological, emotional, and physical health impacted overall health outcomes. The Jamieson *et al.* research group specifically investigated how various treatment interventions affected recovery outcomes for women who had undergone a cardiovascular procedure.²² The researchers conclude that there is a need for cardiac rehabilitation treatment interventions that are tailored to patients' "characteristics and needs".²² This is in agreement with studies that have found mental health to have a correlation with a successful recovery.^{18,22,49} For example, depression has been linked to higher rates in morbidity and mortality among individuals with coronary heart disease.^{18,22} Furthermore, social, emotional, and mental health factors such as depression or anxiety have been found to significantly reduce patient's compliance to their recovery plan and thus need to be treated in tandem with routine recovery plans.^{13,18,36,41,43,49}

These research papers often use "perception of health" to understand the interconnection between physiological and physical health. Perception of health is fascinating because it uses a patient's own subjective experience as a "reliable indicator of an individual's overall health".³⁶

Perception of health is often used for measuring the outcome of treatments and survival because of the numerous studies that have found strong correlations between reported perception of health and mortality rates.^{1,36,43} Some studies have found that a key connection comes from the fact that patients with more positive perceptions of health are more likely to follow treatment plans and lifestyle changes.^{36,43}

The above studies that have been able to identify benefits to holistic care are encouraging. However the question remains; what specifically can change institutionally and in providers' daily interactions with patients? Recent qualitative research has emphasized the use of compassionate care in actively implementing attentive 'bio-psycho-social' care to patients. One recent study, "Compassion in Health Care: An Empirical Model", interviewed over 100 adult patients with advanced cancer on a palliative care unit about the impact of compassionate care.⁴² Most perspectives emphasized the significance of feeling heard and the anxiety and frustration of feeling ignored. For example one patient describes;

Compassion means to me someone listening. Really listening and hearing what I am saying rather than what they think I am saying. It's important that you hear what I'm saying so that we can address this correctly for me.⁴²

Not only does this perspective highlight the importance of compassionate listening and presence, it also suggests a sense of anxiety when feeling unheard.^{31,42} Yet another patient expressed that "your spirit drops" when being cared for by a healthcare professional with a lack of compassion, which gave them a sense of stress and frustration that would not have existed otherwise.^{11,15,20,29,42} Another patient evokes the potentially impactful benefits of compassionate care, describing that compassion is "a very, very strong feeling, it's a solidifying building quality

that makes a person feel whole, it make them feel valued and loved, that brings dignity...it's such a powerful thing.”⁴²

All of these insights highlight how compassionate care is something that is communicated through body language, eye contact, and reactions from the clinicians.⁴² An example of utilizing compassionate listening would be to respond to a patient who indicates a sense of depression rather than ignoring them while taking their blood pressure.^{16,42,50} Such actions allow patients to feel “heard” and “seen” and treated as a human rather than just a patient.^{16,42} Overall these indicators of attention, presence, and caring were extremely impactful to patients’ experiences.

Spirituality can be a sensitive topic due to the intimate experiences that people associate with it.^{2,9,25,31,36,47} The researcher Dwairy points out; spirituality is essential to the holistic practice because “it is impossible to understand the universe and human experience without taking into account the subjective component of the imagination and spirituality”.¹⁴ Dwairy essentially argues that to understand reality we subjectively understand it through a spiritual, moral, and cultural lens.^{14,48} Therefore to engage in effective communication and compassionate listening a person must be able to acknowledge, not just the disease and functions of the body, but the subjective reality a patient is coming from.^{14,44,48}

To better illustrate the importance of subjective experiences that Dwairy discusses consider a patient who comes from a religious community that believes health to be directly related to morality and God’s judgment. This patient would not just be facing their mortality when getting a cancer diagnosis. They may struggle to understand the deeper meaning behind their illness, struggle to cope spiritually and physically, and may struggle to find support from

their community. All of these possibilities can be addressed if a health care professional is sensitive and responsive to the patient's emotional and spiritual wellbeing.

