CULTURE, HEALTH, AND MORTALITY: FACING DEATH IN A DIVERSE WORLD

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> When it's over, it's over, and we don't know
> any of us, what happens then.
> So I try not to miss anything.
> I think, in my whole life, I have never missed
> The full moon
> or the slipper of its coming back.
> Or, a kiss.
> Well, yes, especially a kiss.
> — Mary Oliver, *Swan*

If you are reading this, I suspect you are a human (our household felines, though brilliant in their own way, adamantly reject the value of literacy). You are classified *homo sapiens sapiens* in scientific nomenclature. Sapiens, indicating intelligence in Latin, repeats to emphasize our firm belief that we are doubly the smartest creatures on earth and to distinguish our subspecies from *homo sapiens neanderthalensis* and our other supposedly less intelligent cousins now gone extinct. You and I resemble each other genetically to a remarkable degree: Whatever your gender, skin color, blood type, or preference for Star Trek or Star Wars franchises, we are virtually identical in those spiraled strands of chemical instructions. We are also identical in our opening and closing chapters, however brief, all first gestating in a womb and all eventually ceasing our rhythms of breath and heartbeat somehow. Knowing the inevitability of that cessation point motivated the writing of this book, because despite attempted escape into social media, high art, or sports fandom, that final moment will visit us all, whomever we are and from wherever we are. Precisely because it is such a perennial theme, our understanding of mortality warrants regular updates, if we are to understand our common fate (Havik et al., 2018, p. xiii).

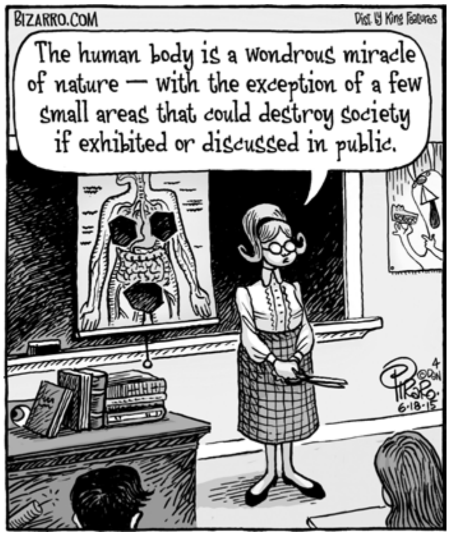
This book is about intercultural understanding, written in a time of wars and rumors of war, pandemics exacerbated by politics, civilian gun fatalities, and other recent additions to the many ways humans die. It's intended primarily to address extreme situations of critical and terminal illness. Death joins us together in biological inevitability, because all humans die, but as we shall see, can be a time when cultures clash. Amidst our similarities, beyond genetics and mortality, we all eat, drink, need shelter, and poop, and we tend to crave company of some sort. That's where the similarities end. We depart commonality via the practicalities of where, how, and why we live and die; the differences increase if we consider our beliefs and thoughts, especially surrounding death (e.g. Selin & Rakoff, 2019). The details depend on when, where, and with whom you grew up: matters of culture. Those factors will shape all of the mind-boggling differences in human existence, as a culmination of generations who created and passed along their behaviors, beliefs, and technologies to us here and now. We have forgotten our commonalities, too often falling into conflict with our forgotten cousins who now embrace other ways of thinking and behaving.

The book provides some tools to understand how culture shapes us and why people of other cultures might think differently from us. The goal is to explain why cultural differences cause issues in healthcare and to give voice to cultures sometimes marginalized in standard healthcare practice. Humans naturally communicate best within their cultures, for reasons to be discussed, and the tendency to favor our own in-groups sometimes causes us to treat people unlike ourselves less favorably, a politically sensitive statement that will be documented later. Healthcare provision happens inequitably almost everywhere. Resources flow to wealthier individuals, groups, and regions who get better treatment. Dominant groups get better education and jobs. Unfortunately, cultural differences and misunderstandings can be particularly detrimental in situations of critical and end of life care, because these are situations where people are less adaptable and their resources are tapped out. Intercultural understanding can help alleviate these issues.

In March 2021, as I first pondered how to present these concepts, a scandal arose around a podcast made for and distributed by the Journal of the American Medical Association, JAMA (Crist & Kalter, 2021). Ed Livingston, MD, flatly dismissed the existence of racism in medicine, despite extensive evidence of differential provision of care for and professional achievement of non-Europeans. Boucher and Johnson (2021) provide just one example of contradictory evidence, highlighting the disparity in hospice utilization between Whites* (53%), contrasted with Blacks (40%), and Hispanics (43%). More disturbing are disparities in treatment, with non-White patients receiving fewer visits from physicians and poorer quality care (Rhodes et al., 2012; Rhodes et al., 2007; Teno et al., 2016). Disparity in care transcends social and economic status; tennis star Serena Williams, internationally beloved, nearly died after giving birth in 2017 (Williams, 2022). African American women die at nearly three times the rate of white women after childbirth, with many of the deaths determined to have been preventable. In North Carolina, ethnic minorities and those diagnosed with intellectual disabilities and/or autism spectrum disorders are less likely to receive treatment and Medcaid Exemption support, reducing their access to care (Franklin et al., 2022; Ming et al., 2022). Some care providers are reluctant to take on disabled patients at all (Iezzoni et al. 2022), another area of discrimination.

The idea for this book arose in a discussion with a psychologist friend who survived cancer and, at the time, directed mental health services for the oncology and palliative care units of a large hospital system. Despite best intentions, cultural differences frequently generate challenges in oncology and hospice care, as well as in other sectors of healthcare and life. Much of what and how health professionals are taught to think during training may include underlying cultural biases, and some of our practices will unintentionally violate the norms and beliefs of those we must help. Is it inappropriate to mention certain body parts? (See Fig. P.1) Can a woman be touched, even on the wrist to take a pulse, by a male not of her family? Who can make a decision about treatment, the person or the family patriarch? Is that service dog a friendly delight to the children's cancer ward or an unclean beast that defiles those it touches? How can we know what is helpful or offensive? Beyond cultural variation, individuals within cultures vary as well, making a comprehensive template or how-to guide impossible (e.g. Koenig, 2011). While there is no way to understand all the cultures one might encounter in healthcare or any other setting, we can develop sensitivity and honor the uniqueness of cultures while interacting with the specific ones we do encounter. This book provides some clues to dimensions of cultural variation that might help you navigate this complex terrain with slightly greater sensitivity.

Fig. P.1: Miracle of nature (Piraro, 2015, used by permission of the artist)



*a note about terminology: the terms of demographic reference from data sources will be used in many cases, even if "white" and "black" are not really colors of humans and Caucasians rarely have any familial connection to the Caucasus. They reflect terms used in data collection and dissemination, so to change them to more realistic terms unfortunately misrepresents data as published.

How this book works

Cultural issues form a growing problem in healthcare, driving a growing need for intercultural competence training, particularly in end-of-life and critical care when the stakes and pressures are highest (e.g. Semlali et al., 2020). This book should enhance intercultural competence and provide insights to help medical and mental health practitioners in cross-cultural encounters, whatever their specialty, and for families and friends navigating passage of loved ones. The task is daunting, because we are not neurologically wired to see beyond our own cultural origins, something I have experienced by living in multicultural contexts and while teaching cultural psychology. These pages are designed to help you understand factors underlying cultural difference and how these differences shape ways people behave and the choices they make. You will encounter cultural processes you have almost certainly experienced, some as you learned your own culture in childhood, along with unfamiliar experiences or ideas you may encounter interacting with people from other cultures. Hopefully, you will gain more understanding of why the differences exist, because familiarity statistically breeds understanding, *not* contempt. We will explore your assumptions and implicit biases by considering cultural dynamics and processes, then exploring some cultural beliefs and experiences in domains of health and mortality.

I have struggled with inclusivity in this book as I do in my cultural classes. There are far too many cultures to include them all, but the point of the book is to provide tools for understanding. I selected examples and quotes I felt best illustrated useful and necessary concepts. The same limitation applies to sources and research; in pulling together research on healthcare and mortality from psychology, medicine, anthropology, sociology, social work, and so on, an overwhelming array of materials become relevant. I've winnowed several thousand sources accessed down to around 400 that seemed most relevant to the specific topic of intercultural understanding in healthcare. I wish there was more to ease your mind when dealing with death, but one book cannot cover everything to discuss around death; perhaps there is a sequel to follow.

We begin by discussing concepts and theories describing culture and cultural variation, providing insights into why people think and behave in particular ways. We will examine cultural processes common across cultures, such as interactions with family and friends, but those common contexts of interaction may function unexpectedly in cultures other than your own, demonstrating human diversity. We then turn to intercultural interactions, because those often disturb our cultural safe-zones, and insight into differences in behavioral norms may be important to your professional work or personal life. The next sections provide an overview of how culture shapes our views of health, healing, and well-being. Then, we turn to cultural perspectives on the great finality of death itself and how culture shapes our experiences and choices approaching the end. The finale looks at the arrangements and adjustments around and after death, hopefully bestowing a bit of solace while discussing the supports our cultures provide as we and our loved ones depart the world.

Module 1: The basic psychological components of culture

Module 1 lays the foundation for understanding of culture and of cultural differences to be discussed later in the text by examining basic elements of the psychology of culture. Anthropological evidence suggests humans evolved cognitive enhanced capacities to facilitate social interaction, but which also made us unavoidably aware of our mortality. Cultures have increased in complexity and diversified, developing unique systems of values and ethics.

Learning outcomes:

- *Understand characteristics of culture and cultural difference*
- *Explain the social brain hypothesis*
- *Describe systems of* values and ethics

Key Terms: Social brain hypothesis, obligatory interdependence, cultural values and ethics

The bird's-eye-view of culture, health, & illness

> *For, in the final analysis, our most basic common link is that we all inhabit this small planet. We all breathe the same air. We all cherish our children's future. And we are all mortal. -- John F. Kennedy*

Half a million years before internet searches, hundreds of millennia before social media, our earliest ancestors came to one overwhelmingly crappy realization: people die. Of course, creatures have always died, as any trilobite could attest, had they survived, but paleontology tells us that cognitions about death began to affect hominid behavior long before we evolved into our present form. Anthropologists know this because earlier pre-humans started choosing particular final resting places and adding special touches, leaving flowers and trinkets to accompany the departed as they lay, forever unmoving, while the quick continued on (Carbonell & Mosquera, 2006). That realization of mortality jumpstarted humanity's continuing saga of cultural creation, fueling our quest to heal or avoid illness and to balance suffering with joy and beauty while we live.

By 80,000 years ago, a cataclysmic drought had devastated Africa for 30,000 interminable years. Myriad species faded forever from the world, including nearly all of our hominid cousins. One isolated group of perhaps 700 individuals remained, whom DNA evidence identifies as our common ancestors, living on the coast of what we now call South Africa at the Bolombos caves (d'Errico et al., 2005; Gugliotta, 2008; Henn et al., 2018; Mellars, 2006). A quirk of climate gave them a fighting chance, but something greater was afoot. Some combination of factors allowed this plucky bunch not just to survive, but to thrive in every region of the globe as they travelled across continents and seas. And flourish they did, with eight billion descendants now spread across the planet attesting their success. We all share snippets of their DNA, 75,000 years later. We are the living evidence of their adaptability, ingenuity, and collaboration, traveling always toward the hope of an ever-greater future, though never able to evade our dreaded companion, mortality.

Spinning many thousands of times more around our modest yellow star, we forgot our common origins on that windswept coast. As we wandered to the furthest reaches of the Earth, we adapted and changed at a pace that has accelerated steadily throughout history, making us more and more different. At this point, we are so unlike each other that we speak mutually incomprehensible languages and our beliefs are so divergent that some feel compelled to kill others to prove whose ideas are right. If there is anything obvious about cultures, it is that we think differently.

These many thousands of years later, we remain remarkably similar to those ancient ancestors and to each other in the details of those twined strands of DNA. We all continue to enter the grand stage of mortal drama through the same feminine portal of biologic creation. Our finales, however, are a marvel of variety as we eventually shuffle off our mortal coil in myriad ways on our journey to the ultimate resting state. Humans have culture; death does not. As English poet Edward Young (1683-1765) said, “Life is the desert, life the solitude; Death joins us to the great majority.” Until we reach that day, we can do our best to understand and help each other along the way, because, though our finale may be highly individualized, we eventually arrive at that same unfathomable destination.

Humanity’s improbable survival

Humans are strange creatures. I refer not to the individual eccentricities that entice millions to watch reality TV. Rather, our species has characteristics unlike other inhabitants of our tiny planet. We lack defenses of claws, fangs, or scales. More often than not, a chimpanzee can bite the face off the most physically fit of human specimens. We are neither fast enough to outrun an alligator nor well camouflaged enough to hide from any carnivore with a good nose and sharp eyes, yet somehow, we survived and spread across the globe. We interact in larger groups than other mammals, though insects have us beat in terms of local community size.

We live longer than most creatures, a surprising fact given our frailty, but unlike a horse or deer who stands and walks within hours of birth, we begin life unable to feed, flee, clean, or protect ourselves for years. Fortunately, we evolved neurochemicals that stimulate bonding, amplifying our tendency to consider baby creatures adorable, because any helpless, squirming, squalling, pooping human bundle of joy depends completely on others for survival. Those around us, parents, relatives, friends, and neighbors, help us learn basic life skills relevant for our socioecological context. We coexist and cooperate in a reciprocal web, giving to and receiving from those around us in lives of what Caporael and Brewer (1995) term ***obligatory interdependence***. We have depended on our social groups for basic needs since before we were morphologically human. Our venerable progenitors, families, tribes, villages, and trade networks perpetually facilitated our existence, evolving over the eons into expansive groupings of economies and governments, which are really just mechanisms for large scale interdependence and cooperation. Eventually these became the cultures surviving today.

Very large heads

Another odd thing about humans: our brains are unexpectedly large for our size, compared to other creatures, dubbed our ***encephalization quotient (EQ)*** (Jerison, 1975). Theorists have proposed a variety of explanations for those big brains. For decades, the popular idea was that big brains developed to facilitate tool-making, but changes in cerebral capacity did not parallel advances of material culture as well as they reflected changes in social group size. The ***Social Brain Hypothesis*** (Dunbar, 2009) says our strangely large brains evolved to facilitate interactions in larger groups than even other primates. In the absence of claws, fangs, or speed, we desperately needed some other advantage, and our unique advantage was group cooperation.

Murders, wars, and anti-social psychopaths notwithstanding, the overwhelming thrust of human activity is cooperative and mutually beneficial. The legendary anthropologist Margaret Mead, asked about the earliest evidence of human civilization, reputedly said it was discovery of an ancient skeleton whose broken femur had healed, because no animal will survive that injury unassisted (c.f. Moodie, 1922). Nurtured back to health by its social group, that early ancestor's recovery demonstrates what have been called humanizing influences. Funny how our languages equate highest and best moral urges with our own species. Evolution operationalizes its effects simultaneously on multiple levels from cells to organisms to societies; for humans, group life long ago became their primary survival strategy and locus for evolutionary adaptation (Brewer & Caporael, 2006).

Breakfast for the family

Those expanding brains had a few unforeseen consequences. One was the ability to observe, remember, and improve actions, allowing human existence to ratchet, not inexorably but mostly, toward ever more effectively complex material and technical abilities (Tomasello, 1999). Another effect drove the blossoming of aesthetic and intellectual culture, because we had a looming problem. We have great memories and the ability to mentally time-travel into both the past we can recall and to any future we can imagine. We observe and remember deaths of those around us and have the ability to imagine our own. We are ticking time-bombs doomed to live, breathe, and expire, probably dying before we want, often in some awful way, and like it or not, we know it inevitably will happen.

This starkly egalitarian menace provided us an overwhelming quandary; how could we keep getting up every day to forage food for our helpless offspring, knowing a thousand ways to die awaited us? One way is the atrophy of the amygdala after severe trauma (e.g. Morey et al., 2012), a key structure for memory consolidation, the shrinkage of which has been observed in autopsies and MRI studies of people with severe PTSD. We strategically forget the worst trauma, to some degree. More normally, we find ways to express our angst, and we desperately seek distraction. ***Terror Management Theory*** (Becker, 1971; Routledge & Vess, 2018) proposes that culture may have resulted from our need to distract ourselves from looming mortality. We maintain functionality by singing and dancing, carving ornaments, and more recently, creating mountains of paperwork to occupy our minds. This will be addressed in more detail later, but with all these tasks and distractions, we don’t have time to think much about dying.

