

BOOK REVIEW

An interfaith anthology grounded in everyday challenges in the NICU

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Ronald M Green and George A Little, editors. *Religion and Ethics in the Neonatal Intensive Care Unit*. Oxford University Press, \$95 (Hardcover), 280 pgs, 2019. ISBN: 9780190636852.

Introduction

This anthology is well put together, with theoretical insights and several case studies that give us a real world view of what happens within the hospital Neonatal Intensive Care Unit (NICU), from diverse perspectives of faith. It is a rich resource for both those caring for critically ill infants, and those studying medical humanities and bioethics. The book addresses the role of religion in determining questions of identity, self and personhood and practices around birth and death. In many religious faiths, the granting of legal personhood to a child ensures a formal position among believers and the blessing of the divine. Parents wish for their child to at least attain this status, even if tragedy strikes early.

Some of the essays address gender issues such as maternal rights, practices around childbirth, and socio-cultural contexts including diversity, alternative practices of healing, and human dignity.

A child's birth and subsequent care is not only the responsibility of medical staff but also of the family, who may have to take difficult decisions. Continuation of life support for a critically ill neonate brings into focus ethical issues such as the right to personhood, and thereby to life, the notion of the quality of life, survival procedures, aggressive treatments, maternal wellbeing and rights, a child's pain and suffering; and for parents, the tragic loss of a new born child. The editors correctly suggest, in the Introduction, that despite their commonalities, religions do not say the same thing. The first four chapters cover diverse views among the Judeo-Christian

faiths. Many of the writers focus on aspects like social practices, maternal rights and racism, and the psychological states of people, including medical practitioners, facing crises in the NICU. Some consider other major themes from faith that may be relevant not only for neonatal health crises, but also for critically ill adults.

Judeo-Christian traditions of faith

Rabbi Elliot N Dorff, picks up on the differences in values between the secular medical system and perspectives of Judaism on the care of critically ill children. This essay is carefully positioned as the first one in the anthology as it raises the problems of methodology while applying religious values in a medical context. The author believes that neither the secular nor the religious framework of moral guidance for the NICU were created anticipating the medical advancement that now supports survival in some very difficult cases. Rabbi Dorff puts forward the idea of "depth theology" as a way of identifying beliefs and practices as resources during difficult decision-making, based on a careful reading of religious values and their impact on contemporary circumstances. He moves on to the position of the Jewish tradition on the personhood of a foetus or newborn, and the religious community's response to the parents of a critically ill neonate under treatment, as also the tragic death of a neonate. He also discusses religious beliefs that may have a bearing on pregnancy, birthing care, and medical inventions for a critically ill child. This chapter also addresses how faith can influence parents after they rejoin the community either with the surviving baby or after the loss of a child. Finally, the rabbi suggests that the general principles of Jewish law may be relevant to all those seeking medical help for critical illness.

The chapter on "Catholicism and the Neonatal Context" by M Therese Lysaught begins with her moving experiential account of her own children's premature births. From this vantage point, she goes on to say, "Catholicism is not a monolithic entity but rather ... a richly contoured tradition that provides a multiplicity of resources for patients, families, and caregivers to draw on." (p 41). She analyses seven themes under which religious instruction and convictions would play a role in influencing perspectives on the dignity of the neonate and parents, decision-making, treatment, assistance and so on. Conditions incompatible with life are addressed briefly in the context of palliative care. Citations from different religious leaders and important injunctions and teachings of prominent theologians enrich the

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discussions in this fine example of a contemporary reading of the Catholic faith through experience, rather than a purely scriptural investigation.

“Reading Tragedy through the Christian Story” by Erin DuFault-Hunter reveals the diversity within the Christian traditions. The story of a couple within the Mennonite (Anabaptist) tradition who faced the birth of a child with limited prospects of survival brings out the experiential nature of the theme. Using this case study from the difficult pregnancy period, with its diagnosis of Trisomy13, the author emphasises with great empathy, the importance of community and family support. Through this valuable experience, she demonstrates the place of faith and belief in dealing with tragedy and grief. In fact, a common theme in this anthology is coping strategies for parents, provided by parents, including prayers; and the kindness and attentiveness of the hospital medical staff (as opposed to the brusque, insensitive behaviour of the diagnosing doctor), counselling through the pastor, and practices followed after the child’s birth. The concluding passage deals with the importance of mourning and grieving and the unusual responses of other people to grief. DuFault-Hunter suggests that medical professionals “attach themselves to families in ways that befit caring in that particular moment.” She concludes with an account of the moving prayer read during the memorial of the child who died just three hours after his birth.

