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Cultural challenges to engaging patients in shared decision making

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ABSTRACT

Objective: Engaging patients in their health care through shared decision-making is a priority embraced by several national and international groups. Missing from these initiatives is an understanding of the challenges involved in engaging patients from diverse backgrounds in shared decision-making. In this commentary, we summarize some of the challenges and pose points for consideration regarding how to move toward more culturally appropriate shared decision-making.
Discussion: The past decade has seen repeated calls for health policies, research projects and interventions that more actively include patients in decision making. Yet research has shown that patients from different racial/ethnic and cultural backgrounds appraise their decision making process less positively than do white, U.S.-born patients who are the current demographic majority.
Conclusion: While preliminary conceptual frameworks have been proposed for considering the role of race/ethnicity and culture in healthcare utilization, we maintain that more foundational and empirical work is necessary. We offer recommendations for how to best involve patients early in treatment and how to maximize decision making in the way most meaningful to patients. Innovative and sustained efforts are needed to educate and train providers to communicate effectively in engaging patients in informed, shared decision-making and to provide culturally competent health care.
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1. Introduction

In the United States, engaging patients in their own healthcare through a shared decision-making model has been highlighted at the national level by the Agency for Healthcare Research and Quality (AHRQ), the Institute of Medicine (IOM) and even the Affordable Care Act (Section 3506) [1–3]. This emphasis directly results from the growing complexity of health related decision making, the exponentially increasing number of medical management options available to patients, and a growing recognition that "paternalistic" physician-directed healthcare does not translate to the best outcomes for most patients [4]. The importance of the patient role in decision making has been recognized most strongly in the context of cancer screening, treatment and surveillance care, which is the focus of this essay.

The evidence base for cancer screening (e.g., mammography, prostate and colorectal cancer screening) has evolved from "more is better" to recognition that patients have options for types of screening tests, time between tests, when to stop screening, and even whether to screen at all. Knowledge about screening and treatment options must be incorporated into patients' values and preferences, which leads to more complex decision making among patients and clinicians [5,6]. Patients with a cancer diagnosis are often faced with a series of complicated treatment decisions that unfurl quickly over the initial weeks following the diagnosis, but can persist for months or even years. This changing landscape has led increasingly to calls for "shared decision making"—*defined as ensuring that patients are informed about and included in the healthcare decisions which are made together with their clinician(s)* [7]—for both cancer screening and treatment.

Few initiatives, however, have noted that cultural backgrounds may influence the ability or desire of patients to engage in this way. Further, patients whose racial/ethnic and cultural backgrounds differ from the majority are disadvantaged when it comes to advocating for their healthcare and they appraise their treatment decision making much less favorably than whites [8].

Given the association between positive perspectives of decision-making and key health outcomes, including adherence to recommended care and improved quality of life [9], understanding barriers to shared decision making for all patients represents a critical area in need of assessment. This essay describes key challenges to involving patients from diverse

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backgrounds in health care decision making, using cancer as a specific prevention and treatment context. We further provide recommendations for appropriate next steps in the effort to engage individuals across an array of cultural backgrounds in their health care decision making.

2. Essential definitions

Multiple definitions have been applied to both "culture" and "shared decision making", which can contribute to the challenges of engaging individuals from various cultures in shared decision making. We recognize the importance of consistent definitions in order to achieve progress in this work, and therefore propose future adherence to an agreed-upon set of definitions for culture and shared decision-making, such as the ones provided below. We further recognize that while research often relies on race and ethnicity as a proxy for "culture," the field needs to move beyond reliance on race/ethnicity to consider the broader context in defining culture. For purposes of this essay and In order to optimize the generalizability and evidence basis for this discussion, we accepted the definitions described below.

2.1. Culture

While the term "culture" often refers primarily to minority or non-majority racial/ethnic backgrounds among people residing in the US, it sometimes applies more globally to describe the backgrounds of those from different countries across the world. In this essay, we define culture as "the sum of attitudes, customs and beliefs that distinguishes one group of people from another" and note that "culture is transmitted through language, material objects, ritual, institutions and art from one generation to the next" [10]. Since this essay focuses on cultural differences in cancer care decision making in the US, we use race/ethnicity and acculturation as a proxy for culture in many of the examples herein.

2.2. Shared decision making

According to the Foundation for Informed Medical Decision Making "... Shared decision making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available as well as the patient's values and preferences. SDM honors the providers' expert knowledge and the patient's right to be fully informed of all care options and the potential harms and benefits. This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care that they prescribe." [7]. For purposes of this essay, we focus on the challenges to engaging patients in shared decision making, but we also acknowledge that shared decision making may need to be tailored to the desires, needs and ability of individual patients to be most effective.

