





# A Theological Response to the Isolation of Medical Displacement

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Illness, impairment and pain are displacing experiences, separating a person from their sense of self and their community. This separation can occur in many forms. In my own life, my impairment, a permanent brachial plexus injury from birth, can come up in jarring ways.

Although I adjust to limited arm strength and motion in my everyday life, this limitation often goes unnoticed by people around me until it suddenly becomes apparent. For example, once in high school, I fell into a mess of tears when I could not practice infant CPR in my health class because I could not hold the practice doll at the correct angle. In moments like this, I did not just feel exposed, I felt physically apart and isolated. On a personal level, I felt that my body had abandoned me, so that I was displaced not only from others but from my own corporeality. How could I feel at home in a body that betrayed me in simple tasks?

This liminal experience of being present in my body, yet set apart by it, resonated closely with other moments of feeling displaced, even if not physically. As the daughter of immigrants, I would sometimes slip up when I was young and say words incorrectly — repeating what I heard at home, with a different inflection or accent — or mention foods with funny names, only to be met with the confused faces of my friends.

These experiences also drew me out of myself so that I no longer existed among my friends, joking as peers, but now seemed to look at them from far away — a distant place marked by other customs and language. The best analogy to describe

these experiences would be that of physical distance: when my physical or cultural differences came into full view for myself and others, I was transported far from myself and the people around me by these differences and no longer felt in the same orbit as them.

As I grew older and developed an interest in bioethics, these experiences of alienation seemed less like unrelated, sporadic events, but representative of modes of *displacement*. I caught glimpses of an experience of being displaced from myself and from my community in ways that were not unique to me. In fact, these experiences mark the lives of most people who experience illness and seek medical care. Thinking about these experiences in terms of displacement can be ethically useful for considering how we can best care for people experiencing displacement due to illness and treatment.

## BEING 'PRESENT' TO THE SICK

It is likely already familiar to think of social forms of displacement. Immigrants and migrants experience a kind of locational displacement when forcibly or voluntarily moving from their original country to another. It is also common to face cultural-linguistic displacement when one is tied



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to a culture and/or language that differs from the social context one currently inhabits. While immigrants likely endure both of these modes of displacement, it is possible to be culturally displaced without physical relocation, as is often the case for the descendants of immigrants. I suggest also thinking of *medical displacement* as an experience in which a patient's illness and treatment displace them from their own self-understanding and surrounding communities.

Two theologians can help us to think of illness and health care as displacing forces: Stanley Hauerwas and Ada María Isasi-Díaz. Hauerwas has an insightful gaze on the alienation that comes with suffering and illness. To him, it is impossible to fully communicate the lived experience of one's suffering because it is always unique to the individual. He explains that "it is impossible for us to experience one another's pain" and to fully understand one another's suffering more broadly. This disconnect in the experience of people who suffer and those who care for them strains the empathetic capacity of both, particularly in the case of long-term suffering.<sup>1</sup> We can understand that another person is in pain but cannot truly feel and understand it ourselves in the same visceral way that the suffering person does.

This separation from others not only drives a wedge between patients and those caring for them but also alienates patients from themselves by threatening their sense of self and their understanding of their place in the world. In short, suffering breaks down one's modes of understanding and connection within oneself and one's community. That is, suffering is an experience of displacement.

For this reason, Hauerwas sees the purpose of health care as being a bridge between the suffering patient and the rest of the human community.<sup>2</sup> This bridge-building challenges the way

that impairment and disease isolate and alienate by reconstituting the ill and healthy as one community. But this work of bridging and binding people together is not simple — rather, it requires the practice and development of a certain kind of ethical character. Hauerwas describes health care as shaping the sick and their caregivers "to remember, learn and pass on the skills of learning to live with a body."<sup>3</sup> In particular, health care professionals bridge the gap between the ailing and the healthy through skills that connect them with the sick by being *present* to them. Hence, ethically, these professionals strive to develop the capacity to steadfastly accompany those who are ill and suffering, regardless of the expected outcomes of care or the possibility of a definitive cure.

