2024 James Wake Memorial Lecture

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MARQUETTE UNIVERSITY'S COLLEGE OF NURSING and the
INSTITUTE FOR PALLIATIVE & END OF LIFE CARE

BE THE
DIFFERENCE.

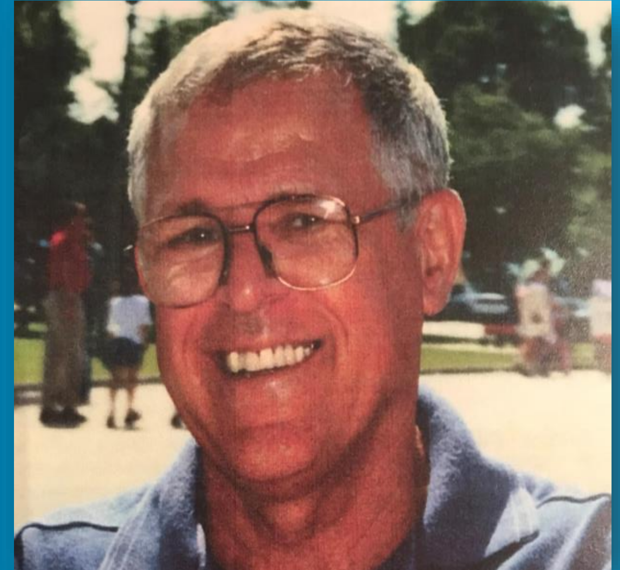
James Wake

I have learned through chaplaincy to honor the spiritual journey of each person, as it unfolds moment by moment, breath by breath, heartbeat by heartbeat.

Each person's journey is valid; each moment of the journey is sacred.

You are a person of goodness, unconditionally loved by God.

I honor your journey; I honor you.



DEATH, CULTURE, AND RELIGION
HOW DIFFERENT WORLDVIEWS IMPACT THE DYING PROCESS

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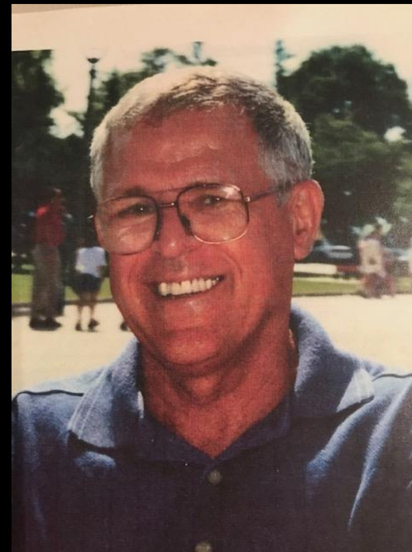
JAMES WAKE MEMORIAL LECTURE



CONCEPTIONS OF DEATH & AFTERLIFE

Our understandings of death are dependent on our religious worldview and our cultural contexts, and changes depending on access to medical technology, and the broader medical system.

But, in today's pluralistic society, it is important to understand that when we talk about death, dying, and the afterlife– we often mean very different things.

And medical culture itself shapes our understanding of both dying and death.

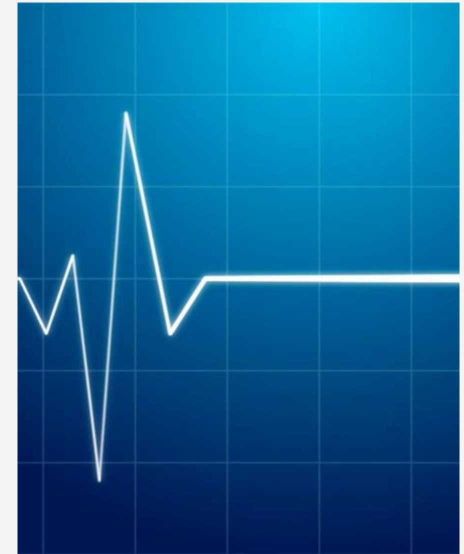
SO, FIRST, WHAT DO WE MEAN BY DEATH?