3. Racial/ethnic and cultural differences in cancer care in the U.S

Racial/ethnic and less acculturated minorities have been shown to receive care differentially from the primarily Caucasian/white majority population in the U.S. [11]. With respect to cancer care, an entire body of literature has shown that race/ethnic minority groups receive cancer screening at lower rates, are diagnosed at later stages of disease, and once diagnosed do not receive all the recommended treatments [12–20]. Table 1 provides a selection of studies that have documented these differences across the continuum of cancer screening, diagnosis, and treatment [12–20].

Several underlying reasons for different or disparate care and outcomes among racial/ethnic and cultural minorities have been suggested, from personal factors related to socioeconomic position or geographic area (e.g., educational attainment, income, neighborhood) to health system factors (e.g., differential delivery of care, reduced hospital resources) [21,22]. Yet few discussions about disparities in receipt or quality of healthcare discuss the role of patient engagement by physicians or involvement in health care decision making, and how this involvement (or lack of) may contribute to differences in use of care.

4. The role of the patient: drawing on a conceptual framework for cancer care decision making

In previous work, we provided the only published conceptual framework focused on the various factors that likely contribute to racial/ethnic and cultural differences in treatment decision making in the cancer context [23]. The model highlights the interaction between several key patient factors (e.g., attitudes, belief system, spirituality, fatalism and acculturation), family factors, and community factors on one side of the spectrum and the healthcare provider/system on the other side which together contribute to treatment decision making [23]. We now build on this conceptual framework (Table 2) using empirical work to provide context for understanding these challenges and to provide a basis for a set of recommendations for improving shared decision making between diverse patients and their clinicians.

4.1. Patient factors

4.1.1. Decision outcomes: differences in decision satisfaction/regret

To better understand challenges to engaging diverse patients in SDM, it is necessary to highlight that racial/ethnic and cultural minorities are indeed most vulnerable to poor decision making outcomes. Numerous previous studies have demonstrated that racial/ethnic minority and less acculturated patients are more

Table 1
Selection of Studies Showing Racial/ethnic Differences in Cancer Care Use in the U.S.

Screening	
Hossain et al. [12]	• Lower rates of prostate specific antigen (PSA) testing in African American (AA) vs. white men
Hawley et al. [13]	• Lower rates of colorectal cancer (CRC) screening in minorities vs. whites
Shokar et al. [14]	
Diagnosis	
Chatterjee et al. [15]	• AA women more often diagnosed with late-stage breast cancer than whites
Treatment	
Baldwin et al. [16]	• AA patients less likely to receive recommended colon cancer treatment than whites
Morris et al. [20]	• Disparities in receipt of rectal cancer treatment
Dehal et al. [17]	• Disparities in breast cancer treatment and outcomes
Corso et al. [18]	• AA patients less likely to receive recommended lung cancer treatment than whites
Survivorship Care	
Palmer et al. [19]	• AA patients report more barriers to breast cancer follow up care than whites

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Table 2
Examples from research relating to themes that drive racial/ethnic participation in cancer care decision-making (Mead et al. [23]).

Theme	Examples From Research
Treatment decision-making	• Perspectives on decision outcomes (decision satisfaction/regret) • Perspectives on decision role
Patient factors	• Understanding of risk/benefit information • Personal belief systems and preferences • Perceptions of discrimination • Trust in providers
Family/Community	• Role of others in decision-making • Community based groups • Involvement of communities in agenda setting

likely to report lower decision satisfaction and higher decision regret than their majority counterparts [24–26]. In our own work, we documented that less acculturated Latina breast cancer patients had significantly greater decision dissatisfaction and regret following their treatment than white patients [24], even when controlling for the type of treatment received (which did not vary by race/ethnicity) or for health literacy. In a similar population-based study of colorectal cancer patients, we also found the lowest rates of decision satisfaction among patients of African American or "other" race/ethnicity compared with whites [27]. In order to improve the appraisal of decision making across all patients—a key component of patient-centered care—we need to better understand what drives differences in the process along the way.

