

**A Humanizing Gaze for Transcultural Nursing Research
Will Tell the Story of Health Disparities**

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Abstract

If we limit our gaze to epidemiologic or medicalized discourse about health disparities, we risk losing sight of the person living in a health disparity context. We may erase or make invisible the person from a health disparity group, pathologize difference at the population level and by extension stigmatize the individual, eliminate the upstream context or causes of the causes of disparities, and obscure the human story. It is crucial for the continued viability of our ideas about health disparities that we maintain cognitive flexibility. The unconscious bedrock of trusted ideas about “culture” and “disparities” can be enriched through a humanized view of the person in the health disparities story. Transcultural nursing research complements the biomedical gaze, placing the patient at the center of a cultural context where health problems are embodied, place-based, and socially-constituted. Humanizing our practice depends on dialogues with those who experience health disparity conditions.

Key words: theory, health disparities, bias, narrative inquiry

A Humanizing Gaze for Transcultural Nursing Research Will Tell the Story of Health Disparities

Culturally competent care can only occur when culture care values are known and serve as the foundation for meaningful care (Transcultural Nursing Society, Philosophy and Values).

As a theory-based practice discipline, we embrace the transcultural nursing goal of assessing people in the cultural contexts where they live, work, and play and then responding with humanistic nursing care. The urgent question is: How do we provide culturally competent care to individuals when health disparities are part of our concern at the population level?

We may begin by considering the topic of health disparities and the potential of the health disparities conversation to dehumanize our patients. Next, examples from transcultural nursing research offer humanistic portrayals of health disparities. In conclusion we can explore how concepts derived from transcultural nursing research aid us in providing culturally competent and meaningful nursing care.

Health Disparities: Definitions

Health disparities are differences between the health of two groups of people. An often-cited definition of health disparities states these differences in health are synonymous with health inequities. Health disparities “are potentially avoidable differences in health (or in health risks that policy can influence) between groups of people who are more and less advantaged socially; these differences systematically place socially disadvantaged groups at further disadvantage on health” (Braveman, 2006, p. 180).

An official definition written into public law in 2000 offers a contrasting definition: “A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population.” (Minority Health

and Health Disparities Research and Education Act, 2000, cited by the Center to Reduce Cancer Health Disparities). A *health disparity* as discussed in the *Healthy People 2020* national agenda is “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.” (US DHHS, *The Secretary’s Advisory Committee*). The *Healthy People 2020* discussion of health disparities is brief but very clear on one point: *Healthy People 2020* adds to the *Healthy People 2010* goal of eliminating health disparities by adding a new emphasis on achieving health equity (US DHHS, *Healthy People 2020*).

Infant mortality rates are a classic example of a health disparity or health inequity. Between 1950 and 2000, infant deaths declined significantly for both blacks and whites. Even though absolute rates are declining for both racial groups, the disparity in these rates for black and white infants is widening. In 1950, 1.6 black infants died for every one white infant. Fifty years later, the ratio is close to 3 to 1 (CDC, 2011a). There are other examples of well-known health disparities. Maternal mortality shows a pattern similar to infant mortality. HIV is one of the most dramatic disparity diseases when examined by race and ethnicity. Heart disease, cancer, and stroke are common in America, but more commonly a cause of death in some groups. The same pattern is evident with diabetes, and all-cause mortality. People with disabilities experience additive disparities, with a disability compounding and exaggerating racial and ethnic health disparities. Disparities can be seen by rural residence or language minority group. What is common to all of these is that social groups with less wealth, power, or prestige are worse-off in terms of their health. In the case of people with disabilities, we know that disparities may be related to biological constraints as well as social exclusion, marginalization, and neglect (CDC, 2011b).

Health *care* disparities refer to differences in the care people receive, rather than their ultimate health status or outcomes. Barriers to access to care, including lack of health insurance, are often identified as health care disparities. Even so, not all differences in the amount of care sought or received index a disparity in the sense of an inequity. Differences in care may reflect differences in the need for care or patient preferences for care. For example, it is possible that differences in rates of hospice care for certain populations could be due to patient and family cultural preferences for alternative forms of palliative care delivery even if access to hospice services was universal.