CARDIOPULMONARY DEATH

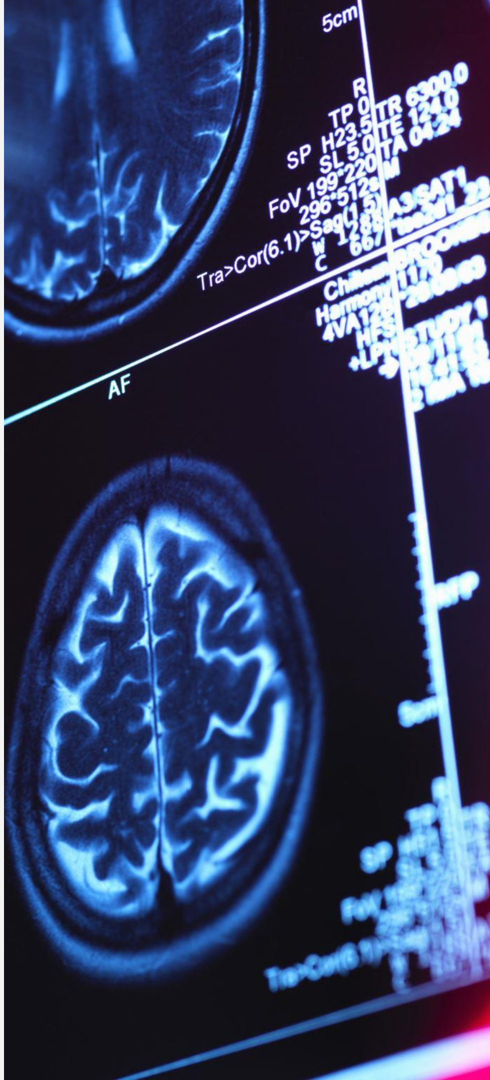
With the invention of mechanical respirators in the 1950s, it became possible for a previously lethal extent of brain damage to coexist with continued cardiopulmonary functioning, sustaining the functioning of other organs.

Was such a patient alive or dead? The widespread dissemination in the 1960s of such technologies as mechanical respirators and defibrillators to restore cardiac function highlighted the possibility of separating cardiopulmonary and neurological functioning.

Quite rapidly the questions of what constituted human death and how we could determine its occurrence had emerged as issues both philosophically rich and urgent.



WHOLE BRAIN & BRAINSTEM DEATH



- Every American state has adopted Whole Brain Death as the definition of death; Whole Brain Death is irreversible end of all brain activity
- The U.K. (& Trinidad & Tobago) has adopted Brain Stem Death as its definition; Consciousness and the ability to breathe are the main criteria for brain stem death (which means less medical costs)

exceptions: human embryos and early fetuses can die although, lacking brains, they cannot satisfy whole-brain criteria for death; brain transplants would also negate this definition for the body could still die while the brain was transferred.

DEATH DIFFICULT TO DEFINE

The understanding of death is culturally influenced, and the impact of the medical care available, and the place given to medicine in the role of death and dying also affect the definition of death.

Some prefer to define death as the sustained (permanent) loss of consciousness (or the awareness of life)

Death as a Process, rather than State (difficult, like adulthood, to define)

"Although no organism can fully belong to both sets [life and death], organisms can be in many conditions (the very conditions that have created the debates about death) during which they do not fully belong to either. … Death is a fuzzy set," (Brody 1999, 72).

According to the World Health Organization (WHO), only a few countries such as Pakistan and Romania do not recognize brain death as human death. In Japan, while the Organ Transplant Law in enacted, brain death is acknowledged as human death only when a transplant is to be performed.

WE ALL WANT THE GOOD DEATH

VIEWS OF DEATH

MEDICINE & RELIGION

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MEDICAL CULTURE

- Medical Culture has its own worldview
- Privileges efficiency
- Views death as something to be avoided or a failure of medicine
- Patient (not family or friends) is Primary recipient
- Macro-level impacts on medical culture are important too: market forces in the U.S. and socialized medical care in countries such as Canada, U.K., China, Korea, etc. impacts decisions regarding medical care at the micro-level.

JUDAISM

- Jewish custom tends to be very matter-of-fact and down-to-earth and dying and death is viewed as another part of life.
- Views of the afterlife vary widely from nothing to resurrection to reincarnation, with an emphasis on THIS life.
- Illness is viewed as a part of the experience of being God's creation, but not something he can control (thus sickness is *not* viewed as a result of a person's choices or actions, as some tend to believe).
- Medicine and doctors are seen as essential to helping God restore healing to his creation, and for this reason, while sickness is viewed as a natural part of living, medicine is viewed as helping to restore humans to their full potential.

PRACTICAL CONCERNS

Because historically there was little intermarriage with other faiths, Jewish morbidity is higher in diseases that are genetically inherited.

