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Cultural Distress: An Emerging Paradigm

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Abstract

Although cultural competence in practice is a common goal within the health care professions, little is known about the consequences of a lack of such competence in health and healing. We propose a novel theoretical framework of cultural distress to describe patient experiences of and reactions to care that does not incorporate attention to cultural needs. Use of the cultural distress model to guide research offers an innovative framework by which researchers may identify potential interventions such that patients never reach a level of cultural distress.

Keywords

culture, person-centered care, patient-centered care, cultural competence, culturally congruent care, distress, allostatic load, structural stress, patient outcomes, otherness

Introduction

Person-centered care is based on the principles of respect, responsiveness, and individual patient preferences, needs, and values (Agency for Healthcare Research and Quality, 2013). The patient–provider dynamic must therefore incorporate attention to the patient’s cultural beliefs, which influence self-identification, socio-location, and perceptions of health and illness (Burton, Halpern-Felsher, Rehm, Rankin, & Humphreys, 2013; Spector, 2002). As the diversity of the population continues to increase, health professionals must develop greater understanding of the implications of culturally appropriate care on patient outcomes and how to incorporate culture-specific preferences into care planning.

We herein propose a theory of cultural distress, which offers a framework for understanding physiological and behavioral outcomes in patients who do not receive care that incorporates their cultural beliefs. Specifically, the theory addresses whether patients return to better health more quickly or more fully when they receive care that is congruent with their cultural values and beliefs, whether or not a lack of culturally congruent care impedes health restoration, and whether or not a biobehavioral component exists that links the receipt of culturally congruent care to patient outcomes. We will define culture, cultural competence and cultural congruence, cultural distress, and the concepts contained within the cultural distress model, which include othering, structural stress, and allostatic load. Finally, we outline some possible implications of cultural distress and suggest some initial steps in research to test this developing theory. We propose that the cultural distress model has the potential to allow caregivers and researchers to systematically and intentionally administer and evaluate the provision of culturally

congruent care, so that patients will never reach the level of cultural distress.

Background

The concepts of cultural competence and culturally congruent care have become increasingly popular across service-related industries, and health care is no exception. Over the past 20 years, we have seen an increase in assessments of race and ethnicity as cultural variables, but utilization of these simplistic measures as proxy for culture may presume that these dichotomous and nominal markers of culture indicate homogenous and static populations (Kagawa-Singer, Dressler, George, & Elwood, 2014; Somers, 1994). Additionally, with these minimal data often collected inconsistently, our ability to adequately and holistically assess the dynamic nature of culture and how it influences beliefs, social norms, practices, and knowledge of groups as they relate to health and well-being is essentially nonexistent (Kagawa-Singer et al., 2014). Finally, strategies and tools for enhancing and determining cultural competence of care providers have been proposed in the body of existing literature (A. Campinha-Bacote & Campinha-Bacote, 2009; J. Campinha-Bacote, 2002, 2011a, 2011b; Giger & Davidhizar, 1990; Glittenberg, 2004; Jeffreys, 2010; Leininger, 1988,

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1997; Papadopoulos, Tilki, & Ayling, 2008; Purnell, 2002); however, delineation of the association between culturally congruent care and patient outcomes is lacking (Fortiere, Brach, & Bishop, 2004; Kagawa-Singer et al., 2014).

Culture. First defined by anthropologist Edward Tylor in 1871, “Culture is the complex whole of knowledge, belief, art, law, morals, custom, and any other capabilities and habits acquired by members of a society” (p. 1). Madeleine Leininger (1988) emphasized culture as “learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions, and actions in patterned ways” (p. 156). Most recently, the National Institutes of Health report, *The Cultural Framework for Health*, defined culture as “a shared ecologic schema or framework that is internalized and acts as a refracted lens through which group members ‘see’ reality and, in which both the individual and collective group experiences the world” (Kagawa-Singer et al., 2014, p. 29). For the purposes of this article, the concept of culture is inclusive of race, ethnicity, language, gender and gender identity, spirituality and religion, communication style, employment, socioeconomic status, political views, education, and personal preferences.