Differences in health outcomes related to health care disparities are attributable to (1) cultural factors and preferences of the patient, (2) stereotypes of the provider, and (3) health system factors (Smedley, Stith, & Nelson, 2003). To achieve health equity, we need to understand our patients' cultural beliefs, preferences, and care expectations and address our own biases. Remediating health system factors will require "ethical clarity" about how we allocate our healthcare resources. One way to approach ethical allocation of resources is through horizontal equity, meaning "equal treatment for equal need." Another way to define an ethical, equitable distribution of resources is by providing vertical equity, or "different treatment for different need (specifically, more resources for greater need)" (Braveman, 2006, p. 170, quoting Mooney, 1983; 1987). It is a practical and ethical undertaking to work for health equity.

Problematizing "health disparities" starts at the definitional level, as definitions of disparities vary, particularly in the emphasis on social inequalities linked to health and healthcare differences. Health disparities and healthcare disparities have different components, and achieving health equity will challenge our ethical framework, since we will need to commit resources to either (or both) vertical and horizontal programming.

How we Talk about and Think about Health Disparities:

Bateson's Theory of Nodal Ideas

Let me link the idea of health disparities and humanization of our discourse to the history of our thinking about ideas. Gregory Bateson's writes about the ways ideas are

culturally linked and socially shared. Bateson was a noted anthropologist and sometime husband of Margaret Mead. His explanations about ideas are useful to us as we talk about the discourse of health disparities. Bateson's influential book, *Steps to an Ecology of Mind* (2000), posits that nodal ideas are woven through our contemporary social discourse. The way we talk about ideas influences how we think about and structure our thoughts about how the universe works. This is the natural ecology of thought. Socially-shared ideational nodes bear traces of the past and are in a state of continual evolution into the future. "Semantic networks," or networks of meaning, are how other anthropologists have explained Bateson's characterization of constellations of thought and nodal ideas (see Boutain, 2001; Nichter, 1981). The connections between socially-shared nodal ideas are "intertwined in dialectical relationships with other ideas and the world in which they are immanent" (Wallis, 2011, p. 57).

Bateson notes that nodal ideas that form constellations of meaning are not equally important. "Ideas which survive repeated use are actually handled in a special way which is different from the way in which the mind handles new ideas," he wrote (Bateson, 2000, p. 509). Trusted or engrained ideas settle to a level "below the scrutiny of conscious inspection and solidify into the bedrock of the unconscious" (Wallis, 2011, p. 59). Related ideas depend on the survival of trusted, unconsciously upheld, and often unexamined ideas. It is crucial for the continued health of our constellations of ideas that we retain, modify, or reject the unconscious bedrock of trusted ideas in order to maintain epistemological flexibility. New ideas can arise through critical inspection, and constellations of thought can adapt to critical inspection and maintain their usefulness as we adapt and renegotiate the dialogue between the legacy of the past and new information. In the vein of invigorating our constellation of nodal ideas, I would like to challenge us to critically reflect on threats to the humanization of our patients through health disparities discourse.

What does this theory of semantic networks and nodal ideas mean in terms of humanizing health disparities discourse? I propose we run the risk of dehumanizing people when we are engrained in a network of nodal associations related to health disparities. How we think, how we put into language our thinking, and how we socially

construct networks of shared meaning in transcultural public health is of import. The language and thought of health disparities stands to dehumanize us. Or, perhaps more accurately, dehumanize the “other,” our patients who are from racial, ethnic, cultural, language, or disability groups that experience health disparities.

How Health Disparities Can Dehumanize

With that background in mind, I propose that there are at least three ways our thinking about health disparities can go awry. Rather than increasing understanding and moving us toward an elimination of disparities, our discourse can, at times, dehumanize the people who experience health and healthcare disparities. The nodal ideas we unconsciously share through networks of association put our thinking at risk. We may erase or make invisible the person from a health disparity group, pathologize difference at the population level and by extension stigmatize it at the individual level, eliminate the upstream context or causes of the causes of disparities, and obscure the human story.

