

The Influence of Culture on End-of-Life Decision Making

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In their research, scholars have documented racial and ethnic differences in end-of-life care preferences, which have translated into cultural barriers. However, few studies have explained the racial differences. In the present study, focus groups with semi-structured follow-up interviews were utilized to elicit explanations for variance in decision making in a sample of Black and White community-dwelling residents. Participants identified specific cultural beliefs, values, and communication patterns that can be used to promote cultural competency among practitioners who provide care at end of life.

KEYWORDS *advance care planning, culture, hospice, racial differences*

INTRODUCTION

Cultural competency is a priority for end-of-life care professionals across disciplines. The National Association of Social Workers (NASW) has developed standards for such care within 11 domains of practice, intended to enhance social workers' awareness of skills, knowledge, values, methods, and sensitivity to the needs of patients and families receiving end-of-life care (NASW, 2004). Furthermore, the National Quality Forum (2008) and National Consensus Project for Quality Palliative Care (2009) have identified culturally sensitive end-of-life care as a core domain of quality care for practitioners. Because

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culture is a complex multifaceted construct, shaped by the interaction between numerous socio-demographic factors and continuously redefined by historical experiences and social realities, research that provides a culturally variant explanation for disparities in use of hospice and palliative care is warranted. An understanding of factors that influence attitudes, beliefs, and behaviors toward end-of-life and palliative care can assist practitioners in achieving cultural competence.

Cultural beliefs, values, and patterns of behavior are critical areas of assessment in the care plan (Crawley, Marshall, Lo, & Koenig, 2002). The cultural variants of a particular group of people determine how they make sense of life and death (Braun, Pietsch, & Blanchette, 2000; Parry & Ryan, 2000), and approach end-of-life decision making (Shrank et al., 2005; Bullock, McGraw, Blank, & Bradley, 2005; Ludke & Smucker, 2007; Smith, Sudore, & Pérez-Stable, 2009). As the overall population in the United States (U.S.) becomes increasingly more racially, ethnically, and culturally diverse, so too will our patient population. This demographic trend increases the likelihood that our patients' values may not be consistent with those of traditional Western-based medicine. Moreover, family structures and functioning may not fit the conventional paradigm for providing care. Therefore, end-of-life care practitioners must consider culturally variant approaches to meeting the needs of our patients and families.

To this end, the present research (a) provides an overview of culturally-variant perspectives on end-of-life and palliative care, (b) offers reasons for differences in attitudes and behaviors in advance care planning, and (c) discusses factors related to social support and family involvement in decision making at end of life. The overarching goal of this research is to promote cultural competency in end-of-life care that is inclusive of extended family networks.

BACKGROUND

End-of-life care refers to multidimensional assessment and interventions provided to assist individuals and their families as they approach death (Fins, 2006; Gwyther et al., 2005), which may include hospice and/or palliative care (Altilio, Otis-Green, Hedlund, & Cohen Fineberg, 2006). Understanding advance care planning as a process of health behavior is one aspect of end-of-life decision making (Fried, Bullock, Iannone, & O'Leary, 2009). More specifically, the constant racial disparities in the utilization of hospice care between Black and White patients are of concern (Han, Remsburg, & Iwashyna, 2006). For the past 5 years, there has been little to no change in the rates of utilization of hospice care among Black and Latino patients. According to the National Hospice and Palliative Care Organization (2010), there has been a steady increase in the enrollment of patients in hospice care

services with an estimated 1.45 million persons receiving hospice care in 2008. Yet, less than 20% of those individuals are representative of the largest racial/ethnic minority groups in the U.S. (Blacks and Latinos). Sources of bias and discrimination in our care systems that enhance the collection of data which provides insight into much needed strategies for eliminating disparities must be identified (Crawley, 2005).

Culture

Culture is a term that incorporates concepts of race, ethnicity, religion, language, national origin, and other factors. Race and ethnicity are interchangeable as a variable used to identify culture. According to Johnson, Kuchibhatla, and Tulsy (2008), ethnicity is a maker for cultural beliefs and values that may influence end-of-life decision making. Furthermore, researchers and scholars have suggested that the cultural world view of a particular group of people determines how they make sense of life and death, and approach end-of-life decision making (Braun et al., 2000; Parry & Ryan, 2000). Knowledge and awareness of cultural values, attitudes, and behaviors can assist practitioners in avoiding stereotypes and biases, while creating positive interactions with patients which lead to better patient outcomes than when the provider is less culturally aware (Reith & Payne, 2009).

