# "I Am Because We Are": Awakening Revolutionary Patient-Centered Care

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While in nursing school, I studied abroad in Cape Town, South Africa to experience different perspectives and to build a socially and culturally conscious medical practice. Nursing is my second career. A decade prior to my travels in Cape Town, I was a grassroots labor organizer. My worldview was shaped by a commitment to the principle of justice long before I donned my scrubs. Justice is the the ethical principle of treating people equitably. Equality is treating everyone the same way. Some individuals or entire communities will require more support or different interventions to reach the same outcome, because of inequality. Values are not innate—they are personal, learned, taught, and shaped by experience. Values inform the choices that we make both consciously and subconsciously. Ubuntu, or "I am because we are," is the belief that the self-interests of any individual are inextricably linked to the self-interests of all individuals. It is the belief that our individual existence is validated by our connection to each other. Collaborative, patient-centered care approaches and the philosophy of Ubuntu are deeply rooted in Humanism.

Perhaps South Africa's unique history with injustice had a role in inciting a synergistic value set. In the mid-20th century, the South African government outlawed interracial marriage and categorized citizens as White, Black, or Coloured (mixed race), marking the beginning of a series of racist legislation that became known as the system of Apartheid. There was already a history of colonial rule and oppression of Black South Africans that resulted in disparate distribution of land, assets, and opportunities. Under Apartheid, the government mandated that races be segregated. Black and Coloured families were forced from their homes under the Group Areas Act and sent to live in government settlements (townships) that continue to house non-Whites today. Areas with resources and proximity to amenities were reserved for Whites only. South Africans who attempted to challenge these practices risked imprisonment or violent force. Endeavors to repeal racist legislation gained momentum after decades of local and global organizing efforts. The agenda in South Africa, since the democratic election of Nelson Mandela in 1994, has been to redefine the national identity and move out from under the shadow of Apartheid. Effective tools for moving forward have been willingness to engage in open discussion, continued education, and advocacy.

Our classroom in Cape Town was a moving van. Reverend Vernon Rose, with his long history of activism and community outreach, was our local instructor. The pedagogy of his approach was to begin our practice in the communities (Figure 1). We were educated on the history of each district and familiarized with the various socioeconomic experiences of our patient populations. The disparities between affluent and impoverished areas were tremendous (Figures 2 and 3). Rev Rose modeled reverence for each of the communities and intentionally articulated that although there was tremendous suffering to address, there was also continued progress and hard-fought victories to be proud of. Our instructor was directly involved in resistance movements to end Apartheid. Collective efforts resulted in measurable success and improvement over time. Taking action came with the initial cost of enormous personal risk with the long term gain of dismantling one of the most inhumane racial injustices of the past century.

Cultural and social awareness is crucial to effective practice. So, bedside nursing was not the initial priority for our education in Cape Town. There are many pressing priorities and many active non-profits responding the needs of their communities. South Africa has a high HIV/AIDS prevalence. We attended a presentation on current efforts to address HIV/AIDS, hosted by Treatment Action Campaign (TAC), an influential public health nonprofit organization. TAC took a lead role in establishing a universal government-sponsored AIDS treatment program.[1] Misinformation surrounding the transmission of HIV/AIDS, poor access to

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FIGURE 1

Reverend Vernon Rose educating on the site of District 6. Photo by Dean Batteson, RN.

treatment, and lack of awareness contributed to the spread of the disease. Advocates have tirelessly raised awareness, performed direct outreach, and legislated for change. Public education and antiviral drug distribution have become a national priority in South Africa largely because of continued pressure from community advocates.

The burden of illness and lack of access to health services continues to disproportionately affect non-Whites. This is the legacy and continued impact of Apartheid. In one of the largest Black townships, Khayelitsha, communicable diseases are nearly 3 times more common than in Cape Town as a whole, and the disparities between Khayelitsha and historically White, affluent communities are even larger.[2] The township populations have grown since Apartheid with the addition of informal housing. The sewage and

FIGURE 2

Another township in Western Cape. Photo by Dean Batteson, RN.

FIGURE 3

Township in Western Cape. Photo by Dean Batteson, RN.

electrical infrastructure built to accommodate the original government settlements are inadequate to handle the current demands of expanding population.[2] In the informal portions of the settlements, families live in close proximity to each other in small structures, conduct businesses out of their homes, and share water pumps and bathrooms. Overcrowding spreads illness and puts families at high risk for violence, unemployment, and mental health complaints.[2] Hypertension and diabetes are seen more commonly in Khayelitsha than in Cape Town as a whole, and the incidence of stroke in women in Khayelitsha is double that of women of Cape Town as a whole.[2] Simply put, the townships are not milieus that support health and well-being. Affluence and poverty are largely divided according to racial lines.

Meeting the needs and increased risks of disadvantaged communities falls to government-sponsored programs and the clinicians who provide the care. Operating in the historically Coloured district of Mitchells Plain, Tafelsig Clinic is a free clinic where approximately 500 patients are seen daily.[3] The staff do not have time to see every patient who arrives each day. Nurses precept international students to educate them and raise global awareness. Resources are limited, yet the clinic attempts to increase the types of services offered to the community beyond basic medical care. The Tafelsig clinic offers outpatient treatment for substance abuse and multiple programs for diseases such as tuberculosis, sexually transmitted diseases, and HIV/AIDS. In an attempt to be comprehensive in assisting the communities, the clinic even distributes food to the neediest in the community.

The choices we make in our practice communicate what we value. Despite the high incidence of communicable illnesses, nurses in Cape Town do not wear gloves. At Tafelsig, I assumed this practice was budgetary, but I encountered the same practice in the private hospitals. In the


FIGURE 4

Gary Pazienza, RN, educating students on sun safety in a Cape Town elementary school. Photo by Meghan Wheeler, RN.

United States, use of universal precautions largely ensures that no one is singled out and is intended to prevent the spread of infection. I had never given the practice a second thought until my experience in Cape Town. As a student I was required to wear gloves, and every patient asked, "Are you afraid of me?" My local preceptor explained that gloves imply that patients are dirty and compassionate touch is disrupted by donning personal protective equipment. She said, "We are nurses and we have to touch our patients." Patient perception is a key element of building trust; it is crucial to the success of patient-centered care.

While participating in an educational outreach in a Cape Town primary school (Figure 4), a values conflict surrounding touch came up again. When we arrived, the children wanted to touch our faces and our hair and hold our hands. I interpreted their behavior as a desire for attention and their touch as gestures of affection. I also noticed that most of the children had ringworm on their hands and faces. Rejecting their touch, even in the name of infection control, conflicted fundamentally with why I had traveled to South Africa. I was grateful to be there and humbled by the energetic welcome. I wanted those children to go home trusting that I had traveled thousands of miles to play soccer with them, because it was absolutely true. There was no better way to validate their joy than to share my own.

We have all had to examine our values to come to the practice of medicine. The hope is that all of our intentions originated from a desire to find satisfaction in helping others achieve favorable outcomes. If so, we help ourselves when we are effective at helping others. Inequality is a barrier to effective health care and we will be confronted inequality so long as we practice medicine. South Africans are negotiating their way forward. In the US, it is a revolutionary act to acknowledge that we participate in a health care system that sustains and exacerbates experiences of injustice and inequality for many patients. Over time, intentional, personalized efforts to address inequality can revolutionize personal practice and preserve the intention of patient-centered care.

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