While many definitions of culture exist, it is generally agreed that the concept embodies three main components: (1) culture is the product of the interaction between humans and environments, (2) culture consists of shared elements, and (3) culture is transmitted across time and generations (Triandis, 2007). Consistent with these elements, evolution of the definition over time underscores the idea of “culture” as the set of characteristics and psychosocial environment in which the person is situated, and which informs how they navigate the world.

While culture can be shared, it is also the embodiment of much that is unique about an individual and shapes how that individual’s worldview is constructed—including the concepts of health, wellness, and illness. Culture influences how individuals communicate and relate to others, make decisions about whether or not to take action when considering life decisions, and choices relating to health care and self-care practices (Kagawa-Singer et al., 2014). Culture provides the context for the delivery and receipt of health services across the lifespan as a foundation for “expectations, actions, interactions, and meanings of care” (Schim & Doorenbos, 2010, p. 256) and is particularly meaningful in the setting of illness—which may include confronting individual mortality (Schim & Doorenbos, 2010). Cultural traditions, beliefs, rituals, and behaviors may in fact be most prominently displayed by individuals and families when faced with significant illness and end-of-life decisions (Schim, Doorenbos, Benkert, & Miller, 2007). When these cultural traditions and rituals are poorly understood or ignored by care providers, we may see a direct impact on the patient and family illness experience. It is important to note, however, that differences among members of the same culture and

changing beliefs across generations and life experiences necessarily imply that culture be considered fluid and dynamic (Garneau, 2015; Kagawa-Singer et al., 2014).

Cultural Competence and Congruence. While there is no universal definition of cultural competence, within health care it is generally accepted that the concept relates to the ability of health professionals to recognize their own culture and cultural boundaries in order to understand and attend to the culture of a patient (R. L. Johnson, Saha, Arbelaez, Beach, & Cooper, 2004). While cultural competence is an essential component of patient-centered care, we suggest that this concept focuses solely on the capabilities of the care provider. Without putting provider capabilities within the context of how the patient perceives the care offered, provider cultural competence may not manifest as competent care to the patient. In contrast, culturally *congruent* care is related to the patient’s perception of the care received. Leininger (1988) proposed the term to describe care that incorporates the patient’s beliefs and “lifeways” in such a way that preserves, maintains, accommodates, and—when necessary—restructures systems tailored to the patient and their culture in order to improve/maintain health and well-being.

The literature suggests that culture is an important component of the patient experience and that it requires attention when planning care, but the questions of *how* culture manifests for the patient and exactly *what* care providers need to know about persist. Despite existing tools to assess the cultural competence, it is unclear if the health professions have captured the full array of either the factors comprising cultural competence or the culture-related lived experiences of patients receiving care. The major stakeholders of culturally congruent care are care providers and patients, but the majority of work related to cultural care has focused almost exclusively on the provider perspective. We propose that cultural competence and culturally congruent care are so inextricably linked that each requires the existence of the other. In order for cultural congruence to occur, the care provider must first display cultural competence and there must be an interaction between the stakeholders such that the care proffered equals the care that is both received and perceived (Kagawa-Singer et al., 2014; Schim & Doorenbos, 2010). When this does not occur, cultural distress may manifest. We therefore propose a model of the pathways by which patients may exhibit the impact of cultural distress.

Cultural Distress: An Emerging Paradigm

Our cultural distress model sits firmly within the framework of Madeleine Leininger’s Culture Care Diversity and Universality Theory, which aims to guide provision of culturally congruent care to people of diverse cultures. Additionally, Leininger’s (1988) theory is intended to assist