Within cultural groups, health is defined for its members. Methods are prescribed for maintaining health, as well as for dealing with illness and death (Lo, 2010; Parry & Ryan, 2000). Shared values, traditions, norms, customs, lived experiences, and the role of institutions (i.e., family, religion, marriage) of a group of people dictate how one will interact with service providers (Braun et al., 2000) and whether one will chose to exercise control and autonomy in an end-of-life care process (Volker, 2005). Previous research has suggested that differences in values, beliefs (Ludke & Smucker, 2007; Bullock et al., 2005; Burr, 1995; Reese, Ahern, Nair, O'Faure, & Warren, 1999), and cultural bound behaviors—including communication patterns (Shrank et al., 2005)—influence end-of-life decision making. Patients' values and beliefs about, and interpretations of what they are told by a member of the care team, and expectations of their care may differ from those of their care providers.

Cultural Competency as a Standard of Care

Cultural competency practices have been widely accepted in social work as a standard that decreases disparities in the quality of services delivered to ethnic minority groups. NASW (2007) Standards for Cultural Competence include guidelines that address several key areas of social work practice—including ethics and values, self-awareness, cross-cultural knowledge, cross-cultural skills, service delivery, empowerment and advocacy,

workforce diversity, professional education, language diversity, and cross-cultural leadership. However, guidelines are insufficient without clearer understanding of what matters to the patients and their families. Studies of race and ethnic difference in end-of-life care preferences (Caralis, Davis, Wright, & Marcial, 1993; Tulskey, Cassileth, & Bennett, 1997; Blackhall et al., 1999) have been used to make inferences to cultural differences end-of-life care decision making.

For example, practitioners are well aware that many patients, irrespective of cultural background, involve family when they are receiving palliative and end-of-life care (Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009; Hudson, Remedios, & Thomas, 2010; Kovacs, Bellin, & Fauri, 2006; Kramer, Boelk, & Auer, 2006; Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010). However, when working with racial and ethnic minority patients, who tend to rely more on informal supports than formal supports, family may be an even greater aspect of the care plan. For practitioners, who operate on a Western-based medical model of care, this may be a source of contention. Moreover, it may seem to the practitioner that the goal of care is directed less at the patient than at the family member. Research focused on ethnic and racial variations in end-of-life decision making document potential areas of conflict (Bright-Long, 2010; Stein, Sherman, & Bullock, 2009; Torke, Quest, Kinlaw, Eley, & Branch, 2004). When conflicts between the value systems of health care provider and the patient arise (Lo, 2010), failure to deal with them properly may result in inadequate care (Fins, 2006) or no care.

Family support has been a consistent theme in end-of-life care research focused on ethnic minorities. African Americans tend to look to family members first in their end-of-life decisions (Klessing, 1992; High, 1994; Hauser, Kleefield, Brennen, & Fishchbach, 1997; Bullock, 2004) rather than consulting with medical staff. Furthermore, distrust of formal providers lead them to choose more aggressive and invasive treatments than palliative care (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Caralis et al., 1993; Crawley et al., 2002). According to Volker (2005), among Hispanic and African American individuals, the importance of using family to voice a patient's wishes was seen as more culturally relevant than completing written directives. Moreover, people who place greater value on familial relationships may prefer to identify a family member or trusted friend to make end-of-life decisions on their behalf rather than to make the decisions themselves.

Systematic exploration of these factors is important because identifying influences of end-of-life decisions among minority groups adds to the body of knowledge currently available for the promotion of cultural competency among practitioners, which can improve the care patients and families receive. Furthermore, cultural awareness and skills can be enhanced when knowledge is expanded. The Factors That Influence the Completion of Advance Directives Among Older African Americans (FICA) research, presented here, was designed to explore values, norms, attitudes, and behaviors

surrounding end-of-life care decisions for the purpose of increasing knowledge and awareness of African Americans' end-of-life decision making.

