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Narrative Inquiry in Bioethics, Volume 12, Number 1, Spring 2022, pp. 77-92 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2022.0018>

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Barriers to Patient Involvement in Decision-Making in Advanced Cancer Care: Culture as an Amplifier

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Conflicts of interest. The authors declare they have no conflict of interest.

Abstract. In advanced cancer care, patient preferences regarding treatment are sometimes insufficiently integrated in the decision-making process. This can be the case with patients from non-Western cultural backgrounds undergoing treatment in the US. This study aimed to understand oncology and palliative care physicians' and nurses' perceptions of factors that impact involvement in treatment decisions by patients from diverse cultural backgrounds. Seventeen participants (6 MDs, 9 RNs, and 2 NPs) were interviewed using a semi-structured guide. Interviews were analyzed using conventional content analysis. Findings revealed six barriers to patient involvement in decision-making: language, socio-economic status, educational status, gender, family attitudes, and healthcare providers' behavior and attitudes. Participants did not view culture itself as a barrier to patient involvement, but rather, noted culture-amplified barriers that occurred with patients across all cultural backgrounds. To overcome these barriers, a wider integration of cultural competence in patient care is needed.

Acknowledgements. This study was partly funded by a faculty development grant from Duquesne University.

Keywords. Decision-making, Culture, Cancer, Autonomy, Cultural Competence

Introduction

In Western healthcare ethics and clinical practice, patient autonomy is generally seen as an important ethical principle (Beauchamp & Childress, 2013). However, even when patients have decision-making capacity, they may not have the opportunity to decide about their treatment. Socio-cultural factors such as hierarchy within the family and

culture-specific beliefs surrounding health and illness may prevent patients from making such decisions independently or even from being involved in the decision-making process at all (Deem & Stokes, 2018).

Situations in which cultural factors prevent patients from deciding about their treatment may arise, for instance, with patients from South Asian

origins who are hospitalized in the United States (Perkins, 2006). South Asia is the geographical region that comprises India, Pakistan, Nepal, Bangladesh, Sri Lanka, Afghanistan, Bhutan, and the Maldives. Driven by job opportunities since the end of the Second World War, many people of South Asian origin, especially Asian Indians, have migrated to the United States (Hoeffel et al., 2012). The fact that many of them did not return to their native countries when they grew older has led to a growing population of elderly ethnic South Asians, who are often in need of advanced medical care because of their advanced age. When they enter Western healthcare systems and treatment decisions must be made, their socio-cultural customs, practices, and beliefs, such as paternalism (Chaturvedi, 2008; Yousuf et al., 2007) and the family's culturally determined unwillingness to discuss a terminal prognosis with the patient (Gielen & Kashyap, 2019), may clash with American notions regarding patient involvement in decision-making.

The influence of socio-cultural factors on patient involvement in decision-making constitutes an ethical problem as it may conflict with healthcare providers' moral convictions that mentally capable patients should be involved in decisions regarding their own treatment or, at least, have the opportunity to decide whether or not they want to delegate decision-making to someone else. This ethical problem may become acute in socio-culturally diverse settings where patients and care providers of different socio-cultural backgrounds interact. Because of the increasing diversity of the U.S. population, this issue is becoming more pertinent, particularly among the elderly. Moreover, due to shortcomings in education and scientific literature, healthcare providers may not always be sufficiently aware of relevant socio-cultural factors, especially when religious or ethnic minorities are involved. This may be particularly challenging for oncology and palliative care nurses and physicians who care for patients suffering from advanced disease, as they are responsible for the daily care of severely ill and dying patients. These patients' vulnerability may make it harder for them to voice their preferences

regarding treatment. Particular socio-cultural factors may further complicate their involvement in decision-making. Hence, these professionals will benefit tremendously from research on these factors to inform culturally competent care. In fact, the Oncology Nursing Society (ONS) in its 2019-2022 research agenda noted a "significant gap in knowledge . . . with respect to the provision of culturally sensitive palliative care" and concluded that "[g]iven the importance of acknowledging and incorporating sociocultural norms into care, additional research in this area is needed" (Von Ah et al., 2019, p. 660).

The current study aims at filling this gap in knowledge by describing oncology and palliative care physicians' and nurses' perceptions of factors that impact involvement in treatment decisions by patients of non-Western origin. "Non-Western" is interpreted as persons who are born outside North America, Europe, Australia, or New Zealand. Given the growing importance of the South-Asian population in the United States and the particular healthcare beliefs and attitudes of this group (cf. above), we are especially, but not exclusively, interested in their attitudes to ethically fraught situations involving medical decision-making in this population. The idea that grounds this study is that situations involving South Asian patients can serve as a case study of how physicians and nurses experience decision-making in cross-cultural care, and analysis of such situations can help healthcare providers better understand barriers to patient involvement in decision-making.

Methods

In order to gain insight into the socio-cultural factors that impact patient involvement in cancer care decision-making from the perspective of oncology and palliative care nurses and physicians, the researchers opted for an explorative qualitative research design in which they derived themes and subthemes from the interview data (Hsieh & Shannon, 2005). Duquesne University's Institutional Review Board granted ethical approval for this research.