4.1.2. Understanding risks and benefits of treatment

To achieve shared decision-making, patients first must be informed to have accurate understanding of the pros and cons of their options, and then must be engaged to seek knowledge they do not have and to voice values, preferences, and opinions [7,28]. Research has found that some racial/ethnic and cultural minority patients may be more susceptible than their majority counterparts to poor knowledge about their cancer care. For example, in a previous population-based survey, we found that Latina and African American breast cancer patients less often understood the survival benefit of treatment options than their white counterparts [29]. Other researchers have similarly shown that patients who are less educated, who face language barriers, or who have low health literacy or numeracy, have lower knowledge about their treatments than their counterparts [30–33]. Reasons for knowledge gaps are likely multi-factorial and relate to historical, language, or socio-demographic reasons. Because being informed is such a key contributor to engagement in SDM, it is important that appropriate methods to ensure accurate understanding of risk and benefit information among all patients are used. Such methods can include established techniques for conveying complex information in simple formats (e.g., icon arrays), as well as more novel methods building knowledge [34,35]. It is further important for clinicians to understand and potentially tailor conversations about complex health information to all patients.

4.1.3. Preferences and belief systems

Achieving SDM also involves incorporating the underlying preferences or values of patients [2,3,28]. Our work has shown that breast cancer patients value various attributes of treatment, and that these values translate directly into the type of treatment they receive [36]. Fig. 1 presents data from ongoing work by our team [37], clearly demonstrating racial/ethnic variation in factors that patients report as "very important" in making their treatment decisions. Indeed, the impact of such variation in preferences for care on decisions for care is documented across the continuum of cancer care from screening through survivorship and end of life care [13,38–39]. There is little to no direction, however, regarding the best methodology for preference elicitation and inclusion in shared decision making, particularly among individuals of diverse backgrounds. Thus the challenge is to develop methods for

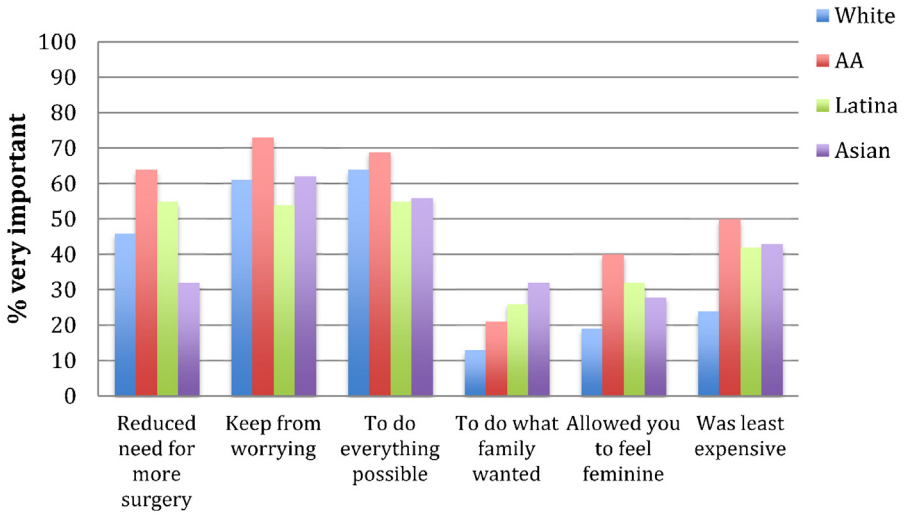

Fig. 1. Proportion of breast cancer patients indicating factors were very important in their surgical treatment decision making by race/ethnicity.

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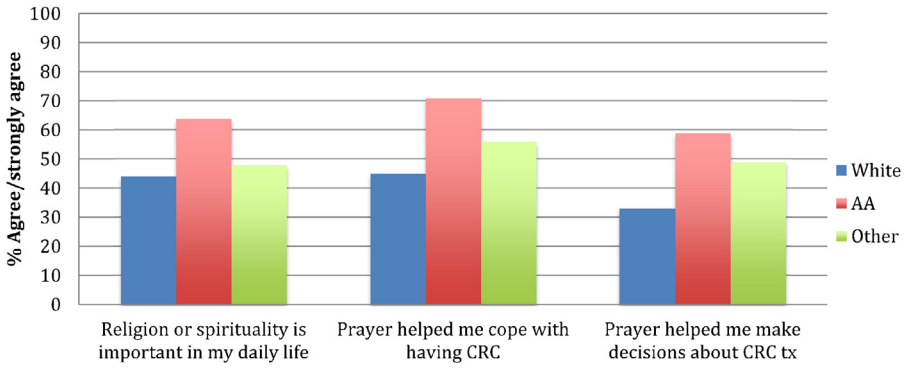

Fig. 2. Spiritual beliefs among colorectal cancer patients by race/ethnicity.

assessment of variation in patients' preferences for care, and to engage in decision making that is appropriately tailored to these preferences.