METHODS

Study Design

FICA was supported in part by the Michigan Center for Urban African American Aging Research (MCUAAAR) and the Research Center for Minority Aging Research (RCMAR). Components of the original study design, not supported by these two research entities, have been reported elsewhere (Bullock, 2006). Those analyses, however, examined within group similarities and differences among African Americans only. The FICA project extended that work to examine variance in decision making across racial groups.

This study examined data from participants interviewed using semi-structured interviews and focus groups discussions. The data were generated from 12 guided focus groups with Black community-dwelling residents and 12 guided focus groups White community-dwelling residents. Each group lasted about 90 minutes and consisted of 10–12 participants. The discrete, racial group design was intended to allow for open and candid responses to questions, as well as facilitate clarity in recognizing cultural variation across racial groups. The criteria for inclusion were self-identification of race (Black and White), resident status (community-dwelling, yes/no), age (55+), and language (ability to speak and understand English). Eligible volunteers were enrolled after giving informed consent to participate.

Participants

Black and White older adults volunteered to participate. The age bound eligibility criterion of 55+ was implemented because black adults are more likely to die of chronic illnesses at an earlier age than are whites and older adults and, in general, are more likely to be grappling with end-of-life care decisions and living with chronic illnesses that accelerate death than younger populations. Participants were recruited through community-based agency and faith-based organizations. Flyers were posted throughout the communities and gathering places of older adults (i.e., senior centers and churches). Community and church leaders helped to distribute flyers and publicized the research study. This purely voluntarily participation was not accompanied by payment of incentives.

Data Collection

Qualitative focus group methodology is ideally suited to elicit participants' responses and experiences in their own words and has become increasingly

accepted as a methodological approach to utilize in exploring issues related to end-of-life care (Bullock et al., 2005; Shrank et al., 2005; Fried et al., 2009). Twelve focus groups were convened with Black community residents and 12 were conducted with White community residents. The principal investigator and a research assistant facilitated the data collection for each focus group. The race of the focus group moderator was concordant with research participants of the group.

A brief questionnaire was administered prior to beginning the focus group discussion. A researcher was available to assist individuals who had difficulty reading. The questionnaire included demographic data such as age, gender, marital status, education, income, self-reported health, number of chronic illnesses, and race in addition to a social support and religiosity questions. After the questionnaire was completed, the focus group discussion was prefaced with educational statements to inform participants about the subject of advance care planning. Advance directives such as a living will, a health care proxy, and a durable power of attorney form were available for review and discussion. This approach to guided focus group research is a technique used to generate organized discussions among participants in a relaxed, nonthreatening environment for the purpose of data collection (Krueger, 2000).

FOCUS GROUPS

The homogeneous racial groups of participants responded to guided questions about preferences for or against end-of-life care, control and autonomy, attitudes and beliefs about death and dying in addition to specific questions about advance directives. For example, one of the initial guiding questions about planning for end-of-life care was as follow: "Now that you have been told what an advance directive is and how it is meant to help people, how beneficial do you think this can be to you or your family members?" A subsequent question was "Are there reasons you would not plan for end-of-life care?" The responses were audiotaped and transcribed verbatim.

FOLLOW-UP INTERVIEWS

In addition to the focus group educational modules, each participant completed an individual, 3-month follow-up interview. There was 100% retention in the completion of follow-up interviews. This measurement tool was formally tested for validity and reliability. Based on previously published literature in this area (Reese et al., 1999; Shrank et al., 2005; Ludke & Smucker, 2007; Johnson et al., 2008; Smith et al., 2009), questions were developed and reviewed by a team of social work researchers for face validity. During these interviews a "Cultural Values Scale" was administered. This scale

consisted of 10 statements that explored values such as individualism, collectivism, interdependence, self-reliance, interconnectedness, future orientation, and present orientation. A “Cultural Beliefs Scale” consisted of 10 statements exploring views about reality, autonomy, advance directives, and hospice care. The 20-item scale was scored from 0 (*does not reflect my values at all*) to 3 (*completely reflects my values*) to measure values and 0 (*does not reflect my beliefs at all*) to 3 (*completely reflects my beliefs*) to measure beliefs. Using the Cronbach’s alpha, the reliability for the measure of barriers to end-of-life care decisions was $r = .74$.