Pathologizing difference

In teaching about health disparities, I had a student who challenged me about this topic. “How is it,” he said, “that the people who have these supposed health disparities are always people who look like me? They’re never people who look like you? And why is it that our problems and diseases and disadvantages are so easy for you to see? Yet I live in a community, like the communities we read about in our textbook, and I just see good, hardworking people. I don’t see poor performers who are always at the bottom of every health outcome chart.” Lectures on health disparities, like the lecture I gave that day, can often make the mistake of “othering” and dehumanizing people from groups with documented health disparities. My student felt singled out, inferior, targeted, and even blamed for the poor outcomes attached to his community. We talked about this, and both came to a new understanding. He felt somehow responsible, as a nurse, for the performance of his community and believed he was being channeled through his nursing education to go back and “fix” a community of “his people.” We came to understand together the dehumanization, stereotyping, and racism he felt in both the

presentation of the problem of health disparities and its solution. I also came to see that his individuality was blotted out, and he became simply a representative of the “problem” or “the community” when classroom discussions of health disparities took place in his nursing program.

The experience of teaching this young man helped me more deeply appreciate that “health disparities” is not a term removed from people’s lives; health disparities come to label groups of people. A “health disparity” label is neither wanted nor appreciated if it is just another way of re-inscribing social disadvantage, but this time with the weight of scientifically measured health outcomes to prove social disadvantages that feel unmoveable and everlasting. At times, “health disparities” may invoke pity for those who are poor or immigrants or from a particular racial or ethnic group, separating them from the whole of America as something less-than. We pathologize the problem, and by extension, we pathologize people through our networks of ideas and our discourse.

Using “health disparities” to take under-performance in health domains as a taken-for-granted reality is similar to using “culture” to explain why poor people or less-educated people have worse health. Paul Farmer, in a book called *Pathologies of Power*, found that “culture” was cited by physicians and nurses as the cause of non-compliance with complex or tedious medical regimens. After conducting long and detailed interviews with both compliant and non-compliant tuberculosis patients in Haiti, Farmer found the nurses and physicians were wrong. Culture was not the problem underlying non-compliance. “Although anthropologists are expected to underline the importance of culture in determining the efficacy of efforts to combat disease, in Haiti we learned that many of the most important variables—initial exposure to infection, reactivation of quiescent tuberculosis, transmission to household members, access to diagnosis and therapy, ...development of drug resistance, ...and most of all, mortality—are all strongly influenced by economic factors. We concluded that removing structural barriers to ‘compliance,’ when coupled with financial aid, dramatically improved outcomes in poor Haitians with tuberculosis” (2003, p. 151). The social determinants of health trumped culture as an explanatory model. Yet the networks of association linking

culture to compliance were active and unquestioned in the minds of the nurses and physicians caring for patients with tuberculosis in Haiti.

There are some antidotes to pathologizing health disparities or mis-attributing health outcomes to culture. One alternative is embracing cultural humility as a form of cognitive flexibility. Humility in cross-cultural interactions means acknowledging our own capacity to continue learning from people, retaining an openness new ways of understanding how a patient or family goes about managing illness and suffering with the cultural and structural resources at hand. Another alternative to pathologizing health disparities is put our professional expertise to use. “Work with poor people as they struggle to change their situations,” as Paul Farmer advises (2003, p. 151). As nurses we are fortunate, Farmer continues, to be among the professions able to offer “dignified service to the oppressed” through direct care to families and communities. Finally, we can change the kind of work we do. Rather than offering generosity born of our own privilege to those who are oppressed or experiencing health disparities, Paolo Friere (1971) suggests a different path: abandon “generosity” in favor of “justice.” Social inequalities and health disparities can be addressed through policy-level work to change the conditions that maintain poverty over the lifespan and across generations. We can advocate for changes early childhood education, meaningful work for adults, safe housing, access to healthcare, and other social determinants of health, the very causes behind the causes of health disparities (Farmer, 2005; Marmot & Wilkinson, 2006).