Recruitment of participants

Two male investigators (DH and JP), both graduate students at the Center for Global Health Ethics (then called Center for Healthcare Ethics) at Duquesne University at the time of data collection, interviewed oncologists, palliative care physicians, and oncology and palliative care nurses. Eligible participants were either a registered nurse (RN) or a board-certified oncologist or palliative care physician with at least two years of recent experience caring for patients within their respective fields of oncology and palliative care in the United States. The investigators recruited them through large urban healthcare networks in the Northeastern United States; the investigators recruited additional nurse participants through local chapters of the ONS and the Hospice and Palliative Nurses Association.

Stratified sampling—in which the larger interviewee population is divided into subcategories—ensured heterogeneity of the sample. Within each group of interviewees (physicians and nurses/nurse practitioners), the interviewers recruited interviewees working in different settings (hospice, palliative care, and oncology) and representing gender diversity. The number of interviewees depended on when theoretical saturation was reached. Theoretical saturation occurs when further data collection and analysis does not lead to the discovery of new themes, subthemes, or insights. Data collection attained saturation after 17 interviews, when the interviewers had conducted and analyzed several consecutive interviews in which they did not discover new themes or subthemes and no new interpretations arose from the data. A study on saturation in qualitative research has shown that 12 is an appropriate number for studies “in which the aim is to understand common perceptions and experiences among a group of relatively homogeneous individuals” (Guest et al., 2006, p. 79). The interviewees in the current study were a homogenous group in the sense that they shared experience in advanced cancer care; however, there were differences in length of professional experience and work setting, and interviewees had different professions (physicians, nurses, and

nurse practitioners). These differences may explain the slightly higher number of interviews that was required to reach saturation.

Content of the interviews

Prior to the interviews JG, who is experienced in qualitative research, mentored DH and JP in qualitative research methodology and provided training in qualitative research interviewing through mock interviews. The investigators used a printed guide that outlined the data collection process and the topics and subtopics to explore in the interviews. The guide first detailed the practical information and ethics procedures pertaining to the study (aims and procedures, confidentiality issues, request to record the information, and invitation to sign the informed consent form). Next, the guide listed the basic demographic information that the interviewers would collect from all physicians and nurses (age, professional background, and nature of involvement with advanced cancer patients). Then, the interview guide listed the main interview topics with subtopics: attitude to patient autonomy, awareness of complexity of culture, and autonomy in advanced cancer. Within the context of this last theme, the interviewers read a hypothetical case of an Asian Indian patient whose husband and son shield her from her diagnosis. This case was preceded by introductory questions regarding attitudes towards and experiences with South Asian patients’ involvement in decision-making. After the interviewers had read the case to the participants, they asked them to reflect upon how the team should respond to the situation and relate this to their own personal experiences with similar cases.

During the interviews, there was no predetermined order of the items. The order in which the interviewers asked the questions depended on each participant’s response, so that the interview proceeded logically. As the interviews progressed, the interviewers developed specific questions and probes, such as “Can you explain?” “Go on,” or “Can you provide an example?” to substantiate and saturate the emerging categories.

Data collection & protection of human subjects

Interviews took place from October 2015 to March 2016. Interviews began after the participants verbally agreed to the informed consent and signed it. On average, each interview took 45 minutes. The interviewers audio-recorded the interviews after they had obtained permission to do so from the participants.

The research team took various steps to respect and ensure the safety, privacy, and confidentiality of participants and data. The interviewers conducted the interviews in locations within the participants' clinical settings that were private, quiet, and comfortable for them to share their experiences freely without being disturbed or overheard. Study participation was voluntary and participants had the right to refuse and withdraw their consent to participate at any time. After the research team had analyzed the data, the investigators allocated a unique categorical code to each participant. The code consisted of a letter (N for nurses or nurse practitioners and P for physicians) and number to maintain anonymity. In this article, these codes have been used to designate the participants.

Data analysis

Data collection and analysis progressed simultaneously. The research team used MAXQDA 11 software for analysis. The two interviewers transcribed interview recordings verbatim and entered them into MAXQDA. Through conventional content analysis (Hsieh & Shannon, 2005), they extracted the socio-cultural factors that affect patient involvement in medical decision-making. First, they identified the key concepts in the interview and, then, they added codes to the data. The team determined categories and clarified the association between categories through constant comparisons. To ensure trustworthiness of the data interpretation, each interviewer coded each interview independently; then, the two interviewers compared findings and resolved differences. The research team discussed and challenged developing categories and sought solutions for interpretation problems during

frequent debriefing sessions with the interviewers, PI, and co-investigators.

Results

Participants' characteristics

Participants included six physicians (P1-P6) and 11 nurses and nurse practitioners (N1-N11). All participants worked within the data collection region and had an overall professional experience ranging from 8 to 31 years with a minimum of 5 years working with advanced cancer patients. Physicians' ages ranged from 35 to 58 years with 50% ($n=3$) identifying themselves as male and 50% ($n=3$) as female. The nurses' ages ranged from 43 to 63 years with 89% ($n=8$) identifying themselves as female and 9% ($n=3$) as male. Among the RN sample, two (18%) were nurse practitioners.

Analysis isolated six contextual factors that determined patient involvement in the medical decision-making process. These factors (themes) have been listed in Table 1 along with their subthemes.

