Amani's Silence

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Amani was a 24-year-old woman in her second year of nursing school in Jerusalem. She lived with her extended family, including her parents, grandparents, and six older brothers, who had emigrated from Syria more than 10 years earlier. They are religious Muslim Arabs who lived in an Arab village not far from our cancer center in Jerusalem.

For more than a year, Amani had experienced symptoms of fatigue, dyspnea, and anorexia. She did not seek medical care and focused exclusively on her professional studies. Her family attributed her physical symptoms to the stress they felt resulted from long hours working and studying, compounded by lack of sleep and poor eating habits. In the summer of 2013, Amani needed to be hospitalized for severe dyspnea and was diagnosed with melanoma metastatic to lung and brain. She underwent surgery, radiosurgery, chemotherapy, immunotherapy, and whole brain radiation with the hope of stabilizing her disease. Throughout this phase of active treatment, all decisions were made by the family. Her father and older brothers provided consent to treatment and trusted the recommendations of the physicians involved in Amani's care.

Eventually Amani's health declined, and 2 weeks before her death there was a marked increase in her pain. The family did not allow her to receive opioids to relieve her pain on the grounds that their religion prohibits the use of drugs with addictive potential. They explained their belief that pain cleanses body and soul, and their faith in Allah, whose mercy is extended to all suffering humans. The family decided for Amani and their refusal was unanimous and final. Amani herself never spoke about her illness or the intensity of her pain and shortness of breath. She remained silent throughout her hospitalization and never questioned her nurses or doctors, who interpreted her silence as acceptance of the authority of her family to make medical decisions on her behalf. Amani remained reserved and withdrawn, and the staff interpreted this as submission to the will of family and deliverance into the hands of Allah. We never saw signs of open dialogue within the family nor signs of discord.

As the end drew near, Amani's family wanted to take her home and demanded that she be discharged into their care. They expressed their wish to have her die at home, in her own bed, facing Mecca and praying. But time eluded the family's wishes, and Amani died in her hospital bed.

Amani's death affected us all on many different levels, and not all members of the team were comfortable with the

family's insistence on avoiding opioid pain medications. The tension and moral distress among clinicians revolved around the helplessness and distress they experienced as they witnessed the suffering of their patient. One of her attending oncologists, Dr. M., visited her two or three times a week, and in the last weeks of Amani's rapid physical deterioration and pain, he confronted her family about their opposition to opioids and expressed his belief that Amani needed morphine. But a junior physician on the team, Dr. C, a Christian Arab, silently disagreed with Dr. M's position. He understood and accepted the family's values, despite witnessing Amani's pain and suffering. He deferred to Dr. M's authority but made it clear that he understood and respected the father's understanding of religious teachings and his sincere desire to protect his child. Ultimately, Amani's eyes closed. . . little by little. Her room became a protective wall of prayers amid the grief expressed by her family, who found comfort in their strong belief in the paradise of the afterlife.

Several weeks after Amani's death, Dr. M. revealed to members of her care team that his daughter was a classmate of Amani's in nursing school, and that he could not imagine her suffering the pain that his patient had silently endured. He could not even bring himself to visit Amani during the last days of her life because he found it unbearable to watch her suffer. As a psychologist, I (LB) sensed the tension between members of the medical team. I was struck by their unspoken grief and their complete focus on addressing all aspects of treatment protocols without explicitly addressing the emotional repercussions of witnessing the agonizing death of a young woman.

Amani's story raises many questions about how best to handle the emotional pain that arises when cultures clash in the setting of a medical crisis when clinician and patient are divided by impenetrable barriers. How do we reconcile the differences in goals, beliefs, and values among members of the multidisciplinary team and between professionals and patients and families? And how can we let go of our own internal monologue telling us what is right and wrong, and, instead, embrace an open, unbiased stance? In reflecting on Amani's story, we are struck by her silence, one that we at times interpreted as a sign of withdrawal, submission, acceptance, or despair. The cultural divide prevented her attending physician from forming any kind of empathic connection to his patient and led to palpable distress among members of the multidisciplinary team. Perhaps their interpretation of her suffering, and ours, was

clouded by projecting fears and helplessness in the face of a tragic illness they could not alter. Death provided the only escape for all parties involved, but the trauma inflicted on members of the clinical team lingered well past her discharge.

Reflecting on this story, we are reminded of the challenges facing patients, families, and clinicians who find themselves unable to reach an understanding because of deeply held convictions about what is right and what is wrong. We are left wondering what it really means to deliver compassionate and family-centered care when cultural beliefs expose irreconcilable differences that lead to moral distress. At such times we need mechanisms for airing our assumptions and dilemmas in order to find clarity and shape a collective narrative that is inclusive

and respects not only cultural, but also individual perspectives and values. There is a growing recognition that religious understanding, tempered with compassion, humility, and sensitivity are essential elements of humane cross-cultural care. With growing numbers of refugees worldwide and a deeper appreciation of the challenges inherent in delivering care that is attuned and respectful of individual preferences and values, it is essential that we take these issues into consideration and arm clinicians with the skills and tools to respond to suffering across personal and cultural divides.

DISCLOSURES

The authors indicated no financial relationships.

For Further Reading:

Eran Ben-Arye, Michael Silbermann, Jamal Dagash et al. Touching the Other's Suffering: Cross-Cultural Challenges in Palliative Treatment Along Geopolitical Crossroads. *The Oncologist* 2014;19:212–214.

Excerpt:

In Israel, because of the bitter conflict between two sets of people living in close proximity, the encounter between Jewish professional staff and Palestinian patients may be colored by feelings of distrust. We here report the case of a Palestinian woman with advanced breast cancer who explained to her Jewish physician that her sisters had been killed by an Israeli soldier. Through the course of her treatment, she grew to put aside feelings of enmity and formed close bonds with the medical team, even as her illness progressed. This dying patient's grace and generosity toward individuals she might have held suspect inspired awe in the staff caring for her. She taught us to put our own petty concerns aside and led all of us to a renewed sense of commitment to our role as healers. The story may serve to remind all health care professionals that when we reach out to those suffering from illness in a spirit of deep respect and caring, we have the capacity to heal wounds with deeper roots even than bodily illness.