When a Jewish person dies, they are not left unattended, and friends and family sit with the corpse until it is taken to be prepared for burial.

During the final moments of a Jewish person's life, it is customary that everyone remains in the room with the dying person, as it is believed this gives great comfort to the dying (there are two exceptions– medical personnel and members of the Cohen tribe).

Jewish law advocates for the alleviation of suffering and thus palliative care is important in the process of dying. There is some disagreement in the area of life-sustaining technologies, with some rabbis arguing that life support can needlessly prolong suffering.

For most Jews, though, observing God's command to return the body to dust is also an acknowledgement of God's role in the Jewish cycle of life from creation to death. Thus, embalming is not customarily practiced in the Jewish community, and is generally frowned upon.

Some Jews observe strict dietary laws and keep kosher (no pork, milk and meat products separated and blessed by a rabbi).

CHRISTIANITY

- For Christians, the reality of death is acknowledged as part of the current human condition, affected by sin, but most Christians believe in a heaven and a hell, with some Christians believing in a Purgatory– or a temporary waiting room where the living and the saints can intercede on behalf of the dead.
- This is turn creates vastly different practices regarding the dead and their memorialization between various denominations. It also creates different conceptions of the afterlife.
- Some Christians may view illness or death as a sign of God's disfavor (an unfortunate by-product of the Health & Wealth Gospel) and may struggle to accept the reality of their illness and/or dying.
- Medical culture is usually embraced (with some rare exceptions such as Jehovah's Witnesses).
- Catholic and Orthodox (and some Protestant) traditions have Prayers for the sick, and practice last confession and Extreme Unction, or the blessing of the dying.

PRACTICAL CONCERNS

Some Christians may incorporate the priest or pastor in the dying person's last moments, though the rituals themselves may follow more scripted expectations, and written prayers, particularly in denominations in which Last Rites / Extreme Unction are practiced.

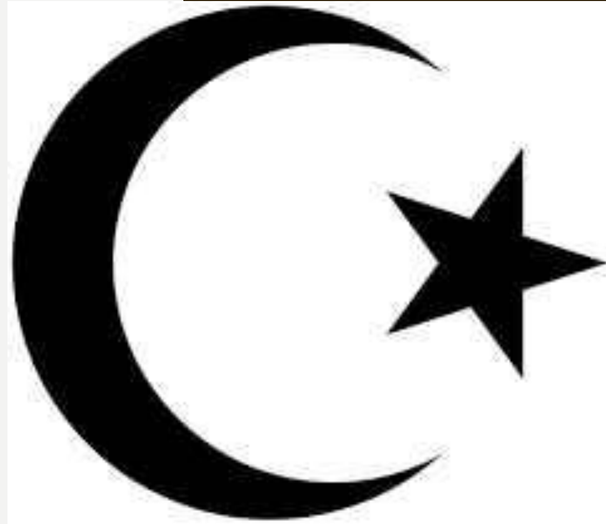
Because of the emphasis on belief (rather than practice) in some Christian denominations, dying can be fraught with fear and anxiety. Hospital chaplains serve important roles in helping both the patient and their family come to terms with dying and death. They can also aid in ethical decisions such as organ donation and removing patients from life support.

The eschatology of Christianity privileges the need for the body to *appear* alive, even if doing so requires highly artificial and invasive means. For this reason, many people will choose extensive medical care even at the expense of the quality of life and following death, some people may be afraid to encounter the dead body.

Seventh Day Adventists are vegetarian, but many Catholics observe meatless Fridays

ISLAM

- Life and death are believed by Muslims to be in accord with the will of Allah – the timing of death is therefore predetermined with a fixed term for each human being. Death marks the passing to the Hereafter – the ultimate destination.
- Muslims believe in a Final Judgement following death, and in the resurrection, though there seems to be some debate about whether people are resurrected all at once or immediately following one's death.
- Like the Hospice movement in the West, the ideal death is one in which a person preferably dies at home, surrounded by many loved ones.



PRACTICAL CONCERNS

In the case that a person dies in a hospital, medical personnel might find a resistance to sedation or the use of strong medicine that might dampen a patient's ability to perform their prayers. Also, if possible a dying person's bed should face Mecca.

in Islam, it is customary for many visitors to visit the dying to pay their last respects and offer prayers on behalf of the dying person. In fact, visiting the sick and the dying is an important duty of a Muslim, so a dying person's friends and family are generally expected in this precarious time. Because of this, however, it is also believed that the dying days are an important part of one's life, and death should not be hastened.

