REVIEW

Cultural humility and end-of-life communication with people with advanced liver disease

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INTRODUCTION

Liver disease is a leading cause of death in the United States (U.S.), and there are racial/ethnic disparities in end-of-life care outcomes for this population. Structured communication approaches can provide guidance for clinicians conducting conversations around end-of-life care; such discussions should be approached without assumptions about values, preferences, and family structures. The purpose of this article is to outline patterns in end-of-life care experienced by people facing advanced liver disease, and to discuss approaches to cultural humility and serious illness communication with this population.

ARE THERE DIFFERENCES IN END-OF-LIFE CARE RECEIVED BY PEOPLE WITH ADVANCED LIVER DISEASE BASED ON RACE/ETHNICITY?

Liver disease is the 11th leading cause of death among U.S. adults overall, but is the 4th and 7th leading cause of deaths among American Indian/Alaska Native and Hispanic individuals, respectively.[1] Black, Asian, American Indian/Alaska Native, and Hispanic patients with advanced liver disease also have significantly lower odds of dying at home, or with hospice or specialty palliative care compared to White patients.[2,3] It is unclear whether these findings reflect disparities in health-care delivery, access, and communication; differences in care; or communication preferences among different groups, or a combination of factors.[4]

WHAT IS CULTURAL HUMILITY AND HOW CAN IT BE APPLIED TO END-OF-LIFE COMMUNICATION?

Culture represents the beliefs, behaviors, practices, and core values of racial, ethnic, religious, social, or other affinity groups that shape how individuals "see" the world.[5] Culture can inform individuals' health beliefs and practices, including preferences for care and how health information is transmitted, their definition of family, meaning of illness and suffering, and medical

decision-making, especially at end-of-life. Not being at-tuned to the impact of culture on our patients' health beliefs and practices may lead to illness and prognostic misunderstanding, late advance care planning, receipt of care that is not concordant with goals and values, emotional and spiritual distress, medical mistrust, and may worsen health inequities.[5]

Deliberate communication practices may be a strategy to help clinicians avoid bias in the context of end-of-life care.[5] First, it is important to remember that patients may make end-of-life decisions differently than those we would make for ourselves. Asserting our value system over those of the patient and family is a form of cultural paternalism that can cause emotional distress at the end of life.[6] Second, due to intersectional identities and lived experiences, it is important to remember that significant variations exist both within and between racial/ethnic groups. Providers must avoid cultural stereotyping or oversimplifying a patient's culture based on their own beliefs about different groups.[6]

Herein, we present two cases (Tables 1 and 2) that highlight the role of culture in end-of-life care and discuss communication practices (Table 3) that may help providers curtail their bias and maintain cultural humility as they engage in end-of-life conversations.[5,6]

HOW CAN A CLINICIAN APPROACH CONFLICT AROUND PATIENT AUTONOMY AND SURROGACY?

In Case 1, the patient's daughter informs the team that all information should be discussed with her first. This is challenging because the medical team must balance respect for patient autonomy, familial structure, and laws about how health-care information is shared and decisions are made.

There are many ways a patient might receive support or define their family. Biological family may differ from legal family (as defined by marriage or adoption), which both may differ from those defined by the patient as (sometimes called) chosen family, particularly among LGBTQ+ people. The informal caregiver who attends medical visits with a patient may be different from the patient's designated health-care agent for decision-making. Clinicians can inquire about these individuals by asking questions such as "Who is your family? Who provides support to you? Have you ever named a health-care proxy?" For complex cases, local resources may include social work, legal, and palliative care teams. Patients should routinely have the opportunity to identify a health-care agent/proxy before losing capacity to do so (e.g., becoming encephalopathic or critically ill); in the U.S. laws about surrogate hierarchy absent a designated health-care proxy may differ between states or territories or between federal and private facilities.

TABLE 1   Case 1

- For the past 2 years you have cared for a 62-year-old non-English speaking woman with decompensated HCV cirrhosis. She is usually accompanied by her daughter who provides interpretation during these appointments, but today she presents to clinic alone.

- She just completed her routine surveillance imaging for hepatocellular carcinoma, which showed new ascites, multiple large liver lesions, new portal vein thrombus, and a newly-elevated AFP to 7500.