Ronald Cole Turner recollects the tenets of the Protestant faith through the trope of “protestant spirituality”. Turner describes what he refers to as unsuitable responses to health crises “that are somewhat automatic or instinctive but are not helpful or sustainable over time” (p 87). The first two include blaming oneself, then blaming God. The third is to hope for a miracle or to imagine that the crisis is a test of faith. All of these, Turner feels, are unhelpful during the health crisis of a much loved child. On the other hand, a spiritual response is given through means such as baptism and its potential significance in creating a moment of faith where parents acknowledge the gift of a child, even when it is ill, and the neonatal is held and welcomed into the community. Supporting this kind of faith and spirituality, the author points out the theological significance of the love of Jesus for the weakest and most vulnerable in the community, and sees the situation as a moment of transformation for the parents, and even medical professionals, that is available to the vulnerable in particular: “The high risk child, the one who is completely dependent on others, the one who in that moment is the “least of the least”, becomes a grace-filled and transformative presence for others” (p 92).

“Seventh-day Adventists and Care for the Newborn” by Gerald R Winslow focuses on the health perspective from the Christian tradition, and therefore belongs with the earlier chapters thematically. Winslow begins with the case study of a child called Olivia, a critically ill neonate. The relationship between the Seventh Day Adventists’ faith and health is introduced, including their abiding belief in the providential

creation of the world, the spiritual and physical unity of each person. Practices based on these fundamental beliefs, such as providential care, honouring the hours of the Sabbath, freedom of conscience and the hope of eternal life, may have implications for care in the NICU. Some principles guiding end of life care also provide insights that may be extended to care in the NICU.

These values particularly in a culturally pluralistic society not only help patients and parents of critically ill children following the faith; but also help medical professionals to navigate health challenges with sensitivity in all communities and faiths.

Cultural traditions of faith

Chapters 5 to 8 deal with Islamic, Hindu, and Buddhist faith perspectives on critical neonatal care. These religions have traditions entrenched in everyday life and customs, and in relationships within families. Like the Navajo traditions discussed in a later chapter, they have important socio-cultural positions with respect to life, death, and birth practices. Across these essays is a plea by the writers for an understanding of these faiths as non-stereotypical and not monolithic. All the authors discussing these four traditions request sensitivity from medical professionals; and an understanding of the diversity of experience, religious injunctions, and scriptures or oral traditions in these religions from a non-stereotypical perspective.

Zahra Ayubi describes the diversity of faith within the Muslim world, making a clear distinction between a “scriptural dependent model” and “the ritual dependent model of Islam”. She clarifies that “...the scriptural dependent model, is based on ethical legal theory as expounded in the text. The second is the ritual-dependent model which is based on Islamic birth and death rituals.” Using these two models, she explains the religious belief regarding the personhood of a foetus or a child, and that according to the scriptural source, a foetus is granted personhood 120 days after conception, while in the ritual-dependent model, a child is considered to attain personhood after rituals like naming, and the whispering of the sacred prayer into the ear. The ritual dependent model seems to impact bereavement and the maternal rights of women, where prematurely born children — even if after 120 days — were not considered for full bereavement and funerary rituals, causing great distress to the mothers, who are denied a period of mourning and bereavement. The author argues that the distress may result from their not being aware of the scriptural and authoritative texts of their own faith, instead being influenced by family and traditions of local practice. She ends with an appeal for the scriptural education of women within their own faith, and a more balanced power dynamic between parents and religious leaders, and between the mother and father within a Muslim family. She also suggests that medical staff should be culturally sensitive in speaking to parents about their religion.

Jyezer M Tyebkhan, a neonatologist from the Dawoodi Bohra Muslim community, describes the spiritual heritage of his faith. After setting out the main teachings of Islam related to healing and health, he discusses pre-birth practices during pregnancy and postnatal practices around the naming of the child, recitation of prayers, and the various rituals of the community. He suggests that many of these ceremonies can be adapted to suit the hospital environment by the family and an empathetic medical staff, if the child is critically ill. He outlines the challenges for neonatal care from Muslim practices surrounding beliefs about breastfeeding and the use of pig-derived products. As breastfeeding is seen to establish a kinship relationship between mother and child, donor milk or other forms of nutrition are not welcomed by Muslim parents. Further, some treatments using products derived from pigs, considered unholy by Islam, are unacceptable. He informs us that the contexts for life-death decisions are guided closely by the current spiritual leader, the Da'i, whom many parents within the faith would consult for help and counselling. This chapter ends with the funerary rites for a child and their implications. Tyebkhan concludes with a suggestion on how families can be supported in the NICU and allowed to follow their faith in a medical crisis.

