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**STRUCTURAL STRESS AND OTHERNESS: HOW DO THEY INFLUENCE  
PSYCHOLOGICAL STRESS?**

**A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor  
of Philosophy at Virginia Commonwealth University.**

**by**

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May 2018**

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## Abstract

### STRUCTURAL STRESS AND OTHERNESS: HOW DO THEY INFLUENCE PSYCHOLOGICAL STRESS?

By Christine T. DeWilde, PhD

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2018

Director: Jeanne Salyer, PhD, RN, FNAP  
Associate Professor, Department of Adult Health & Nursing Systems  
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**Background:** The Theory of Cultural Distress offers a framework for understanding the potential outcomes in patients who do not receive care that incorporates their cultural beliefs (DeWilde & Burton, 2017). This study represents initial steps in researching the theory by exploring the layering of stressors that place the patient at risk for Cultural Distress. **Methods:** Utilized a Cross-sectional descriptive correlational analysis of intersecting identities (Structural Stressors), ethnicity-related stressors (Otherness) and ethnic-identity (Otherness) to develop understanding of the potential effects of these variables on psychological stress. Independent variables included intersecting identities, perceived ethnic discrimination, concern for stereotype confirmation, own group conformity pressure, and group membership. The dependent variable was perceived stress. Participants were also asked to define the word culture. **Results:** Stereotype confirmation concern, perceived ethnic discrimination, group membership, and own

group conformity pressure were significantly associated with perceived stress. Intersectionality was not significantly associated with perceived stress but was significantly associated with perceived ethnic discrimination. Regression analysis revealed stereotype confirmation concern, own group conformity pressure, and group membership as significant predictors of perceived stress. Participant definitions of culture primarily fell under two themes, Collectiveness and Individualness, indicating that the way we live is highly influenced by our shared experiences, and also a product of individual choices. **Discussion:** Results indicated that structural stressors had no influence on psychological stress but were associated with perceptions of discrimination. The experience of otherness significantly influenced psychological stress. Additional research and tool development is needed to better understand how structural stressors may influence psychological stress.

## **CHAPTER 1: STATEMENT OF THE PROBLEM**

### **Introduction**

The concepts of cultural competence and culturally congruent care (CCC) have become increasingly central in service-related industries, including healthcare. For example, organizations including the National Institutes of Health (NIH), U.S. Department of Health and Human Services (HHS), American Nurses Association (ANA), Agency for Healthcare Research and Quality (AHRQ), The Joint Commission, and Health Equality Index (HEI) have made statements about and commitments to ensuring: 1) improvement of person-centered care and reduction of health disparities (AHRQ, 2013; ANA, 2016; HHS, 2016), 2) establishment of cultural competence through organizational and institutional expectations (Human Rights Campaign, 2016), 3) focus on cultural competence education (ANA, 2016; Kagawa-Singer, Dressler, George, & Elwood, 2014), 4) creation of guidelines (AHRQ, 2013; Joint Commission, 2010; Kagawa-Singer et al., 2014), and 5) self-assessment recommendations (ANA, 2016).

### **Statement of the Problem**

While strategies and tools for establishing cultural competence of providers have been proposed in the literature (Anderson et al., 2010; Campinha-Bacote & Campinha-Bacote, 2009; Giger & Davidhizar, 1990; Glittenberg, 2004; Jeffreys, 2006, 2010; Leininger, 1988; Papadopoulos, Tilki, & Ayling, 2008; Purnell, 2002), delineation of an association between CCC and patient outcomes has not been established (Fortiere, Brach, & Bishop, 2004; Kagawa-Singer et al., 2014). With the diversity of the population continuing to grow, greater understanding of how culturally appropriate care, or its lack, impacts patient outcomes is essential (DeWilde &

Burton, 2016). While we have seen an increase in assessments of race and ethnicity as cultural variables over the last 20 years, use of these simplistic measures as proxy for culture incorrectly presume that these dichotomous and nominal markers indicate homogenous and static populations (Kagawa-Singer et al., 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 underdeveloped (Kagawa-Singer et al., 2014).

### **Potential Solution**

A newly developed theory, Cultural Distress (Figure 1), offers a framework for understanding the potential physiological and behavioral outcomes in patients who do not receive care that incorporates their cultural beliefs (DeWilde & Burton, 2016). Cultural Distress is defined 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” (2016, p. 2). In essence, the theory suggests that patients may experience cultural distress through the simultaneous experience of being ill, living within a society in which they do not culturally “fit”, and receiving care that does not tend to their individual cultural beliefs (DeWilde & Burton, 2016). The theory further postulates that this simultaneous experience may manifest in both behavioral and physiologic pathways. The concepts addressed in the model include *othering*, *structural stress*, and *allostatic load*.

**Summary of the model components.** Othering is defined as the experience of feeling marginalized and excluded because of the visible differences from those perceived as more mainstream and socially acceptable (Canales, 2000; 2010). The process of othering marks those who are perceptibly different than the dominant society such that individuals being “othered”

view themselves as “less than” in relation to the rest of society (Lewis-Fernández, Aggarwal, et al., 2014). Structural stress is established by the political, societal, economic, and social structures in which one lives and which can create and sustain otherness (Canales, 2000; 2010; DeWilde & Burton, 2017; Grove & Zwi, 2006; Johnson et al., 2004; Kagawa-Singer et al., 2014; Letiecq, Grzywacz, Gray, & Eudave, 2013; Thompson & Kumar, 2011; Viruell-Fuentes, Miranda, & Abdulrahim, 2012). Structural stress and othering usually co-occur because the individual experiencing otherness subsequently experiences stress from existing outside of the expected dominant social structures (Canales, 2000; Johnson et al., 2004; Kagawa-Singer et al., 2014)

Allostasis is the maintenance of homeostasis in an environment of change or stress (Sterling & Eyer, 1988). Whereas homeostasis minimizes and maintains a static biologic response, allostasis dynamically adapts to changing environments and stressful events (Juster, McEwen, & Lupien, 2010; Karatsoreos & McEwen, 2011; Logan & Barksdale, 2008; McEwen & Wingfield, 2010). With repeated activation of the allostasis mechanism, the ability of the stress response cycle may become impaired, leaving the physiologic systems unable to adapt when needed (Seeman et al., 2004a)--the result of which is an overabundance of neural, endocrine, and immune stress mediators, causing dysregulation of the Hypothalamic Pituitary Adrenal (HPA) axis, Sympathetic Nervous System (SNS), and mediators of low-grade systemic inflammation (Gay et al., 2015; Kaestner, Pearson, Keene, & Geronimus, 2009; McEwen & Seeman, 1999; Sawyer, Major, Casad, Townsend, & Mendes, 2012; Schulz et al., 2012; Seeman et al., 2004).

## **Empirical Model for this Study**

Guided by the Theory of Cultural Distress (Figure 1) and the empirical model proposed in Figure 2, this study explores structural stress and otherness to better understand the potential cumulative psychological stress burden for patients, and is conceptualized through intersectionality, ethnicity-related stress, ethnic identity, and psychological stress.

**Empirical model components defined.** *Intersectionality* refers to the overlapping of identities, experiences, and categories including, but not limited to race, ethnicity, gender, gender-identity, and class (Hancock, 2007). The identities fall along a continuum of disadvantage to privilege (Figure 3) and represent potential sources of structural stress. *Ethnicity-related stress* is defined as, “The outcome of a person–situation interaction in which perception of features of the social environment, in the light of knowledge of one’s ethnicity, leads either to the anticipation of psychological or physical harm, or to the belief that such harm has already occurred.” (Contrada et al., 2001, p. 1777). *Ethnic-identity* is defined as, “an enduring, fundamental aspect of the self that includes a sense of membership in an ethnic group and the attitudes and feelings associated with that membership” (Phinney, 1996, p. 122). The concepts of *ethnicity-related stress* and *ethnic-identity* are congruent with the concept of otherness in that they address the potential stress and repercussions of living outside of the dominant culture. *Psychological stress* has been defined as what occurs when demands exceed what an individual perceives their capacity for coping (Cohen, Janicki-Deverts, & Miller, 2007).

This early testing of the Cultural Distress theory is focused on exploring the cumulative layering of stressors that place the patient at risk of experiencing Cultural Distress. Figure 2 illustrates the empirical model for this study. *Structural Stress* is operationalized by identification of attributes that represent the intersecting identities of patients. *Otherness* is

operationalized through the concepts of ethnicity-related threat and ethnic-identity. The heightened stress-burden of the co-occurring and simultaneous experience of Structural Stress and Otherness is operationalized through the concept of *Psychological Stress*.

### **Purpose of the Study**

What is not known is whether the concepts of intersectionality, ethnicity-related stress, and ethnic-identity adequately capture the experience of stress for patients as it relates to the receipt of healthcare services and specifically for patients of any cultural, ethnic, or racial heritage. As such, the specific aim of this study is to explore the impact of intersecting identities (Structural Stressors), ethnicity related threat (Otherness), and ethnic-identity (Otherness) on psychological stress. Additionally, this study aims to determine if the concept of culture, as offered in the Theory of Cultural Distress, aligns with the definitions of culture provided by the research participants.



## **CHAPTER 2: CULTURAL DISTRESS CONCEPTUAL FRAMEWORK**

### **Manuscript 1 of 2**

(DeWilde & Burton, 2017)

### **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, 2013b). 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; R. E. Spector, 2002; Rachel E. Spector, 2004). 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 bio-behavioral 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 healthcare is no exception. Over the last 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 et al., 2014a; Somers, 1994b). 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 non-existent (Kagawa-Singer et al., 2014a). 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, 2009b; J. Campinha-Bacote, 2002; Josepha Campinha-Bacote, 2011a, 2011b, 2011c; Giger & Davidhizar, 1990b; Glittenberg, 2004b; Jeffreys, 2010b; M. Leininger, 1997; M. M. Leininger, 1988b; Papadopoulos, Tilki, & Ayling, 2008b; Purnell, 2002b), however delineation of the association between culturally congruent care and patient outcomes is lacking (Fortiere, Brach, & Bishop, 2004b; Kagawa-Singer et al., 2014a).

**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” (Tylor, 1871). Madeleine Leininger 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” (M. Leininger, 1997). 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., 2014a). For the purposes of this paper, 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 healthcare and self-care practices (Kagawa-Singer et al., 2014a). 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) 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) (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, 2015a; Kagawa-Singer et al., 2014a).

**Cultural competence and congruence.** While there is no universal definition of cultural competence, within healthcare 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 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 (M. M. Leininger, 1988b).

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., 2014a; 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 theory is intended to assist 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 (M. M. Leininger, 1988b).

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: 1) the disease or illness state, 2) the sense of otherness experienced as a by-product 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; 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 (M. K. Canales, 2010b; Mary K. Canales, 2000b). The model further postulates that when patients perceive that care does not take into account their cultural beliefs--i.e., is not culturally congruent—the care may not adequately support restoration of health. Further, 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 (M. K. Canales, 2010b; Mary K. Canales, 2000b). 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, Krishan, 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; Joy L. Johnson 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 & by, 2012; Krieger, 1999; Krieger & Sidney, 1996), as well as depression and stress responses (Littleford & Wright, 1998; Noh, Beiser, Kaspar, Hou, & Rummens, 1999; Torres, 2010; 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. (Mary K. Canales, 2000b; Joy L. Johnson et al., 2004; Kagawa-Singer et al., 2014a). Ironically, the

structures that create, maintain, and reinforce otherness are often the very structures created to provide equal treatment (Joy L. Johnson et al., 2004). This is particularly true within the healthcare 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 (Joy L. Johnson 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 healthcare 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 sixteen different racial designations and seven specific Hispanic origins offered as potential responses—compared to 2008, when the only racial and ethnic designations included were White, White (not Hispanic), Black, Asian, and Hispanic (any race) (US 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, 2006b). The stigmatization of this population as pathological portrayed these men as a perceived threat to social order, negating any opportunity for full social acceptance (Mary K. Canales, 2000b; 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 upon arrival to the U.S. than native-born persons, but the longer these same immigrants spend in the U.S. 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 healthcare experiences, causing “marginalization, disempowerment, and social exclusion” (Grove & Zwi,

2006b) and can no longer be ignored as a critical element in the health and care of diverse populations (Kagawa-Singer et al., 2014a). 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 (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, 2010b; Karatsoreos & McEwen, 2011b; Logan & Barksdale, 2008b; B. S. McEwen & Wingfield, 2010b). Stressful events, which engender specific physiologic and behavioral responses, can initiate an allostatic response (Juster et al., 2010b; Karatsoreos & McEwen, 2011b; Logan & Barksdale, 2008b; B. McEwen & Seeman, 1999b; Seeman et al., 2004b; Sterling & Eyer, 1988b).

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, 2011b). 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., 2004b). 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; B. McEwen & Seeman, 1999b).