- *You share these results with the patient with the assistance of a medical interpreter.*

- At the end of your clinic, *you receive a call from her daughter who is angry that this new diagnosis was shared with her mother, who is now very distressed.*

- *She tells you on the phone "from now on, all information about my mother's medical care should go through me first."*

TABLE 2   Case 2

- As the inpatient consult attending, you have been following a 72-year-old man with NASH cirrhosis and multiple medical comorbidities who was transferred to your hospital to manage an esophageal variceal bleed.

- This is his fourth hospital admission for complications of his liver disease over the past 6 months.

- After his endoscopy, he has remained intubated in the intensive care unit and is now in progressive septic shock and multiorgan system failure with a MELD-Na score of 37.

- *The critical care team is planning a family meeting, and the family asks for the hepatology team to be present to discuss his eligibility for liver transplantation.*

- Despite his grim prognosis, during the meeting, it becomes clear that the family wants "everything done," including resuscitation if needed.

- His wife states "He has always recovered each time he has been hospitalized. He will get through this just like the last time he was here. *We are not giving up hope for a miracle.*"

- When you share that he is not a transplant candidate, his wife becomes distressed and tearful and *expresses that he is being denied care because of their racial background.*

WHAT ARE BEST PRACTICES FOR ENGAGING TRAINED INTERPRETERS IN LANGUAGE-DISCORDANT ENCOUNTERS?

Case 1 highlights tensions that can occur in language-discordant encounters, particularly when sharing serious news. More than 25 million people in the United States have limited English proficiency, many of whom will have language discordance with their treating teams. Not using a trained medical interpreter leads to worse illness understanding and poor symptom management at the end-of-life.[7] Best practices in the use of a trained interpreter include using in-person or

TABLE 3 Techniques/strategies to use in clinical cases 1 and 2

Issue	Techniques/strategies to address the issue
Tension around patient autonomy and surrogacy	Elicit patient communication, informational, and decision-making preferences early (including who should be with them to receive information) and document their preferences in the medical chart to inform other health-care providers. • "Some people like to know all the details, while others prefer an overview or to have their family hear the information and then share with them. What is your preference?" Explore who the important people are in the patient's life/care so that you can include the right people in any life-changing decisions. Do not assume a particular family structure, and remember that a patient's informal/unpaid family caregiver may be different from their surrogate decision-maker (i.e., health-care proxy). • "Who should participate in discussions about your care?" • "Who helps you with your care?" • "Have you ever named a health-care proxy?" • "Who are your biggest supports?" Who can you ask for help in complicated cases? • Social work • Legal • Palliative care
Communication between language-discordant patients and physicians	Offer the use of a trained medical interpreter during clinical visits. • "We want to allow everyone to participate and understand the conversation." • "We would like for you to be able to listen and be [family role] and not have to play the role of interpreter." Pre-meet with interpreters to brief them about the planned content of a patient/family meeting, particularly when sharing serious news, to discuss interpretation approaches and clarify topics/terminology that will be discussed during the meeting. • In-person/video interpreter preferred over telephone interpreter
Mismatch in patient/family and team prognostic expectations	Ask: • Ask for the latest information that they have been told • Ask permission to proceed Tell: • Deliver news using a short, declarative statement without jargon and then stop Ask: • Explore with open-ended questions • Ask what they understand ("teach-back")
Patient/family share importance of religion/spirituality	First, try not to dismiss the important role that spirituality/religion may play for patients/families, especially at the end-of-life. *Affirm and meet the patient/family where they are* with statements like: • "We share your hopes" • "What would a miracle look like for you?" • "What are your biggest sources of strength?" Who can you ask for help? • Chaplaincy or clergy referral if available • Palliative Care • Social Work • Offer involvement of religious figures from their community
Patient/family name racism in the encounter	Ask open-ended questions like: • "It sounds like you have concerns about racism, would you like to talk more about that?" • "How can we best support you right now?" • "Is there someone we can connect you with who you trust?" Avoid terminating statements like "you will get through this" that may discourage people from bringing up their concerns. Conduct meeting with an interdisciplinary team whenever possible. Ask permission to involve others if appropriate: • Trusted members of their community • Patient advocacy • Social work and/or chaplaincy

video teleconference when possible and pre-meeting to brief the interpreter about the content.[8] If patients decline interpreter services, this presents an opportunity to discuss patient and family preferences concerning communication of health-care information. Ideally, preferences around who should receive serious news and how it is delivered are elicited prior to sharing the news.