Swasti Bhattacharyya in 'Shiva's Babies' discusses Hindu perspectives on the treatment of high-risk neonates. She begins with a conceptual framework of "cultural humility" as opposed to "cultural competency" (as described by Tervalon and Murray-Garcia). Cultural humility, according to her, is a continuing process of listening to patients, learning from them and increasing the capacity for cultural understanding, not something ever to be completed. She considers that cultural humility is not a skill but "a way of being with self-awareness", and suggests that this is the way medical professionals can work with people during crisis situations with multiple cultures coexisting. Having established the context of values in medical care towards people of the Hindu faith, she provides a brief introduction to Hinduism highlighting the basic practices and beliefs that may affect a person facing a health crisis in the NICU. Some of the main metaphysical concepts discussed are the principle of unity of consciousness, *Brahman*, the caste system and the four stages of life, the moral principle of duty called *dharma* and finally, *karma* — both as action and as effect of actions through many reincarnated lives. The idea of reincarnation, as well as values such as nonviolence are also clearly outlined. Following this introduction, Bhattacharyya shares the various responses that she received from a survey she conducted with people who identified themselves as Hindu. Listing the challenges and beliefs that are foregrounded in a health situation around a neonate, she discusses the responses in some detail. In analysing the responses to the survey, she suggests that people of the Hindu faith expect the medical professional to understand the diversities within the faith and not disregard the beliefs of patients as crude or primitive. This is possible if the concerned medical professionals adopt a position of cultural humility towards the affected family. The chapter

covers comprehensively the situation in an NICU in the West. I do wonder how these values would play out in India where both the medical professionals and patients may belong to the same faith and religion is prevalent in everyday life and practices. With respect to both medical professionals and family members of the high-risk neonate, the examples of contrary responses she received to her survey questions demonstrate the multivalent nature of Hinduism.

In the chapter on the Buddhist faith, Karma Lekshe Tsomo refers to the teachings of the Buddha as the philosophy regarding life, birth, suffering, and death, forming a central core of Buddhist faith. The background of the inevitability of suffering and death allows Buddhists to cope with grief and tragedy by allowing them to understand the fragility of life and encourages them to relinquish attachment. This prepares parents to deal with the tragedy of the death of a child. Tsomo elaborates on the four cardinal values of Buddhism, "non-harm, loving-kindness, compassion, and wisdom" (p 145), which, according to her, do not favour aggressive treatment or prolonging the suffering of a child. The point that medical technologies have created new moral dilemmas is also highlighted, as for instance, premature babies are not mentioned in Buddhist texts. Tsomo also emphasises that medical professionals need to show care and compassion to the family in the health crisis, and to avoid being rude or unkind. She concludes with an overview of practices such as prayers that reflect compassionate care.

The Navajo and African American traditions

The two chapters on the Navajo Indian and Afro-American communities contribute unique additions to the anthology's diversity. They offer the different religious perspectives of socio-culturally marginalised communities in an unequal world, and present many challenges in healthcare, related both to culture and faith. The essay on Navajo teachings on care in the NICU not only describes the religious practices of this indigenous community; but the difficulty of confronting world views differing on healthcare choices between traditional and modern belief systems. American Indian indigenous groups have their own understanding of healing and healthcare, differing from that of modern medical healthcare. Navajo traditions, according to Maureen Trudelle Schwarz, have notions of the outsider as "enemy", and of the significance of discarded body parts (hair, placenta, nail clippings) as a form of ritual contamination that affects a person's wellbeing, and even of these parts being used for witchcraft. Some conflicts arise from religious pluralism as the Navajo follow the Christian faith as well as their traditional beliefs, resulting in a unique view of personhood where sometimes each parent responds from a different stream of Christian faith. This makes care in the NICU very difficult for the family of a child. The author sensitively brings out the Navajo philosophical precepts through the case study of a Navajo woman in an accident who required the services of an off-reservation NICU. Separate from her