The significance of spiritual care is further explored by the family practitioner, Dr. Timothy Daaleman. Daaleman found in his research that, not only do academics see compassionate care as foundational to spiritual care, but patients also had similar views. One of his studies from 2008 found that of the spiritual care providers *identified by patients* "41% were family or friends, 17% were clergy, and 29% were healthcare providers."¹² Furthermore, in another study conducted by the research group Hanson *et al.*, it was found that "the most frequently reported type of spiritual care was help in illness coping (87%) and the least common was intercessory prayer (4%)."³⁹ Both these studies findings highlight that more than religious activities patients associate deeper human connections and understanding with spiritual care.¹²

Another trend that the Daaleman research group found was that "providers who were nominated as spiritual care providers by dying patients and their family members...[were predominantly marked]...by physical proximity and intentionality, or deliberate ideation and purposeful action of providing care that went beyond medical treatment."¹² In other words, regardless of the actual title a health professional had the providers who spent the most time with the patient and family, with the most intention and compassion were most commonly identified as spiritual care providers.¹² This emphasizes the fact that from the patient's point of view it doesn't matter whether the provider specializes in spiritual care. Any clinician or health care provider can become a source of spiritual support and care simply from the intention, patience, and compassion in the care and communication they provide.^{11,12,19}

Ultimately Daaleman, along with other academics, places acknowledgment of patients' sense of dignity and their sense of being valued as a person at the forefront of spiritual

care.^{7,11,12,19,31,42,44} While this may seem obvious, the long work hours of health care professionals and the constant exposure to illness, pain, and suffering can lead to ignoring the humanity of patients in order to get through the work day.^{4,12} This can lead to clinicians seeing an extremely dramatic life event for a patient as a mundane and routine event.^{4,12,31,48,50}

Daaleman's work reflects a basic human need and desire to find meaning and purpose especially in the midst of dramatic life experiences, such as struggling to understand death, living with a new illness, or recreating a new lifestyle with a new illness.^{2,3,11,12,16,19,44,48}

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Applying spiritual care to a realistic work environment faces many barriers that conflict with idealistic principles suggested by Engle and Cassell. These barriers include the professionals' sense of routine overshadowing a patient's own unfamiliarity and shock, an institutional need for efficiency, and a health care professional's own emotional wellbeing.

Mammograms are an example that highlights the need to bridge the gap between patients and doctors perspectives in what is commonly seen as an extremely mundane and routine procedure.³¹ For patients such a 'routine' procedure can be met with anxiety, pain, and embarrassment.^{7,16,31} A study done by Dr. Morris investigated the major differences in the way academic medical literature described mammograms and advertised mammograms to patients and the ways in which patients experienced mammograms.³¹ One of the biggest differences was the description of pain and discomfort. For example Morris points out that the American Cancer Society describes compressions as "uncomfortable" but that it "only lasts for a few seconds".³¹ Patients however described a huge variety of pain and there was a pattern of patients conveying a lack of autonomy that was embarrassing and source of stress.³¹ For example one patient described the process "like they are handling a lump of meat. Sort of throwing it on a slab and

doing something to it”.³¹ This exemplifies a sense being disengaged from their body and a lack of autonomy.³¹ Another patient found the process to be extremely painful saying “they always have to press...compress it so hard and ...hold your breath and just pray that they hurry up and take the picture”. This experience also indicates a reduced sense of autonomy.³¹

Data that mammograms provide is necessary for doctors to properly diagnose and properly scan the population for early signs of breast cancer.³¹ However, this does not mean a patient’s sense of dignity and agency has to be ignored.^{16,19,31} Morris found that simple things like talking to the patient while conducting the procedure, asking them how they are feeling, and pausing the procedure when the patient asks would allow the patients to maintain a sense of agency and respect their sense of dignity.^{7,16,31} Even though the biggest barrier in fulfilling these basic professional behaviors is a high demand for efficiency and institutional pressures placed on clinicians the solutions did not seem to overtly increase time but instead change the focus of the time.^{16,31}

Morris’s observations reestablish that a significance characteristic of spiritual care is compassionate listening. Compassionate listening requires the spiritual care provider to help the patient accept and understand reality and to give them a space to feel heard and that their suffering is not being overlooked.^{7,11,12,15,16,19,29,42} Connecting requires surrendering to another person’s reality.^{17,44} Doing this allows for patients to not only feel heard and acknowledged but also for care providers to better understand the treatment that their patients want and need rather than the treatment that will heroically fix them.^{7,12,16,41,50}