Culture also provides a marvelously practical solution to personal mortality; physically, my genes survive in those related to me, and metaphorically, culture allows long-term survival as a member of an ongoing social group that shares behaviors, beliefs, and values. Indeed, many cultures place great importance on the intergenerational transmission of what we call traditions, whether following a set of religious proscriptions or turning tracings of American children's hands into turkeys in November. Identification as a member of a group with ongoing practices and beliefs means I have some measure of immortality, because I can expect that group with which I identify to live on beyond my own demise. Some cultures institutionalize group immortality with traditions celebrating ancestors, such as ***ancestral veneration*** rituals in East Asia or Día de los Muertos, the Day of the Dead in Mexico. In those events, we memorialize our ancestors with our friends, families, and especially, our children, and we expect our descendants to celebrate us in similar fashion, cementing our place in an ongoing chain of ethnocultural existence that will outlive us. If I am not personally immortal, which our robust brains cannot help but notice, I can sleep peacefully at night because I know my culture will live on.

Defining culture?

Every time I hear the word culture I release the safety on my 9 mm.
(Banksy, 2001)

"A barely hidden desire to create a shopping list of cultural characteristics is sometimes discernible: Tamils do this, the Cree do that, and Guatemalans do the other, in order to systematize and 'tidy up' culture in the same way as are other epidemiological variables such as smoking, age, gender, or fertility rates." (Lock, 1993, p. 139)

Of all of the egregious inconsistencies of the English language, different spellings that sound the same, same spellings that sound different, grammatical rules broken helter-skelter, and words with multiple meanings, the word ***culture*** must rank among the most confusing. It can mean a large group of people with common history and customs, such as Serbian culture. It can be the refined characteristics of certain segments of a society, like a cultured Xhosa person with expertise in her culture's practices. Culture can be artistic activities and products, like totem poles or items one finds at an art gallery, or a night at the opera. Culture can be a Petri dish of growing bacteria. With no disrespect to the bacteria, we will only discuss culture as it pertains to groups of people and certain relevant characteristics of those groups, though we will find that the "culture" of arts and music may provide paths to understanding the "culture" of groups. For our working definition, we will say that *"Cultures are constellations of thought and behavior characteristic of a particular group of people, transmitted non-genetically across generations, by which meanings and identities are created and shared"* (Fox, 2020, p. 10).

To unpack that infernally academic statement, humans live in groups that act differently from place to place, the differences amplified over centuries and distance from their common origins. We certainly behave peculiarly when viewed from outside our own cultures. Unique cultural behaviors reflect underlying ideas. We pass those ideas to generations that follow us and they become normal. Those collections of thoughts and ideas tell us who we are, who belongs with us, and how to make sense of the crazy world around us.

Broadly defining culture helps our intellectual grasp, but we need something more practical here, a way to understand how culture works in our lives and hearts on a daily basis. A very Western, Cartesian approach is to break concepts or phenomena down into components, which is how we will begin, but really, culture is a holistic lived experience. The clearest sources of perspective on culture are either examples from one's own cultural life for familiarity or from a very different lifeway for contrast, and we will explore all of these as our discussion moves onward.

Finding your culture

Task: Considering your culture

Please take a moment to think about what is normative for your life.

- What holidays do you celebrate (if any)?
- What is customary activity for those holidays?
- Do you take off your shoes entering a home or sacred space?
- What can you discuss with your grandmother?
- What can you say to friends that you would never say to your granny?
- What constitutes a vacation?
- Can you talk back to your boss?
- At a funeral, what do people do?
- How did you learn the answers you gave?

Johann Wolfgang von Goethe famously said “Behavior is a mirror in which everyone shows his image.” Culture and cultural difference appear most readily in how people act. The questions above indicate some basics of how people might behave in your culture (or cultures). If the answers readily leapt to mind, you may have grown up in a monocultural family or a local context sharing ancestors from similar cultural backgrounds. After centuries of colonization and migration, you may have multiple ancestral lines and your habits may include diverse customs and cuisines. Whatever your personal genealogy, the answers to those questions will provide only superficial clues to your culture, because culture is like an iceberg, most of it hidden beneath the surface. Underlying your answers are systems of belief generated and refined over millennia.

Box 1.1: Shoes: On or off?

One habit that differs across cultures is removal of shoes when entering certain structures, such as homes or ceremonial spaces. Shoe removal is normal behavior in Asian and Polynesian cultures but not in European or Euro-American life. Shoe removal is but the visible portion of beliefs about hygiene and sacredness, translated into behaviors in slightly different ways. Europeans were infamous for their resistance to bathing as they colonized the world; perhaps their feet and foot odors were best kept encased for the greater good.

Asia and the Pacific region have a different view of shoes, partly because they track in dirt, disease, and disorder. You will not be welcomed in a Buddhist temple with your shoes on. A home in Japan may have house shoes available for guests to exchange for their own as they visit, while Euro-Americans may be quite confused if you take off your shoes when entering their homes. At a home in Hawai‘i, guests will leave a pile of shoes by your door and walk in barefoot. Removing shoes leaves the bustle and pathogens of the world outside, protecting the sanctity of homes, temples, and *whare nui*. Similarly, I have seen Māori wince and turn a bit green when someone sits on a table, because the posterior is *kapu* (taboo in colonial English spelling), and that table has then been rendered unclean for serving food. The *kapu* system doubles as a guide to public health far better than anything Europeans dreamed up before the 20th Century.

Hygiene forms an unspoken practical factor in shoe removal, while sacredness and respect exemplify beliefs and values underlying the behavior. Shoes can track in literal feces, while metaphorically, they carry in the turmoil of life. If you respect the health, humanity, and dignity of the host, you don’t soil the carpet or sully the sacredness of the space.

Now ask yourself what you believe. What is true? What is good? Is it better to be honest or rich? Is theft ok if it saves a life? Is all fair in love and war? Is there a Santa Claus? Are people inherently naughty or nice? Behaviors are easy; we can see and measure them. Beliefs are more difficult, though people can generally describe their specific beliefs. Even more subtle are values, the guiding principles “seen to shape and justify the particular beliefs, attitudes, goals, and actions of individuals and groups” (Dobewall & Rudnev, 2014, p. 46). We learn the values of our culture over time and mostly without our awareness or intention.

Human cultures include what was passed to you by your ancestors from your ethnic heritage. Culture may be a national amalgam of traditions brought by people of multiple ethnic origins, leading to the melting-pot and salad-bowl metaphors for “American” culture. Large groups within a nation may create systems of thought and behavior transmitted through time with enough fidelity to have characteristics of a culture themselves, such as the US military. American sports including football include remarkably consistent cultural patterns, with rules, hierarchies, fan and player behaviors, marching bands, etc., and could be considered a subculture. Komarovsky and Sargent (1949) defined subcultures as “cultural variants displayed by certain segments of the population” (p. 143), and the term enjoyed widening use as hippies and Rock and Roll upended social norms in what Yinger (1960) described as counterculture.

For the purposes of this book, the term “organizational culture,” championed by Edgar Schein (1952/2010) may be useful. Schein emphasized predictability and patterning based on non-negotiable underlying assumptions as hallmarks of culture. These could be found to varying degrees, he said, from global culture down to subcultures and microcultures of departments, offices, and teams within individual businesses.

He differentiated three levels of culture: ***macrocultures***, including nations, religions, and globally-present occupations; ***organizational cultures***, which are public, private, and governmental organizations; ***subcultures***, which Schein defined as occupational cultures within organizations; and ***microcultures*** that include teams both within and outside of organizations. The healthcare industry and its components have elements on all of these levels, with macrocultures including doctors, nurses, and other healthcare worker all over the world; organizational cultures of healthcare systems as widespread as the US Veterans Administration with over 400,000 employees; subcultures that could include hospitals or their departments or professional organizations like the American Psychiatric Association; and microcultures that could be as small as specific medical practices or surgical teams. Schein (2010) pointed out that in a globalized world, large organizations will likely draw on multiple macrocultures, which we will see is true up and down levels in the healthcare industry. For the sake of simplicity, we will apply the term organizational culture to structures in the current biomedically-oriented healthcare system in general and to its component educational and professional institutions.

Values: the unseen force

A century ago, McDougall (1919/2001) proposed that, "the fundamental problem of social psychology is the moralisation of the individual by the society into which he is born as a creature in which the non-moral and purely egoistic tendencies are so much stronger than any altruistic tendencies" (p. 25). All cultures include systems of morality, making it a cross-culturally universal concept, but cultures vary incredibly in the content and consequences of those systems, making it a domain of immense cultural variation (e.g. Haidt, 2007). Research into values and morality burgeoned following the horrors of WWII, with people baffled by the cold inhumanity of the Holocaust and the brutality of Japan in Korea, China, and Southeast Asia. Stanley Milgram's infamous obedience experiment and Solomon Asch's inquiries into conformity were designed to reveal how seemingly normal people could cast decency to the winds and commit atrocities on massive scale. Most of the members of the military committing the attrocities probably thought they were doing what they should, obeying orders and furthering their cause while simultaneously violating and upholding other core values. Ultimately, humans mostly behave within the confines and parameters of their cultural context, though they are often unaware of the sometimes-contradictory forces motivating them. Social psychologists began to examine ways of thinking and believing, and of resulting systems of values and morality.

Early research in this direction sought ways to help people be healthy and to build a better world, leading eventually to positive psychology (Seligman & Csikszentmihalyi, 2000). Abraham Maslow (1965) envisaged a world in which everyone can blossom into their fullest self-actualization, his hierarchy of needs outlining a humanistic path to ideal existence, providing an antidote to despair and inhumanity. Lawrence Kohlberg famously investigated moral development in childhood and universal mechanisms of morality, saying "Virtue is ultimately one, not many, and it is always the same ideal form regardless of climate or culture... The name of this ideal form is justice" (Kohlberg, 1971, p. 232). Virtue varies across cultures, apologies to Kohlberg, and we still do not have a world in which all can self-actualize, but cultural patterns of values and beliefs provide valuable clues to human behavior. Values shape our approach to healthcare, influencing who makes decisions, how resources are allocated, and what goals we pursue in that domain. We will explore research describing patterns of values across cultures, to be applied later as these patterns affect people's understandings, decisions, and well-being.

Measuring and mapping values

International business kicked into high gear after WWII, extracting resources, building factories, and sending products all over the world. A practical line of research was funded by the new multinational corporations expanding their manufacturing and sales workforces internationally. Manufacturing had accelerated to fever pitch churning out the machines of war; the US and its allies gained sudden access to resources and markets beyond their wildest dreams. Problems quickly arose, however. At every level, from managers, to labor, to sales staff, people from different countries and cultures had to work with others quite unlike themselves, often with misinterpretations and misunderstandings resulting. International Business Machines (IBM) took the bull by the horns, hiring Dutch social scientist Geert Hofstede (1928-2020) to establish its office of personnel research and develop ways to understand the difficulties and differences the company was encountering. By 1973, he had collected data from 117,000 employees in 50 countries about their attitudes and values in the workplace.

Hofstede published his analyses in 1980's *Culture's consequences*, initially proposing five dimensions: *Power Distance Index (PDI)*, *Individualism Versus Collectivism (IDV)*, *Masculinity Versus Femininity (MAS)*, *Uncertainty Avoidance Index (UAI)*, and *Long-Term Orientation Versus Short-Term Normative Orientation (LTO)*. He later added the sixth dimension of *Indulgence Versus Restraint (IVR)* in subsequent decades of copious research. The dimensions of cultural variation he identified have become a standard in industrial and organizational psychology and human resource management. More recently, the Masculinity dimension has been renamed *Motivation towards Achievement and Success*. The Hofstede-Insights website provides tools to compare country-level scores on the dimensions below (Table 1.1). Scores from 2023 for the US, China, and Brazil are included to demonstrate the contrasts, but many scores from many countries are available on the website.

Table 1.1: Country level scores on Hofstede dimensions of cultural difference (2023)

Power Distance Index (PDI): How important is hierarchy and how do people handle inequalities?	US: 40 China: 80 Brazil: 69
Individualism Versus Collectivism (IDV): Do people identify and act in the interests of a larger group or only themselves and their immediate contacts?	US: 91 China: 20 Brazil: 38
Masculinity Versus Femininity (Now Motivation towards Achievement and Success) (MAS): Is societal emphasis on heroism, material rewards, and achievement or on modesty and caring for others?	US: 62 China: 66 Brazil: 49
Uncertainty Avoidance Index (UAI): Are people comfortable with ambiguity or do they need to control the future? Are behavioral codes rigid or flexible?	US: 46 China: 30 Brazil: 76

Long Term Orientation Versus Short Term Normative Orientation (LTO): Do people prefer maintaining tradition or to change in preparation for the future?	US: 26 China: 87 Brazil: 44
Indulgence Versus Restraint (IVR): Does the society allow for fun and gratification of drives or is restraint required?	US: 68 China: 24 Brazil: 59

In cultural and cross-cultural research, other streams emerged examining the components of morals and values to describe and systematize their differing manifestations across cultures. Schwartz and Bilsky (1987, 1990) proposed that all values spring from underlying goals and motivations, and that, regardless of culture, all values contribute to three universal existential requirements: "needs of individuals as biological organisms, requisites of coordinated social interaction, and survival and welfare needs of groups" (Shwartz, 1992, p. 4). Putting these requirements into practical application should, they explained, yield a universal matrix of values that vary across cultures. Schwartz (1992, 2012) eventually proposed a set of 10 basic human values that would be emphasized or deemphasized by the members of a culture, some opposing like tradition and self-direction, others more closely associated like security and conformity (Fig. 1.1). Confirmed by factor analysis of survey data from dozens of countries, the list includes:

(1) **Tradition**. Respect, commitment, and acceptance of the customs and ideas that traditional culture or religion provide the self

(2) **Conformity**. Restraint of actions, inclinations, and impulses likely to upset or harm others and violate social expectations or norms

(3) **Security**. Safety, harmony, and stability of society, of relationships, and of self

(4) **Power**. Social status and prestige, control or dominance over people and resources

(5) **Achievement**. Personal success through demonstrating competence according to social standards

(6) **Hedonism**. Pleasure and sensuous gratification for oneself

(7) **Stimulation**. Excitement, novelty, and challenge in life

(8) **Self-Direction**. Independent thought and action-choosing, creating, exploring

(9) **Universalism**. Understanding, appreciation, tolerance, and protection of the welfare of all people and of nature

(10) **Benevolence**. Preservation and enhancement of the welfare of people with whom one is in frequent personal contact.

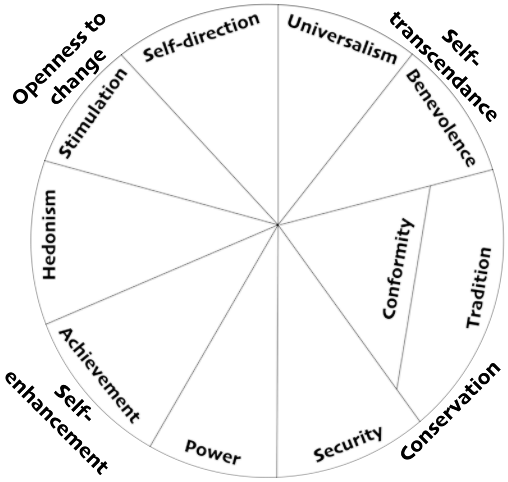


Fig. 1.1: Values Map, Adapted from Dülmer, Schwartz, Cieciuch, Davidov, & Schmidt, 2023, p. 449)

Richard Shweder and colleagues (1997) took a different approach, developing his Big 3 ethical dimensions of moral discourse by asking people in the city of Bhubaneswar, Orissa, India how they would respond to moral transgressions in hypothetical situations. The ethical dilemmas presented included "A poor man went to the hospital after being seriousty hurt in an accident. At the hospital they refused to treal him because he could not afford to pay," and "The day after his father's death the eldest son had a haircut and ate chicken." For the people of Bhubaneswar, these incidents characterized varying degrees of transgression that could expose the transgressor to suffering as consequences (to be discussed later). From the discourses, Shweder and his team (1997) distilled ethics of Autonomy, Community, and Divinity to explain difference in how people understand and respond to the world (see Table 1.2). The ethic of community would prioritize benefits and loyalty to one's ingroup. Autonomy emphasizes individual agency, freedom to choose and act based on personal wants, needs, and inclinations. The divinity ethic emphasizes relations with spirit, sacredness, and higher powers; a person must behave in accordance with the rules, codes, and proscriptions of the religion or cultural group to maintain right relations. Keeping *kosher* or eating *halal* would demonstrate adherence for Jews and Muslims respectively.

