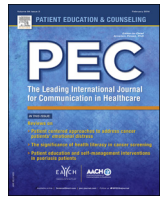




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Cultural challenges to engaging patients in shared decision making

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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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