Even still, it is nearly impossible to foster this practice of accompaniment alone, especially in the face of the magnitude of people's suffering and our inability to simply eliminate suffering. This ability to accompany others in their struggles must be based on communal knowledge and practices. Even being truly present to suffering patients requires a community that is present to one another, supporting and shaping those working in health care.<sup>4</sup>

#### CONNECTING THROUGH NARRATIVES

However, Hauerwas' ethics of presence also challenge us to ask questions about what this practice of accompaniment *practically* looks like for different people. This questioning is even more pertinent for people who are facing multiple layers of displacement, not only from illness and treatment, but cultural, linguistic and locational displacements. How can we think about binding people together and fostering a sense of belonging in cases of those who are isolated by a matrix of displacing forces? Isasi-Díaz provides helpful insight on these issues through what she calls



*mujerista* theology. She draws from theology and ethnographic work to understand and articulate the wisdom of Latina women to inform Christian ethics.

Isasi-Díaz describes Latinas in the United States as “displaced” to capture not only some Latinas’ physical displacement from their original location to the U.S., but also their experience of existing in an in-between space of cultures, practices and communities. Hence, displacement describes how different places and experiences “inhabit” women as they go about their lives, shaping their consciousness and decisions in particular ways.<sup>5</sup>

This approach reveals a new dimension of displacement: it is not only about alienation from one’s surroundings but also about the hidden interpersonal connections people always carry within themselves. The experiences of locational, cultural and linguistic displacement that Isasi-Díaz notices in Latina women’s lives often isolate people from one another. However, by paying attention to these displacements, one can also uncover how human beings are necessarily dependent on and responsible for one another, even across distances and cultural barriers. While Hauerwas articulates how displacing experiences divide us, Isasi-Díaz helps us to understand that even these experiences show how humans are interconnected and interdependent. Moreover, both theologians call for us to make strong efforts to overcome the alienation of displacement.

Like Hauerwas, Isasi-Díaz turns to narrative approaches as key ethical tools to connect people and overcome displacement. The *mujerista* perspective focuses on how sharing personal stories can be a subversive practice for displaced and marginalized people because it reasserts personal dignity and challenges dominant narratives that often undermine the value and wisdom of people experiencing displacement.<sup>6</sup> This sharing contributes to Isasi-Díaz’s vision of justice and liberation operating within the realm of everyday life.<sup>7</sup>

While Isasi-Díaz focuses on cultural displacement, her insights about displacement also provide wisdom for how to approach experiences of displacement in health care. When engaging with patients already alienated from their own bodies and communities, listening to their stories is essential to connect with them and reintegrate them within their social context and relation-

ships. Isasi-Díaz’s understanding of displacement reminds us that seeing patients as whole persons and addressing their displacements requires us to remain attuned to the many ways in which injustice operates at the everyday level. Thus, facing the reality of displacement in health care involves promoting care that seeks flourishing in ways appropriate to a patient’s personal narrative and relationships and strives toward a greater justice within their own everyday experiences.

Drawing on the insight of Hauerwas and Isasi-Díaz also helps us to recognize how patients can experience multiple displacements. Many people facing illness and treatment are already burdened with locational, cultural and linguistic displacements. These forms of displacement are intertwined and compounded in complex ways. For example, for undocumented migrants, the threat of deportation has been shown to negatively affect their health,<sup>8</sup> and in one case, the raids of anti-immigration agencies correlated with lower birth weights for Latina mothers who are both American-born and immigrants.<sup>9</sup>

#### **SOCIAL, CULTURAL ATTUNEMENT FOR BETTER CARE**

By caring for suffering patients, the character of health care professionals should be shaped by practicing accompaniment in ways that are informed by the awareness of the multiple types of displacement that many patients endure. Moreover, health care practices should avoid displacing and alienating patients who are already experiencing multilayered forms of displacement. Health care settings generate their own internal cultures and operate based on specialized knowledge. These characteristics are often unfamiliar and intimidate patients of all backgrounds.

Part of the work of health care professionals, then, is to extend hospitality to patients entering the health care landscape and to consider the experiences they carry with them into this new space. Overall, Hauerwas’ call to build bridges that foster presence and connection and Isasi-Díaz’s call to doggedly seek justice and wholeness within everyday life stand as demanding ethical challenges for modern health care.

In my own experience as a patient, what helped me most to flourish and be healthy was care attuned to the culture and values I inherited from my immigrant parents, while recognizing the social impacts of my impairment. Simply put,

when I and those around me, especially health care professionals, recognized and addressed the ways my experiences made me *other* and displaced me from myself and my community, I experienced care that fostered a sense of wholeness, connection and belonging.

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#### NOTES

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