Allostatic load has been studied among caregivers, immigrant populations (Kaestner et al., 2009b), those with low socio-economic status, those living within poor neighborhoods (Schulz et al., 2012b), as a factor affecting birth outcomes (Wallace & Harville, 2013), and as a factor in resiliency and aging (Juster et al., 2010b) 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., 2009b). 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 bi-directional 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 (HPA) axis and Sympathetic Nervous System (SNS), as well as mediators of low-grade systemic inflammation (Gay et al., 2015b; Kaestner et al., 2009b; B. McEwen & Seeman, 1999b; Sawyer, Major, Casad, Townsend, & Mendes, 2012b; Schulz et al., 2012b; Seeman et al., 2004b). 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., 2009b; 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 healthcare 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 paper, 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, 2015a). 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 healthcare 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.

## CHAPTER 3: METHODOLOGY

### Design, sample and setting

This research explored the antecedents of cultural distress through a cross-sectional descriptive correlational analysis of intersecting identities, ethnicity-related stressors, and ethnic-identity to develop understanding of the potential effects of these variables on psychological stress (Figure 2).

Using a medium effect size ( $f^2 = 0.15$ ), an alpha = 0.05 and a desired power of 80%, it was determined that 92 subjects were needed to determine a non-zero correlation. A convenience sample of 100 participants (48 men, 52 women) was recruited from five outpatient clinics that provide care to patients with chronic illness within the Virginia Commonwealth University Health System (VCUHS), including cardiology, infectious disease, gastroenterology, sickle cell, and pulmonary medicine. Inclusion criteria included male and female adults, 18 years of age and older, having had at least four healthcare encounters over the preceding twelve-month period. Exclusion criteria included the inability to provide informed consent, prisoners, wards of the state, and inability to speak and read English well enough to complete the study questionnaires. VCUHS is located in Richmond, Virginia and is a large, culturally diverse, urban, academic medical center which serves a population that is consistent with the US Census Bureau's 2016 report which includes the following: (1) total population of 220,289, (2) 52% female/48% male, (3) 40% White, 47% Black, 2% Asian, 0.3% Native American and Alaska Native, 0.1% Native Hawaiian or Pacific Islander, with 3% identifying with two or more races, and 6% identifying as Hispanic across all races (US Census Bureau, 2016).

## **Data Collection**

Following IRB approval, potential participants were approached for consent as they awaited their scheduled healthcare appointment and were fully informed about the study, including being given an opportunity to ask questions.

Prior to completing the questionnaires, participants provided a free-text response to the question, “How do you define the term culture?” This was used to explore similarities and differences in the complex meaning of culture for the participants and to develop a taxonomic structure for the concept. The free-text portion of the research was administered via paper and pencil and then transcribed. Participants then completed the demographic questionnaire and study questionnaires for a total of 81 questions and were completed within 20-40 minutes. Responses were entered into the electronic database. Following completion of the study questionnaires, participants were given a \$10 gift card to Walmart.

## **Variables and Measures**

### **Independent variables**

The theoretical model (Figure 1) depicts structural stress as a major contributor to a baseline of psychological stress that can occur for those existing outside of traditional White-American society, however, there is no tool for measuring structural stress. We can, however, use the concept of intersecting identities (Figure 3) as a means of identifying potential sources of structural stress. Potential sources of structural stress included nine “intersecting identities”. Information on age, gender, religion/spirituality, sexual orientation, race/ethnicity, abled/disabled, education level, language, and income were dichotomized as 0=privileged and 1=disadvantaged (Lor, Crooks, & Tluczek, 2016). Responses were summated to calculate a score

ranging from 0-9 with higher scores indicating greater sources of structural stress.

A validated measure of “otherness” does not currently exist, therefore, the concept of ethnicity-related stress and ethnic-identity was used as a means of depicting the experience of otherness in participants. The Measures of Ethnicity-related Threat and Ethnic-identity (METEI) consist of four Likert-type scales developed by Contrada (2001) and include the Perceived Ethnic Discrimination Questionnaire (PEDQ), Stereotype Confirmation Concern Scale (SCCS), Own-Group Conformity Pressure Scale (OGCPS), and the Group Membership Questionnaire (GMQ). Utilization of the measures of ethnicity-related stress and ethnic-identity is rationalized by a lack of any tool specifically designed to identify the experience of otherness and its close association to the concept of culture.

Each of the original measures has been pilot tested and validated, indicating that the instruments are psychometrically sound, can detect meaningful differences between ethnic groups, and offer constructs that may aid in understanding the implications of ethnicity-related stress on physical and mental health (Contrada et al., 2001). The METEI has been used as a measure of ethnicity-related stress in several studies and is intended for use across racial and ethnic groups (Brondolo et al., 2005; Chávez & French, 2007; Contrada et al., 2001; French & Chavez, 2010; Ojeda, Navarro, Meza, & Arbona, 2012). Originally the instrument was designed to assess global ethnicity-related stress over a 3-month period of time (Contrada et al., 2001); however, the measures have been modified, with permission of the author, and named, Measures of Ethnicity-related Stress and Ethnic Identity – Healthcare Version (METEI-HV). The instrument surveys patients’ perceptions of their experiences receiving healthcare services over a 6- to 12-month period. Modifications to the questionnaires were minimal and related to making the tool apply specifically to the healthcare setting where appropriate. Scoring for each



measurement is computed as the mean of the item responses. Higher scores indicate higher stress related to ethnicity and is assessed as a higher potential to experience otherness.

The PEDQ (adapted) measures seven forms of perceived ethnic discrimination in a total of 21 items. The original version had a total of 22 items. In the adapted version, one item was omitted because the item was not applicable to the healthcare setting. The forms of discrimination include devaluation (5 items), threat/aggression (5 items), verbal rejection (3 items), avoidance (3 items), and exclusion and denial of equal treatment (5 items). The measure utilizes a 7-point Likert response scale ranging from 1 (never) to 7 (very often) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .65-.90$  and in this study, the Cronbach's alpha was  $\alpha = 0.97$ .

The SCCS is a tool designed to measure stereotype confirmation concern and includes 11 items through which respondents indicate a level of concern that by demonstrating specific behaviors they may be confirming stereotypes about their ethnic group. Behaviors include, but are not limited to, eating certain foods, dressing, sports, shopping preferences, and talking patterns. Respondents answered the items via a 7-point Likert scale ranging from 1 (never) to 7 (always) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .89-.91$  and in this study, the Cronbach's alpha was  $\alpha = 0.95$ .

The OGCPS is a measure of the degree of pressure members of the same ethnic group feel to conform to certain behaviors. The tool has 16 items and uses a 7-point Likert scale ranging from 1(not at all pressured) to 7 (quite a bit pressured) and refers to style/interests (7 items), social relations (5 items), and academics and partying (4 items) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .79-.89$  and in this study, the Cronbach's alpha was  $\alpha = 0.97$ .

The final measure, the GMQ, addresses how members of an ethnic group feel about being a member of that group. This 12-item survey explores, in general, how persons within an ethnic group feel about being a member of that group. This measurement was utilized to explore levels of ethnicity-related stress because of their affiliation with a certain ethnic group. It consists of 12 statements which refer to public regard (4 items), private feelings (3 items), and identity centrality (4 items) and utilizes a 7-point Likert scale for responses. One additional question did not fit into any of the subscales and refers to participant's perception of benefit for membership within their ethnic group. In previous studies, the reliability estimates have been reported as  $\alpha = .74-.86$  and in this study, the Cronbach's alpha was  $\alpha = 0.55$ .

### **Dependent variable**

Perceived stress was used to capture participant's baseline level of psychological stress to better understand the potential cumulative burden of cultural stressors that may place patients at risk for Cultural Distress. Psychological stress was measured using the Perceived Stress Scale-10 (PSS-10). This questionnaire is used to assess the degree to which people perceive their lives as stressful (Cohen, Kamarck, & Mermelstein, 1983). Participants indicated how often they have found their lives unpredictable, uncontrollable, and overloaded in the last month. The tool has 10 items and uses a 4-point Likert scale ranging from 1 (never) to 4 (very often). Higher scores reflect higher levels of perceived stress. In previous studies, the reliability estimates have been reported as  $\alpha = .78$  and in this study, the Cronbach's alpha was  $\alpha = 0.86$ .

### **Analysis**

A systematic iterative process, informed by a codebook, was used to code the free-text transcripts (Bernard, Wutich, & Ryan, 2016). Four primary themes and 13 sub-themes were

identified (Figure 4). Each theme was defined with inclusion criteria and typical exemplars (Table 1). Participant definitions were reviewed and classified into a typology scheme based upon the codebook rules and analyzed for frequency of use. The relationship between primary and sub-theme frequencies were explored to identify participant definitions of culture. Results were then considered in relation to the results of the quantitative measures. Detailed methodology for the codebook development and coding process are abbreviated here for brevity.

The sample was characterized by demographics, including gender, age, race, and ethnicity. Continuous variables were reported as mean and standard deviation and categorical variables were reported as frequency and percent. Each of the continuous variables were summarized using mean and standard deviation. The METEI is made up of 4 Likert scales, 3 of which characterize ethnicity-related stress and 1 that characterizes ethnic-identity. To examine the reliability of these sub-scales, Cronbach's alpha was computed. A correlation analysis was performed to assess for multi-collinearity among the independent variables as well as to determine the direction and strength of relationship between the independent and dependent variables. A multiple regression using the five independent variables to assess the effect on the dependent variable, perceived stress, was computed.

## **CHAPTER 4: FINDINGS**

### **Manuscript 2 of 2**

#### **Background and Significance**

As diversity in the population increases, greater understanding of how culturally appropriate care impacts patient outcomes is essential (DeWilde & Burton, 2017). The concepts of cultural competence and congruence have become increasingly central in service-related industries, including healthcare (Agency for Healthcare Research and Quality, 2016; Agency for Healthcare Research and Quality, 2013; American Nurses Association, 2017; Human Rights Campaign, 2016; Joint Commission, 2014; Kagawa-Singer, Dressler, George, & Elwood, 2014a). Strategies and tools for fostering the cultural competence of providers have been proposed in the literature (Anderson et al., 2010; Campinha-Bacote & Campinha-Bacote, 2009; Giger & Davidhizar, 1990; Glittenberg, 2004; Jeffreys, 2006, 2010; Leininger, 1988; Papadopoulos, Tilki, & Ayling, 2008; Purnell, 2002), however an association between culturally competent and congruent care and patient outcomes has not yet been established (Fortiere, Brach, & Bishop, 2004; Kagawa-Singer et al., 2014). Though we have seen an increase in assessments of race and ethnicity as cultural variables over the last 20 years, use of these simplistic measures as proxy for culture may incorrectly presume that these dichotomous and nominal markers suggest homogenous and static populations (Kagawa-Singer et al., 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 behavior and beliefs, social norms, practices, and knowledge of groups as they relate to health and well-being is underdeveloped (Kagawa-Singer et al., 2014). This research begins the probe

into how the administration of culturally competent and congruent care may impact patient outcomes by exploring the concepts of structural stress and otherness and their influence on the psychological stress of patients.

### **Conceptual Framework**

The Theory of Cultural Distress (Figure 1), which builds upon the foundations of Leininger's Culture Care Theory (1988), offers a framework for understanding the potential physiological and behavioral outcomes in patients who do not receive care that incorporates their cultural beliefs (DeWilde & Burton, 2017). Cultural distress is defined 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" (DeWilde & Burton, 2017, p.2) and suggests that patients may experience cultural distress through the simultaneous experience of being ill, living within a society in which they do not culturally "fit", and receiving care that does not address their individual cultural beliefs (DeWilde & Burton, 2017). The theory further postulates that this simultaneous experience may manifest in both behavioral and physiologic pathways. The concepts addressed in the model include *othering*, *structural stress*, and *allostatic load*.

Othering is defined as the experience of feeling marginalized and excluded because of the visible differences from those perceived as more mainstream and socially acceptable (Canales, 2000; 2010). The process of othering marks those who are perceptibly different than the dominant society such that individuals being "othered" view themselves as "less than" in relation to the rest of society (Lewis-Fernández, Aggarwal, et al., 2014). Structural stress is established by the political, societal, economic, and social structures in which one lives and which can create and sustain otherness (Canales, 2000; 2010; DeWilde & Burton, 2017; Grove & Zwi, 2006;

Johnson et al., 2004; Kagawa-Singer et al., 2014; Letiecq, Grzywacz, Gray, & Eudave, 2013; Thompson & Kumar, 2011; Viruell-Fuentes, Miranda, & Abdulrahim, 2012). Structural stress and othering usually co-occur because the individual experiencing otherness subsequently experiences stress from existing outside of the expected dominant social structures (Canales, 2000; Johnson et al., 2004; Kagawa-Singer et al., 2014)

Allostasis is the maintenance of homeostasis in an environment of change or stress (Sterling & Eyer, 1988a). Whereas homeostasis minimizes and maintains a static biologic response, allostasis dynamically adapts to changing environments and stressful events (Juster, McEwen, & Lupien, 2010; Karatsoreos & McEwen, 2011; Logan & Barksdale, 2008; McEwen & Wingfield, 2010). With repeated activation of the allostasis mechanism, the ability of the stress response cycle may become impaired, leaving the physiologic systems unable to adapt when needed (Seeman et al., 2004a)--the result of which is an overabundance of neural, endocrine, and immune stress mediators, causing dysregulation of the Hypothalamic Pituitary Adrenal (HPA) axis, Sympathetic Nervous System (SNS), and mediators of low-grade systemic inflammation (Gay et al., 2015; Kaestner, Pearson, Keene, & Geronimus, 2009; McEwen & Seeman, 1999; Sawyer, Major, Casad, Townsend, & Mendes, 2012; Schulz et al., 2012; Seeman et al., 2004).

