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"Not Gonna Be Laid Out to Dry"

Cultural Mistrust in End of Life Care and Strategies for Trust-Building

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> "When the hospice nurse came to finally sign us up, my relief was overwhelming. We could relax as I could trust familiar language, honesty, a philosophy that was ours. In hospice, I know I can relax and let them lead us. To not have to play nurse and decide what's important and when to call the doctor and what to do—amazing relief. We celebrate this hospice referral lol."
>
> (personal communication, August 20, 2012)

As I listened intently to Sarah's testimonial, what joy and empathy I felt for her and her husband in this transition. I shared in her deep sense of relief and celebration and pondered for a moment, how wonderful it must feel to be able to navigate an end of life experience with such blithe confidence. For many underrepresented, marginalized groups, this is just not the case. In fact, the actual concept of *cultural mistrust* (Terrell & Terrell, 1981; Terrell & Terrell, 1984) was originally developed to encapsulate the pronounced worries and fears of African Americans concerning health care settings due to legacies of unjust practices that persist today.

In this chapter, a hospice case countering the opening exemplar is utilized to highlight issues related to cultural mistrust or lack of confidence in a health care provider's ability to act with integrity on the patient's behalf. Barriers to trust will also be highlighted as well as strategies for trust-building and maintenance among marginalized groups.

Case Presentation: "Not Gonna be Laid Out to Dry"

I have years of training and expertise in culture and socially just practices. Yet some of my most affirming complimentary lessons in cultural trust and mistrust have come through experiences with my grandfather in his dying process and eventual death. At the age of 75, he was diagnosed with lymphocytic leukemia, a type of blood cancer common in older age males. He lived the full five-year life expectancy of the disease, walking two miles a day (often in dressy socks), maintaining spiritual practices (e.g., reading the Bible), undergoing chemotherapy, and managing through multiple losses, including home-loss, consequent of Hurricane Katrina. An African American male, reared

in the deep south, he lived through segregation, desegregation, integration and re-integration; experienced the loss of one child, seven of eleven siblings, six of which were to cancer; and through it all, lived and worked to see his home, destroyed by Hurricane Katrina, be rebuilt.

On the night of Thanksgiving, in a room filled with family members engaged in various discussions, my grandfather leans forward in his recliner and casually whispers to me, "I won't be here always." At this cue, I asked my grandmother to reach out to the physician to inquire about his health care status and hospice. Prior to this query, the attending physician neither discussed hospice care as an option nor made a referral to such services. This is significant as families often rely on physicians, the entities most knowledgeable about the patient's health status, to initiate such discussions (Weckmann, 2008). In the final months of my grandfather's life, his mind remained sharp but his body grew weaker. With no guidance to the contrary, my family continued in its two-hour commute (each-way) to scheduled appointments in which my grandfather would no longer be seen by the physician in whom he and my family had come to establish a trusting relationship. He was instead seen by unfamiliar medical personnel and at a time in which both he and my family were most dependent on his physician's guidance, if not care.

The physician ultimately made the hospice referral. In my grandfather's transition to hospice, a staff nurse (European American female) met with the family to discuss the type of care hospice provides. Qualified in her profession, still yet a stranger to my family, she walks over to the table where my grandmother is seated, stretches out her arm, and in a single gesture, scoops away eight of ten bottles of medication. "Mr. Price will not be taking these anymore!" she exclaims. She proceeds through her regimented list of changes, next explaining in third person language that he would no longer be seeing his current doctor, but would now be cared for by the hospice team, which included a *new* doctor. At this, my grandfather, frail and docile, hardly speaking above a whisper at this stage of his illness, began to yell out in protest: "I'm not signing NO papers!!! I'm NOT signing 'em. I want MY doctor!" Banging his thin hands on the arms of his leather recliner, he exclaimed, "I don't know these people. I'm not gonna be laid out to dry!"

Startled by my grandfather's reaction, the hospice nurse eased into the kitchen to make a call to the main office. In the interim, I was able to intervene as a gatekeeper, calming my grandfather and providing him the reassurance needed to feel safe and secure in this transitional experience. Meanwhile, I listened as the well-intentioned nurse described my otherwise sharp grandfather as "confused," mistaking his anxiety and disgruntlement about the abrupt changes and perceived threats to his care for "disorientation."

Reflection

- How does the opening example differ from the case presentation? In particular, what is the role of privilege and marginalization in the differing responses to hospice admission?
- What might be goals and concerns for Mr. Price? And for the hospice nurse?
- Identify potential barriers in the interactions between Mr. Price and the hospice nurse. How might those barriers be overcome?
- Can you identify things that went well in interactions among any of the dyads?