Eliminating upstream context and social determinants

We may forget that disparities happen in a context, often as a “downstream” result of many other social and structural interactions. Using the language of semantic networks of meaning, we can say that constellations of shared ideas about health disparities emphasize nodes that become fixed and “stand for” other complexities. But over time, if we cease to reflect on the metonymic extensions of these nodes, we forget about context. By context I mean thinking of a health disparity topic as something that happens in a place and with people. The context of health disparities are the homes, the workplaces, the families, the communities where people live, work, and play. Our moral imperative is to seek equitable treatment for all of our patients across contexts, so that

their dignity and autonomy is respected and they receive “high quality care regardless of gender, race, ethnicity, religion, sexual orientation, language, geographic origin, or socioeconomic background” (Kumagai & Lypson, 2009, p. 782).

We are entering an era where talking about the complexity of our patients and the scope of health disparities is helping to move our ideas. We’re unfreezing notions of “difficult patients” who are expensive, time-consuming, and perhaps from different cultural backgrounds from our own. Atule Gwande, a noted surgeon and healthcare expert, wrote about a few futuristic clinicians who decided to take on the “hot spots” in our healthcare system. He identified “hot spots” as the geographically-bound constellation of patients with expensive and complicated care. These “complex patients” shared zipcodes and many of the same social determinants of poor health. The goal of taking on the “hot spots” in health disparities is to provide the right kind of care and the right amount of care to the most complicated and expensive patients (Gwande, 2011). This is what Mooney (1983; 1987) refers to as “vertically equitable care.”

The “hot spot” patients Gwande described went from costing hundreds of thousands of dollars in emergency room and ICU bills to being managed reasonably. Prevention and rehabilitation figured into the mix of therapies for patients in “hot spots”. Home visits by nurses and vigorous care management made a difference. All of this care used interpreters, when needed, to cross language differences. As transcultural nurses, we can see the value of getting to know the life circumstances of our patients, especially those who are “complex.” Forward-thinking transcultural nurses do exactly that—we learn about the daily life of our patients, humanizing them and individualizing their care.

When I lived in Denver I became familiar with a community called Globeville. This community was built between two intersecting interstate freeways. It was nestled there in such a way that getting to Globeville was a challenge. There were freeway on-ramps and off-ramps and limited access points. The people who lived there needed buses, but municipal buses did not service this community. So the primarily Mexican American families who lived and worked in Globeville had difficulty accessing healthcare, as well as grocery stores. They also had a problem with environmental contamination.

Globeville's houses were built decades before to house the workers at the neighborhood smelter and glassworks. After those industries closed, the soil in backyards was tested and found to exceed health standards for contaminants left by the smelter, with lead and arsenic at levels high enough to result in a Superfund National Priority Listing designation (U.S. Environmental Protection Agency, 1999).

The benefits of our society, like safe housing and transportation and access to healthcare, did not extend to Globeville. Because of environmental contamination, the community legacy included a disproportionate share of the risks of a modern, industrially-based society. Through a geographic quirk they also faced barriers to transportation. Like other Mexican Americans living in low-income communities, the residents of Globeville sought healthcare health care congruent with their cultural and linguistic needs. The contexts of health disparities, including the historical, economic, environmental, linguistic, and cultural aspects of daily life, shaped the health and healthcare of the people of Globville. Humanizing care in Globeville can begin at any point, from addressing transportation needs to mobilizing community food resources and environmental cleanup. Nodes of meaning link health disparities with social determinants of health and remind us of the history and import of place.

Obscuring the human story

Health disparities can become a shorthand way of thinking for nurses, obscuring the human story of individuals. We sometimes make inferences about an individual based on aggregate data for a group, generating a holistic fallacy. One of my enthusiastic graduate students with a heart-felt interest in eliminating health disparities told me she was delighted to go to a clinic in a barrio neighborhood for her precepted clinical. "I'm sure to see a lot of women with HIV, sexually transmitted diseases, and no prenatal care," she said. Knowing some group statistics, she thoughtlessly generalized, believing that each woman would represent the disparities of the whole. When we humanize our perspective about health disparities, we find stories from our patients about their strengths, their challenges, and the varieties of responses to life's misfortunes. Each human story is different.

