

Inclusion and Use of Race and Ethnicity in Ethics Consultation Research

Rebekah S.M. Angove, Ph.D.
Associate Director of Engagement, Research,
and Evaluation
Louisiana Public Health Institute (LPHI)
rangove@lphi.org

Emmanuel M. Ngui, Dr.PH, MSc.
Community Health and Behavioral Health
Promotion
Joseph J. Zilber School of Public Health
University of Wisconsin-Milwaukee
ngui@uwm.edu

Mark Repenshek, Ph.D.
Healthcare Ethicist
Columbia St. Mary's
Milwaukee
mrepensh@columbia-stmarys.org

Introduction

Racial/ethnic disparities in health, health care, and outcomes of care have been extensively documented in the United States. Research clearly demonstrates that racial/ethnic minority groups in the United States disproportionately bear the burden of poor health, limited access and poor quality of care and have worse health outcomes than whites even after accounting for socioeconomic and other demographic factors (AHRQ, 2013; IOM 2009). For example, African-American patients are less likely than white patients to receive recommended care including A1c and lipid testing and are more likely to suffer long-

term complications of diabetes such as diabetic retinopathy (Harris, 1998), lower extremity amputations (Gornick, 1996; Young, 2003) and chronic kidney disease (AHRQ, 2013; Virning, 2002). These racial disparities in diabetes care have been attributed to patient socioeconomic characteristics and comorbidity, with a large portion of residual disparities attributed to within rather than between physician difference effects (Sequist, 2008).

Given this body of research documenting the health disparities present in health care and the fact that 76 percent of ethics consultations are performed by medical professionals (physicians [34 percent], nurses [31 percent], social workers [11 percent]) involved in direct patient care (Fox et al., 2007), it is reasonable to question whether the same underlying factors that contribute to health disparities also influence ethics consultations. The purpose of this paper is to 1) report on a systematic literature review examining whether race/ethnicity is used or documented in empirical research on ethics consultations, and 2) explore possible implications of these findings related to clinical ethics consultation.

As of 2007, about 95 percent of hospitals had, or were in the process of developing, an ethics consultation service (Fox et al., 2007). Ethics consultation is defined by The American Society of Bioethics and Humanities (ASBH, 1998) as “a service to help patients, families,

surrogates, professionals or other involved persons address uncertainty or conflict regarding value-laden issues that emerge in a health care setting” (p.3). The focus of clinical ethics consultation is to “address the ethical issues involved in a specific clinical case ... to improve the process and outcomes of patients’ care by helping to identify, analyze, and resolve ethical problems” (Fletcher & Siegler, 1996, p.4). Some of the common ethical problems include end-of-life issues (futility, withdrawal of life-sustaining treatment), respect for patient autonomy, and conflict resolution. Religious and cultural issues, professional (mis)conduct, and confidentiality issues have also been shown as important (though less common) triggers of ethics consultations (DuVal et al., 2001). In ethics consultations, the consultant will gather relevant data and attempt to clarify concepts and related normative issues. It is also the role of the consultant to build consensus among those involved by ensuring that everyone’s values and opinions are voiced in a clear and equitable manner. The consultant will then identify and present a range of morally acceptable options (ASBH, 1998).

In most health care systems anyone providing direct patient care (e.g. doctors, residents, nurses, social workers) and patients or their families can request ethics consultation, yet most requests (68 percent) are made by physicians (Swetz et al, 2007; Repenshek, 2009). Some prior research suggests that physicians can influence or be a barrier to other staff requesting general consultations (Gacki-Smith & Gordon, et al., 2005; Danis et al., 2008). Research also shows that clinicians hold strong convictions for or against the use of ethics consultations,

unrelated to an individual case, which may affect the utilization of the ethics consultation service (Orlowski et al., 2006; Davies & Hudson, 1999). It is, however, not clear whether decisions related to the use of ethics consultations, or the outcome of the ethics consultation itself, are affected by race.