These ideas take more or less prominent roles in people's construction of morality and resolution of ethical dilemmas. The ethics are not independent and each may play a role, though their relative importance changes by culture. The theory also describes reactions to violation of the ethic, including emotional responses such as disgust from violations of Divinity morals. More relevant for this book are the metaphysical penalties incurred for violation, which might provide explanations for misfortune or illness (Shweder et al., 1997).

Table 1.2: Shweder's Big Three of Morality, adapted from Shweder et al., 1997, p. 138

Ethical dimension	Description
Community	relies on regulative concepts such as duty, interdependency, hierarchy, and souls
Autonomy	relies on regulative concepts such as harm, rights, and justice
Divinity	relies on regulative concepts such as sacred order, natural order, tradition, sanctity, sin, and pollution

Building on Shweder's concepts, a more recent group including Jonathan Haidt, Jesse Graham, and Craig Joseph proposed ***Moral Foundations Theory***. Like Shweder, they rejected the monistic idea that all morals stem from a single core value (e.g. justice for Kohlberg) or other single sources such as sensitivity to harm or welfare and happiness (Graham et al., 2013; Haidt, 2013; Haidt & Kesebir, 2010). The group included social and cultural psychologists who agreed that cross-cultural variation requires a sophisticated set of parameters to explain the myriad differences in moral constructs. Cultural variation also implies that values are learned, and as such, people in one culture may have no understanding of a core construct in another. Graham and colleagues (2013) give the example of a Hindu girl who grows up automatically bowing to respected elders, contrasted with an American girl who has no awareness of hierarchies or requisite respectful behaviors.

Moral Foundations Theory includes five foundational pairs of opposing values: Care/harm, Fairness/cheating, Loyalty/betrayal, Authority/subversion, and Sanctity/degradation

(Table 1.3). The model provides nuanced explanatory power based on the degree to which ethics are emphasized in a given culture. All of these moral theorists, from Kohlberg to Shweder, to Haidt and his colleagues, operate under the certainty that these systems are learned in childhood or there would be much greater similarity across cultures. Processes of enculturation, the ways we learn and adopt our cultures, provide another path to intercultural insight.

Table 1.3: The original five foundations of intuitive ethics (Graham et al., 2013, p. 68)

Foundation	**Care/harm**	**Fairness/ cheating**	**Loyalty/ betrayal**	**Authority/ subversion**	**Sanctity/ degradation**
Adaptive challenge	Protect and care for children	Reap benefits of two-way partnerships	Form cohesive coalitions	Forge beneficial relationships within hierarchies	Avoid communicable diseases
Original triggers	Suffering, distress, or neediness expressed by one's child	Cheating, cooperation, deception	Threat or challenge to group	Signs of high and low rank	Waste products, diseased people
Current triggers	Baby seals, cute cartoon characters	Marital fidelity, broken vending machines	Sports teams, nations	Bosses, respected professionals	Immigration, deviant sexuality
Characteristic emotions	Compassion for victim; anger at perpetrator	Anger, gratitude, guilt	Group pride, rage at traitors	Respect, fear	Disgust
Relevant virtues	Caring, kindness	Fairness, justice, trustworthiness	Loyalty, patriotism, self- sacrifice	Obedience, deference	Temperance, chastity, piety, cleanliness

Making sense of a confusing landscape

At this point, you have read several different, possibly contradictory, views of foundational elements of culture. Which is correct?

Perhaps all are correct, at least to some degree. Theoretical models arise based on researchers' experiences, observations, and inclinations, meaning each may be valid from a particular perspective. These theoretical models differ in structure but all serve the same purpose, attempting to explain why people act and think as they do. Your culturally informed level on Hofetede's Uncertainty Avoidance dimension might affect how comfortable you are with the discrepancies between the models.

Cultures have no immutable demarcations. They are complex assemblages of ideas, materials, and practices collected over millennia to address problems, challenges, and opportunities of particular environments, some shared from one culture to another, passed imperfectly down through generations. Variation between cultures and within cultures means that everybody falls somewhere on a sliding scale on any measurable factor; there are no absolutes. Theoretical models, though imperfect, provide structure through which to examine, compare, and contrast these aspects of human existence.

Why does it matter?

It is often hard enough to understand the people in our own families, much less those who see the world very differently. This section moves us toward better understanding of people from other cultures by examining some differences and why they exist. Interpersonal understanding requires parameters by which we can gauge and predict how people may think and act, which we usually absorb during childhood in a particular culture. From the foods we eat to the wars we wage, values form the basis of our decisions, at least those we make consciously, and awareness of how different cultures emphasize particular ethical values might help us understand even the most baffling decisions. These concepts will come into play as we discuss issues like informed consent, help-seeking, and decision-making hierarchies in healthcare.

Ancestral veneration: Practices honoring or commemorating familial precursors

Encephalization quotient (EQ): A number comparing brain weight to body size

Obligatory interdependence: Caporael and Brewer's (1995) term describing the impossibility of human survival without the assistance of others, especially in infancy

MODULE 6: DISEASE AND HEALING

Module 6 presents various ways cultures understand, describe, and explain illness. These conceptualizations are based in cultural ontologies and epistemologies, affecting how people communicate about illnesses and their expectations for treatment and outcomes. Indigenous and shamanic traditions are presented impartially to facilitate reduction in ethnocentrism of Western practitioners. Cultural issues around ethics are addressed, including informed consent and issues of agency and authority arising from mismatch between clients/patients from collectivist cultures asked to make decisions based in individualist worldviews.

Learning outcomes:

- Appreciate cultural explanations for illness
- Explain basic elements of traditional approaches to treatment
- Recognize ethical issues that may interfere with trust in treatment

Key terms: Disease, healers and healing, cultural ethics, shamanic traditions, ethnocentrism, informed consent

Understandings of disease and healing

Key domains of knowledge in healthcare obviously include understanding of what needs to be healed and how to heal it. Disease is tragedy, disease is opportunity, disease is moral violations come home to roost, and/or disease is a gift. All of these have been true for cultures and individuals somewhere at some time. Particularly interesting is the idea of disease as a gift; how can this be? In Islam, one *thanks* God for the opportunity for moral improvement that suffering presents (Peiper, 2020). Many cultures have legends and concepts around benefits arising from illness, including providing the key ingredients in creation of healers and healing traditions.

- Chiron, wisest of the immortal centaurs of Greece, learned from his foster father Apollo the arts of medicine, herbology, and music. Poisoned by the blood of the hydra, Chiron could not die; forever in horrible pain, he wandered the earth soothing his own suffering by healing others until he ultimately gave up his immortality to rescue Prometheus, the bringer of fire, and then Chiron died in consequence. The constellation Centaurus reminds us of Chiron's sacrifice.

- The gods of the Nauatl people of central Mexico gathered at Teotihuacan to create the Fifth Sun, the one that lights the world today. Among them was god Nanahuatzin, sickly deformed, and covered in tumors. The ritual required a sacrifice and only Nanahuatzin had the courage to sacrifice himself in the sacred fire (Florescano & Bork, 2014). The sun itself reminds us daily of his courage.
- Shamanic traditions may be passed down a family line through careful tutelage by an elder, but often a shaman is chosen and initiated by a serious illness that befalls them. If the person survives, they may be trained to become the next shaman.
- Black Elk (1863-1950), prophet of the Lakota, suddenly fell ill as a youth and awoke from what resembled a coma with his visions of the future of his people.

In the Republic of Buryatia, at the eastern edge of Siberia, spirits helpers of past shamans began afflicting the living in a minor epidemic of shaman sickness (Jokic, 2008). Under the anti-religious Soviets, shamanism was suppressed, interrupting the line of succession as practices went deep underground, so the spirit helpers were apparently actively seeking new shamans to help. Contemporary Buryats have largely embraced Buddhism, but turn to shamanism when misfortune or illness strikes, which is not infrequent; annual incomes average under $4,000 USD and winters are brutal. Linguistically, they are Mongolic, sharing cultural traditions with Kalmykia and Tuva including multiphonic chanting and trance rituals.

Shamanic sickness appears in cultures of Siberia and Mongolia, but also in other cultures around the world (Kim, 1994; Peters, 1982). A person falls mysteriously ill and remains sick until they have suffered enough or aligned sufficiently with spirit to become a shaman (*böö*, *udgan*); the illness forces the person to take up the shamanic mantle. To heal, a person must have understanding of diseases and their remedies. One path to understanding passes through illness, emerging with knowledge on the other side. Carl Jung credited therapists' understanding of their own inner wounds for ability to heal the patient (Kirmayer, 2003). Shamanic sickness is only one example of illness as a benefit. Other examples can be found in the afflictions of biblical figures and many common phrases equating illness with a divine test. Chiron's pain and eventual sacrifice paid the price for the healing of others. Over all, these examples indicate the existence of other ways of thinking about illness as something good.

Causes of disease

We take for granted how recently humanity achieved a level of scientific sophistication sufficient to identify viruses, bacteria, and errant DNA as causes of disease and disorder. The belief systems of standard medicine evolved gradually over millennia. The concept of humors, with origins four millennia past, has only recently faded; this was the underlying reason for George Washington's blood being let on his deathbed. The horrific vivisections of Galen in Roman times and the scandalous grave robbers supplying dissectionists into the twentieth century gradually increased our understanding of anatomy and physiology on the road to greater medical understanding.

Fortunately, increasingly powerful microscopes helped humanity learn about bacteria and viruses, neurochemicals, and genetics. Instead of vivisection, we can see what happens inside living bodies with MRI machines and sonograms. These are progressive refinements built on centuries of preexisting knowledge, ratcheting knowledge little by little to the present state of conventional medicine. This knowledge has helped improve the health of billions, but conventional medicine is recent, only one of several systems, and not universally available. Cross-cultural responsiveness requires consideration of other systems of thought and belief.

The ontology and epistemology of disease

Etymologically, disease simply denotes the removal of ease, something that takes our feelings of comfort away. Generically, disease can be viewed simply as suffering, manifested in the body, the mind, or some non-physical level. This generic definition allows some latitude in considering illness and care from a culture-neutral perspective, allowing for etiologies ranging from viruses to karma to malevolent spirits. An inclusive approach also helps us to avoid ethnocentricity in diverse treatment settings.

The business of healthcare comes down to repair and remediation of things that have gone wrong with bodies and minds. Those processes require understanding of what has gone wrong and how to make it right. If someone falls and breaks a wrist, though some may blame luck or fortune, a physical cause becomes immediately evident and hopefully someone nearby knows how to set any broken bones. For so much of what goes wrong with people, though, causes and remedies are not necessarily apparent to the naked eye. Humans have only recently had the tools to identify the sources of afflictions caused by viruses, bacteria, and tiny parasites; for cancers and a host of other ailments, we still search for ways to understanding the whys and wherefores of suffering.

To have an explanatory model for illness is to render suffering comprehensible, *this sickness happened because…* Especially important are explanations of cause, because we humans have an obstinate urge to understand why things happen, especially when misfortune befalls us. Practically, we may not be able to change what has already transpired, but we at least want clues to remediation and to prevention of future suffering. Keep in mind that the WHO definitions include the phrase, “whether explicable or not” (p. 1), as we examine these understandings.

Schim and colleagues (2005) investigated effects of cultural competence and training among healthcare providers in Michigan and Ontario finding a positive correlation between cultural competence and previous training. Knowing that people are more comfortable and agreeable in situations of cultural congruence, what is required to help patients and clients feel more at home in the very strange environs of conventional medicine? Awareness that patients may have a different understanding can help one explain situations in a way they can grasp.

The ontology and epistemology of causation, the way of thinking about and understanding etiology of disease, incorporate the world-view, cognitive styles, mythologies, and other elements of culture to model the origins, processes, and remediation of illness. The biomedical ontology includes aberrations of hormones, genetics, organs, and other physiological issues (Shweder et al., 1997). This view is the product of an analytic as opposed to holistic cognitive style, based in the positivistic empirical view that phenomena must be observable to be legitimate and that logical processes can lead to the solitary correct answer. This modality also includes conceptual dichotomies of mind-body, illness-health, and clinician-patient, along with phenomena of chronicity: acute vs. chronic, anomaly vs. normalcy, and static vs. dynamic (Fennell, 2003). The conceptual dichotomies engender objective distance, contrasting sharply with holistic approaches lacking separation between observer and observed.

The causal ontology of the ancient Ayurvedic system from India includes humors, the bodily fluids and energies that should remain balanced for good health. Chinese medicine often places causation with the flow of chi energies or with spiritual sources when people are out of balance with natural forces (McLaughlin & Braun, 1998). These and other systems have existed across the millennia, some still influencing the biomedical system. Importantly, causation in many systems does not necessarily include a proximal physical cause; illness may be caused by some non-physical entity or energy and may happen at the behest of someone or something at some geographic distance from the sufferer. Unseen causation becomes more plausible when one considers limitations of human vision for seeing pathogens; I still can’t see a virus coming.

These ontologies become integral to any diagnostic process. All human decisions arguably involve heuristics, shortcuts by which a decision may be reached as swiftly as possible. We learn our complement of heuristics in cultural processes, of course; med school, abnormal psychology, nursing, or kinesiology all enculturate in us a set of patterns we are most likely to encounter in practice. The more clearly related a set of symptoms, the more integrated the resulting schemata and the more swiftly a practitioner can assess and diagnose the issue. Experience then teaches us that hoofbeats usually mean horses, not zebras, and that 20 people with the same symptoms probably suffer the same malady, refining our heuristic set. In healthcare, heuristics allow practitioners in any tradition to prioritize and interpret patterns of symptoms, or precipitating events, whether physical, moral, or etheric etiologies are involved. The product of a scholastic process or the result of traditional beliefs, they become our best bets for relief of suffering (Koenig, 2011; Leventhal, Benyamini, & Shafer, 2001).

Leventhal, Benyamini, and Shafer (2001) identified five sets of attributes comprising common-sense beliefs about illness: identity (label and symptoms of the threat), causes (external or internal), time-line (duration, consequences), controllability (can it be prevented or cured), and consequences (impacts on the individual or context). These attributes affect behavioral responses as well as the people from whom one would seek help. If the threat is defined solely by symptoms and the time-line ends when they disappear, this explains why people discontinue antibiotics before taking the full course, against medical advice. We all have schema related to illnesses, some as simple as “feed a cold; starve a fever.” Chinese culture encourages moderation in both consumption and emotional expression as keys to maintaining health, so behaviorally, both overindulgence and outward expression of anger are frowned upon. Whether we are the sick person, healer, or just a friend or family member, schema create our expectations and our go-to behaviors aligned with our cultural narratives around diseases.

Awareness that *other* ontologies exist becomes quite important when gathering information from patients for diagnosis. These concepts will inform patients’ understanding of symptoms and their communication with practitioners, and patients will express their maladies in terms drawn from their culture. These may include somatization of psychological symptoms or unfamiliar connection of cause to symptom such as the Indonesian term *masuk angin*, or the wind entring, to describe a cold.

Richard Shweder was interested in understanding moral causal ontology, because numerous cultural explanations involve events set in motion by an individual’s actions. “That causal ontology is notable for its references to transgressions of obligation,” Shweder and colleagues (1997) explain, “omissions of duty, trespass of mandatory boundaries, and more generally any type of ethical failure at decision making or self-control. It is associated with the idea that suffering is the result of one's own actions or intentions, that a loss of moral fiber is a prelude to misfortune, that outcomes-good and bad-are proportionate to actions” (p. 122-123).

