Decision-Making Across Cultures

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7.1 Introduction: Cultural Competency, Cultural Humility, and Structural Competency

Medicine has seen a paradigm shift in its conceptualization of "culture" over recent decades. Whereas at one time culture was narrowly understood in terms of difference from some supposed norm, there is now widespread recognition that all patients are shaped by diverse cultural identities and that cultural factors are central to how every person experiences serious illness and decision-making. One outcome of this paradigm shift is that healthcare providers are now trained in "cultural competency" alongside traditional clinical competencies (see Chap. 2). In part because of the emphasis on whole-person care in palliative medicine, there is a rich scholarly literature on the role of culture in the care of seriously ill patients (see Chap. 3).

Sometimes, education in cultural competency inadvertently reinforces the very problem it is trying to address. Articles or book chapters may try to teach cultural competency by listing broad stereotypes about entire populations. This is not that kind of chapter. Such an approach is built on several erroneous assumptions: that cultures are homogeneous, that they are deviations from some cultureless norm (white people are seldom essentialized in these lists), and that there is a formulaic method for becoming "competent" in understanding them.

For these reasons, scholars have advanced alternative models for understanding the intersections of culture, illness, and health care. On the level of the clinician-patient encounter, the model of "cultural humility" is especially important [1]. Cultural humility is a process rather than an endpoint. It calls for the provider to examine his or her own cultural identity and associated biases, and how these affect his or her interactions with patients of different cultural identities. Because every clinician also belongs to a professional culture, some degree of cultural distance between clinician and patient always exists. Because of the power dynamic inherent in the clinical encounter, cultural differences can contribute to health care disparities due to unequal treatment through bias, stereotyping, and prejudice.

On the other hand, and on a more optimistic note, appropriate attentiveness to cultural dynamics in the care of seriously ill patients can help mitigate or redress broader societal patterns of injustice and racism. This can only happen if the clinician is equipped with the evidence-based communication skills to curiously and humbly elicit the values of each patient [2] and a commitment to advocate for those values to achieve goal-concordant care.

It is also crucial to broaden the focus from the individual patient encounter and to consider the dominant social and political forces, such as racism, that shape patients' trajectories of health and illness as well as their experience of health care. "Structural competency" is a field of study and pedagogy that has been developed to enable clinicians and clinical trainees to do exactly this. Structural competency includes a critical analysis of how attitudes or health conditions that are typically attributed to cultural differences or individual choices may be better understood as the downstream manifestations of societal ("structural") inequalities [3].

In the first section of this chapter, we adopt a framework of cultural humility for discussing the values that inform decision-making in serious illness. On the one hand, values are individual and dynamic: each patient has her own values, and they shift over time and across contexts. On the other hand, culture informs values: a patient forms her values through a process of negotiation between her individuality and her cultural, political, and social situatedness.

In the second section of this chapter, we adopt a structural competency lens. We review the scholarly literature to address one of the fraught questions in the area of culture and end-of-life care. The statistics are clear: racial and ethnic minorities, including but not only African Americans and Latinxs, receive fewer palliative care interventions and undergo more aggressive treatments at the end of life than white people. Should this be considered a health care disparity, and, if so, what are the barriers to equity? Or, is this pattern consistent with the values of specific racial and cultural groups? Is it therefore an expression of implicit bias and discrimination when clinicians exert pressure on dying patients and their families to go down the path of palliative rather than life-prolonging care?

In the third section of this chapter, we present two patient cases that illustrate the complex range of issues in culture and decision-making. Through the analysis of these two cases, we offer a set of practical communication strategies for achieving value-based, goal-concordant care.

7.2   Themes in Serious Illness Communication

7.2.1   Defining Culture

If there is one certainty in this world, it is that every person dies. Yet experiences at the end of life vary dramatically based on factors that include the culture of the patient (which is the focus of the present section) and how the patient's culture interacts with the culture of providers and the culture of medicine (which we will address in the following section).

For the purposes of this chapter, we define culture (following [4]) as a dynamic framework of identity that evolves and adapts through historical, political, and social forces. Cultural groups create systems of beliefs, values, and opportunities and often provide members a sense of safety and of meaning within their particular social, biologic, physical, and political niche. Different cultural groups have different levels of power and privilege, and this can also affect decision-making, especially during serious illness and end of life.

Before entering into cultural differences, it is worth emphasizing priorities at the end of life that tend to be shared across all cultural groups [5]. These include comfort and not being in pain; good communication between patient and doctors; maintaining hope; honoring spiritual beliefs; fixing relationships; making plans; and saying goodbye. These human values, however, are also colored by a wide array of inter- and intra-cultural variations.