Trust: Security or Uncertainty

The foundation for trusting relationships and self-trust typically develop in our formative years, but must be confirmed and reaffirmed throughout our lives (Erikson, 1964, p. 247). Similarly, cultural mistrust does not begin as we near death but rather with betrayals of trust in our daily lives and interactions with individuals and societal institutions. It should be no wonder then why the

bereaved and individuals approaching death who have experienced such betrayals, or possess historical memories, are especially hypervigilant when faced with instilling confidence in others at the final stage of life.

Barriers: Factors Contributing to Mistrust

Multiple factors contribute to diminished levels of trust in end of life care among marginalized populations, particularly among African Americans. Factors related to mistrust include education about the historical exploitation and mistreatment of minority groups in health care settings and personal experiences with discrimination in medical systems and other institutions (Krakauer, Crenner, & Fox, 2002). There are many well-documented cases, past and present, of discriminatory practices in medical care and in research (e.g., Tuskegee Syphilis Study) (Brandt, 1978; Washington, 2006). Similarly, my grandfather's fears and mistrust were deeply rooted in personal and historical experiences. After a series of aversive and discriminatory medical-related encounters, he avoided formal health care services for much of his adult life. Cultural mistrust, related to racism and discrimination, has been associated with delayed, avoided, underutilized health care services (Byrne, 2008; Hammond, Matthews, & Corbie-Smith, 2010; Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010) patient dissatisfaction (Benker, Peters, Clark, & Keves-Foster, 2006; Sohn & Harada, 2008; Moore, Hamilton, Pierre-Louis, & Jennings, 2013; Moore et al., 2013), lack of adherence, and discontinuity or changes in physician (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006). Prior to being diagnosed with cancer, my grandfather had not seen a doctor in thirty years. In fairness, the nurse could not have known that.

Further, due to disparities in health care services among marginalized individuals or "medical racism" (Krakauer et al., 2002; Rosenblatt & Wallace, 2005, p. 10) and "medical neglect" (Holloway, 2002, p. 3), issues of trust may be particularly salient for persons from marginalized groups in interactions with culturally dissimilar care providers (Barrett, 2009, p. 89). In a study of African American adults, Rosenblatt and Wallace (2005) found that 40 percent of participants believed their cared about person's death was related to medical racism or "death by medical racism" (p. 10). That is, they believed the death was due in part to injustice in treatment such as delayed (e.g., ambulance took too long to arrive) or substandard care (e.g., high risk procedure). Although racial similarity has been shown to reduce mistrust and increase patient satisfaction, researchers have also found that physician race was less important in trust-building than the physicians' ability to communicate effectively across cultures (Jacobs et al., 2006) and utilize patient-centered communication (Street, O'Malley, Cooper, & Haidet, 2008).

Overcoming Barriers: Strategies for Trust-Building and Maintenance

We know much about mistrust in end of life care and much less about ways to establish and maintain relationships that are approached with increased confidence and responded to with integrity. Thus, the section to follow focuses on strategies for trust-building and maintenance in end of life care.

Self-awareness, Reflection, and Privilege. On the morning following our visit with the hospice nurse, I began a 12-hour commute back to my home thinking, *THIS was disastrous!* I have completely failed my family. With all of my knowledge, I have failed them.

Appropriately so, it rained for much of my drive, heavy drops pounding against my window like good friends sharing in sorrow. A few hours into the commute, my phone rang. It was the hospice nurse. I had given her my contact information following the visit and asked that she call if I could be of assistance or play any role in my grandfather's care from across the miles. That morning she did just that.

Nurse: *Hi, Tashel. This is Kathy, the hospice nurse. Is this a good time?*
Tashel: *Hi, Kathy. Yes. I could use a short break from driving.*
Nurse: *Last night, I was thinking about my time with Mr. Price. I feel really badly that he seemed so upset during our visit yesterday. I wasn't pleased with the way things went during the visit. I'm thinking that more background information about Mr. Price will be helpful, and I'm calling in hopes that you might be able to tell me more about your grandfather. This will help me better reach out to him and best meet his holistic needs.*

With that, the rain drops seemed to soften, the clouds to dissipate.

Maya Angelou (as cited in Kelly, 2003) once said, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." This simple gesture of a phone call, as a result of self-reflective practice, was monumental in shaping feelings and perceptions of external care and help-seeking. It completely changed the course of my family's relationship and confidence in hospice services and my grandfather's ability to be a willing recipient and participant in his care. The nurse's ability to self-reflect and then, even more importantly, *act* based on reflection, was admirable and courageous, but not only that; it shifted anxiety to peace, uncertainty to assurance, dissatisfaction to contentment, and distress to comfort.

