Robert D. Truog

Tolstoy on transparency and authority in end-of-life decision-making

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R. D. Truog (✉)

Harvard Medical School, Senior Associate in Critical Care
Medicine, Children's Hospital, Boston, USA
e-mail: Robert_Truog@hms.harvard.edu

In this issue of *Intensive Care Medicine*, Devictor et al. [1] provide us with fascinating information about the evolution of end-of-life decision-making in pediatric ICUs over the last decade across Europe. Although a number of insights can be drawn from these data, I will focus on the dramatic changes they describe in the south of Europe, and particularly in France. Between 2002 and 2009, the percentage of parents informed that there would be a staff meeting to discuss end-of-life issues about their child rose from 67% to 92%, and the percentage of parents who were informed about the decision that was reached rose from 68% to 92%.

When the data from 2002 were originally published, an American intensivist wrote very critically about the low rate of parental involvement in end-of-life issues in France [2], exclaiming: “Parents should not be excluded from decisions to forgo life-sustaining treatments!” This commentary highlighted the profoundly different views that existed at that time between the United States and France about the proper role of parents in end-of-life decision-making. Over the last decade, much has changed, but much has remained the same. In making sense of these data, it is helpful to distinguish between transparency (i.e., information sharing) and authority (i.e., who is empowered to make the final decision).

In *The Death of Ivan Ilyich*, Tolstoy [3] gives us a rich description of the interactions between patients and physicians in 19th century Russia. At one point Ivan apologetically asks his physician to comment on whether his illness is serious: “We sick people often probably put inappropriate questions, but tell me, in general, is this complaint dangerous or not? ...”. The physician responds in the opaque manner characteristic of the time: “I have already told you what I consider necessary and proper”.

Today we use Tolstoy's masterpiece as a way to teach medical students and trainees about how it feels to be a patient or family member who is kept in the dark about a patient's condition or prognosis, when the physicians are not transparent about the information they have. From my admittedly North American perspective, I was also disturbed by the evidence that French pediatric intensivists were not transparent with parents; and I am pleased to see that French pediatric ICUs have made dramatic improvements in this area.

But transparency is different from authority. Ivan Ilyich's physicians told him “If you only put yourself in our hands we will arrange everything—we know indubitably how it has to be done, always in the same way for everybody alike”. These physicians controlled not only access to information (transparency), but also had power over decision making (authority). With regards to authority, Devictor and colleagues' data would suggest that little has changed in Europe with regard to who has the power in medical decision-making. As in the days of Tolstoy, it might appear that the physicians hold all of the cards.

Data like these have led to what has almost become a caricature of the differences between North American and European medicine, with European physicians considered paternalistic and Americans as either patient-centered (in the positive sense) or cowardly (in the negative sense). In my view, however, these clichés miss (or at least overstate) the point. As more in-depth ethnographic work suggests [4], clinicians all over the world strongly prefer

end-of-life decisions to be made in cooperation with the patient and family. And this is almost always successful—Devictor and colleagues found that the parents agreed with the clinicians 95% of the time, similar to the widespread agreement reported in North America [5].

Research has shown, however, that North American and European families may prefer to travel by different pathways in arriving at this place of agreement. For example, surrogates for North American patients are more likely to claim that they want the final say in end-of-life decision-making [6], whereas European families tend to want the doctor to decide [7]. But regardless of their preferences about who should have the authority, families on both sides of the Atlantic typically reach agreement with the clinicians on the right course of action. In other words, the often-cited differences between the United States and Europe around end-of-life decision making are likely much less salient than we commonly assume. Instead, our approaches seem to be converging around the importance of an individualized approach to decision making, nicely summarized in a paper by European authors that concluded: “our end-of-life practice should be tailored to the specific characteristics of each region and culture, each clinical situation, each patient, each family, and each ICU professional” [8].

This leads me, however, to a final insight from Tolstoy [9]. In the famous opening line of *Anna Karenina*, he observed that “Happy families are all alike; every unhappy family is unhappy in its own way”. If I can extend this analogy (hopefully not past the breaking point!), when families reach agreement with their clinicians (the happy

families), then practices in North America and Europe look fairly similar. But when clinicians and families become mired in intractable disagreements (the unhappy families), stark differences emerge between the continents. For example, when patients in the UK demand treatment that clinicians believe is not medically indicated, the British Medical Association [10] states that “the decision will be made by the clinician in charge of the patient’s care”. As far as the family, the BMA says that “the treatment decision is not their right or their responsibility”. Similarly, the Belgian Society of Critical Care [10] states that “the family has no decision-making capability”. In North America, on the other hand, families are typically seen as having these rights and responsibilities, and physicians thereby more frequently accede to demands from families for life-sustaining treatments.

Happy families everywhere seem to be mostly alike, with agreement and consensus among everyone involved. Unhappy families are unique, and highlight the different approaches to conflict resolution between North America and Europe. So we can celebrate both the increase in transparency that has appeared in Europe over the last several years and the fact that, despite somewhat different understandings of authority, both North American and European physicians are able to reach agreement with families almost all of the time. But when it comes to the unhappy families, we have profound differences in our approaches that will likely be the subject of much future research and debate. Who would have guessed that Tolstoy knew so much about modern end-of-life care?

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