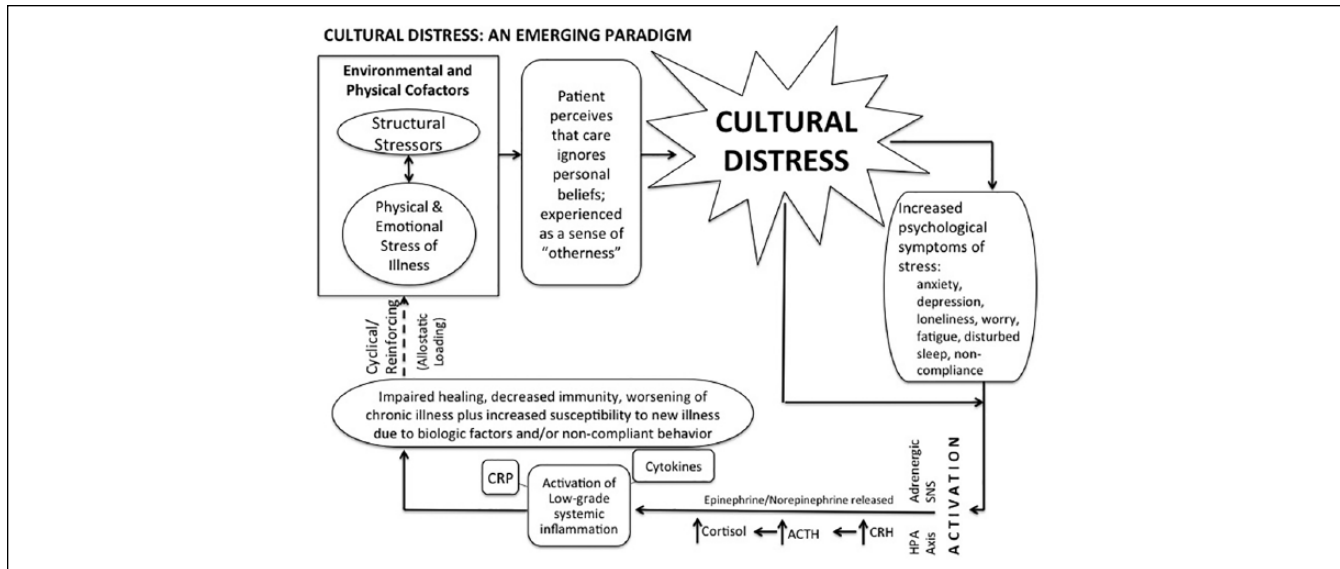


Figure 1. Cultural distress: An emerging paradigm.

Note. The figure illustrates the predictive factors (environmental and physical cofactors, patient perceives that care ignores personal beliefs; experienced as a sense of "otherness") and potential outcomes (allostatic overload) of cultural distress.

in the recognition and understanding of cultural similarities and differences between providers and patients, and inform use of the information to positively influence nursing care and patient health.

We hypothesize that patients may experience a phenomenon we term "cultural distress," when they do not receive culturally congruent care. We define cultural distress as a negative response rooted in a cultural conflict in which the patient lacks control over the environment and the practices taking place in the patient-provider encounter. We further propose that cultural distress may manifest in both physiological and behavioral pathways through the simultaneous experience of stressors related to the following: (1) the disease or illness state, (2) the sense of otherness experienced as a byproduct of stress related to the structure of society, and (3) the power imbalance within the patient-provider relationship. The layered experience of cultural distress may contribute to increased sickness behaviors (Glaser & Kiecolt-Glaser, 2014), delayed healing, decreased accessing and utilization of health services, and ultimately to physiologic responses such as heightened inflammatory activity and allostatic loading (Bevans & Sternberg, 2012; Canales, 2000, 2010; Grove & Zwi, 2006; R. L. Johnson, Saha, et al., 2004; Kaestner, Pearson, Keene, & Geronimus, 2009; Letiecq, Grzywacz, Gray, & Eudave, 2013; McEwen & Seeman, 1999; Viruell-Fuentes, 2011; Viruell-Fuentes, Miranda, & Abdulrahim, 2012).

