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Reflections on Love, Fear, and Specializing in the Impossible

*David M. Browning, Elaine C. Meyer, Dara Brodsky,
and Robert D. Truog*

David M. Browning, MSW, BCD, is a Senior Scholar at the Institute for Professionalism and Ethical Practice, Children’s Hospital Boston; and is a Senior Research Associate at the Education Development Center in Newton, Massachusetts.

Elaine C. Meyer, PhD, RN, is Associate Director of the Institute for Professionalism and Ethical Practice and Director of the Program to Enhance Relational and Communication Skills, Children’s Hospital Boston, and is an Associate Professor of Psychology in the Department of Psychiatry, Harvard Medical School, Boston.

Dara Brodsky, MD, is a Physician Facilitator at the Institute for Professionalism and Ethical Practice, Children’s Hospital Boston, and is Associate Director of the Department of Neonatology, Beth Israel Deaconess Medical Center, Boston.

Robert D. Truog, MD, is Director of the Institute for Professionalism and Ethical Practice and Senior Associate in Critical Care Medicine at Children’s Hospital Boston, and is a Professor of Medical Ethics and Anesthesiology (Pediatrics) at Harvard Medical School, Boston, robert.truog@childrens.harvard.edu. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

*What families need help with in many end-of-life situations is not
a buffing up of their decisional capacities, but compassionate attention
to how the events unfolding before them can be made meaningful or bearable.*

— Larry Churchill and David Schenck

*Being ethical in such situations has less to do with making a single decision
than with initiating a process — often a very slow process — of a person or persons coming to feel that how they
acted was as good as it could have been,
given the inherent impossibility of the situation.*

— Arthur Frank

What we need is more people who specialize in the impossible.

— Theodore Roethke

In the article “How Much Emotion Is Enough?” by Annie Janvier, we are offered a rare and compelling glimpse into the journey of baby Violette and her parents, as told through the voice of her mother.¹ Born on the cusp of viability at 24 weeks and five days, Violette’s parents, both neonatologists, knew all too well the worrisome survival statistics associated with such extreme prematurity, the precarious course that lay ahead, and the range of developmental challenges their tiny infant could face. Violette’s mother lays bare the expe-

rience of parenting a baby whose life hovered at the edge of life and death, suspended in uncertainty. The author's reflections enable us to better understand the limitations of our highly cognitive, linear ways of thinking about decision making in these situations.

A panoply of emotions — anxiety, fear, love, uncertainty, hope — emerged for Violette's parents, uniquely shaping their decision-making process. At one juncture, Violette's parents decide that withdrawal of life-sustaining treatment is in her best interest. The numbers were undeniable; it seemed the correct choice. But then, Violette starts to suck slowly on her pacifier, a sign, for her father, that constitutes hope; the landscape of decision making is transformed.² Violette's father, a "master of evidence-based medicine," finds himself responding to evidence of a different kind, and cannot bring himself to go forward with the plan to withdraw life support. As her mother says succinctly, emotions saved Violette's life.

To structure our commentary, we offer reflections drawn from our experience for the past five years unpacking just these kinds of ethically charged circumstances in our role as faculty facilitators for the Program to Enhance Relational and Communication Skills. PERCS is an initiative of the Institute for Professionalism and Ethical Practice at Children's Hospital Boston and Harvard Medical School. In day-long workshops, an interdisciplinary group of practitioners from a range of experience levels comes together to learn — in a safe and respectful setting — about how best to engage in high-stakes conversations with patients and families.³ Our pedagogy, based on a relational approach to learning, aims to integrate patient and family perspectives, professionalism, and the everyday ethics of clinical practice.⁴

How might a physician, nurse, social worker, or chaplain be helpful to Violette and her parents under such terrible circumstances? What might we say or not say, do or not do? How might we acknowledge and invite the thoughts and feelings of Violette's parents into our team conversations, family meetings, and efforts to help them go forward? How can we create a calm and respectful holding environment that communicates to families our appreciation of their struggles and our willingness to help shoulder the moral burdens they are facing?⁵ As we attend medically to Violette's tiny body struggling for survival, how can we best attune ourselves to her mother and father, poised on their own cusp of viability, striving to find competence as parents?

Violette's mother invites us to accompany her as her world "starts to crumble." By listening to her unique story, we are invited to reflect on a number of rather unquestioned and well-accepted practices in the neonatal intensive care setting. Consider, for example, the common practice of congratulating parents on the birth of their premature and vulnerable babies. For some parents, this acknowledgment is greatly appreciated, but for others, like Violette's mother, such well-intentioned words can fall flat, triggering shame and anger.

Or, consider the practice of providing a substantial amount of medical information to parents (often in a review of systems format) on a daily basis to keep them fully informed about the health status of their infant. Although this is familiar and self-organizing for practitioners, parents can be overwhelmed in this process, and left wondering how all the data really applies to *our* child and *our* predicament.⁶ Some parents, some of the time, want all the details; other parents, some of the time, are looking for something else.

