

Moral Distress Awakens Personal Transformation

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Commentary

Many family, friends and colleagues have expressed interest on my personal responses to a case study on providing family-centered care to a Hindu family deciding no medical intervention for their newborn with Hypoplastic Right Heart Syndrome (HRHS) [1]. I described how for five days many on the healthcare team experienced moral distress as they provided palliative care to the dying newborn, yet the details of how it impacted me remained unanswered. In four decades of providing care to children and families in my roles as registered nurse, educator and later family nurse practitioner, my perceptions were that most families struggled to advocate for the healthcare team to do everything possible to save the life of their child at any cost, even when it seemed all hope was lost. In some cases, legal decisions were required to remove brain dead children from assisted ventilation as the family attempted to block these actions by any means possible. Protecting children from harm and preserving life are at the core of most Western parenting worldviews. Advocating for the cessation of treatment for an adult with a terminal illness can be challenging for those providers protecting a person's autonomy, and doing so becomes even more daunting when it involves the life of a child with the family making decisions on behalf of a child who is too young to make them. The questions that are raised, may lead to an ethical dilemma for answers; who is best to make decisions in the best interest of a child as to whether a child lives or dies? The decisions can be grueling when there are options available that may prolong, or save that life, yet leave many unknowns as to their impact on the child's quality of life as they did in this case. Some even question the ethics of providing only palliative care to a newborn in any situation where treatment and/or cure are viable options.

The question, "Don't they love their child?" was asked by those who could not comprehend why the newborn was not given the opportunity to live although perhaps the quality of life would be filled with suffering from surgeries, procedures and possible heart

transplantation. The hopes and possibilities of good outcomes if the child survived, put in question the parents' choice to only provide comfort measures with no medications, surgeries or treatments. When the parents refused medications for pain, the team was reassured that the congenital defect in itself produced no pain and gradual hypoxemia towards death was unlikely to produce awareness of pain as level of consciousness was suppressed. Yet, many on the team were visibly distressed as they attempted to rock, soothe and comfort the crying newborn. The explanation that the newborn's persistent cries were attributed to hunger from inability to suck and feed, did not convince those providers who expressed helplessness and insisted that the newborn was indeed in pain [1].

My personal bicultural worldview was influenced by my upbringing as a Catholic, Cuban refugee immigrating to the US as a child of eight. My professional values, education, and broad experiences at a free clinic serving many world immigrants, gave me a broad perspective on the impact of culture, religion and family worldview on human lifeways and a passion for culture care. Developing cultural competencies to provide culturally responsive transcultural care is one of my priority legacy goals. As a team leader in the nursery, I aimed to remain detached and navigate the many professional and personal challenges we encountered throughout the five days leading up to the newborn's death. I advocated for the parents' ethical decision, when I too struggled with moral distress and feelings of sorrow, helplessness and guilt. It was very difficult to separate personal from professional beliefs, values and practices and empathize with a worldview that differed greatly from my own.

Once at home, my thoughts were disturbing and my nights sleepless, as I wondered what my contribution was to the death of this baby. The sanctity of life is a prevalent value across many religions and cultures and one I shared. My limited understanding of Eastern and Hindu worldviews left me with little insight and solace as to what had led to this parental decision that differed in many

ways from those I had experienced before in similar situations. I had to keep reminding myself that in spite of the sadness I felt, she was not my baby and thus not my decisions to make. My personal turmoil and aims to cope led me to begin a deep immersion in Hindu philosophy and to express my thoughts and feelings of my lived experience in a journal as I attempted to understand and wrestle with my struggle and grief.

Months later, my personal transformation has led to an expansion of my previous worldview to encompass Hindu philosophical tenets. Sanatana Dharma, or the eternal religion and belief in the Vedas, is at the heart of Hinduism, a name assigned by colonizers. The Hindu identity is deeply enmeshed with the unique cultures, languages, traditions and religious practices seen across India and Asia. Some would argue that to be Hindu is to be Indian, since one cannot be separated from the other. My deepening awakening led me to continue my spiritual development with the help of a Hindu guru who asserted that no one need convert to Hinduism as it was compatible with all religions and spiritual faiths. One of his interesting perspectives, supported by other Hindus, is that our purpose in life is to develop spiritually and as we awaken to our true nature as spirit beings and one with the absolute truth, all will proceed through many paths to the way of Sanatana Dharma as the last leg in the journey, to the point where finally no religion or philosophy will be needed to guide the souls back as they draw nearer to God.

As my knowledge increased, I could see that the decisions of these parents, were made on behalf of the newborn's true spiritual self. The material body is seen as a mere covering that is discarded many times as the soul reincarnates over several lives in its journey towards purification and return to the Godhead. In this lifetime, the newborn's soul was born to a broken body that could not support its true function and death would enable the soul to return in a new birth to continue its journey. The parent's attachment to the newborn's physical body would bring nothing but pain, grief and sorrow to the newborn and family with nothing to be gained. The best action was to let go so the causes of karma would take their effects and at death free the eternal soul. The death of the newborn

would allow the family to leave behind their sorrow and pain as they looked towards the next challenges that would propel them to their final destination. With this new understanding, I began to see these parent's in a new light-as protectors and saviors of that which mattered most for their newborn. I learned that every soul is born with the natures of goodness, passion and ignorance. As the soul develops and purifies over many lifetimes, the nature of goodness has the potential to grow as the other two diminish and are extinguished. Once only goodness remains, the soul will no longer return to the ocean of sorrow that is the material world and remain with God in a state of pure bliss [2].

Scientific theories and research support that life's crises have the potential for great human growth and development. In retrospect, this seismic life event propelled me to evolve spiritually and has brought many blessings to my personal journey in this lifetime. Many may question how a person's worldview, curated over many years, could in such a short time be paradoxically transformed into something quite different. My personal perspective is that my transformation has unlocked many truths already known to me that were veiled by illusion and these truths have made me more grateful, faithful and resilient. Sanatana Dharma and its Vedic truths see no paradoxes as all truth will be reconciled and known once the soul has awakened to its true spiritual nature as being both separate and one with God. Every soul is eternal, yet each material creation is finite. Although the Hindu religious traditions and rituals are complex, the philosophical girders of the eternal religion are enlightening. A Vedic truth I find comforting is that once this Universe completes its finite cycles of epochs and the material world is no more, all souls will return once again to their God source, until that time when God in eternal wisdom, begins the vibratory creative processes that once again brings material rebirth from total annihilation, as it has been and will be forever more [2].

References

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