Literature Review Methods

We conducted a systematic review of published peer reviewed empirical research on ethics consultation that included or examined racial/ethnic information using Ovid, Medline and PubMed database. With the help of experienced librarians, a search was done using the following key words: ‘*ethics consultation,*’ ‘*ethics case consultation,*’ ‘*clinical ethic,*’ ‘*ethics service,*’ *race, racial, and ethnicity.* Terms for racial and ethnic groups were searched individually and also by exploding the terms “race” and “ethnicity” to include any alternate names associated with these terms. The search was then narrowed to include only original empirical human studies published in English between 1990-2012.

Results

Our search resulted in nine original articles (Aulisio et al., 2000; Carrese & Perkins, 2003; Casarett & Siegler, 1999; DuVal et al., 2001; Perkins, 2008; Romano et al., 2009; Schneiderman et al., 2000; Schneiderman et al., 2003; Thompson et al., 2004). Despite filtering for “original empirical human studies” in our systematic literature review, other types of articles were returned in our search. Table 1 summarizes the nine articles found and highlights how race was used in each one. Of the nine, only four were original empirical research (DuVal et al., 2001; Romano et al., 2009; Schneiderman et al.,

2003; Schneiderman et al., 2000). The majority of the studies collected race but did not use race as a study variable anywhere in the analysis. The paper most pertinent to the topic of patient race in ethics consultation was a theoretical paper looking at ethics consultation and cultural diversity (Carrese, 2003), three articles focused on potential cultural factors that influence patient decision making (Rosell, 2005; Nolan et al., 2005; Davis, 1996) and one article looked at cultural issues in a clinician's ethical education (Yarbrough, 2007). Our review of published empirical studies on ethics consultation found no articles that specifically address whether race/ethnicity is used or documented in relationship to ethics consultations nor the question of whether the same underlying factors that contribute to racial/ethnic health disparities influence ethics consultations.

Discussion

Possible Reasons for Lack of Empirical Research

With race and ethnicity being increasingly implicated in disparities in health care delivery and given that ethics consultation is predominantly provided by these same providers, why is race/ethnicity seemingly ignored in the empirical arena of ethics consultations and bioethics?

Although the underlying reasons for neglecting race/ethnicity in ethics consultation are not clear, opinions range from the view that the race/ethnicity of patients is not an important ethical issue for the field, to issues related to confidentiality and data de-identification. Johnstone & Kanitsaki (2010) explored the neglect of racism in health care ethics. The authors proposed the idea of an "illusion of non-racism in health care" and the

tendency of health care providers to overestimate their ability to be unbiased and ethical when responding to unethical situations. Yet, the empirical evidence shows that clinicians may have biases that influence decision making and the care they provide (Green et al., 2007; Khan et al., 2008). As noted earlier, because most clinical ethics consultations are provided by health care providers (e.g. physicians, nurses, social workers) who may hold similar biases as other health care providers, ignoring race/ethnicity in the field could eliminate the ability to standardize care and implement quality improvement assessments in ethics consultation (Appiah and Gutmann, 1996). Given the prevalence of well-documented health care disparities among racial/ethnic minorities, their vulnerability to biased or differential treatment suggests these are the very groups who would likely benefit from ethics services and resources.

Racial and ethnic disparities in health care that go beyond socioeconomic status (SES) and access to quality care are well documented as well (Mays et al., 2006). Patient race has been shown to influence physician treatment recommendations (Schulman et al., 1999) and the patient-physician relationship (Cooper-Patrick et al., 1999). The Institute of Medicine (IOM) recommends the collection of race, ethnicity, and language in order to track and address these racial and ethnic disparities in health care (IOM, 2009). Unfortunately, we cannot determine if racial/ethnic disparities actually exist in ethics consultations because these data are not being collected or documented.

Many studies have looked at the prevalence of ethics consultations, patient gender, patient diagnosis, reason for and effects of the consultation (Repenshek, 2011; Tapper, et al., 2010; Fox et al., 2007; Swetz et al., 2007; Schneiderman, 2006). Yet only one study (Orr et al., 1996) documented race in its demographic information. It is interesting to note that there is more research on the race/ethnicity of physicians and their attitudes towards ethics consultations than there is on race/ethnicity of patients and their attitudes toward the same (Braun et al., 2010; DuVal et al., 2004).