Guided by the Theory of Cultural Distress (Figure 1) and the empirical model proposed in Figure 2, this study explores structural stress and otherness to better understand the potential cumulative psychological stress burden for patients, and is conceptualized through intersectionality, ethnicity-related stress, ethnic identity, and psychological stress.

*Intersectionality* refers to the overlapping of identities, experiences, and categories including, but not limited to race, ethnicity, gender, gender-identity, and class (Hancock, 2007). The identities

fall along a continuum of disadvantage to privilege (Figure 3) and represent potential sources of structural stress. *Ethnicity-related stress* is defined as, “The outcome of a person–situation interaction in which perception of features of the social environment, in the light of knowledge of one’s ethnicity, leads either to the anticipation of psychological or physical harm, or to the belief that such harm has already occurred.” (Contrada et al., 2001, p. 1777). *Ethnic-identity* is defined as, “an enduring, fundamental aspect of the self that includes a sense of membership in an ethnic group and the attitudes and feelings associated with that membership” (Phinney, 1996, p. 122). The concepts of *ethnicity-related stress* and *ethnic-identity* are congruent with the concept of otherness in that they address the potential stress and repercussions of living outside of the dominant culture. *Psychological stress* has been defined as what occurs when demands exceed what an individual perceives their capacity for coping (Cohen et al., 2007).

This early testing of the Cultural Distress theory is focused on exploring the cumulative layering of stressors that place the patient at risk of experiencing Cultural Distress. Figure 2 illustrates the empirical model for this study. *Structural Stress* is operationalized by identification of attributes that represent the intersecting identities of patients. *Otherness* is operationalized through the concepts of ethnicity-related threat and ethnic-identity. The heightened stress-burden of the co-occurring and simultaneous experience of Structural Stress and Otherness is operationalized through the concept of *Psychological Stress*.

### **Purpose**

What is not known is whether the concepts of intersectionality, ethnicity-related stress, and ethnic-identity adequately capture the experience of stress for patients as it relates to the receipt of healthcare services and specifically for patients of any cultural, ethnic, or racial heritage. As such, the specific aim of this study is to explore the impact of intersecting identities

(Structural Stressors), ethnicity related threat (Otherness), and ethnic-identity (Otherness) on psychological stress. Additionally, this study aimed to determine if the concept of culture, as offered in the Theory of Cultural Distress, aligns with the definitions of culture provided by the research participants.

## **Methods**

### **Design, sample and setting**

This research explored the antecedents of cultural distress through a cross-sectional descriptive correlational analysis of intersecting identities, ethnicity-related stressors, and ethnic-identity to develop understanding of the potential effects of these variables on psychological stress (Figure 2).

Using a medium effect size ( $f^2 = 0.15$ ), an alpha = 0.05 and a desired power of 80%, it was determined that 92 subjects were needed to determine a non-zero correlation. A convenience sample of 100 participants (48 men, 52 women) was recruited from five outpatient clinics that provide care to patients with chronic illness within the Virginia Commonwealth University Health System (VCUHS), including cardiology, infectious disease, gastroenterology, sickle cell, and pulmonary medicine. Inclusion criteria included male and female adults, 18 years of age and older, having had at least four healthcare encounters over the preceding twelve-month period. Exclusion criteria included the inability to provide informed consent, prisoners, wards of the state, and inability to speak and read English well enough to complete the study questionnaires. VCUHS is located in Richmond, Virginia and is a large, culturally diverse, urban, academic medical center which serves a population that is consistent with the US Census Bureau's 2016 report which includes the following: (1) total population of 220,289, (2) 52% female/48% male,



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The PEDQ (adapted) measures seven forms of perceived ethnic discrimination in a total of 21 items. The original version had a total of 22 items. In the adapted version, one item was omitted because the item was not applicable to the healthcare setting. The forms of discrimination include devaluation (5 items), threat/aggression (5 items), verbal rejection (3 items), avoidance (3 items), and exclusion and denial of equal treatment (5 items). The measure utilizes a 7-point Likert response scale ranging from 1 (never) to 7 (very often) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .65-.90$  and in this study, the Cronbach's alpha was  $\alpha = 0.97$ .

The SCCS is a tool designed to measure stereotype confirmation concern and includes 11 items through which respondents indicate a level of concern that by demonstrating specific behaviors they may be confirming stereotypes about their ethnic group. Behaviors include, but are not limited to, eating certain foods, dressing, sports, shopping preferences, and talking patterns. Respondents answered the items via a 7-point Likert scale ranging from 1 (never) to 7 (always) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .89-.91$  and in this study, the Cronbach's alpha was  $\alpha = 0.95$ .

The OGCPS is a measure of the degree of pressure members of the same ethnic group feel to conform to certain behaviors. The tool has 16 items and uses a 7-point Likert scale ranging from 1(not at all pressured) to 7 (quite a bit pressured) and refers to style/interests (7

items), social relations (5 items), and academics and partying (4 items) (Contrada et al., 2001). In previous studies, the reliability estimates have been reported as  $\alpha = .79-.89$  and in this study, the Cronbach's alpha was  $\alpha = 0.97$ .

The final measure, the GMQ, addresses how members of an ethnic group feel about being a member of that group. This 12-item survey explores, in general, how persons within an ethnic group feel about being a member of that group. This measurement was utilized to explore levels of ethnicity-related stress because of their affiliation with a certain ethnic group. It consists of 12 statements which refer to public regard (4 items), private feelings (3 items), and identity centrality (4 items) and utilizes a 7-point Likert scale for responses. One additional question did not fit into any of the subscales and refers to participant's perception of benefit for membership within their ethnic group. In previous studies, the reliability estimates have been reported as  $\alpha = .74-.86$  and in this study, the Cronbach's alpha was  $\alpha = 0.55$ .

**Dependent variable.** Perceived stress was used to capture participant's baseline level of psychological stress to better understand the potential cumulative burden of cultural stressors that may place patients at risk for Cultural Distress. Psychological stress was measured using the Perceived Stress Scale-10 (PSS-10). This questionnaire is used to assess the degree to which people perceive their lives as stressful (Cohen et al., 1983). Participants indicated how often they have found their lives unpredictable, uncontrollable, and overloaded in the last month. The tool has 10 items and uses a 4-point Likert scale ranging from 1 (never) to 4 (very often). Higher scores reflect higher levels of perceived stress. In previous studies, the reliability estimates have been reported as  $\alpha = .78$  and in this study, the Cronbach's alpha was  $\alpha = 0.86$ .

## **Analysis**

A systematic iterative process, informed by a codebook, was used to code the free-text transcripts (Bernard et al., 2016). Four primary themes and 13 sub-themes were identified (Figure 4). Each theme was defined with inclusion criteria and typical exemplars (Table 1). Participant definitions were reviewed and classified into a typology scheme based upon the codebook rules and analyzed for frequency of use. The relationship between primary and sub-theme frequencies were explored to identify participant definitions of culture. Results were then considered in relation to the definition of Culture as offered within the Theory of Cultural Distress (DeWilde & Burton, 2017). Detailed methodology for the codebook development and coding process are abbreviated here for brevity.

The sample was characterized by demographics, including gender, age, race, and ethnicity. Continuous variables were reported as mean and standard deviation and categorical variables were reported as frequency and percent. Each of the continuous variables were summarized using mean and standard deviation. The METEI is made up of 4 Likert scales, 3 of which characterize ethnicity-related stress and 1 that characterizes ethnic-identity. To examine the reliability of these sub-scales, Cronbach's alpha was computed. A correlation analysis was performed to assess for multi-collinearity among the independent variables as well as to determine the direction and strength of relationship between the independent and dependent variables. A multiple regression using the five independent variables to assess the effect on the dependent variable, perceived stress, was computed.

## **Results**

### **Sample characteristics**

Forty-four of the 100 participants were male ( 44, 44%) and mean age of 55 years  $\pm$  approximately 14. All participants reported identifying as their gender at birth. Race and ethnicity was consistent with that of VCUHS and Richmond, VA as reported in the 2016 US Census Bureau with 39 (39%) Black, 44 (44%) White, 7 (7%) multi-racial, 6 (6%) Hispanic. Other sample characteristics included self-reports of: mental and/or physical disability (36, 36%), religious affiliation (77, 77%), less than high school education (14, 14 %), family income < \$56,516 (69, 69%), and English as 1<sup>st</sup> language (94, 94%). See Table 2.

### **Participant definitions of Culture**

The four primary themes identified in the participant responses included: 1) Collectiveness, 2) Individualness, 3) Scientific Sample, and 4) High Arts. Thirteen sub-themes were identified for Collectiveness and Individualness while no sub-themes were identified for Scientific Sample or High Arts (Figure 4). Participant responses indicated that culture is primarily viewed as a shared phenomenon with 103 of the responses falling within the Collectiveness theme. Participants also significantly viewed the concept of culture as an individual phenomenon with 92 of the responses falling within the Individualness theme. Three responses were included within the Scientific Sample theme and one within High Arts. While these responses reflect existing and valid definitions of culture, the frequency of use was too few for consideration in this sample set. Eight responses were not coded as they either did not address the question or were not interpretable, and 4 participants did not provide a response. The sub-themes identified most frequently within the Collectiveness theme were *Lifeways* ( $f = 28$ ), *Beliefs* ( $f = 19$ ) and *People* ( $f = 14$ ). Sub-themes most frequently identified within the Individualness theme were *History* ( $f = 21$ ), *Lifeways* ( $f = 20$ ), and *Environment* ( $f = 14$ ).

## **Descriptive Statistics of the Model Variables**

Otherness. Otherness was characterized by 2 variables: ethnicity-related threat and ethnic identity. The three variables characterizing ethnicity-related threat included: 1) perceived ethnic discrimination, 2) stereotype confirmation concern, and 3) own-group conformity pressure. On average, participants perceived low ethnic discrimination (mean = 1.41, SD = 0.93, range = 1-7), low stereotype confirmation concern (mean = 1.46, SD = 0.95, range = 1-7), and similarly participants perceived low own-group conformity pressures (mean = 1.19, SD = 0.70, range = 1-6.5). Ethnic-identity, characterized as group membership, was perceived as a neutral influence on participant way of life and ethnic group (mean = 4.49, SD = 0.78, range = 1-6.25).

Structural Stress. Structural stress was characterized as intersectionality. On average participants reported approximately three identities depicting disadvantage (mean = 2.84, SD = 1.85, range = 1-6).

Perceived Stress. Perceived stress was relatively low with a mean of 18.02 (SD = 7.65, range = 4-37). See Table 4.

## **Correlations Among Model Variables**

Spearman's Rho was selected because some independent variables were non-normally distributed. Table 5 shows correlations among the variables. Significant correlations include that stereotype confirmation concern was significantly associated with perceived stress ( $\rho = 0.468$ ,  $p = <0.001$ ), intersectionality was not significantly associated with perceived stress ( $\rho = 0.125$ ,  $p = 0.222$ ) but was significantly associated with perceived ethnic discrimination ( $\rho = 0.262$ ,  $p = 0.008$ ), perceived ethnic discrimination was significantly associated with perceived stress ( $\rho = 0.401$ ,  $p = <0.001$ ), own group conformity pressure was significantly associated with perceived

stress ( $\rho = 0.267$ ,  $p = 0.008$ ), and group membership had a significant inverse association with perceived stress ( $\rho = -0.332$ ,  $p = <0.001$ ). Correlations are depicted in Table 5 and visually in Figures 6-13 via a scatterplot of each variable, including a fit line and a 95% confidence density ellipse. Positive correlations lead to a positive slope in line while a narrower density ellipse indicates a higher correlation.