Table 7.1 Addressing mnemonic for elements of culture (based on [6])

- Age and cohort effects
- Degree of physical ability
- Degree of cognitive ability
- Religion
- Ethnicity and race
- Socioeconomic status
- Sexual orientation and gender identity
- Individualistic life experiences (such as trauma or level of acculturation)
- National origin
- Gender role expectations

No overarching label for a cultural group will ever capture the diversity of experiences and viewpoints represented within that group. Consider the identity "Asian American." This term encompasses numerous religious affiliations, including Hindu, Muslim, Christian, Buddhist, and Sikh, to name only a few. Every subgroup of Asian Americans has its own unique story and experience. For example, think of acculturated 4th- or 5th-generation Japanese Americans versus members of groups that immigrated to the United States after 1965, such as populations who were part of the brain drain as in healthcare (e.g., immigrants from India and the Philippines) or refugees from war and American foreign policy (e.g., Hmong migrants from Laos and subsets of Vietnamese immigrants). Similar analyses can be done for practically any conventional cultural label in the United States. Thus there is no such thing as a homogeneous Asian American (or, say, African American or Latinx or Jewish) approach to end-of-life decision-making. Culture *informs* decision-making but does not *determine* it.

We often think of culture as being primarily defined by race and ethnicity, national origin, or religion. But there are many additional axes of culture that also inform decision-making, for example, gender identity, gender roles in society, and sexual orientation. One framework for "addressing" the heterogeneity of culture is the ADDRESSING mnemonic (Table 7.1) [6]. This mnemonic can help clinicians attend to the many complexities of inter- and intra-group differences. It also reinforces the importance of cultural humility. Only the patient can tell you which sets of identities are most salient for him or her, and in what ways.

7.2.2   Cultural Values That Inform Decision-Making

But what are the specific ways in which specific cultural identities inform decision-making at the end of life? There are a number of recent review articles which address this question, presenting a gamut of cultural identities and suggesting general patterns of decision-making that clinicians tend to encounter in patients of

different subgroups [4, 7]. However, because there is no one-to-one correspondence between cultural identity and decision-making style, here we will highlight the patterns of decision-making themselves. These are some of the main questions and possibilities to assess with each individual patient and family.

First: who makes the medical decisions? In western bioethics and legal systems, if a patient has mental capacity and legal competence to make medical decisions, that is their unassailable right. Yet patients of different cultures choose to involve family or community in their decision-making to a lesser or greater extent. Some patients wish to delegate some control over decision-making to others, be it a member of their family, their community, or their physicians. It is widely assumed in the scholarly literature that non-white racial and ethnic groups more often outsource their decision-making in this way. However, note that at least one well-designed study found no association between race and such "decision control preferences" [8]. In that study, older age was the sole demographic variable associated with the attitude of "Doctor, make my decisions." Indeed, in the same study, the large majority (82%) of participants across all demographic groups preferred an approach of shared decision-making.

Second: how much information should be disclosed to the patient? Once again, western bioethics and legal systems have one clear approach: it is the patient's right to know everything. Yet some patients will prefer *not* to know all of their diagnostic and prognostic information, and that is also their right. In some communities, there is a belief that bad news or discussing death will hasten death (e.g., see [9]). It has been hypothesized that orientation toward time in a given culture may affect openness to discussing advance directives [10].

Third: what are the health disparities and culturally-associated barriers to care? How can they be addressed? These are too numerous to list here. Some barriers may include the level of English proficiency, the level of comfort navigating health care bureaucracies, and explanatory models for illness and treatment that align or diverge from those endorsed by western biomedicine.

Fourth: what are the meanings ascribed to suffering, to dignity, and to death? How do these differing meanings translate into differing priorities for end-of-life treatments and trajectories? There is research to support the idea that certain cultures tend to value struggle over comfort at the end of life [11]. This tension is the basis of Sect. 7.3 of this chapter.

In sum, these domains of difference give a sense of the great heterogeneity both across and within cultures. The clinician must adopt an open and nonjudgmental approach in order to respond appropriately to the cultural nuances in the decision-making process.

A common challenge arises when the high value placed on individual rights in western medical ethics—the patient's right to know their prognosis and to make their own decisions—is misaligned with the patient's own value system. To reduce bias and stigma, we recommend incorporating standardized assessments of such preferences into the care of every patient, instead of attempting to guess when particular patients or families might have divergent perspectives. Whether it is a question of withholding versus disclosure of prognostic information, or a question

Table 7.2 Recommendations for addressing decision-making in serious illness

1. Adapt existing best practices around value-based, shared decision-making in order to mitigate bias and foster person-centered care.
   a. Resources: ACP videos (https://acpdecisions.org), Respecting Choices (https://respectingchoices.org), Vital Talk (https://vitaltalk.org).
   b. Techniques: Scripting, using in-person interpreters in settings of language non-concordance, drawing on cultural brokers within the health system or from the patient's community.
2. Clarify the different types of decision-making to the patient.
   a. Include the family members of choice to the degree that the patient desires.
3. Acknowledge mistrust and stigma in the healthcare system.
   a. Ask open-ended questions to determine whether the patient has experienced discrimination or breaches of trust from any past or current providers.
4. Evaluate, acknowledge, and make strategies to address social determinants of health and barriers to care, including but not limited to:
   a. Transportation options
   b. Insurance needs
   c. Documented vs. undocumented status

of how involved the family should be in decision-making, the clinician should endeavor to first meet privately with the patient and learn their preferences. Then, if the patient does not wish to receive prognostic information or wishes a family member to make medical decisions on their behalf, we must respect that. After all, the patient has the *right* to know and to decide, but not an obligation. Additional recommendations for practice are summarized in Table 7.2.