Replacing Assumptions with Five A's of Culturally Conscientious Care. In socially just and culturally conscientious practice, openness to learning and dialog are useful replacements for making what might otherwise be gross assumptions. I think of this dialog as analogous to communication with my young daughter regarding her paintings where instead of making assumptions about images in her work, I inquire, "Tell me about your picture." In my work with adolescents who wear memorial t-shirts honoring their cared-about persons, I have inquired, "What do you wish people to understand about your t-shirt? Tell me about the significance of the t-shirt for you. Wayne Carter (*Lil Wayne*), a well-known rapper, once said in a televised interview, "Give me a canvas, and I'll give you art" (VH1, 2009). In essence, create the space, and I may share some data from my life with you.

In my collective experiences in bereavement work, I have established and found it effective to use the *Five A's of Culturally Conscientious Care*:

- *Acknowledge* ("You seemed upset when I mentioned that you will have a new doctor.");
- *Ask* ("Is that correct?");
- *Accept* (Accept that he—Mr. Price—is worried about *being betrayed and not properly cared for* at this fragile stage of life, "knowing" that his lens is based on his social location and life experiences; accept also the notion of "not knowing" or fully understanding another's position.);
- *Align* (Align where privilege is operating) ("Mr. Price I would like to learn more about you so that I can work with you and your family to ensure you get the best care possible"); and if needed,
- *Apologize* (It is human to make an error, humane to apologize.) ("I'm so sorry. I think I moved through the information pretty quickly. I can see how this is a lot to take in right now. Please stop me as I move forward if you have any questions. Because it may feel like a lot of information to take in, during each visit I will also leave you with things to read in your own time that relate to items we discuss. Here's also the number to the main office should any other questions come up for you.").

"Not knowing": barrier or opportunity? Helping professionals in bereavement may feel disadvantaged in terms of "not knowing." Yet, this worry of *not knowing* stifles work in bereavement care in neglecting to create and provide services or offer programs for individuals and groups we think we may not understand or know enough about. It is no surprise though that individuals worry

about not knowing or uncertainty as it is the antithesis of socialization processes within educational systems where individuals are trained to "know," to have the answer, the "correct" answer, in fact. Yet, we receive minimal, if any, enlightenment around death, bereavement, or cultural practices through our formal educational processes (see Harris, 2009). We forget that the greatest advantage remains in bearing witness to the stories, the pain, the joy, and the triumphs of populations we serve and *could be* serving once the barrier associated with fears of *not knowing* is removed. Not knowing is important to recognize but should not be a deterrent. Opportunities exist in not-knowing. Messages such as "I am worried that I don't know . . ." can be replaced with "I am looking forward to learning more about . . ." *Culturally conscientious* practice is being open to evolving knowledge. The expectation to be "all-knowing" is an impossibility and hence a self-defeating frame from which to work. As emphasized by Marilyn Grey (as cited in Carpenter, Fontanini, & Neiman, 2010, p. 112), "Nobody has it all. That's like trying to eat once and for all."

Symbolic Meaning in Interactions. The same behaviors and interactions may have distinct meanings based on our social locations. Thus, even in attempts to connect, cultural conflicts and misunderstandings may arise. They are, in fact, inevitable in human relationships. For the nurse, for example, reducing the number of medications signified relief and better quality of life for the patient (i.e., fewer pills to swallow, less financial costs). For my grandfather and family, this same behavior was concerning as multiple medications were conceptualized as life sustaining. Thus, did the reduction in medication mean they had *given up*? Clarifying the hospice philosophy and role facilitated a shared understanding and unified goals for care.

According to Kagawa-Singer and Blackhall (2001), "culture shapes the way people make meaning of illness, suffering, and dying, and therefore also influences how they make use of medical services at the end of life." Although accepting of the referral, yielding trust to hospice had a certain cultural meaning within my collectivistic family system, heavily reliant on extended, familiar systems (fictive kin—church family, friends) to meet caregiving needs. Thus, it was important to convey that the family was *sharing* care versus *relinquishing* it to hospice.