### **Regression analysis**

The initial model examining predictors of perceived stress included ethnicity-related threat, ethnic-identity, and intersectionality. The three variables characterizing ethnicity-related stress (perceived ethnic discrimination, stereotype confirmation concern, own group conformity pressure), the variable characterizing ethnic-identity (group membership), and intersectionality were used in the regression analysis (See Table 4). Using a backward stepwise elimination model-building approach described by Hosmer and Lemeshow (Hosmer Jr, Lemeshow, & Sturdivant, 2013), the model was trimmed of non-significant variables (perceived ethnic discrimination, intersectionality). This iterative process resulted in a model incorporating stereotype confirmation concern (Beta = 0.502,  $t = 3.443$ ,  $p$ -value = 0.001), own group conformity pressure (Beta = -0.308,  $t = -2.148$ ,  $p$ -value = 0.034), and group membership (Beta = -0.265,  $t = -2.808$ ,  $p$ -value = 0.006) as the significant predictors of perceived stress. Specifically, participants with greater concern for stereotype confirmation and who experience greater pressure to conform by members of their own group, experienced higher levels of perceived stress. Conversely, participants with a greater affinity for group membership experienced lower levels of perceived stress. This model explained 21.6% of the variance ( $R^2 = 0.216$ ,  $F = 8.647$ ,  $p = <0.001$ ).



## **Discussion**

The cultural distress theory suggests a relationship between structural stressors, the experience of otherness and the patient's perception that the care they receive ignores their cultural preferences; the cumulative result of which may be a heightened stress burden i.e., cultural distress and its resultant allostatic overload (DeWilde & Burton, 2016). This research represents an important and necessary first step in the study of the cultural distress model through the exploration of the foundational concepts of the theory (structural stress and otherness) and their potential impact on baseline stress levels, which has not yet been done.

### **Structural Stress**

This research primarily utilized demographic intersectionality to explore associations of the additive nature of multiple disadvantages on psychological stress. On average, participants reported approximately three identities depicting disadvantage, which was not significantly associated with perceived stress. While an association between the collected intersecting identities of the participants did not reveal a statistically significant association with perceived stress, nor was it a predictor, it did reveal a significant association with perceived ethnic discrimination. Given that perceived ethnic discrimination has been associated with activation of the stress response system (Perry, Harp, & Oser, 2013), we should consider that what is lacking is an adequate approach to collecting and analyzing data related to the intersecting identities and the subsequent experience of stress in patients as it relates to health outcomes. Before concluding that there is no association between intersecting identities and psychological stress, we must consider, 1) that there may have been other significant identities that were not captured that depict disadvantage or privilege, and/or 2) that the Perceived Stress Scale may not have been the ideal tool for capturing the implications of disadvantage and privilege.

## **Otherness**

The concepts of ethnicity-related threat and ethnic identity were used to explore the relationship between the experience of otherness and psychological stress. On average, participants rarely perceived ethnic discrimination or stereotype confirmation concern. Similarly, participants did not perceive own-group conformity pressures. Ethnic-identity, characterized as group membership, was perceived as having a neutral influence on participant way of life. It did, however, function as a protective component such that participants who identified strongly with their ethnic group, or with those who share a similar way of life, experienced less psychological stress as measured by the Perceived Stress Scale. These findings are in alignment with previous research indicating that ethnicity-related stressors and ethnic-identity may impact perceptions of well-being, life satisfaction, and self-reported health in the minority populations in which they have been studied (Brondolo et al., 2005; Chávez & French, 2007; Contrada et al., 2001; French & Chavez, 2010; Ojeda, Navarro, Meza, & Arbona, 2012). Also, these results support the theory proposed within the cultural distress framework that the experience of otherness represents a layer of stress that could contribute to a heightened stress baseline on its own or when combined with additional stresses from existing outside of the expected societal norm (DeWilde & Burton, 2017).

## **Defining Culture**

It was of interest to explore participant definitions of the concept of culture to determine congruency with the definition of culture offered within the Theory of Cultural Distress (DeWilde & Burton, 2017). The Theory of Cultural Distress provides that, "...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” (DeWilde & Burton, 2017, p. 2). While there is overlap between participant definitions of culture and what is offered within the Theory of Cultural Distress, it is notable that participants specifically referred to beliefs, way of life, history, and environment, to name a few, which are decidedly missing from what is offered within the Theory of Cultural Distress. Also notable is that the sub-theme, Lifeways, was seen through both a Collectivist or Individualist lens in approximately 25% of the total responses ( $f = 48$ ), indicating that they believe that the way we live is highly influenced by our shared experiences, and also a product of individual choices. This finding is in alignment with previous research indicating that while culture is informed and passed down through generations as a shared body of information or knowledge, it is received individualistically and interpreted by the individual to inform their personal social context, making it flexible or fluid by nature (D’Andrade, 1981; Garneau, 2015b; Kagawa-Singer et al., 2014b; Lakes, López, & Garro, 2006; Pasick & Burke, 2008). Lastly, as shown in Table 3, demographics were not identified as a common theme in the definitions of culture (Collectiveness  $f = 5$ , Individualness  $f = 6$ ), nor was intersectionality (primarily driven by demographic data) found to have a significant association to perceived stress in the quantitative study. This may suggest that the use of intersectionality theory in health research is complex and operationalization may need refinement.

## **Limitations**

Limitations of this research must be considered. This study was conducted in one city and within one hospital. Additionally, the surveys were administered only in English, had a small sample size, and utilized a convenience method for recruitment. Finally, the identities used to

capture structural stress may not constitute the multitude of identities which intersect and place individuals along a continuum of disadvantage to privilege.

### **Implications for theory development and future research**

While the concept of intersectionality has been present within feminist and social science research for the past two decades, it is a relatively new concept within health research (Rogers & Kelly, 2011) and operationalizing the concept for use in health disparities research is complicated (Bauer, 2014). Specifically, deciding which “identities” to include when applying intersectionality to health disparities and social determinants of health research is still under debate. McGibbon and McPherson (2011) suggest a synergistic approach through use of a framework that includes 3 intersectional components: 1) Intersections of Social Determinants of Health, 2) Intersections of Identity as Social Determinants of Health, and 3) Social Determinants of Health: Geographies (Figure 5). They propose that it is precisely where these intersecting identities intersect that reveal the complexities of the social impacts of health across the lifespan (McGibbon & McPherson, 2011). To this end, additional research about how to capture and quantify the lived experience of intersecting identities is necessary. Specifically, determining which identities to include in a tool designed to capture potential sources of structural stress is needed to better understand the potential implications of disadvantage and privilege on health outcomes. Further, the definitions of culture offered by the participants are robust and sophisticated and should be integrated within the concept of culture within the Theory of Cultural Distress in future research and further development of the cultural distress theory.

### **Summary & Conclusions**

This study explored how structural stressors and the experience of otherness influence

psychological stress. It also explored how participants define the word “culture” to determine congruence with the definition offered in the Theory of Cultural Distress. Results indicated that structural stressors had no influence on psychological stress but were associated with perceptions of discrimination. The experience of otherness strongly influenced psychological stress. Given the association between structural stress and perceived discrimination, additional research and tool development is needed to better understand how structural stressors influence may psychological stress. Finally, the characteristics of culture offered within the Theory of Cultural Distress should be refined to reflect the robust and sophisticated participant responses from this study. Findings from this study provide early support for the predictors of cultural distress and suggest fruitful avenues for continued study of the model.

## **CHAPTER 5: DISCUSSION AND CONCLUSION**

The purpose of this study was to explore the impact of intersecting identities (Structural Stressors), ethnicity related threat (Otherness), and ethnic-identity (Otherness) on psychological stress. Additionally, this study aimed to determine if the concept of culture, as offered in the Theory of Cultural Distress, aligns with the definitions of culture provided by the research participants.

The cultural distress theory suggests a relationship between structural stressors, the experience of otherness and the patient's perception that the care they receive ignores their cultural preferences; the cumulative result of which may be a heightened stress burden i.e., cultural distress and its resultant allostatic overload (DeWilde & Burton, 2016). This research represents an important and necessary first step in the study of the cultural distress model through the exploration of the foundational concepts of the theory (structural stress and otherness) and their potential impact on baseline stress levels, which has not yet been done.