Transcultural nursing research offers examples of health disparities as experienced in communities with resulting consequences at the individual and family level. We have learned a lot about health disparities through our rich qualitative tradition. Jody Glittenberg, in her book, *Violence and Hope in a U.S.- Mexico Border Town* (2008) takes us on an ethnographic tour of a community known for drugs, violence, prostitution, and gangs. We meet extended families as we read the book. These families experience personal health problems (which we could also see as exemplars of health disparities in the community). Those health problems range from addictions to violence. We also meet the nurses, policemen, teachers, and pastors who work in the community. When done well, ethnographies (like this one) paint for us a picture of health disparities, how they have come to be over two or three generations, and what it feels like to live in a community with complex social and health disparities. Like Globeville, the U.S.- Mexico border town Glittenberg describes is a community with historic and cultural patterns of resilience and caregiving as well as long-standing structural barriers to healthful environments and culturally-competent healthcare. I was personally and professionally moved by reading this ethnography. Health disparities in this southern Arizona town came to have a story, a face, and a humanized presence. The people in the ethnography are not statistics but wholly human participants rendered with complexity and compassion.

After decades of ethnographic rendering of health disparity communities by nurse-anthropologists and many other anthropologists, we have an audience. The education of health professionals is turning to qualitative research of all kinds. Using Bateson's words, we are expanding our nodal set of ideas. We are challenging the limits of medical care, defined by "its relentless positivism, its damaging reductionism, its appeal to the sciences and not the humanities . . . , and its wholesale refusal to take into account the human dimensions of illness and healing" as stated by Rita Charon, an internist and literary scholar at Columbia University (2006, p. 193). She sees qualitative research infusing medical science to achieve more effective, compassionate and culturally competent care. Others of us around the country are teaching our students how to listen, *really* listen, to our patients' stories. The Transcultural Nursing Society has

valued and developed qualitative health research for many years. As a result, we are publishing work in the increasingly well-regarded *Journal of Transcultural Nursing* that demonstrates our progress in understanding of health and healing across cultures.

What is humanized care?

Conversations about how to humanize healthcare are occurring in nursing and medical classrooms, in clinics and waiting rooms. We see evidence of this interest in cultural aspects of the human experience represented in popular culture (Verghese, 2009), our curriculum committees (e.g. Charon, 2006 for an example from medicine), and in the work of national professional organizations like Transcultural Nursing Society (Douglas, Pierce, Rosenkoetter, Callister, Hattar-Pollara, Lauderdale, Miller, Milstead, Nardi, & Pacquiao, 2009; Douglas, Uhl-Pierce, Rosenkotter, Pacquiao, Callister, Hattar-Pollara, Lauderdale, Milstead, Nardi, & Purnell, 2011) and the American Association of Colleges of Nursing (Ballantyne, Calvillo, Clark, Pacquiao, Purnell, & Villarruel, 2009; Clark, Calvillo, dela Cruz, Fongwa, Kools, Lowe, & Mastel-Smith, 2011).

Several months ago I finished reading a new book by Abraham Verghese called *Cutting for Stone* (2009). In it, Thomas Stone, a fictional surgeon of some renown, asks his bright-eyed surgical interns, “What treatment in an emergency is administered by ear?” The interns are befuddled, unable to identify any treatment that could be dosed by ear and helpful to a person in a health crisis. What could it be? The correct answer is “Words of comfort.” The interns were confused, unable to get past the definitional constraints imposed by their training. The question asked “What *treatment*...” and they immediately considered “treatments” to be medicines and procedures, rather than the human exchange of comforting words.

Before this fictional surgeon was ever penned, Morse declared that the era is of humanizing care here, ushered in by our qualitative research across past decades. She states:

...Our qualitative work from previous decades will now come to the fore and coalesce to form a strong new paradigm for the provision of health care—one in which the patient’s thoughts, feelings and wishes will be given credence; one in

which the family and others loved by the patient, will participate more fully in healthcare care and the decisions that need to be made; one in which caregiving will be valued and considered as a part of the treatment; one which will be affordable, accessible and available to all. (Morse, 2007, p. 2)

What does it mean to humanize our care? “To be concerned with humanization is to uphold a particular view or value of what it means to be human, and furthermore to find ways to act on this concern,” (Todres, Galvin, & Holloway, 2009, p. 69). Todres and colleagues propose 8 dimensions of humanization, each of which exists on a continuum (Table 1). When any one (or more) dimension is compromised, care becomes increasingly closer to dehumanization.