Soon after completing his medical and anthropological studies at Cambridge, Gilbert Lewis found himself doing fieldwork and providing basic medical care in remote villages of the Gnau tribal people, a non-Austronesian ethnic group in the northern region of Papua New Guinea. Lewis spent most of 1968 and 1969 among the Gnau, using his unusual combination of knowledge in anthropology and medicine to survey their healthcare beliefs and practices. Linguistically unrelated to most Pacific peoples and still limited in contact with conventional medicine today, Lewis found the contrast of ontologies fascinating and carefully maintained respect for their beliefs despite the differences from his own.

The Gnau do not ascribe cause of illness by observed symptoms or pathogens, but rather by circumstances preceding the illness (Lewis, 1975). His diagnostic questions for his patients included “what have you done to become ill?” (p. 226). A person may become susceptible to illness by violating prohibitions or protocols. Perhaps a person was made ill by offending a spirit watching over yams they had eaten or a sago palm they cut down. Death of an otherwise vital young person almost certainly involved sorcery. If the patient’s answer seemed insufficient, he would then ask if they knew what had struck them with the disease, if it might be a spirit, or if they might simply be ill for no reason. Some gave highly detailed explanations and sometimes he felt they omitted explanations they surmised he was incapable of understanding. Lewis categorized answers as “spirits,” “sorcery or destructive magic,” and “breaking a taboo” (p. 256). While Lewis notes that the Gnau seemed to lack systematized medical knowledge separate from moral or legal judgement, they actually had a cohesive holistic system connecting values, morality, spirits, actions, and physical health. A serious illness may require careful examination of human relations and activities to find a solution in their world.

Nearby in the Northern Solomon Islands, Hamnett and Connell (1981) observed a blending of traditional and Western healing. The separation of cause and symptom, they suggest, facilitates willingness to undertake conventional medical treatment. The Atamo and Siwai worlds were filled with spirits that could cause illness, much like the Gnau. Also, like the Gnau, less severe illnesses were more likely to be considered just illness not caused by spirit; these were more likely to be acceptable for treatment by imported Western medicine. These cultures had their own extensive pharmacopeia, including some highly effective medicines (Holdsworth, 1977). They still have one of the lowest ratios of physicians per capita at 7 per 100,000, or 2% of the US ratio. The Solomons have slightly more, but average only two per 10,000. For the vast majority of people in both countries, traditional medicine is their only option.

Prevention

Prevention similarly operates based in the worldview and belief system of a culture. If your explanatory model includes bacteria and viruses, your prevention will be based on sanitation and reduction of transmission. Before Leeuwenhoek published *Concerning little animals* in 1677, however, nobody on the planet really knew about microorganisms (Lane, 2015), so a disease without visible cause required another sort of explanation and method of prevention. Lest we judge, remember that millions of Americans did not understand the function of masks in the COVID pandemic and consumed useless medications or undertook metaphysical practices to protect themselves. To be fair, many illnesses do not have a visible cause, including neurological disorders such as epilepsy. How do you guard against something you can't see?

The Old World of Europe teemed with demons, ghosts, witches, goblins, and other malevolent entities. The supernatural was endemic to that world, burbling up into nightmares and causing bad luck and misfortune. Surrounded as they were by these mysterious creatures and forces, people were often quite desperate to repel or vanquish the danger. As with deities, interacting became easier when a physical image provided a focus or target for the efforts (Milne, 2019). Likewise, a talisman you can hold or wear furnishes both protection and comfort. These sorts of practices were widespread if not global, with gargoyles on cathedrals, and with *Shānmén* (China), *Niōmon* (Japan), and *Geumgangmun* (Korea) protecting the temples of Asia.

To prevent the potentially lethal effects of the evil eye, Greeks and Romans believed you had to divert the gaze casting it, which could be accomplished by distraction with a shocking image. The most effective distractor images were of male or female genitalia. These beliefs remained prevalent through the Middle Ages. Good Christians on holy pilgrimages were particularly susceptible to evil thwarting their progress, prompting a medieval cottage industry providing "priapic figures as amulets, to be carried on the person as a preservative against the evil eye and other noxious influences" (Gimbel, 1976, p. 6). *Cornicelli*, horn-shaped pendants, have been popular since ancient Greece and remain so among Italian men, increasing virility by their visual reference to phalli and by warding off the evil eye. Faddishly popular in the US now and then, *cornicelli* can readily be found in jewelry stores, though many wearers probably have no idea of the demon-repellent properties they now enjoy.

Hawaiʻi musician Makana has toured extensively, including in Indonesia.

> *When you go to Bali and you see all of these demonic statues in front of everyone's house," he explains, "it's not because they love demons. It's because they understand they need to give a space for these spirits and these energies. They need to honor that they do exist and by doing that they don't control you. This is same thing with trauma, our attitude around trauma. You can't just ignore trauma; you have to give it your attention in order to release it. And I think with death, if you ignore it, it actually controls you (Personal communication, 1/5/2022).*

Meeting across cultures

Considering that billions of people use both conventional and traditional medicines as well as newer alternative practices, connecting with clients and patients across belief systems requires an open mind. If spirits cause disease, preventative action requires staying in their metaphysical good graces as much as one can. If etiology springs from physiological issues, those bacteria and viruses we can now identify, tangible preventions or remedies will be expected. Of course, all remedies are not created equal and a priapic amulet won't prevent viral infection, but a patient whose worldview revolves around spirits and charms might rest more comfortably with an amulet in addition to a vaccine. And sometimes people's beliefs interfere with the clarity of their thinking even within the Western scientific paradigm. Linus Pauling and his dedication to Vitamin C provides both a cautionary tale about beliefs obscuring rationality and an example of supposedly scientific practices verging on superstition in contemporary American society.

Box 6.1: The vitamin craze

As Europeans of the 15th and 16th centuries set out across the seas on their quest to colonize and to harvest resources, a mysterious ailment afflicted a great many sailors. What came to be called scurvy felled an estimated two million before a prevention or cure was found, plus tens of thousands in the Great Potato Famine of 1845 in Ireland (Carpenter, 2012). The solution came from one James Lind, then a ship's surgeon, placing him below officer rank and much lower in social status than a physician on land at the time. In 1746, twelve sailors on the ship fell ill with scurvy and Lind pioneered controlled experimentation, giving six different treatments to random pairs of sailors (Carpenter, 2012). The ship happened to have two oranges and a lemon, which he administered compared with apple cider, vinegar, sulfuric acid, sea water, and a garlic and spice paste to see if any of the substances improved the sailors' scurvy. The citrus ran out after six days, but the two sailors in the citrus condition recovered, unlike the other poor souls. Lind later attended medical school in Edinburgh and published his results as *A Treatise on the Scurvy* in 1753. By 1795, the British Navy issued a daily ration of lemon juice to sailors and the race for a non-perishable version was on. The actual cause and cure of scurvy was by no means common knowledge, however, and people from lumberjacks to railroad workers suffered on into the 1900s.

The story of Vitamin C takes a surprising turn toward superstition in the 20th century. The relevant chemical component for fighting scurvy, ascorbic acid, would accidentally be isolated by Albert Szent-Györgyi in 1928. Then in 1932, a University of Pittsburg team under Charles Glen King (1896–1988) synthesized a convenient, storable Vitamin C. Demonstrably crucial to health and immune function, Vitamin C became the first commercially produced dietary supplement and kicked off a multi-billion-dollar industry. The story turns sour in the 1970s.

Dr. Linus Pauling had won two Nobel prizes, one for chemistry and one for his anti-nuclear peace work; he was among the most respected scientists in the world when he became convinced that megadoses of Vitamin C were the answer to many of humanity's maladies. He promoted ascorbic acid first as a prophylactic against colds, then he launched full force into a crusade to create cancer treatments using Vitamin C megadoses. Scurvy was conquered, but contrary to Lind's world-altering results, controlled experiments have shown efficacy in cold prevention only for people with vitamin C deficiencies and little benefit in reducing symptoms or duration otherwise. For cancer, Pauling's cure never performed better than placebos (Creagan et al., 1979) and tragically, failed to save his own wife. Pauling never gave up his support for Vitamin C megadoses, despite the scientific evidence, badly tarnishing his formerly stellar reputation.

The myth of Vitamin C as a panacea persists, despite decades of evidence that, while yes, Vitamin C is good for you and you need some in your diet, it does much less than advertised to prevent or cure the common cold, nothing to cure cancer, and probably very little for other corona viruses. The global market for Vitamin C brought in at least $1.3 billion in 2021 and Americans spent $50 billion for dietary supplements in total (Jia et al., 2022). Various sources suggest that as much as 52% of the US population and 42% of UK adults use dietary supplements (Ang et al., 2023). Most supplements are fairly benign, if possibly ineffective, and thanks to the solubility of ascorbic acid, millions of people pass a fortune in excess Vitamin C out in their urine every cold season. Similarly, neither Vitamin C alone or in combination with zinc provided significant benefit against the COVID-19 pandemic in controlled testing, despite widespread hype in the media (Hemilä et al., 2021; Hunter et al., 2021; Murni et al., 2021).

The point here is not to preach a diatribe against supplements (I am among the 52% of Americans taking them), but rather to emphasize that there is probably no healthcare system with more than minimal moral high ground to stand on, Euro-American conventional healthcare included. Considering that Vitamin C and a priapic amulet are equally effective in preventing colds, perhaps we can approach this discussion of healthcare across cultures humbly and without judgement. The term *folk* generally refers to traditions passed down intergenerationally and outside of formal institutions of learning; it also usually privileges academic knowledge and practice above the folk version, whether musical or medical. So-called folk remedies remain deeply embedded in cultures and patients may be deeply suspicious of scientific solutions when they conflict with ways their ancestors have always done things. There is also underlying logic to folk beliefs, when viewed in context of a culture's ontology.

Healers and culture

We have discussed worldview (interconnected vs. discreet, metaphysical vs. concrete), cognition (analytic-holistic), sense of self (individual vs. collective), and causes of disease (physiological, spiritual, moral). It should also be apparent by now that we consider the behaviors and material world in which we grew up to be normal, hence we believe that our own physicians and healers are certainly the best. What if we have to be treated by healers unlike anything we have encountered before? Healthcare in another culture may seem very strange and frightening.

Healers hold a place of reverence and awe in cultures, whether a shaman in Siberia or a cardiologist in New Jersey. Healers deal with the mysterious forces of life and death, bringing hope to the hopeless, relieving our ailments, and soothing our pain. All walk some prescribed path to become competent in their field, gaining proficiency in the lore, tools, and procedures of their craft. A brief discussion of a few alternative types of healers may be enlightening in this regard, though it is, of course, impossible to do justice to even a fraction of cultures.

The Wounded Healer

The healers' own suffering as a source of their wisdom and power characterizes the archetype of the Wounded Healer (Kirmayer, 2003). Chiron's suffering and death were the sacrifices by which he paid for wisdom and relief of the suffering of others. For modern medical doctors, perhaps misfortune earlier in life led them to medicine, but the only required suffering is medical school cost, internship, and residency, which are no small burden. Other healthcare professions receive varying quantities of suffering in their training processes, which may certainly increase empathy. Ultimately, they must gain knowledge of the ontological underpinnings, whether spirits, pathogens, or universal energy flow; they must recognize the signs of maladies within the system; they must become competent with the tools of their system, whether herbs, chemical compounds, feathers, or songs; and they must gain the trust of their patients or clients, whether through credentialing or reputation. For the shaman, that usually involves learning to walk and talk with the spirits. *It is important to consider that no system would exist for long if it was not seen as effective to some degree, at least given the resources and knowledge available within its culture and environment of origin.* Gbadegesin (2022) points out that even the gods of African religion will swiftly be discredited and abandoned if they do not deliver on promises and prayers.

Shamanic traditions

Cultures throughout human existence developed what would be called shamanic practices. The term shaman was appropriated by European explorers in the late 17th century from the Tungusic speakers of Northern Siberia and misapplied to a variety of other practices and practitioners. A shaman, in common parlance, would have skills and access to intervene in metaphysical or spiritual levels of existence, usually through ritual activity including trance (e.g. Hutton, 2007). Spirit entities may include deities, forces of nature, or essential energies of places, plants, or animals. The sun and moon, rain and wind, unusual geologic features, and extraordinary physical and metaphysical creatures fill numinous landscapes that European cultures disavowed over the past two millennia as people distanced themselves from the wildness of nature.

Trance and possession can be viewed anthropologically as a connecting of human with spirits or supernatural forces (Lintrop, 1996; Ward, 1980). Psychologically, trance is a dissociative state in which the person seemingly loses connection to their normal self, memories, identity, and context, perhaps to overcome otherwise insurmountable conditions or inescapably low social status. Ward (1980) cautioned that academic inquiry around possession has been ethnocentric and may mischaracterize the phenomenon. She says, “Fundamentally biased assumptions demand that a normal conscious experience be characterized by a psychoorganic state of striving structured to manipulate the environment and organized toward the achievement of personal goals” (p. 150). Under that view, a cultural experience that is not personal in nature may be misinterpreted as an effort toward personal achievement when it is not. Discounted are psychosocial intents toward community benefit, which may be misconstrued as an effort toward status or esteem, and any metaphysical experience or phenomena are certainly discredited (Lintrop, 1996; Peters, 1982). Additionally, practitioners described as shaman may actually also utilize pharmacopeia or other treatments for ailments of body, mind, and spirit, but the early ethnographers seized on the most exotic and colorful of practices in their descriptions, emphasizing trance ceremonies.

A shamanic tradition survives among the Buryat, one of the Tungusic cultures of the Siberian-Mongolian borderlands, mentioned earlier regarding shamanic sickness. The Buryat shamanic traditions nearly disappeared under repressive conditions in the past few centuries, but have recovered somewhat in recent years. Trade with Russia began under the Treaty of Nerchinsk in 1689 and Peter the Great declared the region part of Russia in 1701, then decreed crushing taxes over the following decades. Russia also sent scores of peasants to live around Lake Baikal to dilute the political potential of the Buryat. Following the Communist Revolution, the Buryat faced brutal persecution under Stalin. The dissolution of the USSR brought a confusing transition from oppression under communism to a capitalist market economy, adding financial stresses to many Buryat families. Monetary woes may lead Buryat families to a shaman, who will consult the spirit world to ascertain what offense has warranted their misfortune. In addition to physical illness, people now call on the new Buryat shamans for what is ostensibly a mental health issue: making sense of radical socioeconomic transitions.

The Buryat now live in towns and villages of Buryatria and Mongolia, shunted from their traditional nomadic lives on the steppes where Siberia, Mongolia, and China meet near the shores of Lake Baikal. The shamans have day jobs as farmers, construction workers, and clerical workers, doing rituals out of love for the culture and their people, though some are now requesting payments. In Ulan Bator, Mongolia, you can find Buryat shamans in the yellow pages of the phone book. They do not remember their trance journeys as the old shaman did, though many are certain they will eventually regain that ability. Still, they strive to negotiate solutions with the myriad spirits for illnesses, family problems, or economic downturns as needed (Buyandelgeriyn, 2007; Delaplace, 2014; Frecska, 2023; Humphrey, 1999).

Fig. 6.1 Buryat shaman (Kuznet͡sova, 1904-1917)

A Buryat shaman, or several, will sing or chant their way into trance, at which point spirits will speak through them. Their utterances may make no sense to those being treated, because they speak the language of spirit, the communication mediated and translated by human helpers (Delaplace, 2014; Jokic, 2008). While trance may seem bizarre, consider two frequent occurrences in Euro-American culture: flow, in which a person may lose sense of self and time while engaged in immersive activities such as sports or musical performance, and speaking in tongues, where a preacher or congregant begins uncontrolled utterances, which happens every Sunday in countless evangelical churches across America.

Philippine healers: babaylan, mambaki, dawac, and balyan

The Philippines are by no means a monolithic cultural entity, with 7000 islands, of which about 2000 are inhabited. Tagalog speakers of Luzon comprise the largest of the nation's 100 distinct ethnocultural groups at about 24%. A huge number of Filipinos have also migrated, with over four million Filipino immigrants in the US and a total of over 12 million sojourners working overseas.