The ideal of rational decision making is well embedded in our Cartesian medical culture. Janvier, a parent and neonatologist, alerts us to the dangers of privileging rationality at the expense of the rest of human experience. She reminds us of the critical role played by emotion in parenting and, by inference, the equally critical role of emotion in being a good clinician. If emotion is undervalued and underdeveloped in health-care settings, and this hinders optimal care, what should we be doing about it?

From a research perspective, we know something about what matters to parents when they are faced with end-of-life decisions. They assess, as best they can, how much pain and suffering their child is likely to bear. They try to ascertain and predict their child's expected quality of life. And, very often, they measure their own success as parents based on their ability to protect and advocate for their child.⁷

When it comes to religion and spirituality, we know that faith can provide guidance and solace at the end of life; we also know, sadly, that many families hesitate to share this part of their lives with clinicians.⁸ We know precious little about the hour-by-hour and day-by-day sojourn of parents facing impossible decisions.

Larry Churchill and David Schenck, for example, found that parents described the process less in terms of having "made a decision," and more in terms of a struggle to find their bearings.⁹ The process of getting to a decision seemed to have less to do with rational cognition and more to do with making sense, locating meaning, and situating themselves as parents in an uncertain moral universe.

As educators, we appreciate having had the opportunity to share our own thoughts and feelings in response to the rich account offered us by Janvier. We close this commentary with her poignant and prescient words: *death is not what parents have in mind for their child at a particular moment*. Indeed, death is not what parents have in mind for their child, not at this moment or any other moment. It is an impossible reality to imagine. But imagine they must, at times. And if we, as caregiving professionals, aspire to be helpful to them, we will need to imagine along with them. We will need, as the poet Theodore Roethke wrote, "more people who specialize in the impossible."¹⁰

We are only beginning to understand how families, in complex and remarkable ways, find their way through these impossible times. To understand better, we can learn more about the meaning and impact of parental love on these times, and all the ways it is pushed, pulled and challenged beyond imagination (and beyond *reason*).¹¹ We can choose to delve more deeply into our ways of thinking, talking, and teaching clinicians-in-training about how these decisions unfold in the lives of real families, and we can cultivate a richer, more sophisticated body of knowledge based on the evidence that is their experience. Finally, we can nourish the values, relational capacities, and ways of knowing that clinicians need in order to be most helpful.

If we're fortunate, we may come to understand, together, what it means to specialize in the impossible.

NOTES

The quotation from Larry Churchill and David Schenck at the beginning of this article is from L.R. Churchill and D. Schenck, "One cheer for bioethics: Engaging the moral experiences of patients and practitioners beyond the big decisions," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 389-403.

The quotation from Arthur Frank at the beginning of this article is from A.W. Frank, "Ethics as process and practice," *Internal Medicine Journal* 34 (2004): 355-7.

The quotation from Theodore Roethke at the beginning of this article is from T. Roethke, <http://creatingminds.org/quotes/impossibility.htm>.

1. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*.
2. J. Groopman, *The Anatomy of Hope: How People Prevail in the Face of Illness* (New York: Random House, 2004).
3. D.M. Browning et al., "Difficult conversations in health care: Cultivating relational learning to address the hidden curriculum," *Academic Medicine* 42, no. 9 (2007): 905-13.
4. D.M. Browning and M.Z. Solomon, "Relational learning in pediatric palliative care: Transformative education and the culture of medicine," *Child and Adolescent Psychiatric Clinics of North America* 15, no. 3 (2006): 795-815.
5. D.H. Winnicott, *Playing and Reality* (New York: Basic Books, 1971).
6. E.C. Meyer et al., "Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations," *Pediatrics* 117, no. 3 (2006): 649-57.
7. E.C. Meyer et al., "Parental perspectives on end-of-life care in the pediatric intensive care unit," *Critical Care Medicine* 30, no. 1 (2002): 226-31; M. Sharman, K.L. Meert, and A.P. Sarnaik, "What influences parents' decisions to limit or withdraw life support?" *Pediatric Critical Care Medicine* 6 (2005): 513-8.
8. M.R. Robinson et al., "Matters of spirituality at end of life in the pediatric intensive care unit," *Pediatrics* 118, no. 3 (2006): e719-29.
9. L.R. Churchill and D. Schenck, "One cheer for bioethics: Engaging the moral experiences of patients

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and practitioners beyond the big decisions," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 389-403.

10. T. Roethke, <http://creatingminds.org/quotes/impossibility.htm>.

11. J. Gillis and J. Rennick, "Affirming love in the pediatric intensive care unit," *Pediatric Critical Care Medicine* 7, no. 2 (2006): 165-8.