Table I. Conceptual framework of the dimensions of humanization.

<u>Forms of humanization</u>	<u>Forms of dehumanization</u>
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenization
Togetherness	Isolation
Sense-making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

(Reproduced with permission from Todres, Galvin, & Holloway, 2009, p. 69).

Obesity-related Disparities and Healthy Lifestyles

I'd like to share an example from my own research about how our transcultural, qualitative research can humanize our interactions with people who live with population-level health disparities.

I recently concluded several years of research on child growth and obesity in Denver, Colorado (Clark, 2006). In my research, Latinas spoke to me about child obesity. They were careful to tell me that there was nothing wrong with their "bigger" children. They loved them the same, whatever their size. By this initial reaction to my study, I knew that the mothers I worked with were sensitive to the health disparities in their community. They realized the societal values about body weight devalued their overweight children.

The mothers told me their "bigger" children took after other family members, and just had "bigger bones." A bigger size "ran in the family." Mothers and fathers talked to me about their children's weight status from an insider perspective, emphasizing their relational bonds with their children. Their children were unique and had inherited characteristics common in the family, like body shape. This connection to family was so important that it was also central to how they fed their young children. Feeding was of course intended to help the baby grow. But it was also intended to make the baby part of a family, a Mexican family. As one mother stated, "What we do that most that the Americans don't do, is feed them food right away." Differentiating a Mexican child from American children was very important to mothers. Initiating early feeding in a Mexican tradition functioned as a form of meta-nourishment, connecting children culturally to their people and community by marking it as a different way of being.

Eating patterns connected children to communities but also to families: "When you're sitting at the table, everyone should be eating," said one mother. Eating is social, and the sooner the child is part of the family, sitting at the table, the better. Another mother explained that eating with the family and eating what the family eats is both physical and social sustenance: "My son at 6 months was eating a tortilla with frijoles. Dip it, give it to him." What could be more iconic than starting babies on tortillas y frijoles to integrate them into the family's Mexican heritage?

The stories I heard during my Latino childhood obesity study problematized health disparities for me. No longer were disparities an epidemiologic concept, abstracted from the human experience of family tradition and filial love. I heard from mothers about their fears that childhood obesity would become adulthood obesity and diabetes, a pattern they knew was common in their families and the community as a whole. Childhood obesity, the disparity topic we nurses tend to notice, is balanced by a need parents feel to enculturate children into the Mexican family and socialize them to eat traditional foods in a family setting. Belonging to the family and to the cultural community were compelling goals for mothers, and how the health disparity concern about childhood obesity fits with this other maternal preoccupation is complicated. Our nursing care can acknowledge competing concerns. Through negotiation processes that value cultural priorities, we can help parents to address childhood obesity without compromising their dedication to family and ethnic identity. The Culture Care Model specifically directs us to consider competing care needs and negotiate with parents and communities to meet their needs in a humanistic process that includes the outcomes they most value (Leininger & McFarland, 2006).

By using qualitative methods, like ethnography and narrative inquiry, transcultural nurses explore the phenomenon of health disparities as they arise and are normalized in families and communities. We come to understand differences in perceived root causes, consequences, and preferred solutions. The stories we hear from our patients and research participants humanize health disparities.

Conclusion

Health disparities present interesting challenges for transcultural nurses. Epidemiologically-based definitions of health disparities fail to inform us adequately about the culture and every-day life experiences of people who experience conditions defined as disparities at the population level. Transcultural nursing research complements the biomedical gaze, placing the patient at the center of a cultural context where health problems are embodied, place-based, and socially-constituted. Humanizing our practice depends on dialogues with those who experience health

disparity conditions. Together we can arrive at rich descriptions of health issues and a culturally-situated understanding of how to think about and work toward meaningful health goals.

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