Fig. 6.2, Filipina Medium Making an Offering to the Guardian Stones (Cole, 1922)

In Filipino communities, traditional healers are broadly referred to as *babaylan*, with local and regional names including *mambaki*, *dawac*, and *balyan* (Fig. 6.2). The closest English term would be shaman, serving as mediators between the physical and spiritual worlds, though they also employ a large pharmacopeia of herbs and medications. They were usually (but not always) female and served as healers, priestesses, and leaders of their barangays, communities technically ruled by a *datu* or *raja*, but in which *babaylan* held great influence (Center for Babaylan Studies, n.d.; Tan, 2014). When the Spanish colonized the archipelago over four centuries ago, they noted the indigenous people already used a large pharmacopeia, with antidotes for poisons and treatments for numerous diseases. Traditional healing also included ritual singing, dance, and prayer or incantation.

During the colonial period, the Spanish found their soldiers ill-adapted to the tropical climate. While far more indigenous people succumbed to diseases brought by the Spanish, hospitals were built to treat the many Spaniards afflicted with tropical diseases or wounded in the conquest. The first hospital was built in Cebu in 1565, using the knowledge and techniques brought by the Conquistadors. It is impossible, centuries later, to judge whose techniques were more advanced or effective, the indigenous or the invader; both contributed effective and unfortunate ideas and both left an enduring imprint on current systems of medicine in the Philippines.

The Catholic friars attempted to supplant the *baybalan*, the traditional healers having the misfortune of being aligned with indigenous religious practices the Spaniards suppressed at the point of the sword. The *baybalan* survived, however, and many in the Philippines and the diasporic communities seek their services today. People from the Philippines have migrated around the world for work, including a high prevalence among immigrant workers in healthcare. *Baybalan* traditions have also arrived on distant shores with Filipino sojourners. Also present are *albularyos*, from the Spanish word *herbolario*, who are more aligned with Catholicism and are currently credentialled by the Department of Science and Technology (DOST) and the Philippine Institute for Traditional Healthcare (PITAH) (Sanchez & Gaw, 2007). The existence of these traditions may provide opportunities for collaboration and communication, if respect can flow both ways.

Connecting cultural dimensions and healthcare systems

Healthcare writ large happens across a variety of dimensions of organizational culture, from the macrocultural level of widespread biomedically educated professionals down to the microculture of a particular doctor's office or an herbal healer in a remote village. Each level includes behaviors, beliefs, and practices that have been refined, transmitted, and stabilized over time. As discussed in the section on Social Identity Theory, our participation in cultural activities includes our identification with and membership in organizational cultures. We tacitly agree to a set of behaviors appropriate for our role, which we are expected to know. If you are a Paiute seeing a traditional healer, you will bring tobacco and perhaps some food for the healer's family. Going to see your family MD, you will bring an insurance card that you will present to a receptionist.

A pronounced feature of the biomedical microculture is a rigid hierarchy of administration, chief doctors or department heads, physicians, residents, head nurses, other nurses, nurse's aides, orderlies, and so on, down to janitorial staff. Somewhere in those layers fall psychologists (psychiatrists are also medical doctors), social workers, imaging technicians, and an arcane array of those who keep the wheels of insurance and financial, nutritional, and supply chain mechanisms chugging along. Also participating are the clients and patients, without whom the systems do not exist. Generally, the patient roles often have been passive, other than following the healer's advice, relying on those in upward levels of hierarchy to make the right decisions.

In the tangled web of macrocultural and ecocultural layers are found norms of communication and authority. These can be examined using Hofstede's culture-level dimensions discussed earlier, with the caveat that Hofstede's scores are averaged across countries or regions and the medical world is by no means monolithic. In addition to individual variation within any culture, many (if not most) healthcare settings will include people from multiple origins who may defy categorical expectations. On the other hand, being aware of trends may assist in responding when differences appear, regardless of cultural origin.

Fig. 6.3: Doctor and Nurses in the Medical Center (WVU, ±1960)

Generally, the *MD* (medical doctor) appears to be the top authority on patient care in conventional medicine, though insurance and administration certainly factor into control over treatments and resources. Note the traditional *white lab coat* that differentiates the medical doctor's status from that of the *nurses' dresses and caps* (Fig. 6.3). Hofstede might have called this a structure high in **Power Distance (PDI)**. Despite some contention over whether doctors, insurance, or administration are actually the top authority, nurses would rarely challenge directives of an MD overtly, though they may find other ways to ameliorate bad decisions when they see one happening. This hierarchy has a long history in Euro- and Euro-American cultures, reinforced by the top socioeconomic status of white males and a preponderance of white males at the top of healthcare system practice and management. Equality can describe distribution of resources, financial or otherwise, authority to direct actions of self or others, and interpersonal factors of respect and status. PDI affects the quality of these interactions.

In terms of **Individualism versus Collectivism (IDV)**, the collective efforts required for many treatments belie the heavy focus on individual achievement in conventional medicine. From surgical teams to Buryat shamans and their helpers, treatment often entails unified effort. How those people think about themselves, however, probably reflects their cultural origins. The success or failure of treatment reflects personally on the doctor, and to lesser degrees, on other members of a treatment team and the institution they serve. In many traditional contexts, the treatment may actually be geared toward restoring connection to the collective and may involve a number of family or community members.

Cultural characteristics may also affect outcomes, for instance instances of better outcomes of schizophrenia in developing nations. Cultural characteristics may explain those differing outcomes, including “(1) differences in structural elements of cultures (e.g., family structure or socioeconomic features); (2) distinct treatment modalities in different cultures; and (3) patients with the same symptomatology may be suffering from disorders with different biological bases” (WHO, 1979, p. 371). Structural elements include collectivist social and familial structures (e.g. Cohen, 1992; Sartorius et al., 1987; Waxler, 1979) and as discussed earlier, connectedness supports health and well-being. On the other end of the spectrum was Samuel Thomson, an herbalist in the late 18th and early 19th centuries who stated that Americans “should in medicine, as in religion and politics, act for themselves” (in Hatch, 1991, p. 29).

Hofstede's dimension of **Motivation towards Achievement and Success (MAS)** focuses on heroism, achievement, and material rewards, and biomedical culture rates very high in these characteristics. In Hofstede's original Masculinity vs. Femininity construct, that achievement motivation stood opposite the "feminine" emphasis on nurturance and care, which also appears in the healthcare world. **Uncertainty Avoidance (UAI)** would definitely tend to rate very high in healthcare contexts, given emphasis on following set procedures to avoid ambiguity and achieve desired healing outcomes. In large bureaucracies of current conventional medicine, charting typically includes a predicted outcome in a prescribed timeline and insistence on evidence-based practices may include penalties when expectations are not met. In traditional or CAM practice, expectations may not be so clearly defined, but too much uncertainty and too many unmet goals may reduce trust.

In **Long- or Short-Term Orientation (LTO)**, healthcare becomes a mix of priorities, dealing with treatment of critical incidents but also striving for lifelong health. Organizationally, healthcare always seeks new solutions and adapts to new challenges, but also maintains existing "traditions," though the conventional macrosystem is really less than two centuries old. Traditional systems may be millennia old and practitioners may descend from lineages passed down for generations. Collectivist cultures may include techniques designed to reconnect a patient with their own ancestral or cultural heritage in a very long-term and time-honored orientation.

One dimension not yet discussed is high- versus low-context. This dimension is slightly confusing—in a low context situation, people will usually offer more information, assuming that the other person cannot ascertain details from contextual cues. High context cultures assume that people know a great deal of information by virtue of context and will not offer details unasked, assuming everyone knows the detail already. In small towns, directions to a location may include landmarks that used to exist, such as “where the big old oak tree was,” which requires long-term knowledge of the locale. Healthcare typically operates as a high context modality, because the providers typically all have years of training specific to the contexts and processes involved. Importantly, clients/patients do not have the same background information, and providers may not realize that the patient needs additional details to understand what’s happening.

These dimensions of cultural variability can aid in achieving a more nuanced understanding of intercultural differences beyond stereotypes, especially when there is a mismatch between people involved. Mismatches may appear between any roles involved, patient-provider, administration-doctor, doctor-nurse, and so on. A doctor from a high PDI culture might take offense at the familiarity of someone lower on the hierarchy from a low PDI culture. Someone from a very individualistic culture may find it confusing when a collectivistic patient wants a number of family members present during consultation or declines to make a decision until family is consulted. Just knowing that these predictable dimensions exist may help to identify and alleviate points of friction.

Ethics and medical culture

As discussed earlier, from the values and beliefs of a culture arise moral and ethical systems. The culture of contemporary conventional medicine does not have generations of history woven into its ethical and moral DNA; circumstance has required it to create its own. In 1979, Beauchamp and Childress published what is now considered a classic set of principles for the biomedical field, attempting to create a “set of universal norms shared by all persons committed to morality” (p. 3). Several editions later, their Four Principles of Bioethics remain:

(1) respect for autonomy (a norm of respecting and supporting autonomous decisions),

> (2) nonmaleficence (a norm of avoiding the causation of harm),
>
> (3) beneficence (a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balancing benefits against risks and costs), and
>
> (4) justice (a group of norms for fairly distributing benefits, risks, and costs)" (Beauchamp & Childress, 2001, p.13).

These principles can be mapped onto the moral, ethical, and value dimensions discussed earlier. Because Beaucamp and Childress were both based at Georgetown University, these principles are frequently described now as the Georgetown Mantra. Though thoroughly entrenched in conventional medical practice, they have faced critiques on several fronts, including the possibility that they reflect an inherently biased values system.

The criticisms directed at the Four Principles of Bioethics have included Kleinman's (1997) charge they are ethnocentric, psychocentric, and medicocentric. Childress and Beauchamp (2022) distilled criticisms down to two primary critiques: first that medical ethics stand outside of common moralities, and second, charging that there is no common morality and such approaches limit accommodation of cultural diversity. They begin their defense by pointing out that the Four Principles are "content-thin principles of obligation" including features "that require further specification to generate more definite content" (p. 164), giving the example of informed consent as one such area. Regarding the critique that medical ethics stand disconnected from common morality, they cite Rosamund Rhodes (2020), who argues that efforts to base medical ethics on common morality are misguided, that medical ethics are of necessity unique. The weighty responsibilities and practices of medicine, she says, are inherently uncommon and should be dictated only by medical professionals with a full understanding risks and benefits in the decisions they face. Childress and Beauchamp (2022) counter that the content-thin nature of their Four Principles allow insertion of specific rules to accommodate these uncommon dimensions while also addressing diversity in specific cultural contexts.

For the purposes of this book, rather than attempting to support or refute the Four Principles, a brief look at some interactions of ethics with culture may be more effective. To recap, systems discussed included Shweder's Big 3 dimensions of Community, Autonomy, and Divinity; Graham and colleagues (2013) Moral Foundations Theory, including Care/harm, Fairness/cheating, Loyalty/betrayal, Authority/subversion, and Sanctity/degradation; and Schwartz' (1992/2012) 10 values dimensions of: (1) Tradition, (2) Conformity, (3) Security, (4) Power, (5) Achievement, (6) Hedonism, (7) Stimulation, (8) Self-Direction, (9) Universalism, and (10) Benevolence. The bioethical principles of nonmaleficence, beneficence, and justice certainly fit well into these maps and are unlikely to cause intercultural ethical conflicts in and of themselves. The principle of autonomy, on the other hand, can be problematic in a number of cultures. Autonomy is rooted in Western individualism, assuming that individual must be free to make their own choices, without coercion or coaxing, and of their own volition. Raanan Gillon (2003), of the Imperial College London, argues that autonomy should be regarded as the primary ethical principle, all others relevant only if autonomy is fulfilled. This approach privileges individualist ideals, ignoring that people of many (possibly most) cultures might be collectivists who see themselves first as members of a group.

The ultimate test of ethical rules is whether they actually guide behavior. Page (2012) attempted to quantify adherence to the Four Principles in decision making. Participants were presented with four realistic scenarios presenting ethical dilemmas for each of the principles. In her sample of 94 students, Page found that participants support the principles but that their decisions would violate the same principles when pressed. Across cultures, differing values systems make adherence to ethical principles even more difficult.

Beauchamps and Childress's (2001) Four Principles of Bioethics provides an accepted version of the Western ethos observed in conventional medicine. A brief overview of contrasting and complementary systems may help to clarify the range of alternative viewpoints. Within the world of conventional healthcare, the National Association of Social Workers has its own cultural values, behaviors, and beliefs. The association uses a slightly different format pairing values with ethical principles (Table 6.1).

Table 6.1: NASW Values & Principles

Value	Principle
Value: Service	**Ethical Principle:** Social workers' primary goal is to help people in need and to address social problems
Value: Dignity and Worth of the Person	**Ethical Principle:** Social workers respect the inherent dignity and worth of the person.
Value: Importance of Human Relationships	**Ethical Principle:** Social workers recognize the central importance of human relationships.
Value: Integrity	**Ethical Principle:** Social workers behave in a trustworthy manner.
Value: Competence	**Ethical Principle:** Social workers practice within their areas of competence and develop and enhance their professional expertise.

Note that in place of autonomy, NASW emphasizes dignity and worth, which are more inclusive concepts. In practical terms, individualized consent usually remains the standard in consent to care for social work, but the NASW values and principles provide a slightly different way to sort out quandaries.

Islam provides an example of ethics in which individual autonomy does not hold sacrosanct status; Islam often emphasizes duty over individual choice. A professor at King Saud Bin Abduaziz University For Health Sciences, Abdullah al Sayyari (2021) suggests Muslim patients are likely to be more receptive to guidance presented in terms of Islamic values and consistent with Shari'a. Training of medical students in Muslim countries generally follows tenets of Shari'a, which is essentially the collected centuries of commentary that supplement the Koran. While the media and certain political factions portray Shari'a as something frightening, the prescriptions, proscriptions, and punishments contained therein do not diverge greatly from the Bible’s Old Testament. Beauties of the Quran, according to a Jordanian friend, stem from the inherent poetry of the Arabic language and from its humanitarian ethos. In the chapter of the Quran entitled “The Feast,” one finds the ethos that “When one saves a life it is as one has saved all mankind.”

There is, according to al Sayyari, (2021), strong social and religious pressure in some Islamic educational contexts to adhere to Shari'a orthodoxy, strictly interpreted. He pushes his students to consider alternative choices within Islam, which encourages debate and interpretation of values and scriptures in light of context, and to consider that their patients may come from other religious systems. In certain cases, a practitioner may need to consider the nuances and subtleties of a particular situation and seek solutions among the many variations of Islam.

Foods, encounters, or actions may be permissible (*halal*), sinful and/or impermissible (*haram*), or improper but not *haram* (*makrouh*) (al Sayyari, 2021). Similar to *kapu* among Māori and Pasifika people, *fatwa* and considerations of what is *halal* or haram may have origins in what would now be called public or mental health; if one eats *halal*, if people avoid social interactions that create conflict, and so on, life flows in a healthy, orderly, ethical, and discord-free fashion. While the Quran and Shari'a provide answers to a great many of life’s questions, the world keeps changing. Consultation with a religious figure (e. g. an imam or leader of a mosque) that may help clarify possibilities for providers or patients and may ease fears in questionable cases.

The ethics of transparency and informed consent

Ethical guidelines of what information should be conveyed to patients or clients may be defined explicitly by law, religion, policy, or custom, or ethics may be a matter of implicit custom or tradition. These people accommodate organically as they develop in childhood. The constraints frame the canvases on which our lives are painted, whether or not we are aware they exist. The healthcare landscape can become a minefield if one sallies forth, ignorant that such constraints exist on all sides of interactions, our own included.

Conventional medicine stipulates full disclosure to facilitate informed consent, an area fraught with ethical complexities in cross-cultural encounters. As discussed, cultures may have definite rules about what kinds of information should be spoken aloud. Disturbing news runs counter to teachings of Islam, which says the sick should be given comfort (al Sayyari, 2021) and delivering news of terminal prognosis cannot be considered comforting making the action *makrouh*, if not haram. Speaking a prognosis aloud, especially a terminal outcome, equates to sentencing a person to that eventuality in some indigenous cultures. The healthcare practitioner then faces the choice of failing to inform or of committing deeply offensive acts that alienate patients and their families by simply fulfilling disclosure obligations. Without that full set of facts, the individual cannot consent to treatment, or consent to cessation of interventions when no hope remains.