Islamic teachings require the requesting of permission from inhabitants of a room before entering—even if it is a temporary room like a hospital room. This means that even (and especially!) medical personnel should expect to request permission to enter a hospital room from a Muslim patient if they want a certain level of compliance

Some Muslim countries have separate wards in their hospitals for opposite genders (though rooms are always gender specific), and it is generally considered unacceptable to combine patients and their attendants. This is true even with medical personnel, and it is usually expected that male healthcare workers should not treat a female patient without another female nurse and a member of the patient's family in the room.

Many Muslims observe Halal dietary laws, which forbid the consumption of pork, alcohol, and regulate the humane slaughter of animals.

HINDUISM

- Hinduism believes in the rebirth and reincarnation of souls. Death is therefore not a great calamity, not an end of all, but a natural process in the existence of soul. Changing lives is sometimes compared to changing clothes; one simply returns to learn a new lesson.
- In Hinduism death is a temporary cessation of physical activity, a necessary means of recycling the resources and energy and an opportunity for the soul to review its programs and policies.
- When a person dies, the soul along with some residual consciousness leaves the body through an opening in the head and goes to another world and returns after spending some time there. What happens after the soul leaves the body and before it reincarnates again is a great mystery .
- The family system is very important and should be included in medical care and the dying process.

PRACTICAL CONCERNS

Suffering in dying is feared as a distraction from one's spiritual purpose or viewed as an opportunity to live one's karmic consequences in this life, while death itself is viewed more as a transition to the next life.

Hindus believe that one should not hurry one's death in order to avoid suffering, and because of this, sometimes medication is viewed in a negative light.

Patients are often unaware of their own diagnosis, and multiple studies reveal that families and doctors often choose not to include patients in their terminal diagnosis. Medical personnel will need to work hard to create an open line of communication with both families and their patients to meet patient expectations and increase awareness.

Gender differences also are important in palliative care, and female patients and their families will often prefer female medical care workers. Also, most Hindus are vegetarians and do not eat meat products.

BUDDHISM

Life is uncertain; Death is certain

- From its inception, Buddhism has stressed the importance of death, since awareness of death is what prompted the Buddha to perceive the ultimate futility of worldly concerns and pleasures.
- A Buddhist looks at death as a breaking apart of the material of which we are composed. However, Buddhism does not look at death as a continuation of the soul but as an awakening.
- For Buddhists, the world, and life creates suffering, so death can be viewed as a relief, but also one's rebirth may be an opportunity to achieve enlightenment if one has not done so in this lifetime.
- Ultimately, though, the goal, in Buddhism, is to cease being reborn and to reach nirvana (which can be similar to returning to God, rather than the nihilistic interpretation often given)

PRACTICAL CONCERNS

One of the most important aspects of Buddhist medical care is its emphasis on the whole body, and holistic healing. Body and mind are not viewed as separate and the Abrahamic distinction between soul and body is non-existent. This means that mind and body are not only inter-connected, but in fact, inter-dependent.

The spiritual component of one's suffering as experienced in both body and mind is essential to one's well-being even in the dying process. Compassionate (medical) care that centers body, mind and spirit as essential parts of palliative care is crucial.

A strong emphasis is made in Buddhist scriptures on the interrelationship of spiritual, mental and physical well-being. The Buddhist view of the good death, then, is one that ultimately accepts death, and fosters an ability to help the patient's family also accept the patient's death.

Buddhists believe the soul lingers near the body for days following the death, and often the body is not prepared for final disposition until it is cold. Absolute respect must be given to the body until it its final resting place, and often the body is treated as though it is still alive; this is why bodies are not generally embalmed, only washed.

There is generally no proscription against either embalming or organ donation and both are viewed from a pragmatic perspective as useful elements of modern life.

Buddhist dietary restrictions vary by culture (Japanese Buddhists eat fish; Thai Buddhists are strict vegetarians, while Tibetan Buddhists eat meat), so preferences will need to be consulted.