Lastly, when at all possible, advance care planning, including assessment of decision-making preferences should take place in the outpatient setting prior to acute crises. The long-term relationship of primary care provides the best setting for eliciting and documenting the patient's preferred approach to decision-making and to the communication of prognostic information. Any transition in care (e.g., hospital admission or discharge) should also remind the clinician to open such discussions. These conversations may have to unfold over several appointments. Due to structural constraints, such as time pressure and the low prioritization of preventive care within health care systems, advance care planning often gets postponed. As a result, complex end-of-life decisions too often have to be made when the patient has reached an advanced state of disease and may no longer be able to communicate his or her own preferences and values.

7.2.3 Trauma-Informed Care

Trauma-informed care is one orientation that providers should adopt in order to mitigate disparities and create a space of safety and support. "Trauma" is defined

Table 7.3 Five principles of trauma-informed care (based on SAMHSA [12])

1. **Safety** - Create spaces that are calm and comfortable by attending to the physical environment and to nonverbal communication.
2. **Trust** - Provide clear and honest information. Ask open-ended questions; seek to understand if medicine or society have breached the trust of this patient in the past; find out from the patient what they would want their providers to do differently.
3. **Choice** - Verbalize that the patient is the one who determines decision-making and treatment preferences; ask, "What matters to you?"; request permission to provide advice based on what you have learned about the patient's values.
4. **Collaboration** - Facilitate collaboration among your team members, the patient and family, and any wider community members the patient wishes to have involved (e.g., cultural broker, spiritual or religious advisor).
5. **Empowerment** - Notice and verbalize capabilities in an individual, with a focus on resilience); verbalize empathy (e.g., "I notice how you are coming together").

as events or circumstances that are "physically or emotionally harmful, or life-threatening, with lasting adverse effects" [12]. Histories of trauma, including adverse childhood events (ACEs), are strongly associated with future burden of physical and mental illness. Most adults in the United States have experienced at least one significant trauma in their lifetime [13]. There is increasing recognition that life-threatening illnesses and intensive medical interventions can themselves be traumatic experiences [14]. This means that past or present trauma may be an active factor in decision-making for any patient facing serious illness, and all the more so when serious illness is combined with social underprivilege.

Several evidence-based approaches to trauma-informed care have been developed. An important element in all of these approaches is the initial screening for histories of trauma, which, ideally should be done as early as possible. Universal screening reduces the risk of providers making assumptions about burdens of trauma merely because of a patient's racial or ethnic identity. One method is to have the patient complete a questionnaire, such as a cumulative ACE survey, which also grants control to the patient to decide how much detail to provide.

In Table 7.3, we present the five principles of trauma-informed care as they are relevant to the context of decision-making at the end of life.

7.2.4 Recognizing Bias and Earning Trust

Trust is the cornerstone of a successful clinical relationship with a patient facing serious illness. Yet stigma and racism are ubiquitous within society as well as within medical institutions, both historically and continuing into the present. Racial discrimination perpetuates health disparities and contributes to worse health outcomes [15, 16].

For this reason, individuals from non-dominant cultural groups often have good reason to wonder whether their providers are genuinely trustworthy. The onus must

Table 7.4 Bias in end-of-life care (based on the SEEDS model from [22])

1. Similarity/difference bias
   - a. Racial bias, implicit or explicit.
   - b. Other forms of cultural bias (see "ADDRESSING" mnemonic in Table 1).
   - c. Lavishing more attention on a patient who reminds you of a family member.
2. Expedience/confirmation bias
   - a. A lack of openness to hearing from the patient something that goes against what you expect or what you already believe.
3. Experience bias
   - a. Projecting your own assumptions about quality of life, especially for patients with disabilities (see Kripke 2017).
   - b. Assuming that you know about the individual in front of you because of past interactions with ostensibly similar patients.
   - c. Assuming that you are the expert (you should have the final say) because you are the clinician (you control access to treatments).
4. Distance bias
   - a. Giving priority to what the most vocal family member is saying in the here and now vs. what is documented about the patient's longstanding values.
5. Safety bias
   - a. Favoring choices based on risk aversion or sunk cost.
   - b. Favoring choices based on a misleading way of framing (e.g., "Should we do everything for your loved one, or should we switch to comfort care?")

be on the provider to demonstrate trustworthiness and thereby earn the patient's trust [17, 18]. This process includes a commitment to openly explore sources of mistrust, to take the sources of mistrust seriously, and, when relevant, to be prepared to change one's own behavior and to advocate for change in one's institution [19].