In the initial transition to hospice services, my family referred to it as "home health care." As a professional and thanatologist, I wanted my grandfather to understand that he was being assisted by hospice services. I wanted to make sure, in the gentlest way that he knew he was dying, that he realized his death was imminent. If he had to die, I wanted his death to be the most well-orchestrated, most perfect death possible, complete with a life fully reflected upon; free of unfinished business, no bucket, no list. This created its own cultural dilemma. I was caught between respecting my grandfather's process and timetable and with doing what I thought was needed. I had forgotten one of the essentials of culturally conscientious care; individuals and families often know best what they need. If we recognize that our view is only one view, acting with cultural humility, the space for trust-building and sharing may widen.

And so it did, and in a most profound way.

In the last interaction with my grandfather, I asked if he wished me to read to him before I left. He had read the Bible each evening and was now too weak to read for himself. In response, and much to my surprise, feeble eyes outstretched, he looked directly into mine quoting several biblical scriptures from memory including Psalms 23: "Yea though I walk through the shadow of death, I will fear no evil" and John 14:1–3:

1. Let not your heart be troubled. You believe in God, believe also in Me.
2. In my Father's house are many mansions. If it were not so, I would have told you so. I go to prepare a place for you.
3. And if I go and prepare a place for you, I will come again and receive you unto Myself; That where I am, there you may be also.

We were united in silence. He had conveyed his understanding of his impending death in a way that was most meaningful to him. Within African American culture, religious beliefs have historically been identified as sources of support, guidance and associated with increased patient satisfaction (Levin, Chatters, & Taylor, 2005)

The quiet was soon broken with, "You can turn off the light though."

With that, assured, I headed out.

Ownership, Accountability, and Self-advocacy Education. When trust in the environment is diminished, it also impacts self-trust or belief in the ability to accomplish one's aims (Erikson, 1964). As demonstrated in numerous studies, trust is a legitimate concern. Yet, there are significant costs for inaction or delayed action due to mistrust. Lack of attention to health and end of life care needs as a result of mistrust leads to unfavorable outcomes such as later-stage diagnosis and reduced treatment options (Ross, Kohler, Grimley, Green, & Anderson-Lewis, 2007), and hence may be just as deleterious. Allies are invaluable in facilitating social change. However, marginalized individuals must also be equipped with tools to advocate for themselves and for appropriate care. That is, if one service provider proves untrustworthy, it is possible to choose a different care provider. It is analogous to any other life experience. If we do not like the service at one restaurant, we do not stop eating. We are compelled instead to choose a different restaurant. *Self-advocacy education* is needed to promote a similar paradigm of thinking about health care and end of life services.

Education and Training. Education and training are desperately needed for service providers and consumers of health and end of life services. Information not only enlightens but often serves to reduce stigma and puncture stereotypes or misconceptions (e.g., "Hospice killed him with morphine after my visit with him last night.").

Show Results. It is paramount that helping professionals in thanatology and end of life care show *results* to build trust and encourage hopefulness. That is, more visible and documented reasons to trust are needed. For example, like many people enrolled in hospice, my grandfather only benefited from services for a brief period of three weeks. However, in that time, the nurse demonstrated trustworthiness by consistently advocating and acting on his behalf to ensure the best quality of life at the end of his life. It was evident that the nurse was able to transfer cultural knowledge and experience to practice.

In an examination of cultural competence measures most used in medical and health care settings, Kumas-Tan, Beagan, Loppie, MacLeod, and Frank (2007) found that most measures of cultural competence assess knowledge of "other" (i.e., minority racial ethnic groups) with minimal or no focus on white identity (as culture), privilege, and power dynamics nor on the ability to put information into practice. Self-knowledge and awareness (including privilege and disadvantage) are germane to culturally appropriate practice with marginalized individuals (Whaley, 2001; Kraukauer et al., 2002; Barrett, 2003; Kagawa-Singer & Kassim-Lakha, 2003). Thus, in addition to cultural competence measures that assess "other" knowledge, more measures are needed to access understanding of privilege and whether and how knowledge and skills are used in practice (Kumas-Tan et al., 2007). Cultural concepts and communication may be taught in "clinical medicine courses, continuing medical education, and risk-management courses" (Krakauer et al., 2002) as well as in death and bereavement courses.

Trust is also affirmed through inclusive and transparent methods in interactions with families. Although some hospital intensive care units include families on medical rounds (i.e., clinical discussions about the patient between the physician treatment team and nurses), family participation remains understudied. In a study of parent participation in pediatric ICU rounds, inclusive practice was found to reduce anxiety both in parents and children (Cushing, 2005).