Language barriers

Most participants reported experiencing significant language barriers during their interactions with patients and their family members while making treatment decisions. Even if the patient and the healthcare provider shared a common language for communication, inadequate comprehension complicated medical decision-making. If the patient and the healthcare provider did not share a common language, communication became exceedingly difficult, even if interpreters were available. N6 recounted the following incident with a patient of Chinese origin:

To me, it was a strange situation, because first of all he didn't speak English. He just kind of laid in the bed and let me do whatever. He wasn't having pain, but he just laid there, and he didn't get up. He only ate a little bit here and there. I don't know what his wishes were, because he didn't really talk. I think he probably was capable of

Table 1
Themes and subthemes

1. Language barriers
1.1. Leading to inadequate comprehension
1.2. Amplified by culture-specific behavior
2. Socio-economic status
2.1. Reinforcing bias and stereotypes by the healthcare providers
2.2. Connected with self-neglect
2.3. Instigating mistrust in the health system
2.4. Impacting comprehension of medical information
2.5. Amplified by cultural attitudes to authority
3. Educational status
3.1. Connected with level of involvement in decision-making
3.2. Amplified by culture-specific attitudes and beliefs
4. Gender
4.1. Directed by prominent role of men
4.2. Amplified by culturally shaped gender roles
5. Family involvement
5.1. Informed by shared familial decision-making
5.2. Overriding patients' decisions
5.3. Driven by desire to protect the patient from emotional harm
5.4. Amplified by culture-specific family relationships
6. Healthcare providers' (physicians' and nurses') involvement
6.1. Informed by shared decision-making
6.2. Amplified by culturally shaped attitudes to authority

talking. Although we had an interpreter it made communication difficult.

These language barriers were prominently amplified among certain populations, such as South Asian patients. Specifically, nearly all participants shared various challenges they have experienced with patients and family members from South Asian origin. In populations such as the Nepalese or other South Asian groups, language barriers amplified culture-specific behavior. The culture-specific

behavior in this case was often a male family member speaking and, also, deciding for a female relative. The female patient's lack of command over English made it easier for the male family member to exert control. An oncologist, P3, mentioned that not involving the patient is a cultural habit among South Asian patients where the family leads in the medical decision-making process:

If you're looking for some commonality, not a generalization as much as a commonality, then

[Asian] Indian groups and Pakistani groups have more family members present for the decision-making. In the Indian and Pakistani groups, the families are more involved in the decision-making and the information-gathering. Sometimes, this may be because there are translation problems and understanding problems because of language barriers. But I think that it's also cultural with the families being close-knit.

Observing the cultural aspect of Indian and Pakistani patients in his experience, P3 described patients involving family members in the decision-making process due to the language barrier as well as cultural norms and traditions. This may lead to a lack of effective communication between the patient and the physician, resulting in the physician not knowing the patient's wishes regarding his or her own treatment; instead, the physician must rely on the information given by the family, which may not truly reflect the patient's wishes.

Socio-economic status

Socio-economic status was another factor influencing patient involvement in decision-making. The participants linked lower socio-economic status to lower involvement in decision-making and, conversely, higher socio-economic status to higher or more engaged involvement. Lower socio-economic status was experienced by most participants as a barrier to involvement in decision-making by patients and their families irrespective of cultural background. Many participants shared various challenges they experienced with patients and family members because of socio-economic status. Socio-economic status as an influencing factor affected decision-making in four ways.

First, socio-economic status reinforces biases and stereotypes held by the healthcare provider that impede patient involvement in decision-making. According to P2, a palliative care specialist, physicians are more willing to respect preferences that go against sound medical advice in patients with a higher socio-economic status, demonstrating that greater socio-economic status is linked to more involvement in decision-making in the view of the participants. P2 stated:

You know I can't tell the specifics, but there are biases that we're all unaware of. There are certain patients in the hospital who don't formally get labeled, but they're clearly identified as "undesirable patients." Those are typically patients of lower socio-economic status. . . . There's a stereotype of some of the patients who come, who are very, very wealthy patients, and they offer to pay cash for their hospital and medical care. And I think given that, physicians are more willing to do things based on their preference as opposed to good medical care.

In this case, the physician ascertained that lower socio-economic status reinforced biases and stereotypes making people less autonomous and more dependent, whereas patients with a higher socio-economic status showed greater involvement in decision-making. In fact, these patients with a higher socio-economic status were able to exercise their autonomy to such an extent that the physicians were willing to regard patient preferences over sound medical opinion and accepted standards of care.

Second, lower socio-economic status may be connected with "self-neglect" and neglect by families no matter their cultural background. In the participants' view, self-neglecting behaviors and conditions often affected patients' involvement in medical decision-making. The oncologist P3, for instance, recalled his experiences with elderly patients from a lower socio-economic background: "Older populations that are maybe more traditional, maybe less from the metropolitan areas. I think our problem is trying to get these lower socio-economic groups involved in their own healthcare. Part of it is because of self-neglect." In this context, P3 explained that, despite having good access to healthcare under the Affordable Care Act, people with a lower socio-economic status often tended to neglect their own health. P3 believed that elderly patients who neglect themselves often do not get involved or get involved less in their medical decision-making process. Self-neglect should not be seen as a conscious choice. People from lower socio-economic status may not always have the health literacy to recognize when it is time to seek medical attention and they may be

less accustomed to advocate for themselves in a medical environment.