SIKHISM

- Sikhs believe in reincarnation. After a person has died, they consider their body an 'empty vessel' or 'empty shell'.
- They believe that cremation will let the soul detach from the body and reunite with God or Waheguru. A person's soul lives on, reincarnated time and time again until they break the cycle and return to Waheguru.
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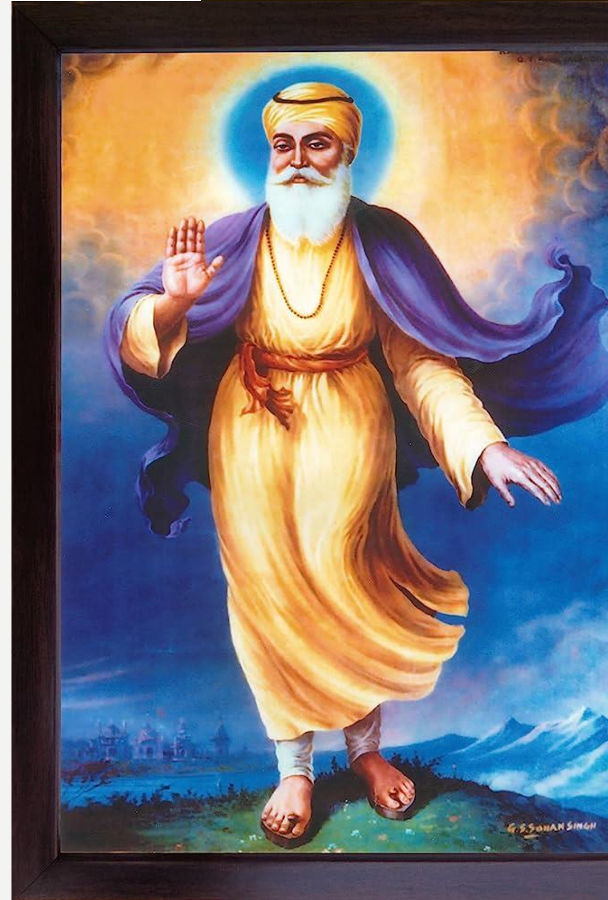
- Sikhs believe that cycles of life, death, and rebirth bring them closer to God, which is something they celebrate. Because of this, crying is generally not approved of. Instead, you might hear Sikh attendees chanting 'Waheguru'. By chanting the name of their God, Sikhs express their devotion to him.



PRACTICAL CONCERNS

- There are a few key rules concerning the dying process, which include not moving a person as they are dying from their bed, and the importance of reciting prayers centered on focusing one's consciousness on Waheguru, or God.
- Family and friends are expected to refrain from weeping as much as possible, because a person's death is seen as an opportunity for the deceased to return to God.
- Sikhs do not generally advocate for euthanasia or suicide, because this is viewed as interfering with Waheguru's plan, and only God is in charge of the time, when, and how of death. Sikhs generally have no objection to organ donation, since a large part of Sikh philosophy relies on the care and compassion of others.
- While only lacto-vegetarian food is served in the temple, Sikhs are free to choose whether they will adopt a meat-free diet.

INDIGENOUS NATIVE HAWAI'IAN

- Native Hawaiians believe that a person's iwi, which is a person's spiritual essence that remains in the bones, lives on even after death.
- Traditionally, illness was thought to be the result of an imbalance in the three anchors of the lokahi triangle, which consists of the physical, mental/ emotional, and the spiritual. Healing thus focuses on the whole person and centers on the person, their immediate environment, and their spiritual relationships with deities.
- It is not uncommon for children to talk and touch the deceased in an effort to realize that a person was dead. Adults also touch, kiss, and rub the deceased to reinforce the reality of death.

PRACTICAL CONCERNS

- Native Hawaiians have the highest incidence of morbidity and mortality and the highest age-adjusted mortality of any ethnic group in Hawai'i. Unintentional injuries is also one of the top causes of death, along with cancer and diabetes.
- Traditionally, healing for the physical body cannot occur without setting right any problems within the mental or spiritual realm. This requires spending time with the patient in order to get to know them and ascertaining the true origins of an illness.
- The extended family was the primary social structure for an ethnic Native Hawaiian. Many still live in multi-generational homes. Illness affects the entire family and family members often expect and want to be involved in decision making.
- Traditional Hawai'ians have no dietary restrictions.