Components of the Cultural Distress Model

The cultural distress model (Figure 1) examines the physical and psychosocial stress states of patients as they enter the

care setting and the trajectory of potential stress responses that may be related to whether or not the care addresses the patient's cultural beliefs. Specifically, the model incorporates the idea that the experience of illness is accompanied by a baseline level of stress (Delgado, 2007). Additionally, it suggests that individuals who do not see themselves integrated into the structural confines of their society, but as being a part of another culture, may experience an increased level of otherness (Canales, 2000, 2010). The model further postulates that when patients perceive that care does not take into account their cultural beliefs—that is, is not culturally congruent—the care may not adequately support restoration of health. Furthermore, by ignoring the cultural beliefs of the patient the care provider may increase the imbalance of power in the patient-provider relationship by imposing their own cultural beliefs, increasing potential for cultural distress and physiologic dysregulation.

Othering and Structural Stress. Othering is the process by which one experiences alienation, marginalization, and exclusion because of visible differences from those perceived as typical and socially acceptable. Differences include skin color, language, physical ability, gender, and accent, among others (Canales, 2000, 2010). Not only does the process of othering identify or mark those who appear outwardly different than the majority, the experience also influences view of self in relation to the rest of society (Jensen, 2011; Lewis-Fernández et al., 2014). Though often unintentional, the act of othering can create and reinforce positions of dominance and subordination, risking feelings of marginalization, decreased opportunities, and exclusion by the recipient (Aranda & Jones, 2010; Fine, 1994; J. L. Johnson, Bootorff,

et al., 2004). Adverse outcomes reported in populations likely to experience othering, for example, African Americans, include shorter life expectancy, increased infant mortality, and hypertension (DeLilly & Flaskerud, 2012; Krieger, 1999; Krieger & Sidney, 1996), as well as depression and stress responses (Littleford & Wright, 1998; Noh, Beiser, Kaspar, Hou, & Rummens, 1999; Torres, 2010; Torres & Ong, 2010). The process of othering can also create barriers to care because those who experience otherness feel unwelcome and are less inclined to seek care (Bowes & Domokos, 1993; Poteat, German, & Kerrigan, 2013).

A related concept, structural stress, is the stress created by societal, political, economic, and social structures in which one exists and which can create and maintain otherness. Othering and structural stress typically occur simultaneously, such that an individual identified as “other” experiences stress due to existence outside the dominant or expected social structures. (Canales, 2000; J. L. Johnson, Bootorff, et al., 2004; Kagawa-Singer et al., 2014). Ironically, the structures that create, maintain, and reinforce otherness are often the very structures created to provide equal treatment (J. L. Johnson, Bootorff, et al., 2004). This is particularly true within the health care industry where rigid institutional structures are in place to ensure the provision of uniform and efficient care; for example, limiting the number of allowable visitors, strict appointment and treatment schedules, limited translation services, and minimal time allotted to spend with patients (J. L. Johnson, Bootorff, et al., 2004). Uniform treatment, therefore, does not necessarily translate to equal treatment, particularly with regard to meeting the cultural needs of the patient. In fact, uniform treatment may contribute to othering and reinforce structural stress.

One way that social structures contribute to the experience of otherness is reflected in the way many health care organizations collect demographic information. When asking about gender on an intake form, options for responses are typically restricted to “male” or “female”—which does not fully account for transgender or gender nonconforming individuals. With respect to race demographics, many forms allow for only the most common racial choices and offer an “other” option. Of note, only as recently as the 2010 US Census questionnaire were 16 different racial designations and 7 specific Hispanic origins offered as potential responses—compared with 2008, when the only racial and ethnic designations included were White, White (not Hispanic), Black, Asian, and Hispanic (any race; U.S. Census Bureau, 2011). Since these demographic categories are socially constructed, the omission of any additional identifiers constitutes erasure of entire groups. This is an act of othering, which exponentially increases the experience of structural stress.

Otherness created by structural influences can also affect specific populations. In the case of men who have sex with men during the emergence of HIV/AIDS, seeking the source of transmission led to AIDS becoming synonymous with

being gay. This simultaneously positioned these men collectively as an “at risk” and “of risk” population (Grove & Zwi, 2006). The stigmatization of this population as pathological portrayed these men as a perceived threat to social order, negating any opportunity for full social acceptance (Canales, 2000; Goffman, 2009).