Third, socio-economic status may instigate mistrust in the healthcare system. An RN specializing in geriatric nursing and hospice care, N5 recollected her experience with patients from various socio-economic backgrounds. She explained that the patients from lower socio-economic backgrounds lacked involvement or had reduced involvement in medical decision-making in general due to the factors discussed earlier, and even more so due to their mistrust in the healthcare system:

There are people who are in the lower income bracket and they know about hospice service and know all of the benefits that they can get from our service. There are other people who are in the lower income bracket that don't know about us, and we try to get into the home and they don't trust the system, so we've had a lot of that.

According to N5, the mistrust among patients from lower socio-economic backgrounds affects the involvement of patients in their medical decision-making and leads to inadequate care.

Fourth, participants believed that patients with a lower socio-economic status may not be sufficiently educated to comprehend the information provided, which affects patient involvement in decision-making and creates difficulties in the decision-making process. P3, an oncologist, recollected his experiences with people with a lower socio-economic status: "I think people that have lower education are more inclined to come in, listen, and not have as many questions. They're agreeable to whatever the doctor recommends. So that might be cultural, but it could be socioeconomic, too."

When P3 mentioned culture, he referred to his experiences with poorer patients, in this case, refugees from Nepal and Bhutan. While the participants saw the impact of socio-economic status on involvement in decision-making among patients of all cultural backgrounds, it was more outspoken or frequent among patients belonging to certain cultural minorities. In P3's opinion, his Nepalese patients retained less of the information given to them by their healthcare providers because

of their lower socio-economic background that had left them less educated, and they tended to agree to whatever their provider recommended. However, in P3's view, the unquestioning agreement with the healthcare provider could also have cultural roots. The statement by P3 indicates that lower socio-economic status as a barrier to patient involvement in decision-making is connected with one's cultural background. As per this argument, culturally shaped deference to authority may make it easier for those patients to accept the doctor's advice when their lower educational level, which is often associated with a lower socio-economic status, prevents them from easily understanding medical explanations.

Educational status

Independent of socio-economic status, educational status was identified as one of the main factors that impact decision-making and not just among patients belonging to cultural minorities. The participants spoke about the challenges they experienced with patients' and their family members' involvement in decision-making due to their varying levels of education. Overall, they associated lower educational levels with lower levels of involvement in decision-making and higher educational levels with higher levels of involvement. All participants found lower educational levels to be a barrier to patient involvement in decision-making. For patients to make informed decisions regarding their treatment, they should undergo the informed consent process. Participants shared their challenges of going through the informed consent process with patients of lower educational levels. N3, a hospice RN with extensive experience in inpatient hospice and hospice home care, recollected her experiences with patients:

I think, maybe education does play a role in decision-making. It seems to depend on the education level of the patient. So, the more education they have, they seem to know what they want, and if they have, say, a terminal illness they don't want further treatment. I see that patients that have a higher level of education are more willing to sign a DNR and have an advance directive. So,

I would say that probably more than anything [else], educational level [matters].

In N3's view, it is much harder to engage patients with limited education in effective and informed advance care planning.

Additionally, culture seemed to amplify these barriers posed by educational status to patient involvement in decision-making. Cultural traits resulted in lower levels of involvement in decision-making for patients who were not very educated and even contributed to paternalism in some cases or self-medication in others. For example, N2, a palliative RN for home care, shared the influence that culture exerted on her patients in the decision-making process, especially when patients lacked education. She shared her experience with some patients from India who were less involved in their treatment decision-making process. She attributed this to a lack of education and cultural traits amplifying this educational factor:

I think sometimes when people come from a particular [cultural] background and they may be used to doing things a certain way, when they come into the oncology world, they're exposed to a whole other world of treatment and options. So, I think that a lot of times they have a tendency to lean more towards what they know culturally versus what they're being offered by the physicians and the people that are caring for them.

Lack of education, in this case, made patients rely more on their traditional culturally shaped understanding of illness and cures, rather than trying to comprehend what the physician had to say regarding their treatment options in order to make informed decisions.

Patients who were less engaged in the decision-making process due to lower educational level sometimes deferred their decisions to relatives who were more educated. P5, an oncologist with extensive experience with South Asian patients, recalled one such case of a South Asian patient who did not engage in the decision-making process due to a lack of education and looked to her highly educated relatives for decisions:

I've been in circumstances where people want so little part in the decision-making about themselves that they will actually defer any

decision to their technically oriented relative. So, I remember, there was a [South Asian] patient of mine, I said, "So, how do you feel today?" And the patient looked to her son, as if to say, "How do I feel today?" And the body language is clear: "I don't make any decisions for myself." So, a lot of times you have to work on autonomy through a family member.

Interestingly, this case not only confirmed the relevance of a patient's educational level, but it also illustrated that culture can amplify the effect of educational level on involvement in decision-making. The patient may have unconsciously conformed to a culturally patterned behavior that delegates decision-making authority to men. The fact that the more educated relative, the son, was also male, may have made it more obvious for the patient to defer decision-making to him.