As several scholars have recently emphasized, prejudice, implicit bias, and racism are universal human traits [20, 21]. The challenge for clinicians is to recognize the forms that these take—both on the individual and the institutional level—and to take active measures to mitigate their impact. Table 7.4 presents some of the most common manifestations and pitfalls of bias as relevant to end-of-life care.

7.3 Differences in Utilization of Palliative Care: Health Disparities or Differences in Values?

Clinicians work within broader systems of care and disciplines, and institutional cultures affect the behavior of every clinician. This may be especially true in end-of-life care, as demonstrated in one qualitative study of palliative care providers' perceptions of their biases. One attending physician expressed, "I do have a personal bias that, I think, because I chose palliative care, I believe in comfort care

and allowing a natural death, and I really don't agree with a lot of intervention at the end of life" [23].

In contemporary end-of-life care, the high emphasis placed on palliative care measures, including hospice and even advance care planning, is a reflection of western ethical principles that are not universally shared [7]. These principles include patient autonomy, self-determination, truth telling, and an individualistic conception of dignity.

Patients of diverse cultural backgrounds have a wide spectrum of values concerning end-of-life care. Often, these values may be challenging to medical providers, who bring their own strong views about appropriate courses of action, informed by culture, by professional training, and by institutional constraints. Whereas in the mid-twentieth century, physicians tended to pressure patients to undergo heroic measures, the situation in the twenty-first century is the opposite: clinicians often pressure patients to accept that they are dying and to accept palliative rather than life-prolonging measures [24]. The patients who are resistant to such pressures disproportionately come from racial and ethnic minorities or other groups that similarly have less power and social capital within American society, such as people with disabilities [25, 26].

There are clear statistical trends in how the results of end-of-life decision-making differ across racial and ethnic groups in the United States. One indicator is Medicare hospice utilization. The Centers for Medicare and Medicaid Services compile data on the use of hospice by white people, African Americans, Hispanics, Asians and Pacific Islanders, and Native Americans. Of these groups, white people are the only ones who are overrepresented in hospice compared to their share in the Medicare population. All of the other groups receive hospice treatment at a rate much lower than their share of the population [27]. Numerous studies have found similar results for whites' and non-whites' engagement with palliative care in general, including advance care planning and the use of DNR or POLST orders [28].

These data do not speak for themselves. How should racial and other demographic differences in end-of-life trajectories be understood? Should the high usage of aggressive medical interventions at the end of life among African Americans (say) be considered a health care disparity, like the countless racial disparities in every domain of health care, from pregnancy to heart failure to chronic pain? Or should this phenomenon be regarded as a positive outcome? One could hypothesize that it is congruent with prevalent cultural values held by many African Americans, such as deep religious faith and a commitment to the struggle for rights—not to mention the struggle for life itself in a hostile society.

Some researchers have tried to answer these questions empirically. Kelley et al. [29, 30] offer evidence that the low use of hospice and the high use of end-of-life intensive interventions among Latinxs in the Los Angeles area should in fact be regarded as a disparity. In this study of 147 older Latinxs in the community, 84% of participants expressed that if they were seriously ill, they would prefer medical care focused on comfort rather than care focused on extending life. However, nearly half (47%) had never discussed this preference either with their family or

with their physician, and over three-quarters (77%) had not completed an advance directive. Thus, there was a high risk that these individuals' wishes for their care would not be honored.

Another study similarly suggests that high rates of aggressive interventions and low rates of palliative care among African Americans and Latinx patients should be considered a health care disparity. Specifically, an analysis of all hospital discharges across 5 states in the year 1999 found that racial differences in terminal ICU use were largely accounted for by between-hospital factors (African Americans and Latinx patients were more often treated in hospitals that had a higher rate of ICU use overall) rather than within-hospital racial variation [31]. This study, however, did not address patient-level differences in preferences for treatment.

If 18% of African Americans and 15% of Latinxs would prefer to die in the hospital rather than forego any life-prolonging intervention, these percentages may seem small. But they are large in comparison with the 8% of white Americans who endorse the same preference, and there must be underlying reasons that explain such a large gap [32]. Yet there is a common assumption in clinical practice that dying patients who want "everything to be done" must be inadequately informed. These patients sometimes receive dismissive labels: they are "in denial," or they are "vitalists." After all, if death in hospice is self-evidently better than death in intensive care, as many clinicians believe, and if one feels that CPR with minimal chance of success is akin to torture, what well-informed patient would choose torture over comfort?