Implications for Practice

The problem stretches beyond the inability to measure racial disparities in relationship to ethics consultations. We are missing valuable data in our evaluation of the ethics consultation as it relates to patient outcomes, patient and provider satisfaction, and emerging issues central to the needs of the patient and their family. If ethics is a significant aspect of “the reflective process by which a particular cultural group’s moral proclivities and choices are systematically interpreted, examined, and defended” (Carter & Klugman, 2001), then it is clear that ethics does not transcend culture; the two are inextricably linked.

As the United States becomes increasingly diverse, the likelihood that physicians and patients are from different cultural groups is also higher. Research has shown that patients in race-concordance relationships with their doctor have higher overall satisfaction with care, report more comprehensive care and feel more engaged in decision-making (Cooper-Patrick, 1999; Saha, 1999). The importance

of understanding cultural differences transcends variances in communication styles and language. A patient’s racial/ethnic and cultural background may influence his/her perceptions of illness, meaning of life and death, how they interpret the roles of clinicians or family, and how they make decisions related to their physical and psychological care. While one cannot stereotype a group and make assumptions about individuals in that group, it is important to understand the cultural differences persons might bring to the ethical issue and use that understanding appropriate to the consultation process itself (Singer & Blackhall, 2001).

There is a wealth of literature on cultural aspects of bioethics, including, for example, documentation of the historical roots of African American mistrust of the health care system to strategies for discussing negative information with Navajo patients (Eiser & Ellis, 2007; Carrese & Rhodes, 2000). Although a summary of this literature is beyond the scope of this paper, the consensus seems to be that there are ethical issues that are culturally specific that need to be addressed by bioethics (Jecker, 1995; Carter, 2004; Eiser, 2007). For example, a qualitative study on advance care planning (Perkins et al., 2001) found that minorities are less educated about, and have less understanding of, advance directives. Specifically, African Americans are less trustful that their wishes will be respected, and Mexican Americans are less likely to have shared their wishes with family members.

While the theoretical attention given to the role of race in ethics consultations seems to

bring to light its importance, the empirical research, data collection, and reporting practices of ethics consultation services do not support this sentiment. Empirical research (Saha, 2003; Van Ryn & Burke, 2000; Doescher, 2000) has shown that several factors – including mistrust, perceived discrimination, unfair treatment and poor provider-patient communication – have been associated with racial/ethnic disparities in health and health outcomes. All of these factors have ethical dimensions that may require consultation (DuVal et al., 2001). By not having the empirical research from which to respond, ethics consultation services run the risk of reinforcing systems that are informed only by the dominant set of attitudes, behaviors, social structures, ideologies and the requisite power needed to maintain them (Guider, 2001).

Bioethical analyses, for example, are often crafted in relationship to four traditional principles: respect for autonomy, beneficence, non-maleficence, and justice—principles that are generally accepted as applicable to all patients (Beauchamp & Childress, 2008). However, different cultural groups may hold varying views of the four principles with some groups influenced more by their collective cultural views of certain health behaviors or procedures (Wolf, 1999; Fagan, 2004). Some researchers have found cultural differences in medical communication. Wieringen and colleagues, for example reported less concern/empathy providing consultation to ethnic minority patients. Additionally, variance exists with regard to the balancing and trumping function of these principles based on the culture that circumscribes the interpretation of the

principles e.g., traditional Hmong culture's deference to family matriarch in patient decision-making at the expense of personal autonomy (Barrett, 1998).