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Figures

**CULTURAL DISTRESS: AN EMERGING PARADIGM**

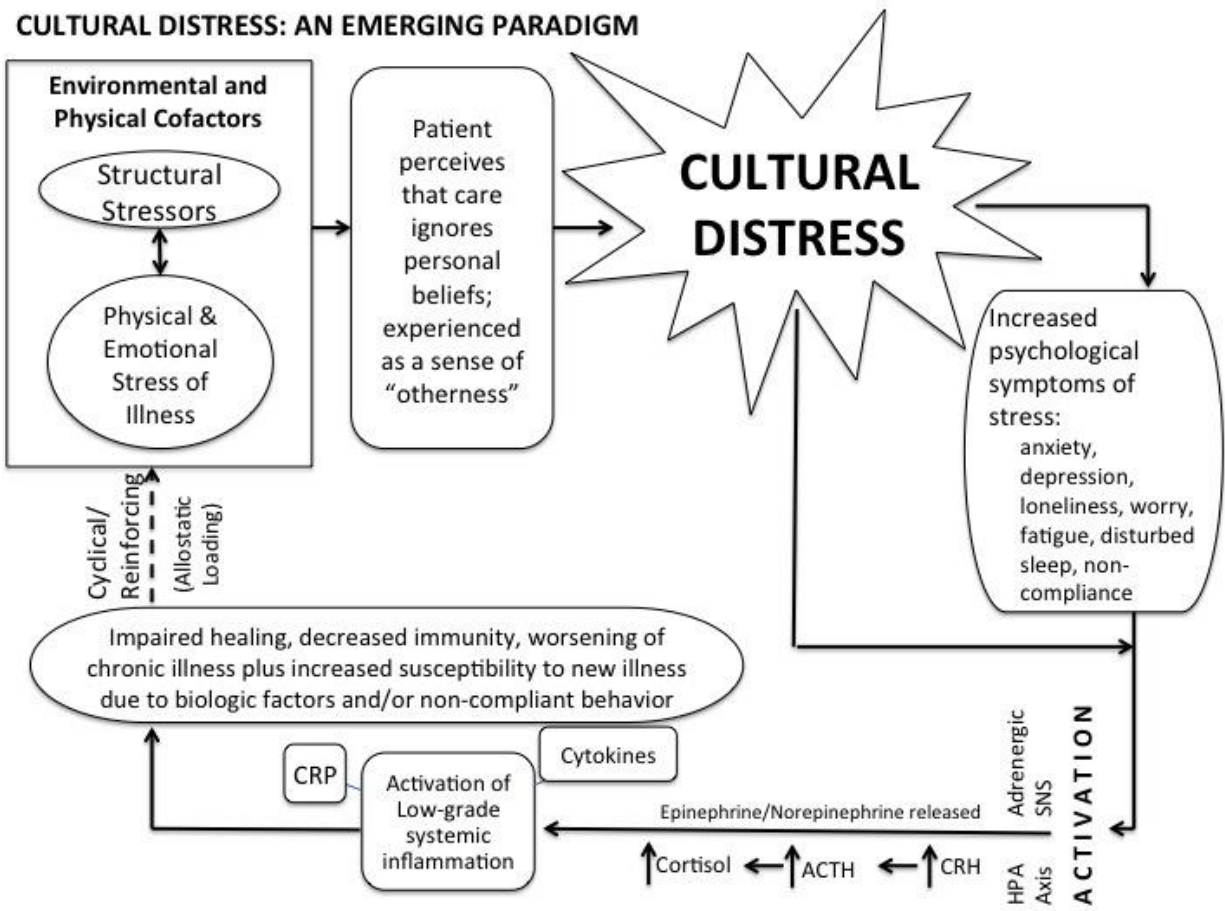


Figure 1. Cultural Distress: An Emerging Paradigm

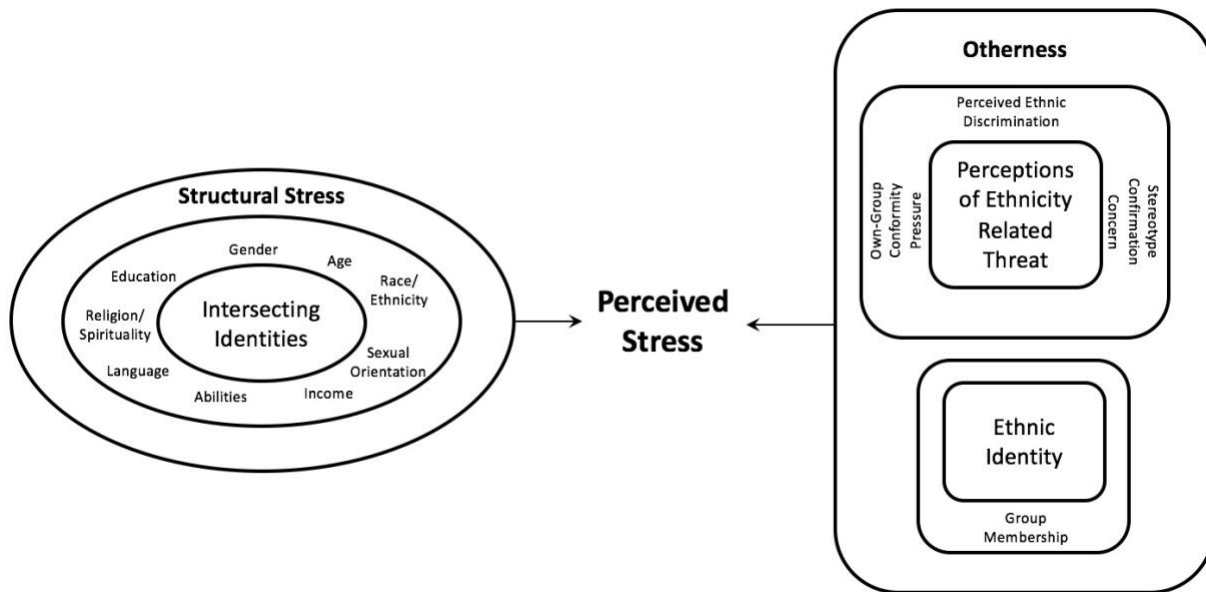
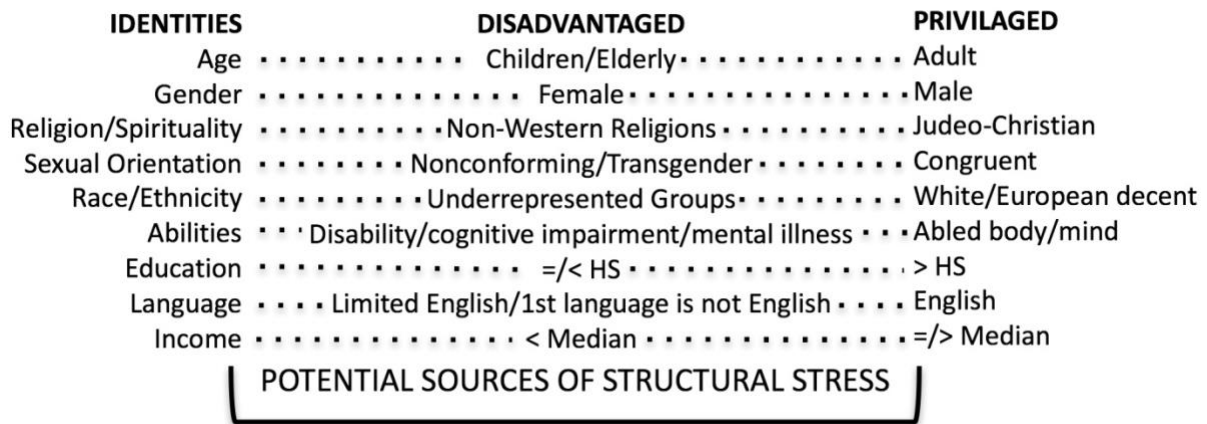


Figure 2: Empirical Model





*Figure 3:* Intersecting Identities as potential sources of structural stress. Adapted from “A proposed model of person-, family-, and culture-centered nursing care” by Macho Lor, MS, RN\*, Natasha Crooks, BSN, RN, Audrey Tluczek, PhD, RN, FAAN, 2016, Nursing Outlook, 64, p. 361. 2016 by Elsevier, Inc.

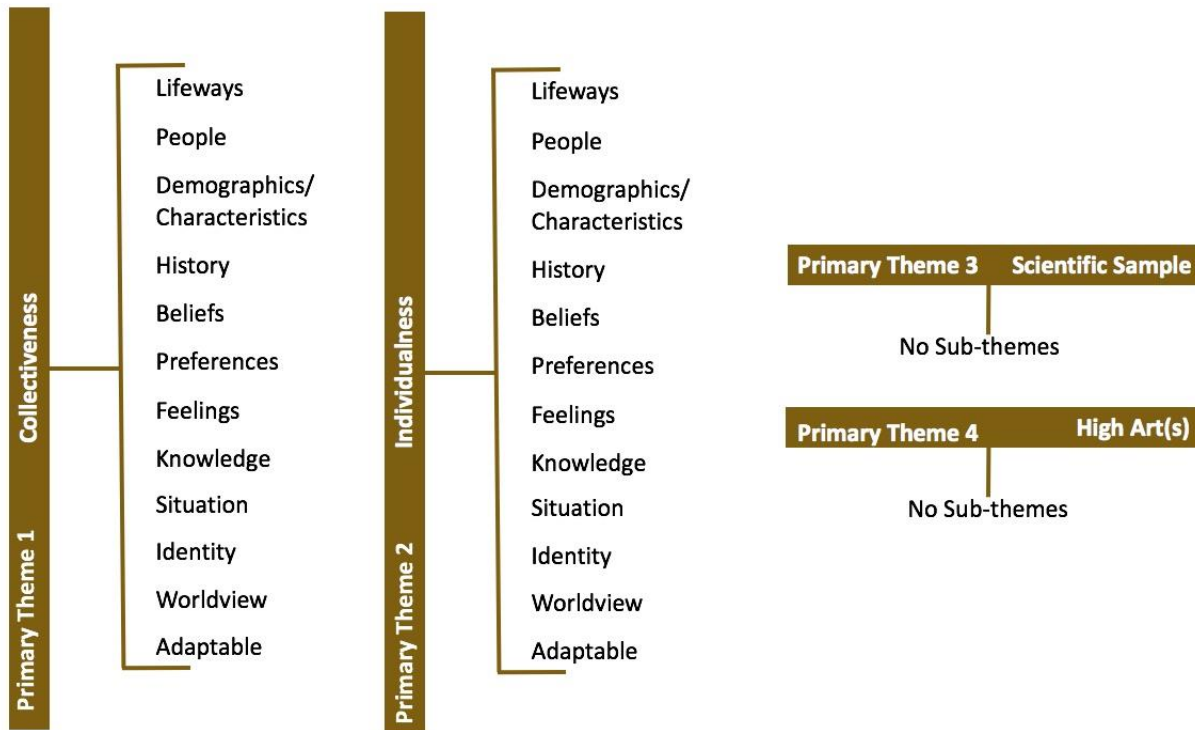
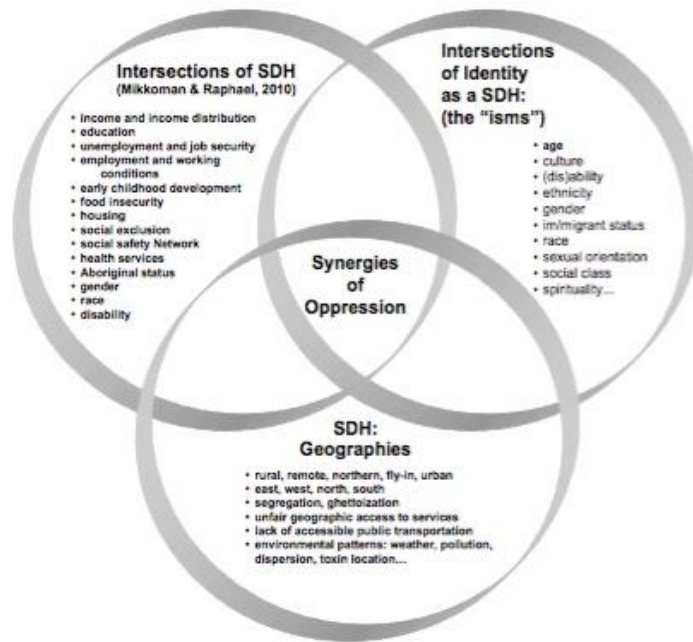


Figure 4: Themes and Sub-themes utilized for coding participant definitions of culture.



*Figure 5* Synergies of Oppression: A Framework for Addressing Social Determinants of Health Inequities (McGibbon & McPherson, 2011)

## Tables

*Table 1: Theme and Sub-Theme Definitions and Exemplars for Codebook Development*

Primary Theme	Description	Exemplars*
Collectiveness	Refers to a group or environment that is comprised of more than one individual	social institutions, Nation, people, social group, social behavior, common language, behavior, beliefs, actions of a group or people, Family
Individualness	Referring to one person	Different backgrounds and origins, how we are accepted and viewed as an individual, depends on you, who you are
Scientific Sample	Refers to a biologic or medical sample used for research	Medical sample, bacteria smear, collection of bacteria
High Art	Refers to the creation or observance or reading of literature, music, visual arts, and performing arts	refers to what is typically called 'high arts', in music, literature, dance, etc..
<b>Sub-themes</b>		
Lifeways	Refers how one lives their life. The specific practices of a person or group of people	Customs, the way people live their lives, how you are raised, the way things are done, food, dress hair, music, actions of a group of people, behavior, How we celebrate holidays and religious beliefs, The way you love and treat your body and living, Actions within a group, organization, or country, family way of raising a child with customs, language, and ideas nature to the area or country (manners, music, foods, relationships), How a group of people live, work, play, how the world around you causes you to think and do
People	Refers Human Beings	People, Nation, social group, person
Demographics/ Classifications	Refers to descriptors of human attributes	Age, race, medical condition, Ethnicity, socioeconomics, color
Environment	Refers to a region of the world or a physical place where one lives, is from, or goes. Can be regional or structured	Where you are from, Medical center, schools, refers to a specific place

History	Refers to past events and experiences of the individual, individual's family, or society	how you are raised, your background, life generations, your roots from the time you were born into the world, the environment you were raised in, environmental effect of people around you, grows up in, my experience of where I come from
Beliefs	Refers to something one accepts as true or real; a firmly held opinion or conviction	What you believe, your beliefs, your religion, how we are influenced by society, code of ethics, set of traditions, behaviors, and norms shared by a group of people, how the world around you causes you to think and do
Preferences	Refers to a greater liking for one alternative over another or others and may or may not impact a person's way of life	music, dress, hair, food, how we are influenced by society
Feelings	Refers to an emotional state or reaction	Way you feel
Knowledge	Refers to an awareness or familiarity gained by experience of a fact or situation	Your education, manifestation of your intellectual achievement
Situation	Refers to an individual's or groups' place (non-physical) in relation to other humans in the world or and the influence of others on the individual	place in relation to the rest of humanity, the atmosphere in which we live, the environment you live in
Identity	Refers to the characteristics of determining who or what a person, group of people, or thing is.	How we define ourselves, how we are perceived in the world, defines who you are, your identity
Worldview	Refers to how a person interprets the world	how a person views life itself, sees the world, the attitudes of people, the way you perceive the world
Adaptable	Refers to the adjustment to new conditions; being flexible or fluid	People can belong to multiple different cultures, culture is a wish-mash of many different cultural aspects blended together, We can adapt to various cultures if we choose to

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\*Note: All exemplars are direct quotes from participant written responses.

Table 2: Sample Characteristics (n=100)

Variable:	f (%)	Mean (SD)	Range
Age		54.69 (13.79)	23-82
• 23-40	14 (14%)		
• 41-60	44 (44%)		
• 61-80	30 (30%)		
• 81-82	2 (2%)		
• Did not respond	10 (10%)		
Race			
• American Indian/Alaskan Native	1 (1%)		
• Asian	1 (1%)		
• Black	39 (39%)		
• White	44 (44%)		
• Multi-racial	7 (7%)		
• Other	8 (8%)		
Ethnicity			
• Hispanic	6 (6%)		
• Non-Hispanic	51 (51%)		
• Did not respond	43 (43%)		
Gender at Birth			
• Male	44 (44%)		
• Female	56 (56%)		
Gender Identity			
• Identifies as gender at birth	100 (100%)		
Religion/Spirituality			
• Judeo Christian	66 (66%)		
• Non-Western	3 (3%)		
• Not Religious	23 (23%)		
• Did not respond	1 (1%)		
• Did not designate a Religion	7 (7%)		
Ability			
• Mentally/Physically Disabled	33 (33%)		
• Did not respond	8 (8%)		
Education			
• < High School	13 (13%)		
• =/> High School	83 (83%)		
• Did not respond	4 (4%)		
Language			
• English as 1 <sup>st</sup> Language	91 (91%)		
• Did not respond	3 (3%)		
Family Income			
• < \$56,516	66 (66%)		
• =/> \$56,516	29 (29%)		
• Did not respond	5 (5%)		

**Note: These sample characteristics were used in the calculation of Intersecting Identities**

Table 3: Theme Frequencies

	<b>Collectiveness</b>	<b>Individualness</b>	<b>Total</b>
Adaptable	1	3	4
Beliefs	19	12	31
Demographics and Characteristics	5	6	11
Environment	13	14	27
Feelings	0	1	1
History	8	21	29
Identity	3	4	7
Knowledge	5	2	7
Lifeways	28	20	48
People	14	2	16
Preferences	2	3	5
Situation	1	1	2
World View	4	3	7
<b>Total</b>	<b>103</b>	<b>92</b>	<b>195</b>