Gender

Throughout the interviews, participants expressed that gender played an instrumental role in patients' involvement in decision-making regarding their medical treatment. For example, P4, an oncologist who provides palliative care to cancer patients, stated that regardless of cultural backgrounds, men being the head of the household played a prominent role in the treatment decision-making process for women in their family.

[There are] patients who come from households where the man is the head of the household and the woman plays the supportive role. So, if the woman is the patient, she's going to kind of look toward the man to help make the decision.

Furthermore, all participants affirmed that, among South Asian patients, gender played a significant role in patients' involvement in decision-making regarding their medical treatment.

Several participants shared stories about the gender roles that are at play among South Asian patients. N2, an RN certified in hospice and palliative care, recollected one particular circumstance while caring for patients of South Asian origin. She mentioned that the patriarchs of the family were more independent in their decision-making compared to the matriarchs of the family. According to N2, the decisions were mostly driven by the sons

and husbands and sometimes by the daughters, instead of the patients:

Regarding the care of the patient by the family, there are specific gender roles that are at play there. Within the family usually the daughters or sisters or whoever, but generally speaking the females do the care and then, on the most part, the decision-making is left up to the male members.

P6, a board-certified palliative care specialist, shared her experiences with female patients from India and Pakistan who relied on their spouse or male patriarchs in the family due to financial and language dependency:

In India and Pakistan, it's often a male-dominated family unit. And they tend to make decisions, especially major decisions about what is going to happen, and they're the spokesperson. Not for all families, but many especially who cannot speak in English cannot communicate, so they are really dependent on the spouse. Also, if she's not working on her own independently, then that makes her more dependent on him for making decisions.

Family involvement

All participants experienced varying levels of involvement from immediate and extended family members throughout the patients' treatments and decision-making process, which had a significant impact on the patients' health, quality of life, treatment options, end-of-life measures, and outcomes of care. Here, too, this involvement was not absolutely restricted to patients belonging to cultural minorities. For example, P6, a board-certified palliative care specialist, shared her experience with patients and the involvement of their family members throughout treatments:

The family is always very involved; no individual exists on their own. So, the patient is at the epicenter of this, but the family is also going through a lot of stress. They may not be in the bed but they're taking care of the patient, they're doing a lot of things. So, they're going through a lot of emotional and physical stress.

This example showed that the professionals considered harmonious involvement and care by family members as a vital and common feature among all patient populations.

Comparably, though, participants saw an even greater amount of trust, confidence, faith, and reliance placed on family members in non-Western cultures, such as South Asian cultures. The participants identified involvement of family members as one of the main factors that played an instrumental role in South Asian patients' treatment decision-making. According to P3, an oncologist, certain ethnic groups such as Asian Indians and Pakistanis had a particularly solid tendency towards shared decision-making with their family members in which they were accustomed to making medical decisions regarding their health, wellbeing, and treatment options in consultation with each other. Many participants shared various challenges they experienced with patients due to involvement of family members. Although these challenges were more often noted among patients of non-Western origin, they were still found throughout all patient populations.

First, the participants expressed shared familial decision-making as an important component that significantly influenced patients' decisions regarding their treatment. N10, an RN involved in treating and caring for advanced cancer patients, recalled her experience:

A lot of times it involves the whole family like the spouse, daughter, or son. I had one patient who made all his own decisions . . . but he was sad. He is probably my only patient who made his own decisions. Whereas other patients always bring their family members and it's always a collaborative thing.

This case illustrates the overall centrality of shared familial decision-making. However, many times this behavior was amplified by culture among specific populations, such as South Asian family members who are more likely to engage in the decision-making process due to their cultural norms, beliefs in traditional values, and unfamiliarity with Western notions of respect for individual autonomy and informed consent. This culture-specific behavior not only consisted of more participation by the family in the decision-making process, but also included involvement by more family members. P3 recalled encounters with patients and their family members from Asian Indian and Pakistani backgrounds in the information-sharing and medical decision-making process:

Most people come here with some family members. [But] I do think that there are some ethnic groups that come with more family members. The Muslim groups [from India and Pakistan] seem to come with more family members that are part of the information-sharing and the decision-making.

Second, a majority of the participants have witnessed cases in which family-centered rather than patient-centered preferences were a crucial component in determining the patients' decisions regarding their treatments, oftentimes overriding the patients' own personal wishes. P6, a board-certified palliative care specialist, related her experiences where the family members' opinions and wishes overshadowed and influenced the patients' own personal preferences regarding their treatment and goals of care:

[The patients] want a natural death, they want to be comfortable, but because of the pressure they feel from their family or loved ones, they feel that they have to go through more chemo or more treatments, because the common term that is used by families is that "I'm a fighter" or "he's a fighter, and he's not going to give up yet."

Thus, family members who were confronted with the possibility of losing a loved one often desperately requested all treatments and measures to prolong life. The physician initially did not refer to specific cultural groups when she made this statement. Nevertheless, the dominance and assertions of family members' wishes and preferences in the South Asian patients' decision-making process and treatments were reflected in many instances throughout the interviews. The family's preferences were guided by culture and, in that way, culture amplified the willingness of the family members to override patients' decisions. P6 also stated culture as a central element in the continuation of aggressive treatments, especially for Indian, Pakistani, and Sri Lankan patients and their family members:

Patients from India, Pakistan, and Sri Lanka need to do everything that you can culturally. Because, [family members may wonder:] "How could we [family members] give up?" I think the process of thinking that there are choices, technology . . . the presence of, faith and spirituality,

it is difficult for them to still see that they have a choice [and] they can stop their loved ones from suffering from futile things.