A related—and less condescending—hypothesis frames the question not as one of an intrinsic deficiency but rather as one of inadequate access to palliative care information and services [33, 34]. This view presumes that patients with access to palliative care will often change their minds about preexisting wishes for intensive treatment. There must be something to this hypothesis, because palliative care providers see this happen all the time.

Cultural competency requires clinicians to seek to understand the different viewpoints of different cultures around end-of-life experiences. But a clinician can understand others' views very well and still insist on imposing his or her own view on the patient.

Cultural humility and structural competency call for greater respect for patients' viewpoints. These frameworks lead us to challenge the widespread assumption that African Americans, Latinxs, and others ought to be persuaded to see eye-to-eye with white Americans—and the culture of medicine itself—on the value of palliative care. Hauschildt [25] relates the story of a critical care resident who reluctantly placed a central line (a large-bore IV that enters via the neck) for a patient who insisted on receiving any intervention that could extend his life, even if only by a day or two. At every step, the physician challenged the patient, "Are you sure?" This anecdote is a microcosm of the trend in medicine and scholarship to refuse to accept that a rational dying person might perfectly understand the difference between a comfortable death at home and a painful death in the ICU and still opt for the latter.

There are relatively few studies that seek to identify the underlying reasons for why members of particular cultural groups might wish to receive more aggressive care at the end of life more often that members of other cultural groups. Perhaps the best-studied group in this regard is African Americans. Johnson (2008) identified a complex of four traits as accounting for the differences in utilization of palliative care between African Americans and whites, namely: a desire not to discuss death, a desire for aggressive care at the end of life, spiritual beliefs which conflict with the goals of palliative care, and a perception that the medical system is not worthy of trust. (Mistrust, it has to be emphasized, is not an innate characteristic of African Americans. It is a product of the reality that the medical system has *breached* trust, both historically and in the present.) More recently, Sanders et al. [35] has suggested that the literature on advance care planning among African Americans may not accurately reflect the realities of individual experience. In particular, clinicians should not think of factors such as religion and spirituality as "barriers" to end-of-life care but rather as assets or sources of strength.

Let's return to the fraught question with which we opened this section. When racial and ethnic minorities in the United States confront serious illness and the end of life, on average, they receive more aggressive medical interventions and less palliative care. Is this a cultural difference or a health care disparity? The answer has to be "Both."

The sociological scholarship and the statistics paint a picture of non-alignment between clinicians and patients, especially non-white patients, in terms of the value placed on aggressive treatment versus palliative treatment at the end of life. The most common scenario in which patients receive care that is not goal-concordant is when patients—often non-white—desire more aggressive interventions than their clinicians are willing to provide.

We propose that clinical strategies can help avert this kind of clash between patients and clinicians, which results in the non-alignment of values with treatment. For example, in order to address patients' underlying fear that palliative care is equivalent to giving up, clinicians can acknowledge that fear and find ways to address its root cause. The answer is not necessarily to provide aggressive interventions merely because requested. Nevertheless, in many instances, a true commitment to value-based and goal-concordant care will require clinicians to respect and to follow the end-of-life wishes of patients even when those wishes run against the ethical system of the clinician or even the culture of the health system in which one works.

7.4 Value-Based, Goal-Concordant Care: Cases and Strategies

In this final section, we present two cases that illustrate the abstract themes discussed so far. We emphasize that any clinician, not just those in palliative care, can and should learn an approach to shared decision-making that is informed by cultural humility and structural competency.

Communication in serious illness and end-of-life care should be regarded as a procedure that improves with practice and a standardized, patient-centered approach. Studies show that patients wish to speak with clinicians frankly, to receive as much information as possible, and to feel that they have been heard as people rather than patients. Yet clinicians use medical jargon, fail to recognize that the patient or family is not following, miss cues that patients are experiencing emotions that affect information absorption, or block patient questions and concerns. The result is divergence in illness understanding between what physicians believe they have communicated and what patients believe they have heard [2, 36].

There are numerous evidence-based approaches to communicating with patients with serious illness in order to achieve goal-concordant care. In this section, we will refer to the SUPER3 model (acronym adapted from the framework proposed in [37], which was created by the Clinician Patient Communication and Life Care Planning group of the Southern California Permanente Medical Group (Table 7.5).

7.4.1 Case 1: A Decision Imposed on a Patient

Even when culturally sensitive shared decision-making occurs in an ideal manner, the results of decision-making have to be acted upon. The case summarized here is one of the institutional values ultimately overriding the values that had been elicited and documented from a dying patient.

Alang Tsaab was a 20 year-old Hmong man with primary mediastinal lymphoma. Even as his cancer progressed, he held on to hope that he would recover and even return to college and basketball. He ultimately enrolled in a clinical trial, but his symptoms eventually required hospitalization, and his providers knew this was likely to be a terminal hospitalization.