Table 4: Descriptive Statistics of Model Variables

<b>Variable:</b>	<b>Mean (SD)</b>	<b>Range</b>
Otherness (METEI)		
• Ethnicity-related Threat		
○ Perceived Ethnic Discrimination	1.41 (0.93)	1-7
○ Stereotype Confirmation Concern	1.46 (0.95)	1-7
○ Own Group Conformity Pressure	1.19 (0.70)	1-6.5
• Ethnic Identity		
○ Group Membership	4.49 (0.78)	1-6.25
Intersectionality	2.84 (1.35)	1-6
Perceived Stress	18.02 (7.65)	4-37



Table 5: Correlations Among Model Variables ( $\rho$ , p-value)

Variable:	Perceived Ethnic Discrimination	Stereotype Confirmation Concern	Own Group Conformity Pressure	Group Membership	Intersectionality	Perceived Stress
		Spearman $\rho$ (p-value)	Spearman $\rho$ (p-value)	Spearman $\rho$ (p-value)	Spearman $\rho$ (p-value)	Spearman $\rho$ (p-value)
Perceived Ethnic Discrimination	1	0.628 <0.001	0.621 <0.001	-0.341 <0.001	0.262 0.008	0.401 <.001
Stereotype Confirmation Concern		1	0.617 <0.001	-0.408 <0.001	0.004 0.970	0.468 <0.001
Own Group Conformity Pressure			1	-0.299 0.003	0.094 0.352	0.267 0.008
Group Membership				1	0.026 0.799	-0.332 <0.001
Intersectionality					1	0.125 0.222
Perceived Stress						1

*Table 6: Regression Analysis: Factors Influencing Perceived Stress*

	Beta	t-value	p-value
Stereotype Confirmation Concern	.502	3.443	0.001
Own Group Conformity Pressure	-.308	-2.148	0.034
Group Membership	-.265	-2.808	0.006

$R^2 = .216, F = 8.647, p = <.001$

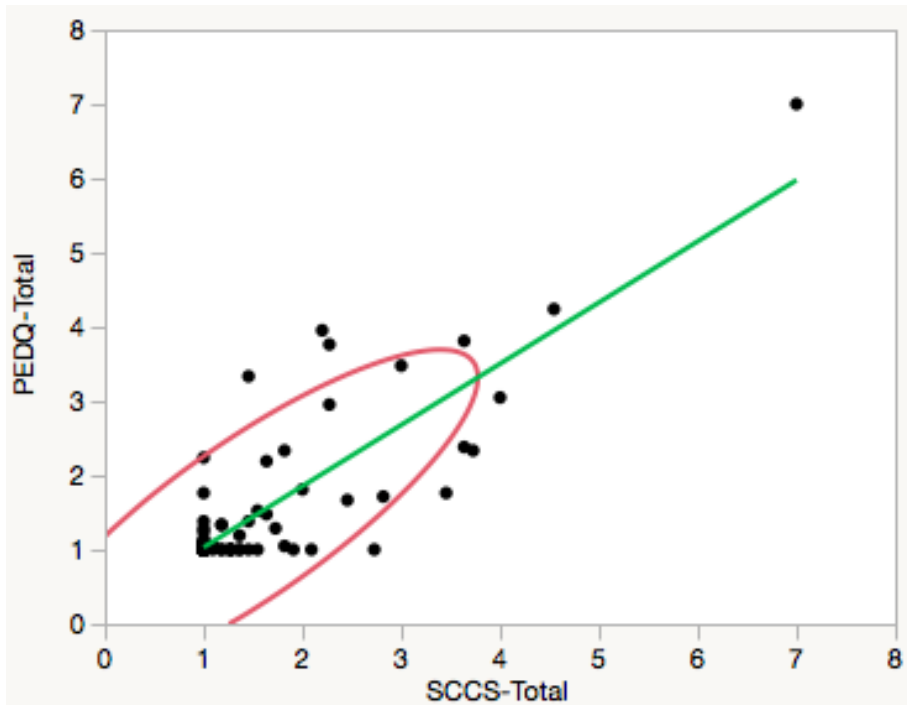


Figure 6: Bivariate Fit of perceived ethnic discrimination (PEDQ) by stereotype confirmation concern (SCCS).  $PEDQ = 0.206 + 0.824 * SCCS$ ,  $p\text{-value} = <0.001$

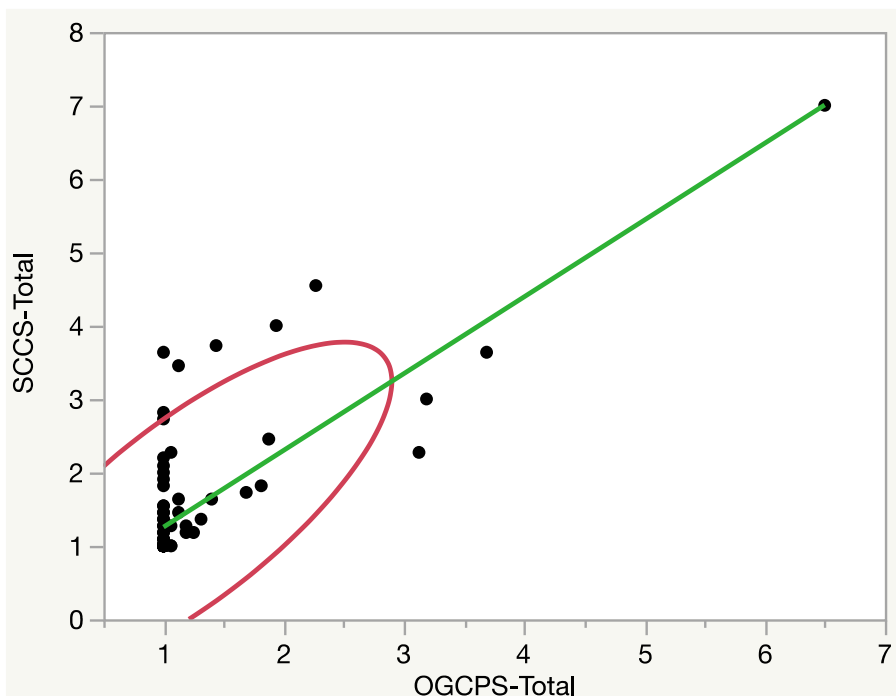


Figure 7: Bivariate Fit of stereotype confirmation concern (SCCS) by own group conformity pressure (OGCPS).  $SCCS = 0.211 + 1.045 * OGCPS$ ,  $p\text{-value} = <0.001$

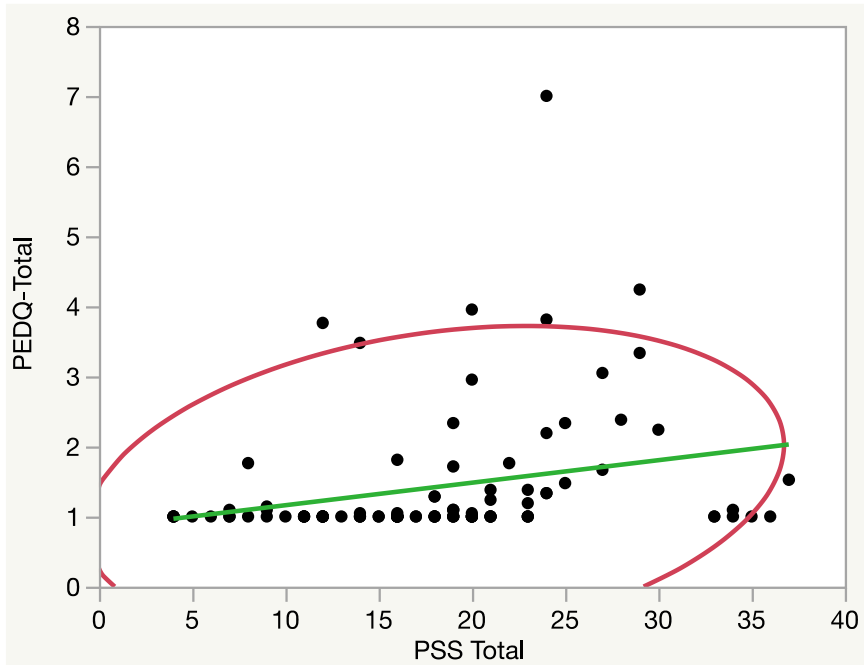


Figure 8: Bivariate Fit of perceived ethnic discrimination (PEDQ) by perceived stress (PSS).  $PEDQ = 0.838 + 0.032 * PSS$ , p-value =  $<0.001$

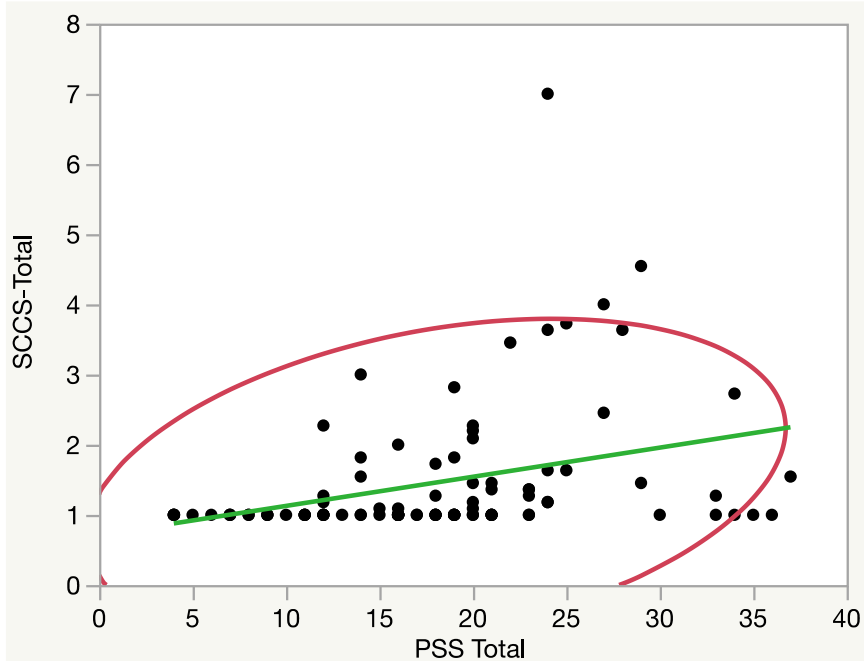


Figure 9: Bivariate Fit of stereotype confirmation concern (SCCS) by perceived stress (PSS).  $SCCS = 0.713 + 0.041 * PSS$ , p-value =  $<0.001$

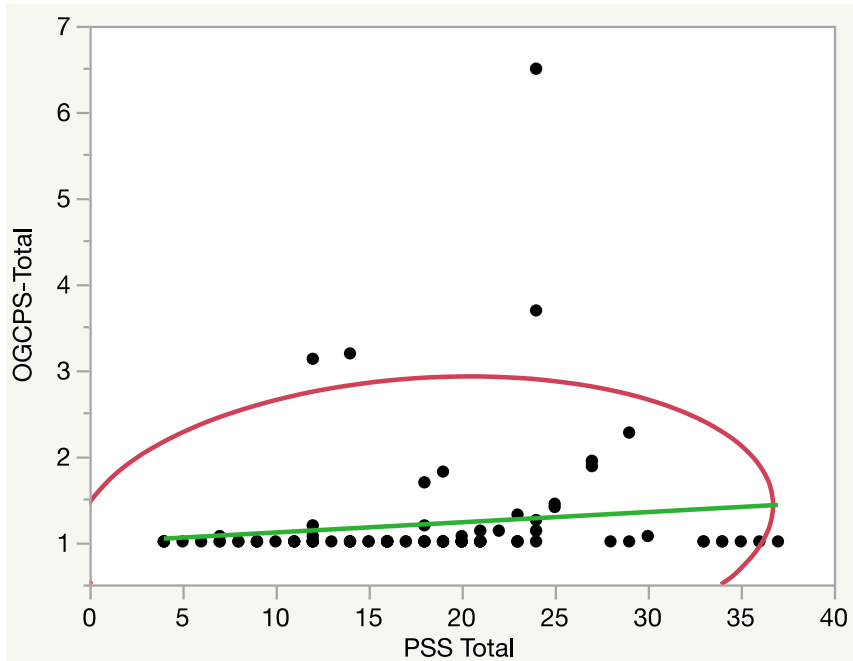


Figure 10: Bivariate Fit of own group conformity pressure (OGCPS) by perceived stress (PSS).  $OGCPS = 0.984 + 0.012 * PSS$ , p-value = 0.008