For the purpose of this study, data are derived from the pre-focus group questionnaires, guided focus group discussions, and from follow-up interview questions all designed to examine cultural values and beliefs that can create barriers to end-of-life care. This mixed-method approach was necessary to add insight to what we already know about culture influences end-of-life decisions.

Data Analyses

Qualitative analyses of focus group data were conducted in accordance with the recommendations of experts in qualitative research (Crabtree & Miller, 1999; Miles & Huberman, 1994) and several methods were used to enhance the validity and reliability of the findings. Experienced transcribers transcribed the audiotapes of all the focus group sessions verbatim. Independent coding occurred and after the initial reading of the transcripts was reviewed by the coders, a “start list” of coding categories was created. This process involved sorting and coding the words, themes, and meanings and what were construed as findings (Krueger & Casey, 2000). A summary of each narrative was prepared for comparison with the content analysis and grounded theory (Crabtree & Miller, 1999; Strauss & Corbin, 1990). Through group discussion and negotiation, the research team resolved any discrepancies that arose in coding and interpretation. NUD-IST software (Version QRS*NUDIST 4) was utilized for analysis (QRS International, Melbourne, Australia).

Quantitative analysis focused on comparisons of Black and White older adults. First, the two groups were compared with respect to demographic characteristics, using t tests for continuous variables and chi-square tests for categorical variables. Wilcoxon tests were used to compare mean scores by race on each scale. Demographic factors and the completion of an advance directive (yes/no) were compared by race. Logistic regression was used to determine if race had the primary influence on the completion of an advance directive. Next, linear regression was employed to determine the extent to which race was a primary predictor of values and beliefs about end-of-life care. The Cultural Values and Belief Scale was the outcome measure for these analyses.

FINDINGS

Sample Characteristics

The demographic characteristics of the 202 participants are summarized in Table 1. They ranged in age from 55 to 89 years, with a mean age of 72 years. This is an equal sample of Black and White participants with most being female (80%). The mean educational level of the sample was 11 years. The participants' annual income ranged from \$6,000 to \$35,000. Seventy-five percent (75%) were Baptist, 20% were Methodist (including African Methodist-Episcopal), and 5% reported other religious affiliations. Black participants tended to be younger, had lower educational attainment, fewer chronic illnesses, and had better self-reported health.

Key Focus Group Themes

Participants' responses to focus groups questions generated thematic codes, which were further analyzed to identify variance in themes that emerged

TABLE 1 Demographic Characteristics and Health Status

Variable	Black (<i>N</i> = 102)	White (<i>n</i> = 100)
Age (years)		
55–64	29.4	20.0
65–89	70.6	80.0
Gender		
Women	84.3	75.0
Men	15.7	25.0
Marital Status		
Married	10.8	43.0
Not Married*	89.2	57.0
Health Status		
Excellent	6.9	5.0
Fair	58.9	20.0
Poor	34.2	70.0
3 + chronic illnesses	50.7	65.0
Religion		
Baptist	78.4	75.0
Methodist	20.0	20.0
Other	1.6	5.0
Annual Income		
\$6,000–\$18,000	86.3	30.0
\$18,001–\$35,000	13.7	70.0
Preferred Place of Death		
Hospice	3.9	20
Home	9.8	30
Hospital	86.3	50
Completed AD		
	14.7	20

Note. *Includes widowed, divorced, separated, never married.

across racial groups. Based on the analysis of focus group data, the following thematic categories emerged with the greatest variance across groups.

ADVANCE CARE PLANNING

Only 15% of Black participants in the study had completed an advance directive and 20% of White participants. When asked, “What are some reasons you would or would not plan for end-of-life care?” White participants were more likely to identify benefits of advance care planning, while Blacks were more likely to describe barriers. For example, White older adults frequently commented about “wanting to make sure family members knew their wishes” and not wanting other people to make medical decisions for them.” Whites were far more likely to prefer autonomous decision making than Blacks. Furthermore, White group participants tended to believe that planning for care at end of life would make a positive difference in their dying experience, while Black group participants tended to believe that advance care planning would not make a difference in their dying experience. Black older adults were more likely to remark, “I don’t think it would help at all” and/or “there is really no need to talk about it or plan for it.”