One of the biggest concerns when discussing the subjective experience of a patient and taking the time to acknowledge their perspective is efficiency.^{7,10,16,31} Currently there is a shortage of doctors especially in primary care fields and various work environments such as an

emergency rooms demand doctors to make fast paced decisions in order to stabilize the patient.^{16,50} Recent research has found that taking extra steps to bridge the divide between a patient's understanding of a disease and treatment takes time that often is pushed aside due to institutional time pressures.^{7,10,16,50} A lack of interest in patient's own subjective experience can reduce the quality of communication in a doctor patient relationship.^{11,16,31,42,50} This gap in communication can have amplified significance, emotional impact, and consequences for patients suffering with a terminal illness.¹⁰

In a comprehensive essay that outlined research investigating how spiritual and compassionate care interventions effect efficiency in high stress environments such as the ICU, Dr. Alexander Cist and Dr. Philip Choi describe how spiritual care interventions can play a role in attentive communication. Cist and Choi emphasize that the ICU is unique from other health care environments due to its "high mortality, the prominence of prognostic uncertainty, and the high rate of surrogate decision making."¹⁰ These factors make spiritual care more significant and impactful as both families, loved ones, and patients struggle with uncertain treatment outcomes, harsh realities, and celebrate lives that are saved.^{10,19,20} Despite this the authors contend that "the pace of the ICU care hinders clinicians' ability to address religious and spiritual needs" and that often clinicians may be required to spend "hours performing procedures such as intubation ... simply to stabilize the patient."¹⁰ Ultimately this leaves spiritual care such as deeper discussions about treatment plans, values, and psychological health to "receive lower priority than the medical problems bringing a patient to the ICU."^{10,50}

There is an obvious need to address life threatening physical conditions in the ICU. However, Cist and Choi point out that spiritual care remains an important tool to address the uncertainty that many treatment plans in the ICU can carry and to address the emotional and

psychological stress patients or surrogate decision makers may be under.^{10,11,19} For example, the authors point to one study that found patients with “a higher degree of religiosity” were more likely to opt for more aggressive treatment plans in the ICU. While another study done by the same investigators found that if religious and spiritual needs were addressed, patients “tended to choose more hospice care.”¹⁰ Cist and Choi attribute this to the fact that, when spiritual needs were addressed, patients were more likely to be accepting of their illness, were more capable of finding coping strategies, and had a greater ability to find meaning and purpose in life.^{2,3,10,11,12,15,19,23} This further suggests that when spiritual care is addressed patients and surrogate decision makers are given space to contemplate their options with social support.^{2,3,4,7,15,16,19,44} This could enhance their understanding of the treatment plans available and allow for more opportunity to understand the reality of the illness.^{16,44,50}

A qualitative research project conducted by the nurse practitioner Dr. Nessa Coyle conveys the depth patients relate to and understand their illness through their spiritual and subjective experiences.¹¹ One patient in particular says that “I think I have more fear of dying now than I had before maybe because my faith is a little more shattered than it was.” Coyle argues that this sentiment reveals a sense of uncertainty in God and a desire for “support from something greater than themselves.”¹¹

Another patient’s experience reveals how an illness’s progression and pain can increase a patient’s sense of anxiety.¹¹ The patient describes that:

The pain makes me worry about dying because if I'm in pain because the tumor has gotten significantly larger that means I'm losing and the tumor is winning—but if I am in pain simply because the pain medication wore off then that's not so scary. I just don't know which it is. I'm beside myself with anxiety.

Coyle asserts that this experience is common for patients suffering from advanced cancer and that, there is a “considerable amount of time and energy orienting themselves to their disease” and struggling to understand what a new or worsening symptom means.¹¹

Yet another patient intimately describes the fear and frustration associated with a status update that confirms the cancer has become too advanced to further treat.¹¹

The change in my status took place without my knowing it was going to take place ... all of a sudden the word hospice came into it... pressing me to make a decision, do I want to go home or do I want to go to a terminal care facility...