A series of goals-of-care family meetings proved frustrating to the clinicians caring for Alang. Both Alang and his mother Kaj, his designated decision-maker, were consistently adamant that he wished to remain full code; that they were not going to despair of recovery; and that the physicians should "not give up" and should do everything possible to "fix the cancer."

Hospitals have their own culture and values, and Alang's hospital prided itself in valuing patient autonomy, truth-telling to the patient about prognostic information, the documentation of goals via advance directives or POLST forms (Physician's Orders for Life-Sustaining Treatment), and a preference for DNR (Do Not Resuscitate) status in cases of advanced disease.

In this case, the hospital's preference for DNR status in advanced disease came into conflict with the hospital's other values. Most of the teams caring for Alang were convinced that he should opt for palliative rather than life-prolonging measures and go home with hospice. Notably, one of the consulting teams disagreed: the palliative care team, which had built a trusting relationship with Alang and his mother over several weeks. They recommended the continuation of life-prolonging treatments in accordance with the patient's clearly stated values.

Table 7.5 Sample scripting using the SUPER3 model

1. **Setup**
   a. Assess decision makers, awareness of clinical circumstance, evaluation of family:
      i. "Who is someone you trust to make decisions for you if you are very sick?"
      ii. "I'd like to talk about some decisions that people with your health conditions often face—is that OK?"
      iii. "How are healthcare decisions made in your family or support system?"
   b. Ensure shared understanding of the decision-maker role:
      i. A person who knows your values, wishes, and what is important to you.
      ii. A person who agrees to be your decision-maker.
      iii. A person who is able to make decisions in difficult situations
      iv. A person who agrees to follow your wishes even if different from their own

2. **Understanding**
   a. Assess patient's or decision-maker's understanding of the situation and address gaps:
      i. "What do you understand about his/her illness?"
      ii. "What have the doctors told you about that?"
      iii. "Do you feel that you have a good understanding of what to expect over time?"

3. **Past experiences**
   a. Assess prior hospitalizations, prior treatments, and context and experience with the condition (e.g., family members who went through a similar illness):
      i. "Do you know anyone else with this condition?"
      ii. "What did you learn from your last treatment? Last hospital stay?"
      iii. "Have you had experiences with family members who were very sick? Family members who were in the ICU? Who were on life support?"

4. **Elicit values**
   a. Assess personal goals, spiritual/religious affiliation, other cultural influences:
      i. "What abilities matter so much to you that you can't imagine living without them?"
      ii. What do you look forward to each day?"
      iii. "What does quality of life (living well) mean for you?"
      iv. "Do you have spiritual or religious beliefs that might inform your medical decisions?"

5. **Review/Recommend/Record (R3)**
   a. **Review** - recap the discussion to ensure agreement. You may need to provide additional information to bridge any misunderstanding.
      i. "It sounds like…"
      ii. "What I heard was…"
   b. **Recommend** - seek to align patient's goals and values with the treatment options being offered, asking permission to provide your own clinical recommendation:
      i. "Based on what we know about your health condition, and what I heard you say is important, I have some recommendations. Would that be OK?"
      ii. *If* the patient's values lead you to recommend DNR status:
         1. "I recommend a natural dying process. We'll make sure to prioritize your comfort and support your children. In medical language, this is a DNR order."
         2. "I wish intubation and tube feeding would cure the underlying _____."
      iii. "If you were to receive _____ what would you expect?"
      iv. "What concerns, if any, do you have about making this decision?"
   c. **Record** - make note of the information you have learned in the discussion somewhere it will be easily accessible later on. Especially document any changes in the course of treatment or code status

6. **Repeat** as many times as necessary, as the disease and the situation evolve.

Alang's respiratory status deteriorated, and he was transferred to the ICU and intubated. At the next family meeting, the primary physicians were still more adamant that Alang was dying despite anything that medicine could do for him, and they strongly recommended switching to DNR status and allowing Alang a natural death. For her part, Kaj remained calm and stood firm with the previous decisions. She expressed an understanding of the situation and what full code status would entail but expressed also that the family's religious faith was a source of tranquility and hope. She had no doubt that Alang would have wished to remain full code.

Yet, to the ICU providers who were caring for Alang and who would be the ones to attempt resuscitation, Kaj's decision seemed futile, even cruel and pointless. The same evening, they called for an urgent consultation with the hospital ethics committee. The ethics committee heard the arguments of the ICU providers to transition to comfort care and the arguments of Kaj to continue life-prolonging treatment. (The palliative care team had not been called.) Kaj later described this as a traumatic event, as she had to attempt to justify the values of her son without any support. The ethics committee ruled that Alang should be made DNR, informing Kaj that this was in Alang's best interest, that it was consistent with the ethical principle of "do no harm," and that they were merely following the hospital's policy of not providing "futile care."

Alang's heart stopped the following morning. Due to the decision of the ethics committee, he did not receive resuscitation, and he was pronounced dead in his ICU room.