In addition to preferences, personal belief systems often vary across different cultural backgrounds. Individuals from different racial/ethnic groups or cultures may have religious or spiritual belief systems that contribute to their medical care seeking [33,40–41], as we have demonstrated among patients with colorectal cancer (Fig. 2) and breast cancer (Fig. 3) [27,37]. In both studies, patients of minority race/ethnic background were much more likely to endorse the role of spirituality in care seeking than their white counterparts. It is plausible that the importance of spirituality and faith in these patients' lives influenced how they approached management of their illnesses and engaged with their providers around treatment decision making.

4.1.4. Perceptions of discrimination and trust in the health system

In the U.S., the legacy of discrimination toward racial/ethnic minority individuals has led to an entrenched distrust of the health care system, reinforced by events such as the Tuskegee Syphilis Study [42]. More recent research has documented that African Americans and other racial/ethnic minorities report significantly less trust in their providers specifically and the healthcare system in general compared with whites [43–46]. Consistent with this, our work with colorectal cancer patients suggests a pattern of lower trust and higher perceived discrimination among African American patients relative to white patients [27]. Given that SDM requires communication between patients and their physicians, patients who have lower trust in their physicians may be less inclined to engage in this type of interaction, and may be wary of sharing preferences and values necessary for shared decision making.

4.1.5. The role of desire for involvement in the decision process

Improving the process and quality of decision making requires physicians to understand the degree to which patients desire—or are able—to participate in decision making. The idea of making one's own healthcare treatment decision, or of "sharing" that decision with one's provider, may be a difficult concept to those patients who either lack trust in the health system or believe that physicians are "supposed" to make decisions; and these patients may be those who come from different racial/ethnic or cultural backgrounds. For instance, our work with colorectal and breast cancer patients supports the notion that patients may have different communication style preferences; we found racial/ethnic minority patients most often reported that they preferred their physician "tell them what to do" when it came to their treatment decision [27,37]. Yet research has shown that the provider's communication style can influence patients to become more active participants in their decision making; specifically when providers themselves engage in partnership building and supportive communication approaches, patients tend to more actively participate [47]. Work by Gordon and colleagues found that variability in the amount of information given to African American lung cancer patients by their clinicians was in part explained by the finding that African American patients were more passive in their discussions than white patients, providing evidence to support different communication styles on the part of patients [48]. Thus, reasons for differences in desired participation in decision making

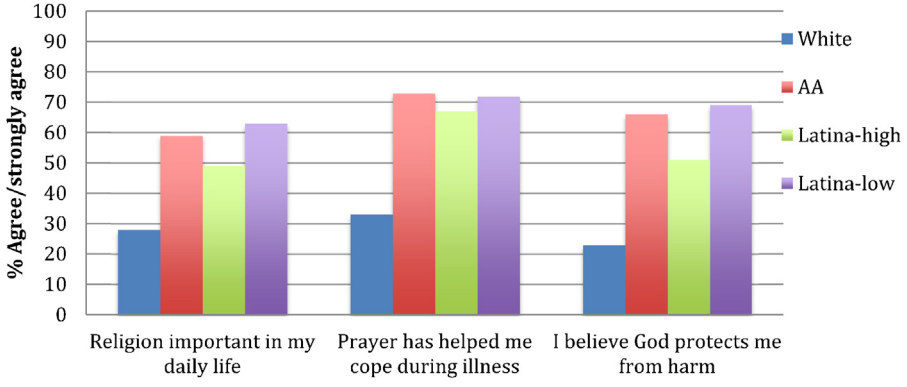

Fig. 3. Spiritual beliefs among breast cancer patients.

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among patients need to be better understood with further research. At the same time, the role of providers in engaging patients in their healthcare decision making must be recognized.

4.2. Response to interventions

In addition to understanding patient-level differences in their healthcare decision making, patients from different backgrounds may also respond differently to interventions designed to engage patients in their healthcare. Previous work indicates that interventions are more effective when differences in cultural and race/ethnicity are considered [49–51]. Work by Siddiqui and colleagues, for example, found that the more positive uptake of a colon cancer screening intervention among white compared with African American participants was due primarily to differences in response to a mailed print intervention [49]. In a sample of African American members of a large health plan, Resnicow and colleagues found that the participant's communication preference moderated the impact of the intervention, which was most effective among those who desired to participate in their decision-making [51]. To effectively engage patients in shared decision making, these data support appropriate cultural tailoring of interventions to meet the needs of individuals from diverse backgrounds.