Another benefit/barrier variance emerged as participants discussed the usefulness of advance planning in facilitating discussion with one’s doctor. Whites were more likely to have favorable beliefs about the potential to strengthen their relationships with doctors through a discussion about advance care planning, while Blacks expressed feeling of mistrust and lack of positive relationship with a “regular” doctor. Whites were more likely to be self-reliant and to prefer to have discussion with their doctors, while Blacks preferred to have a family member with them at the time of visits with doctors (or other care providers) and/or speak with the doctor on their behalf, if the need arose.

Black respondents were also more likely than Whites to believe that the completion of an advance directive may result in the withdrawal or withholding of care at times when that is not the wish or desire of the patient. Whites tended to express desires to discontinue aggressive treatment at points when the doctor has recommended such because it is of no benefit to the patient. One White participant commented:

I don’t want my family making decisions for me at the end. The reality is, if the doctor decides to take me off the machine, then I die. I don’t want them [family] to keep me alive just because they don’t have the courage to say “pull the plug.” I’m putting it in writing so there will be no questions about what I wanted.

Other White group members affirmed his comment as representative of their own beliefs. Far more Blacks than Whites stated that they would not be

comfortable with a doctor's decision to withdraw or withhold treatment in the absence of family discussion and agreement.

RELIGION AND SPIRITUALITY

The data from these focus groups suggested that there may be a difference between religion and spirituality. While all participants identified a religious affiliation, there was notable variation in beliefs about spirituality at end of life. Black participants tended to talk more about a belief in a "higher power" and "believing in miracles," while Whites expressed confidence in the medical team and health care system to address end-of-life and palliative care treatments. Although both groups of participants (Black and White) were regularly engaged in religious practices and rated themselves as somewhat or very religious, Whites were more likely to view religion as a support in their end-of-life decision making and not a guide to how they would make their decisions. A common theme among Black research participants was, "If you are God-fearing" and/or "a true believer" . . . "you will wait on the Lord." According to the Black participants, there is a difference between religion and spirituality. Going to church and engaging in formalities of the institution of religion is not the same as "believing in God." Those who "believe" do not "hasten death" through the use of advance directives and hospice care plans.

Specific questions were asked about the use of hospice and palliative care. Whites had far more favorable remarks coded as indicative of positive end-of-life experiences, including hospice care experiences. Much of the data from the White participants groups revealed themes of social supports, symptom management and comfort care during times of medical crisis and illness, and home as a preferred location of death. Among Black participants, the discussions about end-of-life experiences and hospice care suggested more negative experiences such as having witnessed loved ones refused nutrition and hydration by formal care providers, given too much medication, and denied inclusion of spiritual and community leaders in the care. Furthermore, the notion of "giving up" and refusing treatment or intervention until the end is considered to be inconsistent with their values of hope, belief in miracles, and suffering as justified, according to these research participants.

The various experiences discussed among the older Black and White focus group members are factors that they report as influencing their end-of-life care decisions (Table 2). From the common themes that emerged, core values that impact end-of-life care decisions were identified among the different racial groups (Table 3). From a set of guided questions about core values related to how one seeks information, engages in decision making, and thinks about planning, culturally variant values among and across White versus Black Participants were identified.

TABLE 2 Values and Beliefs Scale

Please rate each of the following statements about to end-of-life care according to how you feel it reflects your own values.

0 = Does not reflect my values at all 1 = Reflects my values very little 3 = Reflects my values a lot, but not completely 2 = Reflects my values somewhat 4 = Completely reflects my values

