Dying well is a social and community act. Except for sudden deaths (and even these usually occur in the presence of a community of bystanders), we die in social settings, in the embrace and care of three groups: family, “loved ones”, and the health team that includes not only nurses and physicians, but also therapists, palliative care specialists, housekeeping staff, and volunteers. As this extraordinary book, edited by Professors Kristina Orfali, Brigitte Feuillet-Liger and Thérèse Callus, demonstrates, there are many similarities about the dying process in modern clinical settings in countries from Europe, North America, Asia and Africa. There are also significant and telling local differences on how people die that are explored in the more than twenty superb essays in this meticulously edited, scholarly volume.

In the mid-19th century, in Anna Karenina, Tolstoy observed that “Happy families are all alike; every unhappy family is unhappy in its own way.” In considering the modern context of dying, we could extend Tolstoy’s observation in at least two dimensions: first, by noting that often the definition of “family” remains unsettled and contested. In this volume, the authors often wisely extend the concept of family to include “loved ones,” that is, those people who have very close relationships with the dying person and are often best friends. This move from family to loved ones raises difficult legal and clinical questions about decisional authority at the bedside and about how different countries try to bridge the gap between their formal laws and the human reality of permitting a role in decision-making for loved ones who are important to the patient and who should have a role to play at the end of life. For many years, I have proposed that every routine medical history, especially histories taken long before an end-of-life crisis develops, should include one more question as follows: “If you are unable to make decisions for yourself, whom do you trust to make a decision
for you?” This simple question would clarify who should serve as the patient’s surrogate decision-maker.

The second issue raised by Tolstoy relates to “...every unhappy family is unhappy in its own way.” Drawing on my forty-five years of practicing medicine, I can state without equivocating that families of dying patients are always, inevitably unhappy, each in their own way. Families import to the dying process of their loved one a lifetime of experiences and feelings that are intensified during the dying process. It is not surprising that end-of-life care, often negotiated with one or several surrogates, is a complex process in every country around the world.

Even the goals of surrogate decision-making are not always clear. In the North American context, dominated by the autonomy model, the goal usually is to try to reach a decision that dying patients would make for themselves if they still retained decisional capacity. The basis by which surrogates try to reach such decisions is either advanced directives (written or oral), substituted judgment, or the patient’s best interest. None of these approaches is perfect; each has limitations. In many countries outside of North America, the critical determinant seems not to be autonomy but rather the nebulous concept of the patient’s best interest, which is meant to include not only medical interests but also the patient’s psychological and moral welfare.

There are problems with relying on surrogates to make decisions, and these problems exist around the world: 1) patients sometimes do not have either family or loved ones to serve as surrogates; 2) conflicts frequently emerge among surrogates about what is best for the patient; 3) conflicts emerge between the surrogate(s) and the health team; and finally, 4) the question arises about whether surrogate decision-makers — family or friend — have the same ethical standing to make life and death decisions as the dying person. Despite the problems that surrogacy raises, there is a feeling, shared in many countries, that the surrogate process works well enough to meet legal, social and clinical requirements. It now appears that, for patients, the most important issue is who makes the decision rather than what a particular decision is.

In the late 1960s, I had the privilege to work for five years with Dr. Elizabeth Kubler-Ross at the University of Chicago. Kubler-Ross in her great work *On Death and Dying* (1969), helped launch
the field of end-of-life care. Along with Dame Cecily Saunders in England, Kubler-Ross shifted the care of the dying from a practice shrouded in mystery to one that permitted in-depth analysis, study and improvement. This current volume, carefully assembled by its three scholarly editors, builds on the great work of Kubler-Ross and Saunders to broaden the field of end-of-life care to a new international context and to improve the care of dying patients around the world.

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