4.3. Role of family and community

Inclusion of family and significant others is another important consideration for effective engagement of all patients and particularly those from diverse cultural backgrounds. Patients rarely make cancer or other significant health treatment decisions without consulting their support system, typically consisting of close family or friends. Patients also reside in communities that may support cultural or other belief systems that influence their vision of engagement in their healthcare. Research has shown that cancer patients, particularly those from cultural or racial/ethnically diverse backgrounds, involve family and friends in treatment decision making more frequently than white patients [52–54]. Thus, engaging patients from diverse backgrounds in shared decision making will likely mean involving and incorporating their key support people. Furthermore, by targeting communities through initiatives such as cancer councils [55], it may be possible to build trust and identify issues specific to diverse patients that can be used in development of tailored interventions. Involving communities in development of interventions through employment of community based participatory research [56] may be an effective way to engage non-majority patients—typically those from diverse cultural backgrounds—in health care.

5. Recommendations

In this essay, we have built upon our previous framework to focus primarily on the need to consider how patient-level factors contribute to the ability to engage patients from diverse racial, ethnic, and cultural backgrounds in shared decision making. We further note the importance of considering key influential factors in patient decision making, including family and community. As noted by Street and colleagues, "patient participation in medical encounters depends on a complex interplay of personal, physician and contextual factors" (p. 960) [47]. While we cannot address all these factors in this essay, we offer the following recommendations to address these challenges. First and as noted earlier, we strongly endorse the development of definitions of culture that extend beyond race and ethnicity. Second, o address the goal of increasing informed decision making, and ensuring accurate knowledge of risks and benefits, the field must consider identifying the best method to convey risk and benefit information to all patients, with a particular attention to sub-groups that may find usual risk-benefit information especially challenging. As noted earlier, approaches could include existing methods that have been shown to improve understanding, or more novel methods developed to convey complex information in comprehensive ways to all patients.

Third, clinicians must improve responsiveness to unique issues of culturally diverse patients, such as lack of trust in the health system. Clinicians must also improve their ability to communicate effectively with diverse patients and engage them in decision making. This could be accomplished by increasing clinician awareness of variation in patient preferences for treatment and in training physicians in effective communication skills. Both of these clinician-level targets could be improved through increased attention to communication and cultural competency training [57–60]. Fourth, decision scientists and interested others should expand the frame of traditional shared decision making beyond just the patient and clinician to also considering the important role played by key support persons and communities in the decision making process of patients, particularly those from racial/ethnic minority groups. Provider training in cultural competency can increase awareness of this issue [57], but further work is needed to develop new models for approaching shared decision making. Finally, to ensure that interventions designed to support patient engagement are effective, developers need to engage stakeholders—in particular patients from diverse cultural and racial/ethnic minority backgrounds—in the development and testing of interventions. Further work to understand how tailoring can be most effectively used to increase uptake and engagement in diverse patient populations is also needed. Table 3 outlines the

Table 3
Recommendations for addressing challenges to engaging patients in decision making.

Target: Area of shared decision making to be addressed	Recommendation	What is needed
Informed decisions	Ensure understanding of risk/benefit information in those from diverse backgrounds (culture, race/ethnicity, literacy, numeracy)	Existing methods (icon arrays), novel methods such as "knowledge building"
Improved responsiveness by clinicians	Provider awareness of differences in belief systems, the existence of real/perceived discrimination and lack of trust in health system among certain subgroups of patients.	Cultural competency training
Improved patient activation and patient-provider communication	Further work to understand how culture shapes the preferences and values of patients for different attributes of treatment and desired level of involvement. Provider education and training around methods for activating patients to engage in decision making and communication.	Focused research Provider training in communication techniques: partnership building and supportive communication
Expanding to include the patient's support system in SDM	Involvement of family and friends needs to be considered (potential missed opportunity) in the decision-making and support process. Community involvement and engagement	Cultural competency training Community based participatory research Cancer councils
Effective interventions to improve engagement	Innovations in interventions to use tailoring to engage patients from different cultural backgrounds are needed.	Stakeholder involvement in intervention development

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targets, recommendations and potential approaches to begin to address these challenges.

6. Practice implications

We provide several areas for providers to consider in thinking about the challenge of engaging patients from diverse cultural backgrounds in shared decision making about their health. While additional research is needed to consider the best methods to provide patients with information about risk and benefit, and to develop interventions that can most effectively enhance patient engagement, the role of providers in ensuring positive interactions with patients is critical. As noted in our recommendations, the focus on increasing awareness of the underlying factors that drive patients to participate in their healthcare decision making is consistent with a model of improving cultural competence in medicine [57–60]. We further recommend the need for formalized and longitudinal cultural competency training beginning early in clinician careers where work has shown it is likely to be most effective [61,62]. Although not a new concept, it is imperative that continued efforts to educate and train providers to provide culturally competent health care and to communicate effectively are needed. Without such efforts, challenges to achieving shared decision making for all patients will remain.

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