This account showed that family members were also heavily influenced by their culture, as well as their faith and belief in the will of God, which frequently guided their treatment decisions on the patient's behalf. Notably, giving up was seen as a sign of failure of their responsibilities towards the patient, whereas family members believed that pursuing further aggressive treatments helped their loved ones acquire more time. In fact, P6, a physician of South Asian origin herself, shared her own personal experience involving her family members' role in overriding her elderly uncle's wishes regarding his treatment. This story highlights that the involvement of determined family members, who often imposed their wishes or overrode patients' decisions, played a decisive role in South Asian patients' medical decisions and treatment outcomes.

Finally, most participants noted that a desire to protect the patient from emotional harm was a crucial component of family involvement, evident in the behavior of family members from all cultural backgrounds. For example, N1, a hospice and palliative care nurse with extensive experience in inpatient and home care hospice, described her experience with patients and their family members:

In my 38 years as a nurse, families will call you outside of the room and say, "I don't want to talk about this in front of the patient" and the patient is alert and oriented. Or they'll say, "Don't say the 'h' word." You know, the "hospice" word.

N1 further clarified the dilemma associated with such requests for her and other healthcare providers when some families ask them not to tell the patients about their prognosis or mention certain words such as "hospice" in front of the patients. According to N6, a hospice and palliative nurse:

Probably more often is the "we don't want you to say the word 'hospice'" than "we don't want you to say 'cancer.'" And in a way it's kind of ridiculous, because the patient knows they're dying. Nobody has to tell them they're dying. They know. So, we try to respect if the family says, "Please don't say hospice." We'll respect

that wish to not say ‘hospice,’ but it’s kind of a silly request.

P6, a board-certified palliative care specialist, asserts: “There is a denial in the family itself. Because they may be coming from a very emotional point, where they just want to do everything that they can for her [the patient] and save her.”

Thus, family members across cultures—not just non-Western cultures—feared that being in hospice would cause the patient emotional and psychological distress and may even cause the patient to give up and lose hope. Oftentimes the families had more hope than the patient and were reluctant to disclose the prognosis to the patient. Meanwhile, many times this behavior was amplified among specific populations, such as South Asian family members due to their cultural values, beliefs, perspectives on health and suffering, and their views on the patient’s role in the decision-making process during end-of-life care and treatment decisions. P2, a palliative care specialist, shared one particular circumstance while caring for a Bhutanese patient:

A woman from Bhutan had a heart attack, myocardial infarction in the emergency department. . . . When I saw them [the patient and her son], her son said, “Talk to me. I don’t want my mother to know about this.” And it was primarily because he thought it was going to be stressful—his statement was that it’s going to be too stressful for her.

Healthcare provider’s involvement

Independent of the involvement of family members, the majority of participants identified the involvement of healthcare providers throughout the patients’ treatments as one of the main factors that had a significant impact in the patients’ involvement in their decision-making process. For example, P4, an oncologist who provides palliative care to cancer patients, shared her experience with patients and her involvement as a healthcare provider during the consultation and decision-making process:

Ideally, it’s a shared decision-making process between everyone. The primary decision-maker

is the patient. My job [as physician] is to use my expertise and knowledge to explain the patient’s clinical situation and guide them to what I think is the most appropriate plan of care and be able to explain to them why I think it’s the best plan of care.

This statement illustrates the willingness of healthcare providers to play a very collaborative role and be actively involved with patients and their families when making recommendations and treatment decisions. However, many times, due to their close involvement in the treatment process and their intimate knowledge of the patients’ personal goals, values, and background, healthcare providers often had substantial authority and influence over the patients’ treatment decisions. While this involvement was not restricted to patients from particular cultural backgrounds, it may be amplified for specific populations such as South Asian patients, who, due to their cultural values, customs, and respect for authority figures, may place an even higher degree of trust and dependence on their healthcare providers. The participants identified involvement of healthcare providers as one of the main factors that played an instrumental role in South Asian patients’ decision-making regarding their treatments. N2, an RN certified in hospice and palliative care, shared her overall experience while caring for patients of South Asian origin: “They [South Asian patients] are not always very receptive to the nursing component of care. But they’re definitely more proactive with what the physician says and their recommendations . . . they definitely look very heavily to the physician.”

Interestingly, this statement not only confirmed the relevance and importance of physicians’ guidance for South Asian patients, but also illustrated how culture amplified the physicians’ involvement in decision-making. As per the participants, South Asian patients predominantly favored a more doctor-oriented approach. N7, an RN involved in caring for advanced cancer patients, also encountered similar experiences with South Asian patients: “Of course, a lot of it depends on the personality, but I also feel that [the South Asian] population is more willing to just accept whatever the doctor

says. They don't question authority. The doctor is more educated."

In this way, culture may amplify tendencies towards physician paternalism that still exist in healthcare, as the participants observed. P1, a board-certified oncologist, elaborated the predicaments for healthcare providers in shared decision-making, especially when dealing with patients who, irrespective of cultural background, lacked a medical background or failed to comprehend their disease progression and treatment implications.