Individuality and ethics

The concept of individualized informed consent encapsulates the Western mindset. Individual bounded entities have autonomy to make decisions over the physical self which is solely their domain. Individual agency and autonomy represent and amazing evolution of human culture; people were enslaved, the ruling class controlled medieval vassals, women and children literally belonged to husbands and fathers. Rights and choices were rare until The Enlightenment fostered individualized ideas like Descartes' "*I* think, therefore *I* am," so *I* get to choose. Irish social worker Marie Fitzsimons eloquently explained the cultural necessity of individual consent, saying, "care should always be client-centered. None of us are the experts in another person's culture. They are the experts in themselves, and they can teach us about their needs and wishes." In this ethos, the patient is the expert on what they need and what they can accept.

Conversely, autonomy and individual agency bedevil cross-cultural research and the informed consent demanded by institutional research ethics often violates the norms and values of the people they are designed to protect. At issue is the idea that the ability to agree to participation, or to treatment in healthcare, lies within individuals as isolatable self-contained systems whose decisions affect only themselves. These ideas stand at odds with existence in collectivist cultures. In research, asking an indigenous person about their beliefs and practices may quickly cross into territory of collective ownership that no individual alone can give away. People in Shawi and Shibo communities of the Peruvian Amazon expressed confusion and suspicion when presented with detailed informed consent documents (Sherman et al., 2012).

Numerous tribes and ethnocultural groups are now demanding repatriation of artifacts, stories, and songs collected by explorers, archaeologists, and anthropologists. The concept of ownership, control, access, and possession, or OCAP, has become increasingly important for First Nations (Indigenous tribes) in Canada. Before they agree to participate in research, they want clear agreements on ownership of all data collected and resulting analyses, and definitely require control over use of materials collected. For example, recorded performances collected in fieldwork have been incorporated into highly lucrative commercial productions with no benefit accruing to the source cultures, contributing to a strong distrust of researchers. More difficult for the individualist to grasp is that members of a collective may not feel entitled to make decisions about what seems one’s own body without consultation with and approval by elders, spiritual leaders, or other authorities. Movements to indigenize social science and humanities research is beginning to address these issues but medical consent remains individualized.

Confidentiality and anonymity can present difficulties, though they are designed to protect the vulnerable. Asked about certain aspects of culture, people may feel obliged to establish the credentials or lineage that allows them to express views or relate facts. The Māori practice of whakapapa establishes a person’s authority immediately upon introduction. The right to reveal information may be limited by a culture, such as songs that can only be sung by and for family. Copyright law and consent guidelines assume individual authorship and ownership, concepts that fall apart when ownership of cultural knowledge properly falls to collectives such as family, clan, or tribe; an individual may lack the authority to share the songs, images, stories, or other information.

Traditional cultures also constrain what can be spoken and what must remain tacit. Particularly, revealing diagnosis or prognosis can violate proscriptions against saying something bad will happen to a person, especially in cultures where words are considered to hold evocative power. As with Islamic practices discussed earlier, speaking aloud that a person with a potentially terminal illness will die potentially condemns them to death. If terminal patients cannot be informed of their condition and prospects, they cannot consent and cannot designate proxies or agents who could make necessary decisions for those who are incompetent. Competence and consent are required to create living wills or advance directives that would allow others to provide consent.

Cultural variation in individual agency further complicates matters. An individual from a culture where agency resides with elders or with male family members may not feel able to make a decision. On the islands of Chuuk, in the Federated States of Micronesia, people are members of both families and clans. The eldest male of the clan holds authority to make important decisions for clan members, including healthcare, marriage, and burial. Pushed by rising sea levels and economics, the people of Chuuk are moving to other countries, especially the US, relying on favorable immigration status. While they do not receive the same benefits as citizens, better opportunities for work and education have brought thousands of Micronesians to Hawaiʻi. They are the latest wave of immigrants suffering prejudice and discrimination, beginning with the Chinese in the mid-1800s; like their predecessors, Micronesians are now targets of suspicion, under-employment, and mistreatment in human services.

Jonas Kinchiro Madeus arrived from Chuuk several decades ago as a student at the University of Hawaiʻi at Hilo. He now works as an anthropologist assessing sites for cultural and archaeological significance. For members of his clan in Hawaiʻi, he is now the eldest in the state and must advise and intervene for relatives on a constant basis. He explains the disconnect between Chuuk culture and the conventional medical systemʻs consent requirements, saying, "I have nieces and nephews where I have more say over them than their father, but you come into the United States, that doesn't work." The issue is the Chuukese norm of clan elders prividing approval. "The immediate family has to make the decision. There are other tough cases where uncles tried to step in and make decisions for the immediate family, and they end up mad because the wife or the father says that this is the paper only we can sign and not you. It works back there [Chuuk], but in the United States, it doesn't work here."

Alien concepts like informed consent are among many interfering with quality of care for immigrant and minority groups including Micronesians. Language and cultural gaps, worldview differences, and other factors to be discussed lead to an array of documented issues in treatment and employment.

Health and arts

Much has been written about health and healing benefits of arts, though modern culture considers them more a pastime or novelty than serious sources of benefit. Music and art therapy are now regular features of behavioral health support in treatment regimens, including inpatient addiction programs, cancer wards, children's hospitals and other treatment venues. In more traditional times, though, what we now term arts were inseparable from the life and health of communities.

Ritual use of music, dance, painting, and drama are among arts activities used historically to create, maintain, or restore health of communities and individuals. Among its social functions, music aids in construction of identity, in transmitting and supporting cultural knowledge and values, and in enhancing interpersonal relationships (Boer et al., 2011; Hargreave & North, 1999). Much of that literature is qualitative, but a growing body of research has begun to document scientifically what generations of traditional cultures have known. Fox (2010) modeled effects of participation in traditional arts such as Hawaiian hula, Japanese taiko drumming, and Māori kapa haka, demonstrating benefits including identity support, connectedness, resilience, and reduced pathology indicators. Olvera (2008) reviewed studies of physical and physiological benefits to arts participants, with results demonstrating benefits in cardiovascular health, BMI, affect, and trauma recovery (see Table 6.2).

Table 6.2: Studies of physical and MH benefits of dance (adapted from Olvera, 2008, p. 355)

Author	Year	Benefit	Ages	Sex/Race	Description of findings
Robinson	2003	Physical	8-10 y.o.	African-American girls	Girls participating in African dance, step, or hip-hop watched less TV & decreased weight concerns
Flores	1995	Physical	7th grade	Predominately African-American boys and girls	Girls decreased resting heart rate and BMI after culturally-based dance

Engels	2005	Physical	Children & women	African- American	African dance activity: Children improved BP & diet, women reduced BMI & improved fitness
West	2004	Mental	College undergrad	Men and women, no mention of ethnicity	African dance lowered stress & negative affect, increased positive affect
Hestyanti	2006	Mental	Children	Indonesian boys and girls	Children participating in traditional dance did not have trauma symptoms after tsunami
Harris	2007	Mental	Adolescent	African (Sudanese and Sierra Leonean)	Improved anxiety and depression symptoms; fostered group identity & social integratiion after violence
Kim	2003	Mental	Elderly	Korean women	Increased life satisfaction, lower cardiovascular risk following Korean dance participation

Humans naturally synchronize their breathing and heart rate to music in their environment (Bernardi, Porta, & Sleight, 2006; Clayton, Sager, & Will, 2005), a process that happens individually and for groups. Neurochemically, music is associated with increases in oxytocin, a chemical that increases when women give birth and when people fall in love (e.g., Chanda & Leveitin, 2014; Fukui & Toyoshima, 2014). Kreutz (2014) measured blood levels of oxytocin before and after people sing in choirs, finding a significant increase. Music literally brings people together (Boer et al., 2011), on multiple levels.

Murray (2023) discussed the use of drum dance in Inuit society. He describes the culture as ecocentric, deriving healing and well-being from connection to the natural environment. After decades of cultural disintegration, traditional drum dance has been recognized as a support for well-being, especially of youth. Traditional music and dance are proving to be particularly powerful in connecting indigenous youth to their families, communities, and cultures. In community halls or under the stars, singing and dancing together to the beat of the drum literally unifies hearts and minds.

MODULE 11: CRITICAL & EOL CARE

Healthcare providers try to prepare their patients and clients for death, but encounter obstacles from their own ethos in addition to client resistance. Palliative and hospice care provide affordable and humane avenues that differ slightly. Palliative care focuses on client comfort and may coincide with other treatments. Hospice, by definition, follows cessation of treatment. Previously discussed issues of agency, consent, and epistemology now coalesce, potentially to impede or prevent provision of best EoL care, whatever that may be for the patient. Controversial issues include euthanasia and organ donation, though euthanasia is probably millennia old. Patient-centered communication provides tools to bridge understanding. People need support in these situations, which may need to be offered in particular ways.

Learning outcomes:
Differentiate palliative and hospice care and when they may be appropriate
Discuss cultural issues for and against organ donation and euthanasia
Recognize avenues for providing care and solace

Key terms: Suicide, euthanasia, palliative and hospice care, organ donation, patient-centered communication

What do we expect at the end?

"If expectation helps create reality no wonder we view dying patients as our failures and turn from them, for the focus of health professionals is cure." Mervyn, 1971, p. 1988

Of course, this story had to arrive at the less-pleasant topics of critical illness and mortality. Through the earlier sections, we have discussed how culture shapes our thoughts and interactions differently. Hopefully, the many decisions we encounter unlike what we may choose ourselves make more sense, the underlying motivations clearer now.

Culture of life?

Biomedicine in the American model has historically emphasized treatment over preventative care, but this is changing slowly. Research provides examples of lifestyle and diet choices that reduce risk, and these are increasingly part of conversations between providers and patients, along with screenings when indicated by history or age. Also appearing more and more are conversations about advance directives and EoL planning. Greater financial incentives still accrue to intensive treatments, and both patient and provider are heavily invested in survival, for obvious reasons both biological, humanitarian, and cultural. People want to live, and we want those in our care to survive. Part of the problem lies in how we think (or don't think) about death.

Dying represents failure in conventional medicine, and the topic of death is avoided, even when people approach their end. The common idiom in these medical situations is *fighting* disease, *fighting* for survival, *defeating* death when a patient survives. Death is the enemy in this conflict and one *loses* a patient when they die. When a heart stops, CPR and other more drastic measures happen immediately and automatically, unless patients created legal documents to prevent it (Quill, 2011). In other words, continued life signs constitute winning and cessation constitutes defeat. These conceptual terminologies place medical staff in a metaphorical war against a foe that can never be defeated fully, because no matter how heroic the efforts of healthcare providers, all patients eventually die.

Culture of death

The extreme focus around survival at all costs led Thomas Quill (2011), emeritus of the University of Rochester, to suggest the biomedical industry paradoxically promotes a culture of death. The entire system focuses on defeat of death, conceptually equating hospice care with giving up. In a cruel twist of the inverse care law, patients who might have lived longer with much smaller sums spent on better preventative care earlier in their lives suddenly receive enormous resources to claw them back from the jaws of death. The expenses accruing to the family may ruin them financially, but everything possible will have been done, even if an exercise in futility. In short, the systems revolve around and depends upon death to survive.

Understandably, conversations with providers tend more toward optimism than honesty, because nobody wants to take away hope. Further, political rhetoric pairs discussions of Advance

Care Directives with the concept of “Death Panels,” making these necessary discussions a political hot potato. For these and other reasons, patients rarely enter later stages of care having considered where and how they would prefer to pass, much less being informed of options for palliative care or hospice. As a result, Quill (2011), a palliative care specialist, complained that 70% will not get to hospice.

Given the cost of intensive treatments, the US sees millions of families balance fear of failing to provide all possible treatments with fear of financial ruin. Costs at the end of life vary by ethnicity, with Europe’s descendants spending the least (Koenig, 2011). Once a person enters acute care, it can be very hard to get out without actually dying (Quill, 2011). In fact, even dying is complicated by the standard practice of resuscitation. A patient can be a century old, wracked with incurable and horribly painful disease, and will be revived unless a DNR document has been completed (Koenig, 2011). Hospice provides an alternative that does not include the expensive but futile last-ditch treatments and the excruciating pain of resuscitation.

Sharita tries to prepare her terminal patients for what is coming. “I try to have these conversations with patients and their spouses or their adult children before they are terminal, like really the end of life. We call this anticipatory guidance, what things to expect, when do we call in hospice, explaining what hospice is. People hear the word hospice and they automatically think that you're just condemning them to this death sentence. But a hospice is more than that; it's comfort” (personal communication, 10/1/2022).

Negotiating death

In an oddity of the Western medical system, individual patients must acknowledge that they are dying to enter hospice care. Koenig (2011) comments that the emphasis on individual choice, however well intentioned, has made matters worse in general. Personal autonomy, the

“Georgetown mantra” (Koenig, 2011, p. 49) of bioethics, has become the paramount concern of EoL care. It is not a universal value, as discussed earlier, though it has spread as part of the contemporary biomedical paradigm. For the terminally ill, autonomy may offer more obstacles than protections.

Patients of any cultural origin may resist the idea they are dying. Drawing on years of experience helping people transition out of life, Kübler-Ross (1969) described five stages of grief that she thought were common to terminal patients and those dealing with loss: Denial, Anger, Bargaining, Depression, and Acceptance. Though her stages of grief have been critiqued and may not proceed in order, few people happily admit their end is near. Needless to say, a person who denies they are terminal is not likely to feel favorably disposed toward acknowledging their terminal status and their loved ones may support this delusion.

Palakiko’s sister took a very different route from their mother, exhibiting denial that would affect the family when she declined a DNR. “She was like, ‘no I don't need to sign off on the document. I'm going to go home in a few days, and I'm totally well.’” Palakiko recalled. “Unfortunately, she didn't realize she was actually very sick at the time. She was battling breast cancer that went away for three months and it came back. It was in every part of her body imaginable at that point. So she made it harder for us because she didn't really have a clear direction for us.”

Providers often encounter patients and families who will try anything to put off death. Attempts may include standard medical treatments, experimental or untested medical processes, or traditional, complementary, or spiritual efforts. In Kübler-Ross‘s (1969) lexicon, these constitute a bargaining stage. Patients’ reasons for the “everything” treatment path may include cognitive (I want to be sure we did everything we could), emotional (I love my family too much to leave), or spiritual (God decides) rationales. (Quill, 2011). Growing segments of the post-industrial world have secularized, moving away from religion, but Pew Research found that while 28% of Americans claim no religious affiliation, most of those still maintain belief in a higher power (56%) and 13% believe in the Biblical God. Great comfort comes of having a destination to send one's prayers (Smith et al., 2024).

On the other end of the spectrum, patients may negotiate a hastened death. It was the 1997 case of Vacco v. Quill that launched Timothy Quill into the national spotlight, though that case failed to overturn New York's prohibition on assisted suicide. The June 1997 Supreme Court decision stated that a patient could refuse treatment, but a physician could face charges for speeding the process medically. Oregon swiftly passed the Death with Dignity Act (DWDA), allowing physicians to write a prescription for lethal medication. In actuality, very few people actually request and receive such a prescription (Koenig, 2011).

Palliative care, hospice, and culture

When hope of a cure fades, choices depend on the predicted trajectory. Cable-Williams and Wilson (2015) differentiate palliative and end-of-life care: palliative care becomes appropriate when a patient is terminal but not expected to die immediately, and end-of-life care describes care provided when death is imminent, likely to occur within hours or days. Hospice care shares elements of both descriptions, coming into play when death is predicted within six months. Palliative care and hospice theoretically involve slightly different ethics and methods. Both are relatively recent innovations; patients only gained the legal right to refuse care in conventional medicine with 1991's Danforth Amendment (20 U.S.C. § 1688). Unbelievably, before that time, patients did not actually have the right to choose or refuse their treatment, left to the determinations of doctors and hospitals.

Palliative care & hospice

The term palliate derives from a Latin term for a Greek style of cloak, repurposed by English-speakers in the 15th century (Merriam-Webster, 2023). To palliate is to cloak or hide something, to make an excuse, or to lessen severity. Palliative treatments cloak symptoms without providing a cure (Oxford Reference, 2023). In medical practice, palliative care refers to pain reduction, usually in final stages of a fatal condition or advanced chronic conditions nearing their conclusion (Gómez-Batiste at al., 2017). Duffin (2014) suggests palliative care is the world's oldest profession, the relief of suffering. Most beneficially, the language in palliative care changes from success = life and failure = death to emphasize comfort of a patient; in palliative care, freedom from suffering constitutes success. Comfort = success.