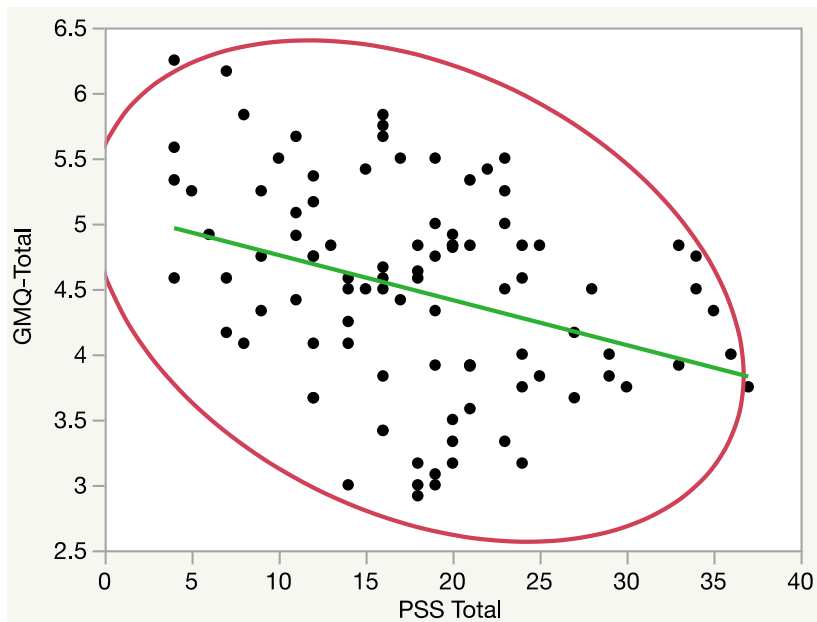


Figure 11: Bivariate Fit of group membership (GMQ) by perceived stress (PSS).  $GMQ = 5.103 + 0.034 * PSS$ , p-value = <0.001

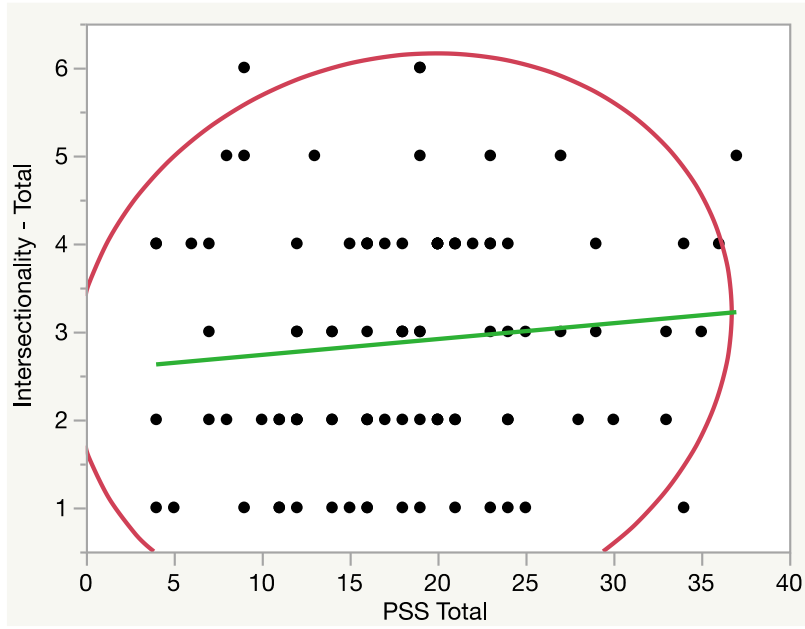


Figure 12: Bivariate Fit of Intersectionality by perceived stress (PSS). Intersectionality =  $2.552 + 0.018 \cdot \text{PSS}$ , p-value =  $<0.222$

APPENDIX A

STRUCTURAL STRESS AND OTHERNESS: How do they influence psychological stress?

# SURVEY

**Define the word "Culture":**

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## Demographics

Which of the following racial designations best describes you? More than one choice is acceptable.

- American Indian or Alaska Native
- Asian
- Black or African American
- White
- Other

If Other, please describe: \_\_\_\_\_

Do you consider yourself:  Hispanic/Latino  
 Not Hispanic/Latino

Age: \_\_\_\_\_

You were born a  Male  
 Female

You identify as:  The sex/gender you were born  
 A different sex/gender than how you were born

Please list all diagnoses for which you see a care provider: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Where do you primarily receive your healthcare?

- VCUHS
- Outside of VCUHS
- Both VCUHS and outside of VCUHS

Do you consider yourself to be a religious person?

- Yes
- No

If you answered "Yes" write your religion here:

\_\_\_\_\_

Are you physically/mentally disabled?

- Yes
- No

What is your education level?

- less than high school diploma
- high school diploma/greater than high school diploma

Is English your first language?

- Yes
- No

Describe your family income

- Less than \$56,516
- \$56,516 or more

**Please think about these questions as they relate to receiving health care services over the past 12 months. Healthcare services are defined as any care received from a licensed healthcare provider, e.g. Doctor, nurse, physical therapist, respiratory therapist, etc...**

Please think back ***over the past 12 months*** and then, unless instructed otherwise, for each item below indicate how often the event occurred using the following scale:

\_\_\_\_\_

1	2	3	4	5	6	7
never			sometimes			very often

Write the rating (from 1 to 7) on the line provided in front of each item.

We would like to know about acts of discrimination that have been directed against or toward you personally during the past 12 months. Please respond to the following questions using the 7-point scale above.

1. \_\_\_ When receiving health care services, how often have you been subjected to offensive comments aimed directly at you because of your ethnicity or way of life, spoken either in your presence or behind your back?
2. \_\_\_ When receiving health care services, how often have you been exposed to offensive comments about your ethnicity or way of life (e.g. stereotypic statements, offensive jokes), spoken either in your presence or behind your back?
3. \_\_\_ When receiving health care services, how often have you been subjected to name calling related to your ethnicity or way of life?
4. \_\_\_ When receiving health care services, how often have others avoided physical contact with you because of your ethnicity or way of life?
5. \_\_\_ How often have healthcare providers avoided contact with you because of your ethnicity or way of life?
6. \_\_\_ When receiving health care services, how often have others outside of your ethnic group made you feel as though you don't fit in because of your dress, speech, or other characteristics related to your ethnicity or way of life?
7. \_\_\_ How often have you been denied access to a hospital, doctor's office, healthcare facility, pharmacy, or other place designed to offer healthcare services because of your ethnicity or way of life?
8. \_\_\_ How often have you felt that hospitals, doctor's offices, healthcare facilities, pharmacies, or other places designed to offer healthcare services were off limits or that barriers were erected to keep you out of certain places because of your ethnicity or way of life?

1	2	3	4	5	6	7
never			sometimes			very often

9. \_\_\_ How often have you received unfair treatment from physicians, nurses, physical therapists, dieticians, social workers, or other licensed healthcare providers because of your ethnicity or way of life?
10. \_\_\_ How often have you received unfair treatment from nurse aids, hospital technicians, hospital housekeeping staff, hospital cafeteria staff, or other hospital service people other than those listed in question 9 because of your ethnicity or way of life?
11. \_\_\_ How often have healthcare providers had low expectations of you because of your ethnicity or way of life?
12. \_\_\_ How often have healthcare providers implied or suggested that because of your ethnicity or way of life you must be unintelligent?
14. \_\_\_ How often have healthcare providers implied or suggested that because of your ethnicity or way of life you must be dishonest?
15. \_\_\_ How often have healthcare providers implied or suggested that because of your ethnicity or way of life you must be violent or dangerous?
16. \_\_\_ How often have healthcare providers implied or suggested that because of your ethnicity or way of life you must be dirty?
17. \_\_\_ How often have healthcare providers implied or suggested that because of your ethnicity or way of life you must be lazy?
18. \_\_\_ How often have healthcare providers threatened to hurt you because of your ethnicity or way of life?
19. \_\_\_ How often have healthcare providers threatened to damage your property because of your ethnicity or way of life?
20. \_\_\_ How often have healthcare providers physically hurt you or intended to physically hurt you because of your ethnicity or way of life?
21. \_\_\_ How often have healthcare providers damaged your property because of your ethnicity or way of life?
22. \_\_\_ How often have you been subjected to nonverbal harassment by healthcare providers because of your ethnicity or way of life (e.g. being made to feel less than, rolled their eyes at you)?





In many cases, members of an ethnic group or those who share a similar way of life have expectations or informal “rules” about how they and other members of their group should or should not behave in particular situations or when interacting with certain persons. Each of the questions that follow ask about pressure that you may have felt to conform to informal “rules” of this kind from members of your own ethnic group (family, friends, etc.) or those who share a similar way of life. Please respond to each question in terms of your experiences during the last twelve months.

	1	2	3	4	5	6	7
	Not at All		A Little		Somewhat		Quite a Bit
	Pressured		Pressured		Pressured		Pressured

Please think about these questions as they relate to receiving health care services over the past 12 months. Healthcare services are defined as any care received from a licensed healthcare provider, e.g. Doctor, nurse, physical therapist, respiratory therapist, etc...

1. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to interact in a particular way with members of the opposite sex?
2. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to interact in a particular way with members of your own ethnic group or with those who share a similar way of life?
3. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to interact in a particular way with members of other ethnic groups or those who do not share a similar way of life?
4. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to listen to a particular type of music?
5. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life not to listen to particular types of music?
6. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to pursue particular interests and hobbies?
7. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life not to pursue particular interests and hobbies?
8. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to wear a particular style of clothing?

	1	2	3	4	5	6	7
	Not at All		A Little		Somewhat		Quite a Bit
	Pressured		Pressured		Pressured		Pressured

9. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life not to wear particular styles of clothing?
10. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to speak a certain way (or use a certain language)?
11. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to avoid or minimize social interactions with members of other ethnic groups or those with whom you do not share a similar way of life?
12. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to date or enter into romantic involvements only with members of your own ethnic group or with whom you share a similar way of life?
13. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life not to take academic work too seriously?
14. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to party more?
15. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to party less?
16. \_\_\_ To what degree have you felt pressured by your healthcare providers who are members of your ethnic group or share a similar way of life to pursue a particular major?

We are all members of different (various) social groups or social categories. Some of such social groups or categories pertain to *gender, race, religion, nationality, ethnicity, and socioeconomic class*. We would like you to consider your WAY OF LIFE and membership in your ETHNIC GROUP and respond to the following statements on the basis of how you feel about your WAY OF LIFE and your ETHNIC GROUP and your membership in it. There are no right or wrong answers to any of these statements; we are interested in your honest reactions and opinions. Please read each statement carefully, and respond by using the following scale:

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Disagree Somewhat	Neutral	Agree Somewhat	Agree	Strongly Agree

1. \_\_\_ I often regret my way of life or that I belong to the ethnic group that I do.
2. \_\_\_ Overall, my ethnic group or way of life is viewed positively by others.
3. \_\_\_ Overall, my ethnic group or way of life has very little to do with how I feel about myself.
4. \_\_\_ Most people consider my ethnic group or way of life to be more effective than other ethnic groups.
5. \_\_\_ The ethnic group that I belong to or my way of life is an important reflection of who I am.
6. \_\_\_ Overall, I often feel that my way of life or being a member of my ethnic group is not beneficial.
7. \_\_\_ In general, others respect my ethnic group or way of life.
8. \_\_\_ The ethnic group that I belong to and/or my way of life is unimportant to my sense of what kind of person I am.
9. \_\_\_ I feel good about my ethnic group and/or way of life.
10. \_\_\_ In general, others think that my ethnic group and/or way of life is unworthy.
11. \_\_\_ In general, my way of life and/or belonging to my ethnic group is an important part of my self-image.
12. \_\_\_ In general, I'm glad about my way of life and/or to be a member of my ethnic group.



**Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.**

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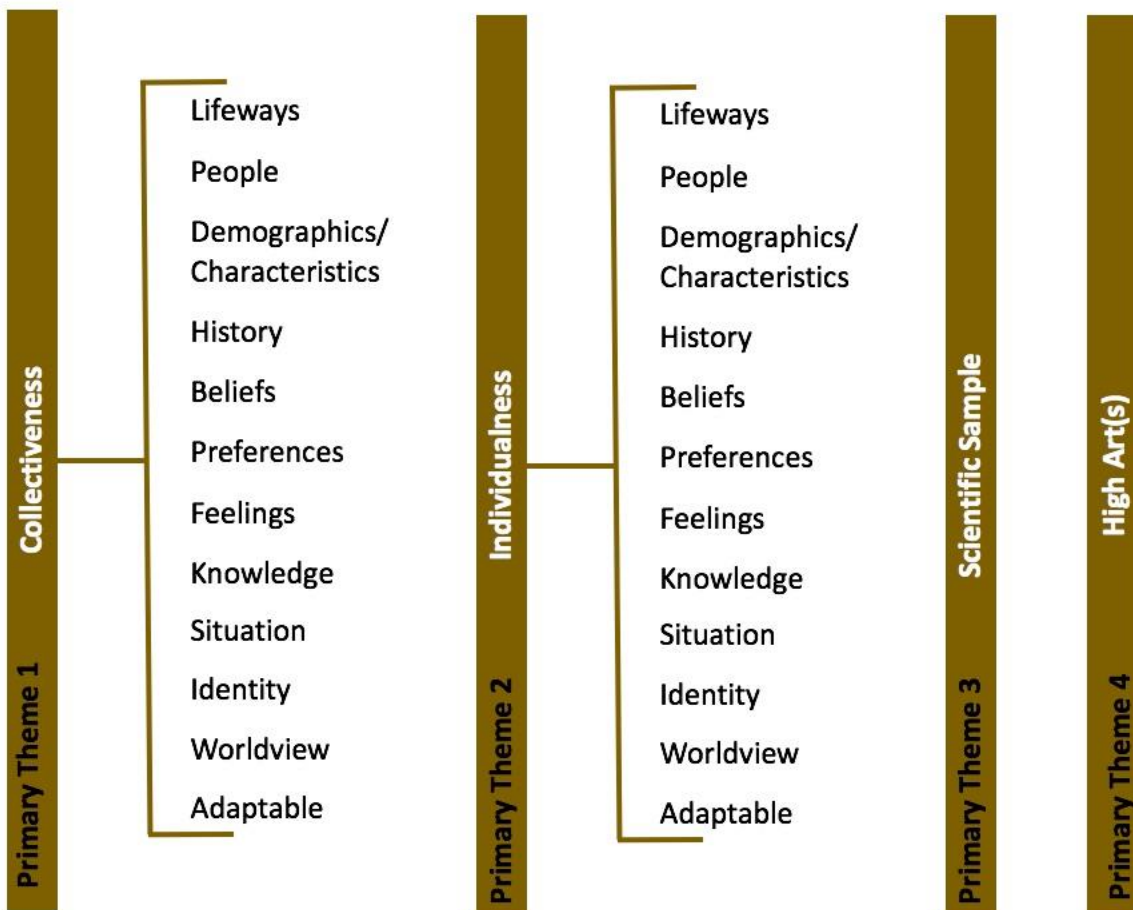
0	1	2	3	4
Never	Almost Never	Sometimes	Fairly Often	Very Often

1. \_\_\_ In the last month, how often have you been upset because of something that happened unexpectedly?
2. \_\_\_ In the last month, how often have you felt that you were unable to control the important things in your life?
3. \_\_\_ In the last month, how often have you felt nervous and "stressed"?
4. \_\_\_ In the last month, how often have you felt confident about your ability to handle your personal problems?
5. \_\_\_ In the last month, how often have you felt that things were going your way?
6. \_\_\_ In the last month, how often have you found that you could not cope with all the things that you had to do?
7. \_\_\_ In the last month, how often have you been able to control irritations in your life?
8. \_\_\_ In the last month, how often have you felt that you were on top of things?
9. \_\_\_ In the last month, how often have you been angered because of things that were outside of your control?
10. \_\_\_ In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

## APPENDIX B

### DATA CODEBOOK

The following codes constitute a hierarchy of Primary Themes and Sub-themes identified in participant statements when responding to the question, “How do you define the word “culture”? The Primary Themes include the terms “Collectiveness” (CLV), “Individualness” (IND), “Scientific Sample”, and “High Art(s)” which represent the overarching idea within the participant response. Sub-themes include: “Lifeway(s)” (LWY), “People” (PPL), “Demographics and Classifications” (DEM), “Environment” (ENV), “History” (HIST), “Beliefs” (BEL), “Preferences” (PREF), “Feelings” (FLG), “Knowledge” (KNW), “Situation” (STN), “Identity” (ID), “Worldview” (WVW), and “Adaptable” (ADP). The themes titled “Scientific Sample” and “High Arts” are themes that do not fit within the hierarchy of “Collectiveness” and “Individualness” and are represented as stand-alone Primary Themes.



**Themes and Sub-themes were identified by the following process:**

1. All responses were read through, as a group, three times for understanding
2. Each response was read individually, three times without coding for understanding
3. After reading the response a fourth time, a Primary, or overarching, theme was recorded
4. The response was read a fifth, and sometimes sixth, time to identify and record a sub-theme(s)
5. This was repeated for all responses.

**Instructions for Coding the Participant Responses:**

1. Each response will be read 3 times for understanding without coding
2. The responses will then be interpreted in sentence form to determine to which Primary Theme(s) it best belongs
3. The response will be read again, considering each word in context to the sentence, to determine to which sub-theme(s) it best belongs

Sub-themes may fall below one or any of the overarching Themes.

**Focal Theme: Collectiveness**

Mnemonic	CLV
Short Description	Referring to a group
Detailed description	Refers to a group or environment that is comprised of more than one individual
Inclusion criteria	Use of the words: group, we, us, nation, society, together, Human (as in Humankind), customs (can infer shared), common, organization, family, Race, peoplehood, language, Country, Community, Family, Ideaology, shared
Exclusion criteria	Use of the words: I, mine, someone
Typical exemplars	social institutions, Nation, people, social group, social behavior, common language, behavior, beliefs, actions of a group of people, Family
Atypical exemplars	Different backgrounds and origins, how we are accepted and viewed as an individual, depends on you, who you are
Close but no	

**Focal Theme: Individualness**

Mnemonic	IND
Short Description	Referring to one person
Detailed description	
Inclusion criteria	Use of the words: People (in the singular sense), person, you, your, me, I, different, diverse, choice
Exclusion criteria	Use of the words: group, we, us, nation, society, together, Human (as in Humankind), same
Typical exemplars	Different backgrounds and origins, how we are accepted and viewed as an individual, depends on you, who you are
Atypical exemplars	social institutions, Nation, people, social group, social behavior, common language, behavior, beliefs, actions of a group of people, Family
Close but no	

**Focal Theme: Lifeway(s)**

Mnemonic	LWY
Short Description	Lifestyle
Detailed description	Refers how one lives their life. The specific practices of a person or group of people
Inclusion criteria	Use of the words: Custom(s), traditions, modes, actions, behavior, activity
Exclusion criteria	Use of the words: Belief, thoughts, preferences, feelings...
Typical exemplars	Customs, the way people live their lives, how you are raised, the way things are done, food, dress hair, music, actions of a group of people, behavior, How we celebrate holidays and religious beliefs, The way you love and treat your body and living, Actions within a group, organization, or country, family way of raising a child with customs, language, and ideas nature to the area or country (manners, music, foods, relationships), How a group of people live, work, play, how the world around you causes you to think and do
Atypical exemplars	The way that I feel, what I believe,...
Close but no	

**Focal Theme: People**

Mnemonic	PPL
Short Description	People
Detailed description	Refers Human Beings
Inclusion criteria	Use of the words: Human(s), people, peoplehood
Exclusion criteria	No reference to humans
Typical exemplars	People, Nation, social group, person
Atypical exemplars	
Close but no	

**Focal Theme: Demographics and classifications**

Mnemonic	DEM
Short Description	Attributes
Detailed description	Refers to descriptors of human attributes
Inclusion criteria	Use of the words: Age, race, color, education
Exclusion criteria	
Typical exemplars	Age, race, medical condition, Ethnicity, socioeconomics, color
Atypical exemplars	Beliefs, customs, knowledge
Close but no	

**Focal Theme: Environment**

Mnemonic	ENV
Short Description	Refers to a physical place or area

Detailed description	Refers to a region of the world or a physical place where one lives, is from, or goes. Can be regional or structured
Inclusion criteria	Use of the words: Environment, place, where, area, Country, City,
Exclusion criteria	
Typical exemplars	Where you are from, Medical center, schools, refers to a specific place,
Atypical exemplars	Situation, influence,
Close but no	The environment you were raised in

**Focal Theme: History**

Mnemonic	HIST
Short Description	Refers to past events and experiences of the individual, individual's family, or society
Detailed description	Refers to past events and experiences of the individual, individual's family, or society
Inclusion criteria	Use of the words: Background, history, ancestors, generations, heritage, roots, environmental effect, outside environment, experience, origins
Exclusion criteria	
Typical exemplars	how you are raised, your background, life generations, your roots from the time you were born into the world, the environment you were raised in, environmental effect of people around you, grows up in, my experience of where I come from
Atypical exemplars	Where you are from, where you grew up
Close but no	

**Focal Theme: Beliefs**

Mnemonic	BEL
Short Description	Convictions
Detailed description	Refers to something one accepts as true or real; a firmly held opinion or conviction
Inclusion criteria	Use of the words: Beliefs, dress, hair, religion, ideas, values, code of ethics, law, politics, views, norms, standards, appearance, thinking, rules
Exclusion criteria	Lifestyle, preferences
Typical exemplars	What you believe, your beliefs, your religion, how we are influenced by society, code of ethics, set of traditions, behaviors, and norms shared by a group of people, how the world around you causes you to think and do
Atypical exemplars	
Close but no	music

**Focal Theme: Preferences**

Mnemonic	PREF
Short Description	Likes
Detailed description	Refers to a greater liking for one alternative over another or others and may or may not impact a person's way of life
Inclusion criteria	Use of the words: Preference, prefer,
Exclusion criteria	Beliefs, way of life
Typical exemplars	music, dress, hair, food, how we are influenced by society
Atypical exemplars	How you were raised
Close but no	beliefs

**Focal Theme: Feelings**

Mnemonic	FLG
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Short Description	emotions
Detailed description	Refers to an emotional state or reaction
Inclusion criteria	Use of the words: Feelings, How we are influenced by society
Exclusion criteria	Knowledge, thinking
Typical exemplars	Way you feel
Atypical exemplars	
Close but no	beliefs

**Focal Theme: Knowledge**

Mnemonic	KWL
Short Description	Awareness
Detailed description	Refers to an awareness or familiarity gained by experience of a fact or situation
Inclusion criteria	Use of the words: Knowledge, intellectual achievement, education
Exclusion criteria	Beliefs, preferences, lifeways, history
Typical exemplars	Your education, manifestation of your intellectual achievement
Atypical exemplars	How you feel, what you believe, thinking
Close but no	Beliefs, feelings, thinking

**Focal Theme: Situation**

Mnemonic	STN
Short Description	A person's place or station in relation to others
Detailed description	Refers to an individual's or groups' place (non-physical) in relation to other humans in the world or and the influence of others on the individual
Inclusion criteria	Use of the words: Situation, environment, atmosphere
Exclusion criteria	Where you were born, where you live
Typical exemplars	place in relation to the rest of humanity, the atmosphere in which we live, the environment you live in
Atypical exemplars	Environment, where you were born, where you grew up
Close but no	Community

**Focal Theme: Scientific Sample**

Mnemonic	SS
Short Description	Biology/Medicine
Detailed description	Refers to a biologic or medical sample used for research
Inclusion criteria	Use of the words: Medical sample, bacteria, smear
Exclusion criteria	
Typical exemplars	Medical sample, bacteria smear, collection of bacteria
Atypical exemplars	
Close but no	

**Focal Theme: Identity**

Mnemonic	ID
Short Description	Sense of self
Detailed description	Refers to the characteristics of determining who or what a person, group of people, or thing is.
Inclusion criteria	Use of the words/phrases: Who they are, who I am, perceives the world, perceives others, how we are viewed as an individual, your identity, your nature, my group
Exclusion criteria	How you live
Typical exemplars	How we define ourselves, how we are perceived in the world, defines who you are, your identity,
Atypical exemplars	
Close but no	

**Focal Theme: Worldview**

Mnemonic	WWW
Short Description	Philosophy
Detailed description	Refers to how a person interprets the world
Inclusion criteria	Use of the words/phrases: Views life, sees the world, attitudes, Ideology
Exclusion criteria	Feelings, beliefs, knowledge
Typical exemplars	how a person views life itself, sees the world, the attitudes of people, the way you perceive the world
Atypical exemplars	What you believe, how you feel
Close but no	

**Focal Theme: Adaptable**

Mnemonic	ADP
Short Description	Flexible
Detailed description	Refers to the adjustment to new conditions; being flexible or fluid
Inclusion criteria	Use of the words/phrases: Adaptable, multiple, mish-mash, choice
Exclusion criteria	Rules, modes, laws, code
Typical exemplars	People can belong to multiple different cultures, culture is a wish-mash of many different cultural aspects blended together, We can adapt to various cultures if we choose to
Atypical exemplars	
Close but no	

**Focal Theme: High Art**

Mnemonic	HA
Short Description	Literature, music, visual arts, performing arts
Detailed description	Refers to the creation or observance or reading of literature, music, visual arts, and performing arts
Inclusion criteria	Use of the words/phrases:



	Music, literature, dance
Exclusion criteria	Music, dance, literature referring to traditions or beliefs
Typical exemplars	refers to what is typically called 'high arts', in music, literature, dance, etc..
Atypical exemplars	
Close but no	