Accessibility and Availability of Study Findings to Individuals and Communities

Helicopter research, wherein investigators collect data from marginalized groups and then leave the communities without offering information ("never to be heard of again"; Montour & Macaulay, 1988) should be avoided. It reinforces mistrust and serves as a reminder of unjust historical events in medical research (e.g., Tuskegee study) (Scharff et al., 2010). In socially just practice, information gathered through research in end of life care should be made available both to participants and to the communities that serve them. This may be accomplished in numerous and multi-level ways including: provision of interview transcripts, if applicable, to research participants; dissemination of study findings to community agencies; development of guide sheets (e.g., Myths and Facts about Hospice Care) which convey study findings in language appropriate for lay audiences; development of community workshops or trainings (Hospice Education) that are both available and accessible to marginalized populations and interfacing entities (e.g., health care workers, therapists, educators, policymakers); press releases; and presentation of research findings and implications at professional conferences.

Services Beyond and Within the Margins

Provision of Services Outside of the Community. If supportive services related to end of life care are provided beyond the margins of communities of interests, what methods will be used to provide access to the services or information about the programming (e.g., webinars, pamphlets at churches, "lunch and learns," shuttle to the grief support camp)?

Located versus Present. Conversely, if services are *located* within communities of interests, how will program *presence* be communicated? Recognizing that trust may be an issue, community outreach and rapport building activities that include gatekeepers (e.g., clergy or school teachers and administrators) may help increase awareness and establish trustworthiness.

Trust and Care Satisfaction Beyond Death. Although the literature focuses on cultural mistrust among individuals (e.g., physicians, nurses) in the context of hospice and health care settings (e.g., Winston, Leshner, Kramer, & Allen, 2005; Moseley, Freed, Charrell, & Goold, 2007), it is noteworthy that a myriad of entities interface with families in end of life care (e.g., funeral homes, spiritual and religious institutions, law enforcement). Further, trusting relationships and satisfaction with care remain central for many families when life ends or the death occurs. As survivors create memories and make meaning of loss experiences, entities interfacing with individuals and families in end of life care become part of the dying, death and even the after-death story.

I was not present at the time of my grandfather's death, but based on family accounts there remained a deep respect for his body, the presentation of it, and my family's grief at this most vulnerable time of significant loss. Consistent with the reverence and respect paid to the dead within African American culture (Barrett, 2009, p. 83), the funeral home director and staff, for example, were respectful in the display and procession of his body as he was physically removed from the home for the final time. They proceeded slowly and intentionally past my bereaved family with my grandfather now on a stretcher, resembling a bed. His body was neatly wrapped in a white blanket with his eyes closed as in peaceful transition or death. This image presented on the night of my grandfather's death was not only respectful but also affirming and enfranchising for both my grandfather and surviving family members after a life lived amid many otherwise disenfranchising occurrences. He died a dignified death that I attribute to family goals in communion with entities and allies in end of life and after-death care acting on his behalf. The experience parallels with *death justice* imagery poignantly captured in *Thanatopsis*, a classic work of William Cullen Bryant (1817/2003, p. 166).

So live, that when thy summons comes to join
The innumerable caravan, which moves
To that mysterious realm, where each shall take
His chamber in the silent halls of death,
Thou go not, like the quarry-slave at night,
Scourged to his dungeon; but, sustain'd and sooth'd
By an unfaltering trust, approach thy grave,
Like one who wraps the drapery of his couch
About him, and lies down to pleasant dreams.

Conclusion

As outlined in the case presentation, barriers to trust in end of life care are present and may be numerous for marginalized groups. It is important to enter service-oriented experiences recognizing the role of privilege, power, and oppression in interactions. It is also important to enter such relationships with an understanding that there may be a strong possibility that trust needs to be established; and among the trusting, that it will need to be reinforced in intangible and concrete ways.

Key Terms

Cultural mistrust—term originally developed to encapsulate the pronounced worries and fears of African Americans concerning health care settings due to legacies of unjust practices that persist today; may be extended to include any pattern of fear or distrust by members of a minority culture toward members of the majority culture and toward institutions that are largely controlled by the majority culture.

Helicopter research—studies in which investigators collect data from marginalized groups and then leave the communities without offering information.

Medical racism—injustice in treatment provided to marginalized individuals, including delayed or substandard care.

Questions for Reflection

1. Considering the concepts of "cultural mistrust" and "medical racism" (real and perceived), how would you—as a culturally conscientious practitioner—build trust with a client from another cultural group? To what extent do you believe these concepts are relevant in your interactions? To what extent might your beliefs about relevance/irrelevance influence the interaction?
2. Consider your own areas of "knowing" and "not knowing." Can you identify ways in which you venture into some areas of "not knowing"? What areas do you avoid because of discomfort with "not knowing"?

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