Similarly, the experience of immigrants and others who are considered culturally different than traditional White-American society has been shown to contribute to declines in health: evidence suggests that immigrants are healthier on arrival to the United States than native-born persons, but the longer these same immigrants spend in the United States the more this health advantage declines (Antecol & Bedard, 2006; Cho, Frisbie, Hummer, & Rogers, 2004; Dey & Lucas, 2006; Harker, 2001; Jasso, Massey, Rosenzweig, & Smith, 2004; Kandula, Kersey, & Lurie, 2004; Landale, Oropesa, & Gorman, 2000; Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005; Singh & Hiatt, 2006; Singh & Siahpush, 2011; Stephen, Foote, Hendershot, & Schoenborn, 1994; Torres, 2010). One explanation for this process is the structural stress that results from lack of integration within the host society and the subsequent experience of otherness (Araújo & Borrell, 2006; Burnam, Hough, Karno, Escobar, & Telles, 1987; Finch, Hummer, Kol, & Vega, 2001; Finch & Vega, 2003; Gee, Kobayashi, & Prus, 2003; Torres, 2010; Vega, Sribney, Aguilar-Gaxiola, & Kolody, 2004).

These examples demonstrate how the legal, political, and social structure of U.S. society can create otherness, which can in turn facilitate or hinder access to care for affected populations (Bourdieu, 1986; Drew & Schoenberg, 2011; Salway et al., 2011; Smedley, Stith, & Nelson, 2003; Torres, 2010). The sense of otherness that results from social structures based on gender, ability, ethnicity, race, language, or health status thus clearly has consequences for health care experiences, causing “marginalization, disempowerment, and social exclusion” (Grove & Zwi, 2006) and can no longer be ignored as a critical element in the health and care of diverse populations (Kagawa-Singer et al., 2014). One such consequence may be the development of allostatic load, an impediment to health and healing.

Allostasis and Allostatic Load. Allostatic load is the burden of multiple stressors experienced at the same time and without sufficient time for recovery between stressful events (Bevans & Sternberg, 2012). First identified by McEwen and Seeman (1999), the theory of allostatic load offers a more fully descriptive term than “stress” when referring to physiologic responses to multiple and simultaneous environmental and psychosocial stimuli. Allostatic load builds on the term allostasis, first coined by Sterling and Eyer (1988) and defined as the maintenance of homeostasis throughout change or stress. Allostasis can be differentiated from homeostasis by its emphasis on dynamic or flexible adaptation to changing environments or stressful events rather than on minimizing variability and maintaining a static biologic system response

(homeostasis; Juster, McEwen, & Lupien, 2010; Karatsoreos & McEwen, 2011; Logan & Barksdale, 2008; McEwen & Wingfield, 2010). Stressful events, which engender specific physiologic and behavioral responses, can initiate an allostatic response (Juster et al., 2010; Karatsoreos & McEwen, 2011; Logan & Barksdale, 2008; McEwen & Seeman, 1999; Seeman et al., 2004; Sterling & Eyer, 1988).

Allostasis is the response in which physiologic mediators of cortisol secretion and catecholamines are deployed in effort to return the body to its normal state and is an essential, adaptive response for survival in a changing environment (Bevans & Sternberg, 2012; Karatsoreos & McEwen, 2011). Allostatic load, on the other hand, results from repeated activation of the allostasis mechanism, which may culminate in the inability of the stress response cycle to shut off, leaving physiologic systems unable to adapt when necessary (Seeman et al., 2004). The individual's stress baseline rises with each subsequent stressor until there is no difference between baseline and stressed states. Such a state represents allostatic overloading, in which the overabundance of neural, endocrine, and immune stress mediators can lead to decreased healing and ultimately a lack of resistance to new or idiopathic disease processes (Bevans & Sternberg, 2012; McEwen & Seeman, 1999).