7.4.1.1 Analysis of Case 1

Kaj later expressed to the palliative care social worker that this experience had tainted the family's views of health care in the United States, but that it was not inconsistent with her previous experiences of racial discrimination. She continues to ask why the hospital constantly insisted on knowing the patient's wishes if those wishes would ultimately be overridden.

In this case, there was a fragmentation of communication and of trust. The palliative care team had built a relationship of trust with Alang and Kaj, eliciting their values—cultural and religious and otherwise—and making recommendations consistent with those values. But other providers did not see eye-to-eye, and some even felt that the palliative care team had "too much empathy" to see matters clearly. In the end, the hospital ethics committee had the last word in an urgent session that was not about understanding the individuality of the patient but about focusing on the impersonal medical facts of the case and upholding the institutional values and policies.

7.4.2 Case 2: Serially Restaged and Dynamic Shared Decision-Making

What is the best course of action when a patient, informed by their cultural values, opts for a course of treatment that is felt to be unreasonable by medical providers? This, after all, is one of the way of interpreting the previous case. The ICU providers and the ethics committee may have felt that they were making a difficult but necessary decision. This is also the theme of Case 2, but the ending is different.

Chana Feld was a 95 year-old Holocaust survivor. She had several chronic diseases, including moderate dementia, but was still able to ambulate, feed herself, and enjoy time with her sons and her grandchildren. She contracted Covid-19 in late 2020 and survived the acute respiratory illness but developed encephalopathy, delirium, and dysphagia (difficulty eating).

To illustrate the technical nature of the family meeting as a communication procedure, and the sequential, dynamic nature of shared decision-making, we present three-time points in the course of Ms. Feld's experience of serious illness and medical treatment.

7.4.2.1 1st Family Meeting

The first meeting was brief. The hospital physicians tried to convey the severity of Ms. Feld's Covid-19 symptoms combined with her preexisting dementia. The family, however, resisted the medical recommendation for DNR status with no intubation. They said that withholding curative measures would be inconsistent with Ms. Feld's Jewish faith and longstanding values as a Holocaust survivor and refugee who rebuilt her life and family in a new country.

7.4.2.2 2nd Family Meeting

The family members opened the second meeting with their frustration that the initial team recommendations were so demoralizing. They felt that the clinicians had been making biased recommendations due to their assumptions about Ms. Feld's dementia and quality of life.

The clinicians heard this as important feedback and recognized that they had indeed made assumptions and allowed biases to dictate their approach in the previous family meeting.

They adopted the SUPER3 model to structure the conversation.

Setup (S)

This was largely accomplished in the previous meeting. It was established that Ms. Feld did not have decision-making capacity and that the family members would reach decisions through consensus, based on their understanding of what Ms. Feld would want for herself.

Understanding (U)

The clinicians learned that the family members had excellent understanding of the medical and ethical details of the case and were able to recount them.

Past Experiences (P)

Ms. Feld's prior hospitalizations were 2 years ago and 10 years ago. She received 24/7 help from caregivers at home for safety. In the course of the meeting, the son mentioned that his father had received a long-term tracheostomy and lived at a Long-Term Acute Care (LTAC) facility for the last years of his life. The family members felt that he had suffered unduly.

Eliciting Values (E)

The family was encouraged to share information about who Ms. Feld was as a person before this acute worsening of her illness, as well as information about her baseline physical and cognitive level of function. Her caregiver of 8 years, Kim, was also present and able to share information about Ms. Feld. The family and Kim described Ms. Feld ("Bubbe") as a matriarch, a person defined by resilience, "feisty," and opinionated. They emphasized that she was a survivor of unimaginable trauma as a girl and, later in life, had survived several episodes of illness that had also seemed hopeless at the time. Before this hospitalization, she had been looking forward to spending time with her grandchildren after Covid-19. She had run multiple businesses together with her husband, most recently a restaurant. She loved watching TV of all kinds and listening to music, especially her favorite song, "Que Sera Sera."

Recommendation (R1)

The physician leading the meeting: "Based on what I have been hearing from you about Ms. Feld's quality of life before the Covid-19 infection and the hopes that her cognition will improve and that she will be able to appreciate and listen to music like 'Que Sera Sera'—we would like to make some recommendations. Is that OK?"

The recommendation was framed in terms of the patient's underlying values. Ms. Feld might very well return to her previous baseline, but neither CPR nor mechanical ventilation could reverse the underlying conditions causing her health to deteriorate.

The family agreed not to pursue resuscitation or ventilation, but, citing their Jewish faith, they thought Ms. Feld should continue to receive food however possible. Given the medical circumstances, the only option for nutrition was via a nasogastric (NG) tube.