As Wolf (1999) argues, “It seems that the individual patient-by-patient way in which bioethics has applied principles such as autonomy and beneficence has obscured patterns of stereotyping and prejudice that are themselves ethical problems” (p.70). Some of the racial disparities we see today in patient trust and confidence or help-seeking behaviors have been influenced in part by historical ethical failures in upholding these principles in the clinical decision making process (Jones, 2010). Research, for example, shows that physician biases influence their clinical judgment and care decisions (Schulman et al, 1999; van Ryn, 2002). Bioethics analyses need to consider the centrality of race/ethnicity and gender and how these factors occasion unethical health care and research behaviors. Moreover, such analyses need to be informed by the troubling historical contributions of medicine and biomedical sciences to racial and gender disparities (Wolf 1999). Wolf observes that “there is no such thing as a patient without race, ethnicity, and gender... A bioethics ignoring race, ethnicity, and gender will fail in moral analysis of these cases” (p.70). Mays (2012) observes that African-Americans are not a monolithic group, but a population with diverse ethical values, shaped by different experiences and historical contextual factors that influence important bioethical spheres including their personhood, individual autonomy and moral views (Randell, 2012; Wiredu, 1992a; Wiredu, 1992b). Instead of focusing on understanding their mistrust of the health care

system, according to May and colleagues (2012), there is a need for a “science-based bioethics for conducting research on African-American[s]” that goes further than merely examining why African-Americans mistrust the health care system.

Recommendations

Research is needed to examine racial/ethnic disparities in ethics consultation services and whether there are breakdowns in provider/patient communication and institutional policy that increase ethical and value conflicts for these groups. A better understanding of facilitation and barriers to ethics consultation faced by racial/ethnic groups is also needed. Finally, a critical self-reflection may be needed to examine whether ethics consultation services themselves are adequately informed about their own “blind-spots” to recognize that the consultation service is embedded in a system that already delivers demonstrably inequitable treatment. Further research is needed to look at racial and ethnic variations in: (1) the central ethical issues presented in ethic consultations, (2) how these issues are communicated, (3) how the need/desire for ethics consultation is communicated, and (4) the relationship between patient satisfaction and racial concordance of the consultant[s]. In doing so, it will then be possible to assess the effectiveness of cultural competency/engagement training for those engaged in ethics consultation as a mere first step.

Changes, such as the development of a universal code for ethics consultation with specific subcategories of types of ethic consultations, are needed in order to

successfully document and analyze these consultations and the patients and clinicians involved. Such efforts would be an entry point for important ongoing quality improvement studies, both internally and as an entire discipline. Determining and interpreting the prevalence of ethics consultations in different ethnic/racial groups is, therefore, just the beginning—nonetheless, an important one.

Conclusion

In reviewing the literature, we found very limited documentation of race/ethnicity in ethics consultation empirical studies. Indeed, reporting of race/ethnicity in ethics consultation literature is almost non-existent. The paucity of research in this area may highlight limited awareness, referral, and utilization of ethics consultations in our health care system. Collecting data on race and ethnicity would provide a framework to connect cultural issues and strategies in bioethics with actual practices. If disparities do exist, we need to examine why. Based on the increasing racial/ethnic inequalities in health, quality of care, outcomes of care, and the increasing diversity and complexities in clinical care, a better understanding of racial/ethnic and cultural factors in ethics consultation research is needed.

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Table 1. Summary of Key Ethics Consultation and Race/Ethnicity Articles

<i>Article</i>	<i>Study Type</i>	<i>Role of Ethics Consultation</i>	<i>Role of Race</i>	<i>Race/Ethnicity used as study variable</i>
DuVal et al., 2001	Empirical	Focused on factors associated with request of ethics consultation	Physician Race collected	Yes (physician race)
Romano et al., 2009	Empirical	Explores effect of mandatory ethics consultation policy	Collected	No
Schneiderman et al., 2003	Empirical	Effects of ethics consultation in ICU	Collected	No
Schneiderman et al., 2000	Empirical	Effects of ethics consultation in ICU	Collected	No
Perkins, 2008	Case Study	Importance of using patient culture in ethics consultation	Highlights importance of culture.	No
Casarett & Siegler, 1999	Case Study	Describes the role of an ethics consultation service in withholding resuscitation	Collected	No
Thompson et al., 2004	Conference Summary	Makes recommendations to call for consultation when needed	Recognizes influences of patient culture.	No
Carrese & Perkins, 2003	Editorial	Looks at ethics consultation and cultural diversity	Focuses on importance of culture in consultation.	No
Aulisio et al., 2000	Position Paper	Proposes standards for bioethics consultation services	Importance of cultural sensitivity in ethics consultation services.	No