INDIGENOUS: ALASKAN INNUIT

- According to Inuit belief, the spirit is eternal. The souls are purified in an underworld in preparation for the journey to the Land of the Moon, where they find eternal rest and peace. Only those who have lived a pure life go to the Land of the Moon and the rest are reincarnated on earth.
- For the Inuit, the way one dies carries great importance and has an impact in determining the path the soul will take in the afterlife. It is not only the moral behavior of the deceased that determined the location of their afterlife, but also the way in which they died. Men who die while whaling or women who die in childbirth are assured an afterlife in the sea.
- Dying is a process, rather than a fixed point, and for this reason, autopsies and medically invasive disposal practices such as embalmment are discouraged because it is believed that this can disrupt the spirit's journey in their afterlife.

PRACTICAL CONCERNS

- Medical transportation remains a primary concern among Innuit communities.
- Climate change is a common concern among Alaskans and is associated with depression, increased rates of suicidality.
- Unintentional injuries account for nearly a quarter of all years of potential life lost from premature death.
- Alaska Native COPD mortality rates have increased since the 1980's
- Traditional Alaskan natives have no dietary restrictions,.

THAT'S A LOT OF INFORMATION!

NOW WHAT?

Religious worldviews and Medical Systems intersect in times of extreme stress for the patient and their family and friends. Sometimes, those intersections can lead to conflict, particularly as they have different aims.

It is also important to know that patients and their families are visiting the hospital, and many of the rules, regulations and practices that you view as common-sense may not make any sense to non-medical personnel. Think of them as visitors to a strange land.

It is important to focus on Holistic Health and Death. Dying can be a Holistic experience and viewing it as something to be prevented/ beaten can sometimes miss the point.

It is also important to view the patient as part of a larger system (family/ faith/ social group). You don't need to KNOW the system; just be respectful of it, and willing to learn about it to provide optimal care.

BEST PRACTICES FOR INTERDISCIPLINARY PALLIATIVE CARE TEAMS

Cultural Competence Training (what we are doing today!)

Awareness of Practices– Dietary/ Gender restrictions and end of life practices need to be better incorporated

Tailored Care Plans-- Create individualized care plans that incorporate patients' beliefs, values, and spiritual needs as integral components of care.

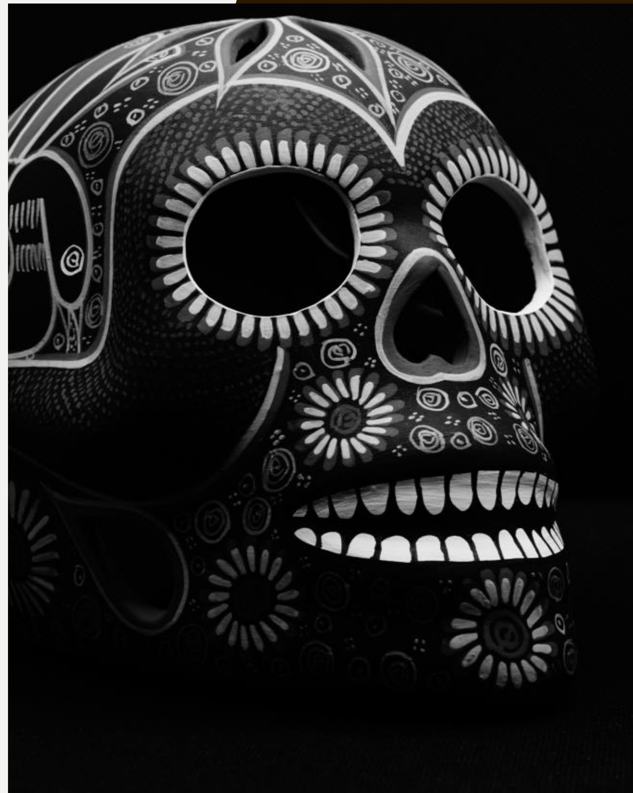
Patient and Family Engagement– Patients operate in larger frameworks and those systems need to be included in care

Flexibility and Adapatability– Teams need to be willing to accommodate religious beliefs and practices such as prayer and fasting

Collaboration with Religious Leaders– Access to Spiritual care aligned with Patient needs

Effective Communication– Teams need to ask questions and get feedback, and also pay attention to non-verbal communication, which varies culturally!

THANK YOU!



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SLOWING DOWN

LESSONS FROM END-OF-LIFE CARE

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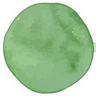

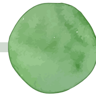

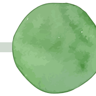

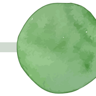

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Thank you!

Q & A with the Speakers

Online attendees, please put your questions and comments in the Q & A box

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Thank you for joining us today!

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