	0	1	2	3	4
1. It is important to involve a friend or family member in end-of-life care decisions before a final decision is made.					
2. I prefer to have someone close to you make important decisions for me.					
3. If I had a serious illness (like cancer) that doctors could not cure, I would be best cared for by friends or family.					
4. I would be willing to be the primary caregiver for a friend or family member who had a non-curable disease.					
5. The best decisions are made after talking things over with others who care about you.					
6. It is up to me to provide for myself.					
7. It is important to plan for the future.					
8. There is no need to plan for end-of-life because God will take care of everything.					
9. If I suffer at end-of-life, it's all in God's plan for me.					
10. Hospice care is not important to me because I have my loved ones who will take care of me should the need arise.					
Please rate each of the following statements about end-of-life care according to how you feel it reflects your own beliefs.					
0 = Does not reflect my values at all 1 = Reflects my values very little 3 = Reflects my values a lot, but not completely 2 = Reflects my values somewhat 4 = Completely reflects my values					
11. Planning for death could make it happen sooner.					
12. Completing an advance directive will give doctors a reason stop caring for you even if you needed the treatment.					
13. Completing an advance directive will help to ensure that my wishes are followed if I could no longer speak for myself.					
14. When I plan for something, it never works out as planned.					
15. If I do not write my end-of-life care wishes down, family members may not do what's best for me when the time comes.					
16. Hospice care deals with pain and other symptoms to help patients live comfortably with serious illness.					
17. People who receive hospice care have given up all hope.					
18. What happens to me is up to me. I am "Master of my Fate."					
19. God is in control of my life and death. "Fate of my Master."					
20. The only way to avoid disappointment is to not plan ahead.					

TABLE 3 Variant Cultural Values and Beliefs**Variant cultural values****White participants vs. Black participants**

Individualism vs. Collectivism
 Independence vs. Interdependence
 Self-Reliance vs. Interconnectedness
 Future Oriented vs. Present Oriented

Variant cultural beliefs**White participants vs. Black participants**

Views on Reality: Structured, Tangible vs. Spontaneous, Supernatural
 Views on Autonomy: "Master of my fate" vs. "Fate of my master"
 Views on Advance Directives: Written vs. Oral
 Views on Hospice Care: Symptom Management, Comfort Care vs. Giving up

DISCUSSION

The findings of this study confirm reports and suggestions concerning the need to understand cultural values and beliefs that influence end-of-life care. Advance care planning can be conceptualized as a set of health behaviors (Fried et al., 2009), which practitioners can intervene with in order to help patients to receive optimal care at end of life. The common themes that emerged from these focus groups and interviews with older adults highlight potential barriers to advance care planning and the use of hospice care. They also contribute to our knowledge about an area for development of cultural competence. Core values of individualism versus collectivism, independence versus interdependence, self-reliance versus interconnectedness were identified. White older adults tended to value individualism, independence, self-reliance, and future orientation. Blacks, on the other hand, tended to value collectivism, interdependence, interconnectedness, and present orientation.

Furthermore, Whites were more likely than Blacks to have completed an advance directive, wanted to make their end-of-life care decisions independent of family members' influence, and viewed hospice care more positively than Black participants. The overall themes of cultural beliefs were helpful in eliminating the underlying principles for these values. For example, the view of reality for White participants is one in which events tend to be structured and tangible. For Blacks, the view of reality is one of spontaneity, with the proclivity of the supernatural occurrences. The culturally variant perspectives contribute to the differences in decision making at end of life.

Practice Implications

This study has implications for education and practice. Providers need to understand their patient's values and beliefs about end-of-life and palliative

care. For those individuals who value collectivism and interdependence, family should be involved in all aspects of the care plan. We also need to respect the cultural differences in how individuals and families make sense of issues related to death and dying. For those patients and families who refer to God and wish to pray and hope for a miracle, it would be helpful to allow them to express their cultural views and values without saying or doing things that suggest that practitioners are insensitive, lack acceptance, and lack cultural competence. Additionally, the provider can ask a screening question regarding faith-related concerns and also ask if the patient or family would like to involve a spiritual leader in the care plan. It is recommended that members of patients' social support network be accommodated as much as possible without disruption to the care setting. Social workers are the ideal care team members to carry out these responsibilities because cultural competency is a core social work value and we have standards of care that prepare us to take up this charge.

NASW (2007) clearly states that cultural competency is:

the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each. (p. 12–13)

Conducting research that further explores cultural values and beliefs can contribute to the knowledge that is available to practitioners to expand their repertoire of effective skills for working across cultural groups. End-of-life and palliative care teams need to identify points of entry to move a patient and/or family along the continuum of care to make difficult decisions when death is imminent. Getting a patient or family to the point of accepting hospice care and forgoing aggressive treatment may require looking for cultural tools and strategies for bridging gaps in variant perspectives. The acquisition of knowledge and understanding of views different than one's own is the role of cultural competency (NASW, 2007).

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