Why you should think about “tokothanatology”

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There are only two days in your life that are less than 24 hours long—the day you are born and the day you die. This is far from all that birth and death have in common: they are the most momentous days in our lives; they are family, social, and cultural events surrounded by rituals and laws; they are the stuff of stories, poetry, art, and films; and these days they involve healthcare and both have been medicalised to an unhealthy degree.

The central argument of Susan Boron’s book Bookends: A Family Doctor Explores Birth, Death, and Tokothanatology is that we can learn much about birth by thinking about death and vice versa. Boron is that possibly extinct creature, a doctor who facilitated both births and deaths. She describes her practice as “pre-crade to post-grave.” Now general practitioners are not trusted to facilitate birth, and palliative care specialists are sent for when people are dying.

Perhaps recognising medicine’s love of specialities and Greek words, Boron’s father, Murray Enkin, created the word tokothanatology: tokos is the Greek word for childbirth and thanatos the word for death. The word thanatology already exists, but tokology exists only as the title of a book published in 1885. Boron does not describe herself as a tokothanatologist, rather she observes that, “In the field of tokothanatology, I’m no expert. I have never given birth; I have never died. The real experts have always been my patients.”

Boron comes from distinguished stock. Her father Enkin is best known in the UK for co-authoring with Iain Chalmers Effective Care in Pregnancy and Childbirth, the forerunner of the Cochrane Library. An iconoclast by nature, Enkin fought against the medicalisation of birth. Boron writes: “He said he made a commitment to himself very early on to do something about the way women in labour were treated. He vowed to change the status quo of the doctor being in charge and the woman having no involvement other than just being there....Daddy was the first obstetrician in Canada to have fathers in the delivery room.” Enkin was key in establishing midwifery as a discipline in Canada, and helped end the empty obstetric rituals of episiotomies, shaving of the pubic hair, and enemas.

Enkin recognised the close links between birth and death and became more interested in death and dying as he moved into his 90s. I never met him in person, but we corresponded often—and I was pleased to be made a (then) junior member of the “old farts’ club.”

Boron quotes Enkin’s account of his wife’s death: “I held her in my arms. I kissed her with each breath. And after there were no more breaths, I kissed her again.” Enkin died aged 97 in June 2021.

Boron trained in family medicine, wanting to care “for the whole person, to see them as a complex sum of all their parts, mind and body.” And birth and death are the times when this is most important: “I came to realize my most satisfying work was at the bookends of life—the births or the deaths of my patients. And I realized that, in many ways, those bookends were the same kind of practice.”

For most of human history people were born and died without any involvement of doctors, and in many parts of the world traditional birth attendants still oversee births and community healers and elders oversee deaths. Both Boron and her father realised that “both of these life-altering events are going to happen regardless of any intervention.” Babies will be born, and people will die—but, writes Boron, “we can walk alongside our patients and help make their experiences better physically, emotionally, and spiritually.” Doctors can also undermine the specialness of both events. Boron acknowledges this but doesn’t dwell on it.

Her book is mostly positive. Constantly switching between birth and death, she covers the history of obstetrics and palliative care; principles of family-centred care; the psychological, spiritual, and socioeconomic aspects of and the rituals around birth and death; symptom management; and the ethical and legal issues around birth and death, which grow steadily more complex.

Humans are storytellers, and the singular importance of birth and death mean that everybody has stories to tell about them. I remember my wife’s need to tell the stories of the birth of our three children again and again, but now we hear and tell more stories about deaths. “Telling one’s story,” writes Boron, “is a way to clarify thoughts, feelings, and memories. And listening to people’s stories increases empathy and acts as a kind of witnessing.” That’s true for friends, family, and health professionals. But, warns Boron, with more deaths taking place in hospitals and intensive care units, families are marginalised and “the story is often lost.”

Boron practices in Canada, which has in the past introduced Medical Assistance in Dying (MAID). It is probably the best model for Britain to follow, and, although there was inevitably controversy around its introduction, MAID has quickly become accepted and part of Canadian life. Boron describes how her husband, who volunteered for palliative care work and had a “palliative soul,” opted for MAID. He had motor neurone disease and “lost control of his ability to speak, to swallow, and eventually even to move in his bed.” After her experience of the death of her husband, Boron asked: “As a society, are we better off having this option? Yes, in balance, I think we are.”
Boron ends her thoughtful book based on years of both professional and personal experience, with lessons learnt. There are many, but I picked out two: “Doing some work on ourselves, acknowledging our own mortality, is hard but vital to being an effective caregiver”; and “When it comes right down to it, the main thing in caring for people, especially as they live through the major transitions at both ends of life, is good communication.” Technical competence without compassion and good communication is almost worthless.

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1 Bookends BS. A Family Doctor Explores Birth, Death, and Tokoanthanatology, 2022.