community, and from medical personnel familiar with her cultural and religious belief system, the woman experiences distress and fear even as the medical staff tries to treat her and save her child. The case study brings out Navajo beliefs about the contamination of the body through contact with a non-Navajo person (such as the white man) considered an enemy, particularly in surgical procedures. This creates a crisis of faith and leads to the avoidance of biomedicine as an aspect of resistance and collective identity. The author lists other challenges faced by the indigenous community in a modern hospital setting. Similarly, the relational view of the mother establishing a bond with the child through physical touch just after birth and through the act of caregiving may be disturbed by a biomedical intervention. The indigenous community also has an oral history of understanding physical or mental impairment where congenital abnormalities are seen as caused by the breaking of taboos during the prenatal period whereas conditions that occur after birth or early childhood are seen as the practice of harm directed at the family through witchcraft. Medical professionals working with indigenous communities may encounter concepts such as a predetermined lifespan resulting in parents rejecting aggressive life-support or cardiopulmonary resuscitation. These beliefs hold deep significance for American Indians, particularly the Navajo community, as does the power of language arising out of their immersion in an oral culture. Thus, conflicts would arise if the allopathic caregivers provide negative "truthful" information to the parents. Such a negative prognosis has a debilitating influence on the minds of the parents and medical professionals need to be sensitised to this issue. The writer concludes with suggestions on how the medical staff could be sensitive to religious and medical pluralism and take traditional beliefs into consideration particularly with respect to CPR, blood transfusion, surgical procedures, protection prayers and the language used to discuss the illness. It is very significant that the community of indigenous peoples has been addressed in this anthology. These guidelines could be modified to suit healthcare for other indigenous communities across the world where some belief systems directly confront modern medical healthcare.

Patrick Smith in his chapter on African American perspectives addresses both the idea of religious faith perspectives of neonatal care, but also foregrounds the African American perspective based on justice and equality as central values of Christianity. Based on the writer's own experience in counselling parents and working in the hospital ethics committee, he also reflects on the medical crisis spilling over into the everyday life and struggle of black people in the west. He points out that healthcare disparities between blacks and whites in the area of neonatal care arise from other deeper contributory factors. He includes genetic disparities, socio-economic conditions and the most crucial issue of systemic racism and life course perspective that impact health statistics. He suggests that part of the challenge is the maternal health of African American women, who face chronic social stresses impacting the health outcomes of birth and the

delivery process. Following these very astute observations, he posits that "the systemic dimension of racism naturally leads to the dehumanization and depersonalisation of people of colour in terms of how they are viewed within a radicalised imagination and treated in a radicalised society." (p 193) He argues that, in the black Christian tradition, righteousness and justice form the central idea in faith practices. He describes in some detail the Christian framing of theological notions of the image of God, as well as God's intention of a relationship between people based on love and solidarity. Having explained the social cultural background of the faith for the community, the writer goes on to see how medical professionals may be inspired to look beyond just the interpersonal dynamics with regard to the care of the Afro-American neonatal in the NICU. He suggests that as health professionals, they might have been earlier blind to such injustices that are reflected in "social systemic and institutional relations" (p 194). His call for the dismantling of structural racism forms a part of the ethical response and responsibilities of healthcare professionals, inspired by the prophetic dimension of Black Christian theology. This part of the essay is deeply insightful as it not only draws from religious ideas but also discusses the social cultural position of a faith that exists within a background of systemic racism. The final sections of the essay explore the theological and scriptural resources available within the Black Church tradition that could provide support in dealing with the tragedy of death within a NICU. He suggests that these values and practices would be directed towards understanding the sanctity of life. Here Smith makes a strong argument for the concept of the sanctity of life that is very different from versions of medical vitalism. He asserts that people have value by virtue of their humanity, which is not reduced by a disease injury or disability in any way. He suggests that neonatal healthcare professionals must learn to appreciate the language used to describe impaired newborns within the African-American community which does not reflect an unconscious dehumanisation or depersonalisation world-view that shows up as medical vitalism. He also points out that healthcare professionals need to contextualize their communication and understand how the resources of the Afro African American Christian tradition may influence the decision of parents and community not only at a personal level but also at the social economic and racial dynamics of discrimination. He concludes with a discussion on the faith practices of healing through prayer and the process of lament that allows people to grieve after a tragedy within this tradition.

The book concludes with an afterword by Winston Smith. His perspective as an African-American neonatologist may be of special significance for healthcare providers. After a discussion on his own faith, he continues with his perceptions of the role of belief systems affecting families in the NICU. He shares his challenges and learnings as he encounters other beliefs and disparities and challenges for different communities in the NICU. He suggests that critical

and end-of-life care for newborn children involves not only personal beliefs but a complex set of interactions between the medical professionals' own values and the values of caregivers and parents facing a crisis. He shares how he has witnessed evidence of the power of beliefs and their effect on patients. He concludes that belief systems can give hope and support in times of stress, both for medical professionals and the parents and community.

This book is informative, insightful and relevant across cultures. Far from being just a theoretical interfaith volume on medical ethics and religion, this book is grounded in the everyday challenges faced by medical professionals who work in critical care units. Given the current attention to critically ill people in ICU units all over the world and the recent pandemic, this book would provide resources to any professional or to families dealing with a critically ill person.

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