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Shared Decision Making in Cancer Screening and Treatment Decisions for American Indian and Alaska Native Communities: Can We Ethically Calibrate Interventions to Patients' Values?

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Abstract

Shared decision making has been advocated as a key ethical strategy to improve quality of care and cancer control, especially in relation to screening and treatment decisions at various stages of the cancer continuum. Recent research on cancer in American Indian/Alaska Native (AI/AN) communities has highlighted significant disparities, raising questions about how best to implement prevention and screening programs in often fragmented and underfunded Indian Health, Tribal and Urban systems (I/T/U). Incorporating shared decision making initiatives routinely may provide opportunities to address the complex choices AI/AN patients face.

The burden of cancer and the complex choices it often presents necessitate balancing the risks and benefits of screening tests and treatments. Disparities in many cancer outcomes, and the importance of distinctive community values, combined with limited data describing the population-specific benefits of prevention and screening strategies, compounds the complexity of screening and treatment choices in American Indian and Alaska Native (AI/AN) healthcare delivery systems. The American Cancer Society (ACS), the National Cancer Institute (NCI) and other esteemed bodies have advocated for shared decision making [1], a process of patient engagement and mutual deliberation, as a key to improving quality of care and cancer control for important screening and treatment decisions [2–7].

In theory, shared decision making is a logical alternative for AI/AN communities due to the uncertainty of the evidence in support of interventions [8, 9], the need to incorporate patient/family values and preferences [10–12], and the potential for prudent use of limited resources.

The sheer diversity of cultural values, languages, and customs among American Indians and Alaska Natives suggests that there should be a strong role for elicitation and incorporation of group, as well as individual, values. At present there are 565 federally-recognized tribes in the United States [13]. Rather than assuming there is one “American Indian” or “Alaska Native” belief or value at play in a decision, it is imperative that care processes deliberately

elicit such information directly on a case-by-case basis – something shared decision making is ideally suited to promote. Furthermore, because the process of cultural assimilation with the dominant North American culture remains quite varied for different Native groups, it is inappropriate to assume what a given patient will or will not believe regarding health, social norms or other basic values.

Shared decision making could also bring pragmatic benefits. Health care systems in AI/AN communities are often underfunded for even basic needs, let alone prevention and screening strategies. According to most recent estimates, health care services at American Indian and Alaska Native facilities operate at less than half the per capita budget of other federal health care systems [14, 15]. With this reality, shared decision making provides an opportunity for “investment planning” [9], where patients can contemplate the burdens or benefits of screening and treatment. Investing in services that patients value most, and from which they derive the most benefit, should be the goal.

Whether AI/AN communities and their fragmented IHS/Tribal/Urban care delivery (I/T/U) system are ready to promote shared decision making conversations is unclear. Shared decision making may be a difficult concept for application in AI/AN cancer control for a number of reasons, including: lack of resources, lack of clinical relationship continuity, and dissonance with AI/AN culture (community or societal values vs. individualism/autonomy).

Many AI/AN communities have low budget health care systems. Shared decision making presupposes options; however the number of options available for treatment or preventive measures is often limited. For instance, in many AI/AN communities there may be only one colorectal cancer screening option available – fecal occult blood testing. Even when there are options, a lack of other resources threatens the decision making process. These resource constraints, such as the necessary time to engage in shared decision making and money to cover recommended testing, are significant.

In AI/AN communities, particularly those in urban centers or on reservations, patients have a wide range of literacy and numeracy levels which may require more explanation from primary care clinicians. Clinicians in AI/AN communities might rightly counter that they do not have the time to engage patients in shared decision making. Beyond that, facilitating shared decision making requires physician training and a specific set of skills. When successful service delivery is determined by how many patients are seen per unit of time, the ultimate impact of initiatives to promote shared decision making could be interpreted as negative in an already under-resourced environment.

Shared decision making requires a strong, trusting patient-physician relationship [8, 9, 16]. There are several patient-physician relationship stresses unique to AI/AN communities. On one end of the spectrum, past abuses may lower trust in healthcare providers generally [17–19]. Other patients may not form a trusting relationship with primary care clinicians due to the high turnover rate [20]. On the other end of the spectrum, some patients may show traditional deference to authority, making a shared dynamic uncomfortable [16].

Complicating matters further, it is not always clear how to extrapolate the existing evidence of benefit for screening or treatment to AI/AN populations. AI/AN men and women have lower five-year survival rates in some cancers, higher mortality rates in some regions of the country and generally present with more advanced disease [7, 21–26]. Motivated by these disparities, one common response by community, local, state and federal leaders has been a “we’ve got to do more” approach, in which screening and early aggressive treatments are strongly advocated. While the specter of cancer disparities is real, equally real are the side effects of treatments and the uncertain applicability of much of the evidence. This raises the questions: Is doing more “best”? How should prevention and screening programs be

implemented? We speculate that among non-native care providers, there may be a tendency to aggressively screen for and treat all cancers to avoid the perception of withholding potentially beneficial care from “disadvantaged” individuals. However, screening and treatment decision making for cancer is rarely a one-size-fits-all endeavor in the general population, much less in AI/AN populations. For instance, breast cancer trends in the AI/AN population suggest a disproportionate number of cases diagnosed in women in their 40s. Conversely, lower life expectancy and comorbidities in AI/AN men may make chronological age criteria for offering PSA screening (if offered at all) quite different. These trends should give pause to those trying to uniformly implement emerging general population screening guidelines in this population. At this point, there is not enough evidence for us to know whether screening guidelines in specific populations (apart from known genetic syndromes) need further tailoring for AI/AN populations.

Despite the role for shared decision making in addressing the excess burden of cancer and its associated care in the general population, little literature addresses the potential challenges and opportunities in making shared decision making a reality in AI/AN communities. If shared decision making is to be a component in the solution to addressing cancer health disparities in AI/AN populations, the feasibility of doing so in I/T/U settings must be studied. Health systems and communities partnering with investigators should consider assessing the feasibility of already validated shared decision making tools in I/T/U contexts and determine any necessary adaptations needed for AI/AN care. Are there fundamental barriers to having a truly collaborative conversation in an I/T/U setting? Are there key examples of exemplary providers who overcome contextual barriers and ensure that patients are engaged in their treatment decision making to the extent they desire? Can technology promote a more collaborative dialogue between patients and providers? Do the current survey data of clinician attitudes toward shared decision making and screening generally reflect the opinions and practices of those taking care of patients in I/T/U contexts? By addressing these and other practical resource questions, we can begin exploring in earnest whether the time for shared decision making in AI/AN communities has come.

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