Efforts are underway to expand palliative practice beyond the domain of EoL care to include the needs of patients with serious illness or multiple chronic conditions (MCC) (Murali et al., 2020). The World Health Organization (WHO, 2020) states that "Palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well" (online). The WHO estimates that 56.8 million people utilize palliative services, including both pain relief and EoL care, with 25.7 million accessing palliative care in their final year of life. Researchers at Vrije Universiteit Brussel, Six, Bilsen, and Deschepper (2020) list cultural difficulties arising in themes of "truth telling, coping with pain, non-treatment decisions, palliative sedation, and euthanasia" (p. 1). Problems also arise if a patient or culture has proscriptions against use of opiates or other substances or if "giving up" on treatment constitutes a moral violation.

Palliative care resembles hospice in provision of pain management and psychosocial supports. Palliative care differs from hospice in that treatment does not necessarily cease; patients continue to receive life-prolonging medical intervention along with symptom management such as pain relief. Patients do sometimes refuse pain medication, fearing they will become addicted and shorten their lives. The body of evidence shows pain management actually prolongs life, though palliative care requires considerable expertise, keeping dosages and interventions sufficient to manage pain but not so strong as to diminish the patient's experience of living (Quill, 2011).

Anesthesiologist and palliative care physician Tonia Onyeka became National President of the Hospice and Palliative Care association of Nigeria (HPCAN) in 2023. Onyeka (2011) reported that palliative care is a relatively new subspecialty of medicine in West Africa and is gradually being included in the healthcare systems of developing nations. Impediments to adoption of those practices lack of familiarity, but also some skepticism of conventional medicine. Patients are more likely to turn to traditional and alternative treatments (about 80%) or to faith and prayer.

"Both patients and the family have a deep belief in God," Onyeka relates (personal communication, 6/30/2021). "They tend to want to believe that when they leave the hospital, they can find a solution in the church. So when they leave, that's where they go. They have a strong belief in God and a strong belief in the miraculous. They'd rather not give up; they'd rather believe there will be a miracle."

Belief in traditional healing aligns on very deep levels with patients' world views and reflects generations of family custom. "Traditional healing practices are very common," Onyeka says. "They've gone to all the traditional healers before they come to us. So we tend to try to discourage them. They spend all their resources there, so they spent all their resources and cannot even afford simple tests when they get to the hospital." Resistance to EoL care often means patients arrive later in their disease progression, meaning treatment may be out of financial reach. Late arrival means cancers may have already metastasized, for example, and many cancer patients will die even after receiving conventional western medical treatment. This weakens faith in conventional medicine, including diseases that might have been treatable in earlier stages.

According to conventional practice, including informed consent requirements, decisions around EoL care must be made by the individual (Koenig, 2011), but this does not comport with life in collectivist cultures. Onyeka explains, "it's very rare that patients make decisions on their care all the way from admission to the end of life. Usually, the family will make decisions as things progress." Collective decision-making will probably skew away from conventional medicine unless family members are familiar and hold favorable views.

Hospice

The tides are turning away from hospitalized death. A growing number of people choose to enter hospice care in their final days, which often includes palliative care and other supports for both the terminal patient and their loved ones. The origin of hospice care is credited to Dame Cicely Mary Strode Saunders, who opened St. Christopher's Hospice in south west London in 1967 (Corr et al., 1983; Richmond, 2005). Saunders came to the rather obvious conclusion that not everyone can be cured and that people in the final days or weeks of their lives deserve to come to the end of their lives with dignity and with as little suffering as possible. She stood in opposition to the ethos of standard medical care, that treatment should continue against all odds until the patient has ceased to function, despite continuing efforts.

The ethos of hospice aligns with the revivalist cultural script (Hilário, 2020), which should be “pain-free death; death at home, surrounded by family and friends; death as personal growth; death according to personal experience; an aware death, in which personal conflicts and unfinished business are resolved; and open acknowledgment of the imminence of death” (Clark, 2002, p. 327).

The hospice movement in the US began as a counter-culture reaction to what was perceived as overzealous treatment by the medical establishment (Quill, 2011). As of 2018, hospice served about half of Medicare recipients who died in that year, totaling 1.55 million patients in 4,700 hospice facilities (CDC, 2022; NHPCO, 2020). Hospice serves around 35% of those who die in the US, including a wide variety of terminal conditions (Quill, 2011). Referral to hospice care currently requires that a physician certifies that it is most likely that the patient will die within six months. Relaying that news makes for a difficult conversation, from the perspective of patient, family, and, most likely, the medical provider. The news is dire; “You’re going to die very soon and we can do nothing further except ease the pain.” Factually, many patients do not meet their maker on schedule, surviving months or years beyond their projected demise. As long as they continue to deteriorate, they can remain in hospice, but remission does happen (Quill, 2011).

Hospice patients tend to be Non-Hispanic White (82%) and middle or upper-middle class. Other ethnic groups comprise only a small number, at 8.3% for Non-Hispanic Black, 6.5% for Hispanic, and 3% other ethnicities (NCHS, 2022). Non-Whites may distrust the medical system due to abuses such as the Tuskegee syphelis study discussed earlier. Western medicine has provided ample justification for pervasive distrust preventing minorities from accessing EoL care. In a number of cultures, hospice may be wrongly associated with giving up or with suicide.

Hospice care at home

Some people want a managed passage but they want it in their own home, though as discussed in the case of Hong Kong, this is not universal. If family members have the capacity to watch over the dying person, the death may be much like they have long happened, perhaps with more effective pain relief. Hospice allows for varying levels of support from hospice organizations, if the patient agrees with cessation of curative treatment. Depending on need and finances, nurses or physicians might visit to monitor palliative medications. Home health aids may take on some portion of practical care, bathing and changing the patient, administering meds, feeding, and so on. Constant care is still quite expensive, but home care may have financial benefits compared to hospital stays, in addition to the solace of familiar surroundings.

For Marie F.'s father, when he was diagnosed with cancer, the decision was about being able to stay at his home in Ireland, with his family caring for him. "He didn't like to be in hospitals," Marie recalled, "and he just wanted to be at home, where he was comfortable. He stayed at home through the trajectory of his illness and through his decline and ultimately through his death. As he became more homebound, friends would come by come by and talk story with him. In Ireland we call that chatting. They'd chat with him, have the craic. We call it having a bit of craic, craic's the Irish word for fun."

Diagnosing death and EoL systems

Given a terminal diagnosis, it would seem a clear process predicting when someone will die. It is not. The first step is identifying the medical condition from the patient is dying and that the condition is irreversible, but unpredictable factors include dying trajectories, progression of disease, more or less aggressive treatments, and a host of individual characteristics of the patient. Further, the prognosis may depend on the technologies and medications availabile.

Kennedy and colleagues (2014) in the UK and Sweden undertook a review of relevant literature regarding diagnosis and response, finding 23 papers that met their inclusion criteria. Among their findings, diagnostic clues include physical, social, spiritual and psychological decline, along with withdrawal from social situations. Treatment response was influenced by suffering as perceived by the doctor. Residents of nursing homes had high levels of physical and emotional symptoms that were not necessarily well managed. In one study reviewed of patients in a large German hospital (n=252), EoL plans were implemented late and not with fidelity, 52% dying in ICU with life-prolonging interventions underway.

Cancer diagnoses are best documented and tend to receive more accurate death diagnosis, other conditions tending to receive hospitalization rather than EoL care. Further, the prevalent focus on biomedical treatments stands at odds with cessation of treatment, the training and mindset of medical professionals being focused on solutions and cures. Also observed was a tendency of staff to avoid or postpone EoL conversations due to anxiety over misdiagnosis or misstating of timing; these are tough conversations in any culture. The unpredictability of timing interferes with preparation and participation of loved ones and the tendency to delay bad news disrupts familial goodbyes.

Looking across cultures, including multicultural situations within nations, these plans include staffing with multidisciplinary teams beyond the means of many settings. Communication of delicate information may also be an impediment culturally; in addition to the hesitancy of staff to relay bad news, such conversations may be inappropriate. Finally, these plans assume availability of palliative and hospice services, issues with which shall be discussed shortly.

European countries have prioritized improvement of EoL care, mandating that patients receive appropriate care, maintaining comfort and dignity while avoiding unnecessary or invasive procedures that reduce chances of a peaceful death. Efforts in this regard included multi-professional care teams and frameworks to operationalize benchmarks for effective practice. The Liverpool Care Pathway (LCP) for the Dying Patient became the predominant framework for EoL care in the UK during the 1990s but fell out of favor and was abandoned in 2014. Conversely, the framework was adopted by a number of other countries, with some modifications, and is still in use in some of those (Clark, Inbadas, & Seymour, 2020). The LCP has three stages: Initial assessment, Ongoing assessment, and Care after death.

The LCP attempted to provide an integrated care system crafted from successful techniques used in hospice care and was quickly implemented across Great Britain. Perhaps scaled up too quickly, complaints emerged, leading to the Baroness Neuberger Report (2013), which pointed out enough missteps that it was abandoned in the UK. Families and patients felt excluded from process, communications were unclear, staff engagement actually *decreased(!)* once patients entered LCP, and accountability was insufficient. Interestingly, this was not what happened when LCP was exported.

Clark and colleagues (2020) synthesized findings from 95 publications and 18 qualitative interviews regarding implementation of LCP outside of the UK. Word had spread among healthcare professionals who then sought to implement the system, followed by funding in Europe of the OPCARE9 initiative from 2008 to 2011. Implementation was monitored and facilitated by an LCP International Reference Group (IRG), initiated in 2011and including members from 13 participating countries. Perhaps it was lessons learned, greater fidelity of implementation, or both, but LCP remains an ongoing practice in a number of countries.

Particularly, greater collectivism in other cultures may contribute to success where the UK version failed. The sense of exclusion LCP families and patients reported stems from feeling that providers were not listening. Some of that isolation is part and parcel of systems that requires providers churn through dozens of patients per day, charted and billed to standardized codes. Sharita described her method for assuring that her patients feel heard. “

> *Sharita A. (personal communication, 10/1/2022): “I think that with the utilization of the electronic medical record, physicians tend to look at the computer screen more than the patient. So that's something that I make a conscious effort to do is I look at the patient. part of the reason I'm always delinquent and late in my charting is because I'm not typing as I go, I'm listening to the patient, and if I have a good conversation, I don't have to take notes because I'll remember what we talked about, and I can put it down in in the nice little pretty package for coding people to get their money's worth later.”*

Intentional endings

Mostly, humans want to live until death takes them, but life sometimes becomes too hard to endure, raising questions around ethics and obligations when an early exit seems preferable. In 1976, massive debate erupted in the US over the fate of Karen Ann Quinlan. The year before, Quinlan had consumed valium and alcohol recreationally while out with friends and had fallen into a coma. She persisted until 1985 in a vegetative state, breathing assisted by respirator, fed by gastro tube. One small area of her brain remained active, which is why the case went to court when her parents requested that life support be terminated. Though she would never regain consciousness and could not have survived prior to the advent of life support just a few years prior, Quinlan’s fate became the subject of intense controversy.

At the time, Ian McColl Kennedy (1976) was a professor of law at King's College, London, and wrote about three issues he identified: "1) When is someone dead," "2) The so-called 'Right to Die,'" and "3) What is the extent of the doctor's obligation to his patient?" (pp. 3-5). Kennedy harkens back to Lear's use of a mirror to test Cordelia's life-signs, contrasted with the technology already advancing in the '70s and the need to determine death swiftly for the use of organs in the nascent techniques of transplantation. The term brain death had recently been coined in 1968 and Quinlan's still had minuscule activity. The doctor was previously obliged to treat until futile then to relieve pain until death, but the lines had blurred. These questions have in no way been resolved, despite the passage of five decades, and especially bedevil intercultural interactions.

Religious and humanistic ethical issues abound. Does God, other deities, or some other metaphysical force determining our fate and should we have agency to disagree? Are sacrifice and suffering essential parts of existence? Scriptures provide conflicting views, and the purpose here is not to answer existential questions, but simply to remind the reader that they exist and that there is no consensus.

Two belief factors particularly affect termination of life support; penance and faith. In Islam, the suffering of a father can abnegate sins, penance for his wrongs in life (al Sayyari, 2021). In belief systems where pain and illness happen by divine decree, alleviation of suffering may violate that will. In the case of familial penance by paternal suffering, the father could lose his opportunity to pay for sins, thereby passing them to his children.

Conversely, faith in the intervention of a higher power can be a powerful motivator for continuing life support and treatments, even when there is little chance of success. Rhema (Nigerian physician) points out that families and patients in Nigeria are reluctant to stop treatment or to acknowledge that death has become inevitable and enter hospice. “They tend to want to believe that when they leave the hospital they can find a solution in the church,” she says. “So when they leave, that’s where they go. They have a strong belief in God and a strong belief in the miraculous. They’d rather not give up, they’d rather believe there will be a miracle.”

Suicide and euthanasia

“‘*Accabadora*’ in lingua sarda è colei che finisce i moribondi" (Foddai, 2023, p. 1). In the Sardinian language, the *Accabadora* is the one who finishes off the dying. The sparkling waves of the Tyrrhenian Sea lap gently on the shores of Sardinia, across the waters from Naples, Italy, home to an ancient practice we would now call euthanasia. When a person becomes severely ill, suffering in pain, and without hope, an older woman draped on black from head to toe would enter the house, careful to pass nobody as she drifts to the sick room. Perhaps a few brief words would be spoken, the mysterious woman offering a caress. Then she raises the large wooden hammer she carries, the *mazzoccu*, and in one swift stroke, the skull cracks and the suffering ends.

It's nothing new, helping someone find release from their suffering or to be freed from becoming a burden in old age. Sardinian proverbs extoll laughter in the face of death, a sardonic chuckle signaling the approaching end, or perhaps a dose of *herba sardonia*, identified as *Oenanthe crocata*, (hemlock water dropwort) to help the process along (Preti, 2013). Several cliffs on the island have a history of helping reduce the effort and expense of elder care, as does the process of Thalaikoothal, a ritual passage for the elderly of India (Sandhya & Isaac, 2023). In that process, the elder receives a ritual oil massage and bath followed by ingestion of something lethal. Thalaikoothal is not an ancient practice, appearing amidst famines coinciding with the British Raj invasion of the 1800s, culturally defined as suicide despite occasional use of force.

In 2021, the US saw 1.7 million suicide attempts, 48,183 successful (AFSP, 2024; CDC, 2023). The word suicide derives from the Latin *sui*, for self, and *cidium*, for killing. Ancient Greek idioms including grasping death or dying by one's hand. Certainly, the ending of a life is involved in those acts, but the distinction between suicide and other acts of termination remains surprisingly murky. Velasquez (1987) discussed legal definitions, which have become highly relevant as US states discussed living wills, advance directives, and ultimately, assisted suicide or euthanasia. Variously, suicide might involve an intentional act or failure to act resulting in death.

The act of ending one's life has been considered moral or immoral, legal or not, as centuries passed. European and Euro-American cultures increasingly emphasized individual choice as key. In the late 19th century, as psychopathology became systematized, suicide became associated with mental illness (Wreen, 1988). More recently, assisted suicide or medicalized euthanasia has been legalized in a number of countries and states. The volitional component of the conceptualizations discussed greatly confuses matters, both as a product of individualized self-construal, and in considering that choosing to cease unbearable pain does not seem like much of a voluntary choice (Andriessen, 2006).

Hawai‘i singer/guitarist Makana has lost more than his share of loved ones, becoming well acquainted with Hospice Hawai‘i founder Mits Aoki along the way. In 2020, his Asian-American mother committed suicide, not because of a physical illness, but because her mental illness provided no prospect of relief for her inner pain. “I've come to realize that mom wanted to die, and she chose to die, and there's something that I respect about that,” he related via Zoom (1/6/2022). “At the time of mom's suicide, I was Kaiser's [Kaiser Permanente] spokesperson for suicide. The irony's heavy here you know.”