People [healthcare professionals] are people. And shared decision-making takes a lot of time. I don't think people [healthcare professionals] really mean to bowl people [patients] over or do all of the decision-making, but involving patients and families in the decision-making process is incredibly time-consuming. Because you have to first give them a background, so you have to give them a knowledge base. And then you have to go over the options, and then you have to tell them why each one is a good or not a good idea from your point of view. And then they talk amongst themselves, and it takes forever. It's long.

Discussion

The nurses and physicians interviewed for this study listed six barriers to patient involvement in decision-making in advanced cancer care: language, socio-economic status, educational status, gender, family involvement, and healthcare providers' involvement. In the literature, these barriers have been found to be associated with disparities in health and healthcare. Language is not only a barrier to patient involvement in treatment decision-making but can also be a barrier to accessing healthcare. In the United States, people who do not speak English have been observed to be less likely to have had a physician visit, mental health visit, mammogram, or an influenza vaccine in the past year (Fiscella et al., 2002). Lower socio-economic status has been associated with lower access to health insurance and healthcare (Cohen et al., 2018). Regarding educational status, more years of education and schooling have been associated with better life expectancy (Olshansky et al.,

2012). Gender has remained a barrier for women in accessing healthcare and healthcare research, even in developed countries that proclaim gender equality (Benchetrit et al., 2019; Melk et al., 2019; Moore et al., 2018). Even the family or the broader community can be barriers to healthcare by instilling attitudes and views that make it less likely that patients search for needed care or adhere to recommendations by healthcare professionals. For instance, in the United States, African American patients have been found to be less trustful of healthcare than white American patients (LaVeist et al., 2000). Such attitudes are not without basis since bias and even discrimination are known sources of disparities in health and healthcare (Smedley et al., 2002). In this way, the attitudes and behaviors of healthcare providers can be a barrier to healthcare.

Barriers to patient involvement in decision-making regarding care are also factors contributing to disparities in health and healthcare. Reduced involvement of patients in such decision-making may lead to care that does not consider the patient's entire medical history or is not well-aligned with the patient's goals. Such care will often be inadequate and/or unsatisfactory (Smedley et al., 2002). In this way, less involvement in decision-making regarding care may contribute to disparities in health and healthcare.

Whether or not patients are involved in decision-making may help explain how specific practices and attitudes in healthcare lead to disparities. For instance, regarding socio-economic status, physicians have been found to consider patients from lower socio-economic backgrounds significantly less independent, responsible, and rational than patients from higher socio-economic backgrounds (van Ryn & Burke, 2000). Our study showed that healthcare providers may not actually discriminate against patients from lower socio-economic backgrounds, but because the wishes of these patients are less likely to be heard and respected, these patients may be less likely to receive the care they need than patients from higher socio-economic backgrounds.

This study further demonstrated that, in the experience of the interviewed physicians and

nurses, barriers to patient involvement in decision-making are not restricted to any particular culture, just as inequalities in health and healthcare are found across cultures, races, and ethnicities in the United States. At the same time, specific groups within the United States may be more vulnerable to barriers than others. An integrative review of research focusing on Asian immigrant cancer survivors has shown that they are confronted with healthcare barriers that native-born Americans may not face to the same extent (Lockhart et al., 2020). Likewise, the nurses and physicians who were interviewed for this study reported experiencing barriers to involvement in decision-making across all U.S. cultures, including the majority white population. However, culture amplified these barriers among specific groups. In that sense, culture appears as a decisive force in determining the degree of patient involvement in decision-making. This illustrates the centrality of culture to patient care. Culture functions as an amplifier that may, directly or indirectly, guide or reinforce the barriers to involvement in decision-making. Culture may amplify barriers directly through cultural values and norms in the patient's culture that dictate the patients' and their relatives' behavior. This phenomenon was clearly seen in barriers related to gender and family involvement. In the experience of the interviewees, certain cultures encouraged men to speak for women or encouraged family involvement. Culture may also amplify barriers indirectly when factors such as language barriers, healthcare providers' involvement, and socio-economic and educational status provide a context in which cultural values, norms, and practices more easily suppress the patient's voice in decision-making. As shown in the interviews, men from paternalistic cultures may find it easier to take over decision-making from female patients who struggle with English or have limited healthcare literacy due to lack of education.

It is important to realize that some patients may actually be quite content with the involvement of family members in the decision-making process, and they may actually prefer not to be engaged in the process themselves. Patients may have internalized the norms and expectations of their culture

and may not want to be active decision-makers. The study participants experienced this, too. It is ethically acceptable for a patient to permit others to be involved in the decision-making process or, even, to let others decide. Beauchamp and Childress state that "the duty of respect for autonomy has a correlative right to choose, but there is no correlative duty to choose" (2013, p. 108). Nevertheless, in Western healthcare, emphasis is often placed on individualistic autonomy and, consequently, many healthcare professionals are unprepared to respectfully incorporate family members into decision-making when the patient still has decision-making capacity.