Allostatic load has been studied among caregivers, immigrant populations (Kaestner et al., 2009), those with low socioeconomic status, those living within poor neighborhoods (Schulz et al., 2012), as a factor affecting birth outcomes (Wallace & Harville, 2013), and as a factor in resiliency and aging (Juster et al., 2010), among others. Allostatic load provides a conceptual framework to explain the deleterious psychological, behavioral, and physiological health effects of repeated stressors—including impaired functioning of the immune system, coronary heart disease, and early death that have been elucidated among these populations (Bevans & Sternberg, 2012; Kaestner et al., 2009). We anticipate that cultural distress will share many of the risk factors, signs, and symptoms of allostatic load.

Diagnoses including anxiety, depression, loneliness, disturbed sleep, fatigue, and an inability to carry out recommended health practices may be seen as having a bidirectional relationship with allostatic load, at once being caused by the stress of not receiving care consistent with cultural beliefs, and at the same time acting as sources of additional stress and contributors to allostatic load. The allostatic load, in turn, activates dysregulation of the hypothalamic pituitary adrenal axis and sympathetic nervous system, as well as mediators of low-grade systemic inflammation (Gay et al., 2015; Kaestner et al., 2009; McEwen & Seeman, 1999; Sawyer, Major, Casad, Townsend, & Mendes, 2012; Schulz et al., 2012; Seeman et al., 2004). With this comes the potential to impair healing, decrease immunity, worsen chronic illness, and increase susceptibility to new illness, thus increasing the baseline stress of the existing and new chronic disease. If not mediated, the cycle repeats unabated, risking a

cascade of metabolic, immune, cardiovascular, and neuroendocrine maladaptation (Kaestner et al., 2009; Wallace & Harville, 2013).

Application of the Model to Nursing Research

As equal stakeholders in cultural congruence, patients and providers each bring values, beliefs, and expectations to the encounter. Each, therefore, has the potential to influence interaction—whether positively or negatively (Schim & Doorenbos, 2010). Understanding how patients and care providers define culture and perceive the role and implications of culture when receiving health care services is lacking in the literature (Im, 2015). In developing research on patient outcomes in the context of culturally congruent care, it is imperative that scholars ask these questions. By first establishing a shared language about the concept of culture, it will be possible to develop research investigating potential links between culturally congruent care and patient outcomes. Biobehavioral indicators represent a possible means of elucidating the impact of cultural distress on overall health and wellness outcomes.

Biobehavioral research refers to investigation of the interaction between biology and behavior as well as their bidirectional effects on each other (Grady, 2006). Seeking a biobehavioral link between the administration of culturally congruent care and patient outcomes is one possible means of determining how effectively cultural needs in the delivery of care are addressed. Such a link would provide an objective measure for the provision of culturally appropriate care that is operationalized in a standard, yet individualized, manner. Application of the cultural distress model to guide biobehavioral nursing research may elucidate some of the as yet unidentified pathways by which culture and health are related. Discovery of a biobehavioral association between culturally congruent care and patient outcomes may be a critical component in the development of interventions that support safe and effective care.

Conclusion

In this article, we proposed a possible model for cultural distress, or the stress of receiving care that is incongruent with the patient's cultural needs and beliefs. The potential for cultural distress experiences is likely to increase rapidly across care settings as globalization continues and accelerates (Garneau, 2015). Leininger's work, on which our proposed model is based, provides the foundation for recognizing the importance of culture in patient-provider relationships. It is crucial to listen to the voices of patients during this early research phase, which intends to test the predictive elements in the cultural distress model. Through the amplification of patients' voices, researchers have the opportunity to expand the science in cultural care and to understand how culturally

appropriate care affects patients. Providing this care appropriately will allow providers to support patients more effectively and safely through healing, coping, and wellness preservation. While it is unrealistic to expect health care providers to be experts in the cultures of every patient, understanding what constitutes culturally congruent care, and uncovering the trajectory and implications of cultural distress is realistic and imperative. Only then will we be able to develop tools to aid caregivers in the identification of risk factors for cultural distress and guide implementation of interventions to mediate its occurrence.

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