HOW MIGHT ONE ADDRESS MISMATCH IN PROGNOSTIC EXPECTATIONS BETWEEN CLINICIANS AND PATIENTS OR FAMILIES?

Case 2 presents a mismatch between team and family expectations about prognosis. Other examples of

language that might be used in the setting of differences in prognostic understanding include clinicians labeling patients and families as having "unrealistic expectations" or as having "poor health literacy."

One tool used widely in the field of palliative care comes from VitalTalk*: "Ask-Tell-Ask" is one framework for sharing information in a conversation about serious illness.[9] The first "ask" is to inquire what the patient and/or family have been told previously, and to ask for permission before proceeding. The "tell" is the delivery: straight-forward "headline" statements that avoid medical jargon followed by silence to allow for reaction. The second "ask" refers to exploring patient or family reactions and understanding with open-ended questions. Other tools that can be used in these scenarios can be found through organizations such as VitalTalk and Serious Illness Conversation Guide (AriadneLabs.org).

HOW CAN EXPRESSIONS OF FAITH OR SPIRITUALITY BE ANSWERED?

In Case 2, the family expresses hope for a miracle. Data on the role of faith or spiritual needs of people facing advanced liver disease is sparse. Although there are no communication tools to address these issues in the context of liver disease, Cooper, et al. offer a framework to allow clinicians to remain open to patient or family expressions of faith or religious beliefs.[10] Briefly, the protocol includes affirming the belief, meeting the patient or family where they are, providing education on the role of the clinician present, and assuring that "no matter what" the individual or team will be with them.

In addition, chaplaincy and spiritual care services may be available for referral or embedded within the hospital setting. They can provide spiritual support and help address existential distress and coping and can help connect the patient or family with services to meet religious needs if desired. Some patients and families may also benefit from the support of members of their own religious community, including as part of the medical decision-making process (e.g., in a family conference for a patient in the intensive care unit).

HOW CAN CLINICIANS RESPOND WHEN PATIENTS OR FAMILIES NAME RACISM?

Finally, consider that the critically-ill patient in Case 2 is declined for liver transplantation and the family expresses concern that that he was declined because of his racial/ethnic background. One tool at the individual level to address these concerns was published by VitalTalk in 2020: they published a communication map

to guide clinicians through serious illness discussions that address racism and health inequity.[11] In this guide, the authors point out that communication alone cannot bridge inequity or structural racism in health care. The talking map addresses recognizing behavioral cues, naming and probing for experiences with racism, acknowledging harm, finding ways to try to partner, and inviting inclusion of other members of the person's community.

Ideally, clinicians will conduct serious illness conversations like this one with an interdisciplinary team (e.g., with social work and/or chaplaincy) whenever possible, and in doing so incorporate additional expertise, while being mindful that people may not feel safe elaborating on racism concerns with their providers.

HOW CAN THE ABOVE PRINCIPLES BE APPLIED TO EACH CASE?

To address the issues that arose in Case 1, clinicians might modify their practice by doing the following: (1) Consistently asking about a patient's family support system, informational preferences, and decision-making preferences early in the course of therapeutic relationship and especially prior to the delivery of any bad news; (2) Normalize the use of trained medical interpreters during language-discordant clinical visits, optimally in person or by video; and (3) Schedule time to pre-meet with medical interpreters prior to language-discordant clinical visits with patients to discuss content and delivery of serious news.

To address the issues that arose in Case 2, clinicians might modify their practice by doing the following: (1) Eliciting patients' and/or families' illness understanding with open-ended questions; (2) Affirming the role that spirituality and/or religion may play in patients' and families' illness experiences; and (3) Invite early collaboration from community members and supportive care services such as chaplaincy, social work, palliative care, and patient advocacy as needed to provide patients and families with additional support.

CONCLUSION

Although there is limited evidence supporting these communication approaches specifically among patients with liver disease, there is evidence for their use in other seriously ill populations. These strategies may help clinicians approach patients and families with openness and without assumptions about family structure or values; they are meant to foster trust and improve patient and family satisfaction. Sustained engagement at both individual and systems levels, with research that incorporates diverse voices and communities, is needed to improve the care received by

minoritized and marginalized people facing liver disease at the end-of-life.

CONFLICT OF INTEREST

V.S. consults Saol and is on the speakers' bureau of Gilead and Abbvie.

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ENDNOTE

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