Moreover, the situation becomes ethically problematic when patients want to be involved in the decision-making process but their family members, driven by dominant cultural practices and convictions, do not let them. Studies from India, where it is the customary practice to exclude advanced cancer patients entirely from decision-making, have shown that many patients in India want to be informed about their illness, be involved in decision-making regarding their treatment, and are dissatisfied about the information they receive and their level of involvement in decision-making regarding their own treatment (Raja, 2007; Sanwal et al., 1996; Seetharam & Zanotti, 2009). While this may initially appear as a non-Western phenomenon, in the experience of the study participants similar situations arose among patients of the majority white population. Research has shown that in Western contexts healthcare decisions are most often made with some degree of influence from the family and are rarely only made by the individual patient. In this context, Broom and his coauthors speak about a "spectrum of relationality" in which Asian-Indian cultural attitudes show a stronger inclination towards family involvement (Broom et al., 2017), which may not always be desired by the patient. This aligns with the finding from the interviews that culture is a direct or indirect amplifier of barriers to patient involvement in decision-making.

That finding leads to an important conclusion. If barriers to involvement in decision-making in healthcare are not restricted to particular cultures,

then many attitudes, insights, and skills that are central in culturally competent care and that will boost patient involvement in decision-making regarding their care need to be implemented much more broadly. Relevant examples of such aspects of culturally competent care include the healthcare providers' awareness of their own background and biases, knowledge about the impact of poverty, and skills such as verbal and non-verbal helping styles (Sue, 2001). Such components of culturally competent care will be helpful in engaging patients from all cultural backgrounds in decision-making.

Within the context of culturally competent care, it is essential that healthcare providers question their own pre-conceived notions and expectations, particularly regarding involving patients from different cultural backgrounds in decision-making. This requires knowledge and skill, but also cultural humility. Healthcare professionals need to be aware of limitations in their knowledge and skills regarding cultures and need to be open to learning from patients (Foronda et al., 2016). They must accept that certain patients may challenge their pre-conceived notions and biases. Cultures are dynamic. Cultural traits do not manifest themselves in exactly the same way or to the same extent across people who identify as belonging to that culture (Gregg & Saha, 2006; Kleinman & Benson, 2006). A patient from a culture where it is customary not to involve the patient in decision-making may not necessarily favor that approach for himself or herself. Likewise, patients from a more individualistic culture, such as the majority culture in the United States, may sometimes prefer others to make decisions for them; or, at times, the family may dominate the decision-making process regardless. This shows the dynamic nature of culture as a factor amplifying barriers to decision-making. Therefore, cultural competence—which, in our view, should integrate cultural humility (Danso, 2018; Greene-Moton & Minkler, 2020)—should be broadly applied to all patients, with the understanding that specific cultural groups may require additional attention.

The broader relevance of cultural competence to involvement in decision-making aligns with the observation that there are substantial overlaps

between patient-centeredness and cultural competence in healthcare (Saha et al., 2008). However, the overlaps between patient-centeredness and cultural competence do not mean that cultural competence is entirely subsumed under patient-centeredness. Our study showed that, in the view of the interviewed nurses and physicians, culture amplifies transcultural barriers to involvement in decision-making. This means that cultural competence remains necessary and will allow providers to gain the relevant skills, knowledge, and attitudes needed in order to involve patients in the decision-making process in a way that respects their wishes and values. Healthcare professionals need these attributes in order to explore in a culturally sensitive manner how the patient prefers to be involved in decision-making. Specific components of cultural competence, such as understanding the meaning of culture to patients and effective use of interpreter services (Saha et al., 2008) will help healthcare providers better address barriers to patient involvement in decision-making when those barriers are amplified by culture.

The findings of this study contribute to a better understanding of the experiences of nurses and physicians who are caring for advanced cancer patients from different cultures and offers a way forward by explaining how cultural competence may support these healthcare professionals. This study has some acknowledged limitations. A first limitation is that patients were not interviewed. Consequently, the study only looks at the problem from the single perspective of healthcare providers. A second limitation is that healthcare providers were asked about their experiences involving patients from various cultures in decision-making, but the investigators did not directly study interactions between such patients, nurses, and physicians. As a result, the reliability of this study may be impacted by recall bias or mis-recollection on the part of interviewees. The participants' recollections may also have been influenced by unconscious cultural, socio-economic, religious, ethnic, or racial biases and stereotypes. A third limitation is that the interview guide included a case that focused on a scenario of an Asian-Indian patient. This may have

steered the interviews away from experiences they may have had with patients from other non-Western cultural backgrounds.

Conclusion

This study demonstrates that, in the view of the interviewed oncology and palliative care physicians and nurses, six barriers obstruct involvement of patients in decisions regarding their care. The interviewees did not see culture itself as a barrier to patient involvement. Rather, they saw culture amplifying barriers that occurred across patients from all cultural backgrounds in the United States. Our findings suggest the need for a broader integration of cultural competence whenever decisions regarding healthcare are made in order to stimulate patient involvement in decision-making.

Just like cultural competence, it may be hard to prove that involving patients more fully in decision-making regarding their care will lead to better patient outcomes (Lie et al., 2011), particularly in the context of advanced cancer care, where “good” outcomes are rare. However, overcoming barriers to patient involvement may lead to patients who are more satisfied with their care (Goode et al., 2006), because the decisions will be better aligned with their life goals.

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