All of these experiences are extremely different but are tied to the consistent theme of needing emotional support to manage anxiety, to better understand the symptoms and disease progression, or to discuss fear of dying and fear of an uncertain future.¹¹ Coyle concludes that clinicians need to understand that “living in the face of death” is a position of extreme stress, frustration, and fear that needs to be better understood to provide more support.¹¹ The most vital support she recommends is communication: providing patients with a clear understanding of the potential course of an illness and clearly explaining the treatment choices they have available.¹¹

By providing patients with treatment options that are best suited to their values, physical needs, and social/emotional needs clinicians can give them the support they need to cope with a new disease or lifestyle.^{7,11,14,15,16,22,36,49,50} For instance, framing hospice and palliative/holistic care models as giving up hope and pulling the plug can put pressure and a sense of guilt on surrogate decision makers and makes the number of options available seem significantly less than there actually are.^{10,16,50}

One study conducted by Saito *et al.* compared end of life care among elderly patients

with lung cancer who opted for hospice ,with minimal procedures, to patients that opted for a more intensive care protocol for end of life care.⁴¹ Their study, with a sample size of over 5,000 patients, did “not detect a detrimental effect on survival by entering hospice”.⁴¹ Even more interesting the paper found that “hospice patients were found to have comparable or even longer survival compared to non-hospice patients”.⁴¹ As a result the paper concluded that “continuing aggressive care close to death did not necessarily translate into better outcomes or inaccurate estimation of the prognosis.”⁴¹ This study highlights a flawed assumption that many patients, surrogate decision makers, and even some doctors believe. More aggressive care does not necessarily translate to a longer life span among patients who are suffering from a terminal illness.^{41,50}

This is not meant to suggest aggressive care does not have value in extending life among patients. It is only meant to emphasize the need for treatment that seeks to provide for the unique needs of patients.^{16,50} It also underscores that even when dying there are options available that can dramatically reduce suffering.

It is impossible to contemplate how health care can better address the spiritual needs of a patient compassionately without addressing the working conditions of health care clinicians. Dr. Jessica Zitter, introduced at the beginning of this paper, is not alone in her struggle to find emotional support for the suffering she was exposed to as a health care professional.⁵⁰ Dr. Cynda Rushton looked specifically at health care professionals who cared for children with terminal illnesses.³⁹ Unsurprisingly there was “significant distress among health care professionals”. However, respondents also reported a lack of “explicit professional or institutional support for their grief”.³⁹

Further investigation also found that it was not only grief that health care professionals

were experiencing but suffering caused by “role conflict, or situations that caused moral distress, or loss of professional integrity.”³⁹ Another paper from the academic journal, *Pediatric Nursing*, found that the consequences of stressors like secondary trauma among emergency room nurses included 46% of nurses reported having intrusive thoughts, 52% of nurses reporting that they avoided specific types of patients, and 43% reporting emotional numbing.²⁶

Just like their patients, health care clinicians also need to be heard, to have their experiences acknowledged, and to receive support. The compassionate care that could provide patients with a greater sense of wellbeing and higher perception of health cannot be given by a health care professional who is also suffering without support from secondary traumatic stress or moral distress. In this way the needs of health care professionals and the needs of the patients under their care mirror one another.

The family physician Dr. Ronald Epstein describes a slow but hopeful change in the support given to health care clinicians struggling with moral distress and guilt after making a medical mistake.¹⁶ Hospitals are beginning to have anonymous support groups that offer employees a space to talk through their guilt or uncertainty and learn from their mistakes.¹⁶ Other programs are slowly being implemented to more quickly support and address trauma and grief of staff in hospitals through bereavement programs or personal reflective critical incident reviews which provide staff with prompts to help conceptualized and understand their emotional and physical symptoms.²⁶

Ultimately there has been increasing evidence and support for the idea that patient’s subjective experiences matter to their overall health. There are many theories and tools to better provide whole person care and of them spiritual care directly demands providers to acknowledge existential, moral, and cultural needs of a patient. Overall this means allowing patients the space

and comprehensive information to contemplate a realistic treatment plan that fits their values and needs best.^{4,16,50} The rapidly growing palliative care field, integrative medical teams that include physiologists and chaplains, and increasing support for health care staff are hopeful signs that the human experience is heard when providing care. To do this Zitter recalls learning “to ask more than tell, to sit with the sadness and despair of patients and their families, and to acknowledge uncertainty.”⁵⁰

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