It may be unfair to group suicide and euthanasia together, though they are often equated in media and public debate. Both terms reflect the intentional ending of one’s life, but the terms carry very different emotional and legal valence. Cultures, religions, and laws forbid suicide with diminishing uniformity; you couldn’t escape from life that easily, it would seem, at least not in the Western paradigm. Japan has long held a different view. In the Japanese traditions of seppuku, a samurai chooses death over dishonor, but if dishonor is worse than death, is the death really a volitional act?

The term physician-assisted death carries less emotional valence than the terms euthanasia or suicide, but it carries a huge political charge. California, Colorado, DC, Hawai‘i, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington currently allow what is usually termed Death with Dignity, though New Jersey’s law is being contested politically. Generally, the more liberal states are more receptive to such laws, the same being true on country levels. Hawai‘i proposed its Hawai‘i Patient Choice at End of Life Act of 2017, and it was signed into law as the Our Care, Our Choice Act (OCOCA) in 2018. Six requirements must be met to qualify:

- Be an adult (18 years old or older).
- Be a Hawaii resident.
- Have a medically confirmed terminal illness with fewer than six months to live.
- Be able to make medical decisions for themselves as determined by health professionals.
- Voluntarily request a prescription without influence from others.
- Be able to self-administer (eat, drink, and swallow) the prescription (Kōkua Mau, 2022).

Common criticisms of assisted suicide include fears that availability will lead to risks for vulnerable populations, including those who are elderly, minorities, socioeconomic disadvantaged, disabled, or mentally ill. Physician assisted suicide was legalized in Oregon in 1997 and in the Netherlands in 2002, and has actually been common practice in the Netherlands since the 1980s. Both places track demographics carefully. In the first ten years of legality, 85% of Oregon's assisted suicides had already entered hospice. No over-representation of vulnerable populations appeared in either location (Quill, 2007), though the idea of assisted suicide in extreme cases of mental illness is becoming less controversial.

In the Netherlands, people and government are more accepting of the right to end one's life, including physician-assisted death in severe psychiatric cases. A qualitative study of Dutch physicians and psychiatrists enumerated three categories of those seeking such assistance: "(a) impulsive suicidality, (b) chronic suicidality, and (c) a well-considered and persistent wish to die" (Pronk et al., 2021, p. 271). Among the 16 psychiatrists and 19 GPs, there was some disagreement, with one respondent insisting that all suicidality results from emotional distress. The consensus was that physicians should determine whether the death wish is part of the psychopathology, is consistent over time, and/or part of a treatable condition. Assisted suicide, for those with severe enough pathology, was seen as more humane and less-risky way to alleviate unbearable suffering.

In the very Catholic country of Colombia, religion prohibits euthanasia. The legal system, however, decriminalized the practice in 1997, one of the few countries to do so, and the issue remains politically and socially divisive. Support is widespread, with 72.5% of the country saying people with terminal illnesses should have a right to die by choice. The case of Colombia is unusual in that the decision to decriminalize euthanasia was based in the country's constitution, with rights enumerated similar to the USA's life, liberty, and happiness. Rewriting their constitution in 1991 during the upheaval of Pablo Escobar and Colombia's drug wars, the new document emphasized human dignity and enshrined separation of Church and State. The right to die was endorsed in terminal cases, but also in cases of intense suffering, both physical and mental. The government assiduously ignored the issue until 2015, when the court ordered those guidelines be issued. Sen. María del Rosario Guerra decried the ruling, saying it promoted a "culture of death" (Schmidt & Durán, 2021, online). By 2021, only 157 people had died by euthanasia, a tiny number in a country of 50 million with over 7,000 annual deaths; most of those were cancer patients.

One case in Colombia grabbed international headlines in 2021 as their society and legal system struggled with this right to end one's life. Diagnosed with amyotrophic lateral sclerosis (ALS) in 2018, Martha Sepúlveda knew that she was dying and, by 2021, was quite prepared to end her life (Schmidt & Durán, 2022). "I know that God is the owner of life," she is quoted. "But God doesn't want to see me suffer" (online). She was scheduled to die in June 2021, but was blocked by the courts until January of 2022. For her son Frederico, Sepúlveda's decision was tumultuous, called upon to aid in defending her decision and facing mixed feelings about her death. Most difficult was watching her mental anguish in the face of delays; her ebullience when her request was approved became its undoing, a photo of her celebrating with a beer going viral and shifting public opinion (Limón, 2021). Proponents hope her struggle and eventual relief will spark a change in laws across South America.

If dying in Varanasi assures mokṣa, ultimate release from reincarnation for Hindus, it would be logical to assume people wishing to end their lives intentionally would be among those going there to die. The purāṇa texts do not forbid this possibility of intentional death, but current Hinduism frowns on suicide, which can be construed as a desire to die and shows attachment to personal desire (Geilen & Kashyap, 2019; Justice, 1997). Those who go to die in Varanasi often cease eating, and while fasting may hasten death, is regarded as a sacred action bring a person closer to the divine. Likewise, IV nutrition and other treatments will likely be refused as the person travels to a Varanasi home to die. People everywhere normatively lose appetite and decline food as death approaches, so this tendency may be more a biological than cultural imperative. Fasting serves a spiritual purpose, providing psychological supports by reassuring the terminal person that they can rest peacefully.

Caring and condolences

At various points in health processes, we may need to hear or give comfort or condolences. Regardless of our origins, everyone has strong emotions about their own mortality and safety of their loved ones. When someone (whether ourselves or another) learns they or a loved one have a serious ailment or they lose someone following some sudden or prolonged event, we need to receive or want to give comfort. How comfort is given affects whether the recipient feels better. While knowing what to say depends far too much on culture and context to generalize, some guidance may be available.

People usually want to be heard rather than told, a rather obvious rule, but when we feel moved to help, the most obvious move is to tell people everything will be all right. In cases of loss, it won't and a person may feel dismissed. Listening works much better.

Ring Theory

Susan Silk and Barry Goldman (4/7/2013) described Ring Theory as a guide to staying on the right path in supporting friends and family through illness and difficult passages. Their examples appear to be based on their experiences of such situations. Adapting their guide slightly to generalize across situations, the visual guide begins with a point labeled to represent the person(s) to whom the experience is directly happening, the one who has the cancer or whose spouse just died. Around that, draw a circle designated for the person closest to the trauma, perhaps a spouse, child, or parent; this may also be the person making decisions. Each circle radiating outward represents the next closest person, creating what they call a Kvetching Order, from the Yiddish word meaning to gripe or complain. The person at the center has free rein to kvetch to anyone anywhere; for being at the center of the trauma, they gain the right or privilege to voice how badly the situation sucks, how unfair it is, and how angry, hurt, or disturbed they are. The further out from the central point, the less one can complain, and then only to those further out from the center. Only material and emotional support should go toward the center, and only as much as those on the inward rings want.

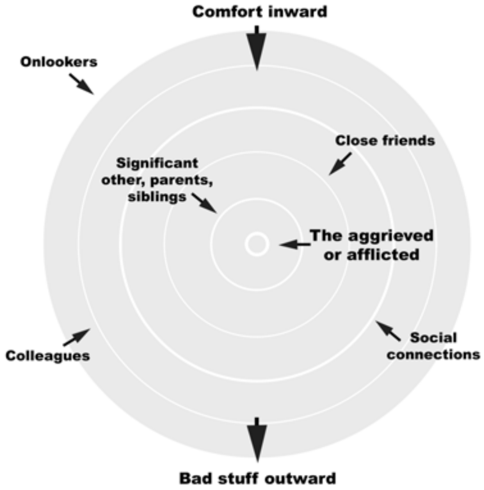


Fig. 11.1: Ring theory model, adapted from Silk & Goldman, 2013

Ring theory has the potential to work across cultures. The model aligns with Bronfenbrenner’s ecocultural model (Fig. 2.2), simply adding the details of closer others including family, friends, coworkers, etc. While there may be specific norms and prohibitions about who can say what to whom, we generally want to help lighten the burden of those who suffer, kvetching only outward and giving aid inward toward the person in need. Conversely, it is not uncommon to encounter friends and family who make the tragedy about themselves, sometimes placing blame on the afflicted or aggrieved person. The model provides an example of a more humane flow of communication and emotion.

Organ donation, culture, and ethics

Organ donations and transplants save an increasing number of lives annually, a miracle snatching life from the jaws of death. The topic is also exceedingly difficult to discuss on a good day; in the midst of tragedy, it may be impossible. The Gift of Life Donor Program (2018) estimates that a donor can benefit up to 75 other lives. Laws and ethical mandates require that donors or family members never feel manipulated or coerced into donation. Potential for saving lives may push doctors to be assertive when recruiting potential donors from those nearing their ending. Of necessity, physicians must be involved in EoL care of potential donors; death is unpredictable and organs are fragile, some requiring nearly immediate transplant and underscoring the careful balance between sensitivity and promptness.

The ***doctrine of double effect*** describes situations where good intention may make an act morally justifiable even when it entails risk of harm (van Haren et al., 2020). Donation places physicians in a quandary of choosing between the moral good of saving a life by encouraging the ill of letting a patient die. Stewart and colleagues (2021) therefore recommend that treating physicians be removed entirely from the EoL decision process. Though sale of human tissue is illegal in most of the world, the surgical procedures of transplantation carry a hefty price tag, generating income for the hospital and surgeons and possibility of ethical issues. livelihood depends on availability of organs (Stewart et al., 2021).

Factors influencing the decision to donate include personal or religious beliefs, rumors, misinformation, or lack of information (Riether & Mahler, 1995). Cultural values may encourage or forbid donation; the dying patient’s wishes may include donation as a final altruistic act or, at the other extreme, some cultures may find the entire prospect horrifying, particularly if their religion requires in-tact burial. The black market for organs creates a slipperier slope, in an endeavor inherently conflicting with the interests of the (potentially) terminal patient. In short, these questions are best answered with advance directives and living wills, when no exigencies color the decisions.

Warren and colleagues (2021) point out a number of impediments to social and ethnic parity in organ donations, beginning with simply getting on waiting lists. That requires access to primary care, specialists, and sufficient insurance, which the disproportionate care law says is unlikely to result in equitable access. The authors used data from the United Network for Organ Sharing to compare rates of ethnicities in the transplant process. In the 109 US transplant centers they identified as performing more than 250 transplants per year, they found Non-Hispanic Blacks (NHBs) and Hispanics are underrepresented on waitlists, compared to their proportion in the population. Once on the waitlist, these groups actually received transplants at a slightly higher rate, bringing numbers closer to, but not achieving, demographic parity.

Consent is central to donation. Under English Law, express consent has been required since the Human Tissue Act 1961, though this probably yields fewer organs than are received in Belgium, and Austria, where consent is presumed. Swedish law allows both for consents and non-consents to be registered (Dunstan, 1997). A risk remains that family members may face coercion for live donations (i.e. kidney), particularly in Christian or Islamic communities that sanction failure to support family, though the sanction may happen via emotional manipulation.

Krekula, Forinder, and Tibell (2018) found donation in Sweden was inhibited by fear that the body would be disrespected or manipulated during donation. Reither and Mahler (1995) noted that much of the resistance to donation was based on misinformation, such as rumors of sale of organs, some of which erupted from fictional TV show scripts about abuses of the system. An understandable distrust of the medical system and belief in the sanctity of the body decrease donor willingness among African Americans, the sanctity issue being particularly strong for

Caribbean ethnicities. Asian Americans donate at a lower rate than other groups, possible reasons including belief that death happens over an extended time, lasting several days. Chinese beliefs also see the body as housing the soul and requiring reverent treatment (Alden & Cheung, 2000).

Doerry and colleagues (2022) surveyed views of Christians, Muslims, Jews, Hindus, and Buddhists in Germany, finding favorable views among all. Christians and Jews expressed that donation is an altruistic act, Muslims that the act is praiseworthy, Hindus that donation is virtuous, and Buddhists that donation shows generosity and compassion. As the worldview and techniques of conventional medicine spread, for good or ill, attitudes toward organ donation are softening.

Connecting to family and culture

Jessie faced a number of deaths on her Mexican side before and during the pandemic. When her great aunt was passing in a hospital, the family faced a common hurdle that affects many families in that context: limits on who and how many people can visit at any given time. Of course, the worst-case scenario was prohibition of any visitors at the depth of the pandemic. But for collectivist cultures with an emphasis on surrounding loved-ones as they pass, having only one or two family members allowed in at a time is tantamount to torture. Jessie described the experience:

> *Jessie V. (personal communication, 10/26/2023): One person in my family at a time could go up and see my great aunt when she was passing, so we had to take turns. And it was really hard to be out in the parking lot and her husband, my great uncle, would not go home. Everybody had to just take turns taking care of him in the parking lot because*

he was just devastated. But he couldn't stay overnight in the hospital with her, and he didn't want to be away from there when she passed.

There are no cognitive acculturation issues for Jessie and her family; they understand the reasoning behind hospital rules and protocols, but the experience was uncomfortable and demeaning. The actual issues are accommodation of customary practices and recognition of the ways those customs aid psychological well-being. Families like hers could benefit from facilities that would ease their participation in the passage. She suggests,

Jessie V. (personal communication, 10/26/2023): --maybe having a better patio outside the hospital for people to hang out in or so they're not sitting in between cars leaning against the light post. Recognizing that family support can help manage the stress can sometimes pull people through if they're feeling down, or at least give them a better quality of life in whatever short life they have left.

Other traditions may be seen as a disruption, even if visitation rules are not violated. Jessie's family was successful in bringing some symbolic resources into the hospital context, as discussed earlier regarding food and music. Though that hospital did not interfere with the family's gathering or songs, not all facilities are so welcoming, despite potential benefits to patient and loved ones. The family visit, the familiar foods, and the music may not have repaired the grandfather's failing body, but they restored the man's spirit as his passage approached.

Jessie V. (personal communication, 10/26/2023): He was trying to be positive where he knew he had a terminal issue, but he was like 'I can't wait to go back to Mexico again.' And I think he was just dreaming of the future to try to be positive to just feel normal and feel happy in the moment.

Patient-centered communication (PCC)

Communication in EoL and critical care becomes more arduous. For best patient satisfaction, emotional adjustment, and health outcomes, research trends point to patient empowerment using systems like Patient-Centered Communication (PCC) that are individualized and responsive to the particular patient's needs (Albari & Woodward-Kron, 2020). PCC acknowledges "the whole person, their personality, life history, and social structure in order to develop a shared understanding of the problem, the goals of treatment, and the barriers to that treatment and wellness" (Naughton, 2018, p. 18). Hashim (2017) lists basic skills for PCC, including "exploring the patient's feelings, ideas, concerns, and experience regarding the impact of the illness, as well as what the patient expects from the physician" (p. 18).

Albari and Woodward-Kron (2020) interviewed Ukrainian doctors about their experiences of PCC in intercultural experiences in English-speaking clinics. The doctors acknowledged the importance of information functions of medical communication and used traditional methods of gathering information. They had limited responses to emotion and difficulty with treatment-related behaviors interacting with Western patients. Regarding emotional response, they express that it is not part of their medical training. Primary obstacles included high hierarchic distance from patients, insufficient staffing, negative perception of doctors in Ukraine, and a lack of training in PCC. These issues are not unlike issues in US healthcare.

Barriers to Patient-Centered Communication arise on institutional, cultural, and contextual levels. Institutionally, administrators are concerned about maximizing patient panels, with a downstream effect of providers feeling time pressure. Culturally and ontologically, providers tend justifiably to think in terms of data and evidence-based practice, concerned about providing proven treatments, but also pressured by insurance to justify treatments, leading providers to think and speak in terminologies unfamiliar to patients. To the patients, this is a foreign language and alien way of thinking. Further, a clinical setting is just that: clinical. People open up less in uncomfortable environments.

Solutions come from the field of communication: allow patients time to articulate their symptoms and concerns, listen respectfully, be mindful of body language, avoid jargon and keep terminology simple without condescending. Informal communication, including chit-chat and humor on an egalitarian basis, may be more effective than previous modes of hierarchic, formal communication. As Sharita discussed regarding her experiences of intercultural PCC with patients from the Marshall Islands, it was primarily by listening with sensitivity and watching for subtle non-verbal communication that she could treat her Marshallese patients effectively.

Doctrine of double effect: situations where good intention may make an act morally justifiable even when it entails risk of harm