Review (R2) and Record (R3)

The decision was reviewed and recorded (with a POLST) that Ms. Feld would have DNR/DNI (Do Not Resuscitate/Do Not Intubate) status and receive a trial of nutrition through an NG tube. It was also established that these conversations

would be continued. Ms. Feld returned home and had some improvement in her delirium.

7.4.2.3 3rd Family Meeting

One month later, Ms. Feld was readmitted to the hospital with acute shortness of breath, stridor, and vocal cord paralysis. This meant that she needed urgent respiratory support, which would be difficult in light of her NG tube feedings. The family members had already spoken with an ENT surgeon, and they believed that the best way forward would be tracheostomy and cordectomy.

The hospitalist physicians were alarmed by this suggestion and immediately mentioned that this would likely be a case for the ethics committee to decide. But the providers who had cared for Ms. Feld during the previous hospitalization were present at the time, and they urged further exploration before resorting to bureaucratic or antagonistic procedures.

At this family meeting, in addition to the medical teams and the assembled family, the family had invited Ms. Feld's trusted rabbi—Rabbi Levi—to be present, as the religious framework was an important element in their decision-making. The SUPER3 process was reinitiated.

Rabbi Levi explained to all present that Jewish law dictated certain approaches. Namely, that the patient's preferences should be respected, that heroic measures were not mandatory if they were to cause more suffering than benefit, and that the basics of human life (nutrition, hydration, oxygenation) should be pursued as long as this did not cause undue suffering. Furthermore, it was permissible to discontinue life-sustaining interventions (like tube feeding) as long as that withdrawal did not directly cause death within a certain time frame.

The clinicians reflected back to the family that they understood that the Jewish faith was guiding the decision-making process and that any decision to withdraw treatment was very difficult. They recommended, based on the information from the family and rabbi, that the goal should be to "continue providing basic necessities" (within the framework of Jewish values they had just learned about), not to hasten death, and to support the body and minimize suffering. Respiratory support (with a BIPAP machine) and IV fluids would be important; but NG tube feedings and any kind of surgery would be inconsistent with Ms. Feld's values.

The family wholeheartedly agreed with the summary and recommendations. Ms. Feld was discharged home on hospice, with BIPAP as needed and medications to treat her symptoms.

7.4.2.4 Analysis of Case 2

This case illustrates the nuances and importance of viewing communication like a procedure. Ms. Feld benefited from a continuity of providers, who were able to intervene during her final hospitalization when her new physicians (who did not know her) thought this would become an "ethics committee case." The providers who had gotten to know Ms. Feld through the multiple family meetings were able to adopt a lens of trauma-informed care and understand how her experience as

a Holocaust survivor and her resilience were informing the interventions that she and her family wished.

Importantly, the providers did not reach a place of trust with this family right away. They initially made a serious misstep early on, when they made assumptions about Ms. Feld's quality of life based simply on the fact that her medical record included "moderate dementia." Through recognizing this bias, verbalizing that they had been wrong, and pursuing open discussions with the family decision-makers, the providers earned the trust of the family members. Still more importantly, the same providers were present at the crucial moment so they could advocate for Ms. Feld's values to be upheld—unlike what happened in Case 1.

To conclude, this case also illustrates how one might respond to a family request thought to be "unrealistic": the tracheostomy and cordectomy. One option is to assume an antagonistic stance and argue with the family about each specific intervention. However, bringing the case to the ethics committee would probably have alienated this family, damaged the trust that was built over time, and potentially compounded their grief. Instead, the matter was readily resolved through another round of staged shared decision-making. As the family had identified the Jewish religion as a key determinant of their decision-making, and none of the care team members had direct experience with Judaism, the presence of Rabbi Levi at the last family meeting as a cultural broker was essential for clarifying and validating the decisions made by the family.

We conclude this chapter here, presenting the following graphics by way of summarizing the clinical strategies we have presented for achieving value-based, goal-concordant care for patients with serious illness across the spectrum of cultural identities (Figs. 7.1 and 7.2).
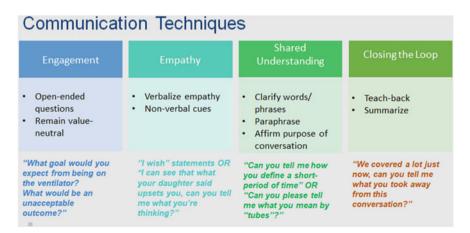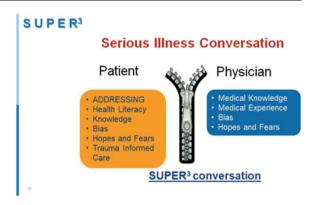

Fig. 7.1 General communication techniques in value-based shared decision-making. Original content developed by SCPMG (Southern California Permanente Medical Group) Life Care Planning and Clinician Patient Communication

Fig. 7.2 Aligning patient and physician values (SUPER3). Original content developed by SCPMG (Southern California Permanente Medical Group) Life Care Planning

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