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Parent-authored memoirs: Lessons in the practice of narrative medicine

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Abstract

Healthcare professionals, including practitioners of medical genetics and genetic counseling, have much to learn about the experiences of parents who are raising and caring for a child with a rare disease or developmental disability. Knowledge and understanding of the challenges in the care of a child with conditions such as Down syndrome and Wolf-Hirschhorn syndrome are at the core of the practice of genetic medicine. Insights into this experience can come from active listening to stories and from deep reading of memoirs and narratives authored by parents of children having these challenges. A recent book, *Raising a rare girl: A memoir*, by writer, poet, and teacher, Heather Lanier, represents a relevant and prototypic example of this genre. Spending the effort in the contemplation of the parental stories provides a valuable lesson in narrative medicine and the experience of empathy for the plight of the family.

KEYWORDS
narrative medicine, empathy, Wolf-Hirschhorn syndrome, Down syndrome, disability

> There are more things in Heaven and Earth, Horatio, than are dreamt of in your philosophy. (Act I, Scene 5, *Hamlet*)

Prince Hamlet's notion of "philosophy" that he asserted to his friend, Horatio, is often interpreted in the literary community as an indication of the limitations of human knowledge. Hamlet is essentially saying to all of us that there are many worldviews and realities that we do not even realize we do not know. I would suggest that Shakespeare's aphorism could be applied to genetics care professionals in our knowledge of the plight of families who have a child with a rare disorder or developmental disability: Knowledge and understanding of the rewards and challenges in the rearing and the care of a child with conditions such as Down syndrome and Wolf-Hirschhorn syndrome (WHS) are central to the practice of genetic medicine. And we have much to learn. Genetics professionals, both clinical geneticists and genetic counselors, should aspire to comprehend and learn of these experiences. The classical (Fraser, 1974) and more recent (Resta et al., 2006) definitions of *genetic counseling* both include text that underscores the skills needed in helping families adapt to and cope with a genetic condition.

In this light, I am reminded of a seminal paper that appeared in the *Journal* almost 10 years ago. Madeo et al. (2011) presented a review and commentary on the relationship between the genetic counseling profession and the disability community. The article has lost none of its timeliness. In discussing this relationship between genetic professionals, who practice genetic counseling, and the disability community, Madeo et al. "argue that to authentically serve and support individuals in the family with disabilities, those who practice genetic counseling must individually and collectively strive to more firmly establish and maintain relationships with members of the disability community as well as professionally and clinically convey a more balanced view of living with disabling conditions…" Although these words were written in the context of the prenatal setting, they are equally applicable to all medical genetics encounters.

A recently published book, *Raising a rare girl: A memoir*, by Lanier (2020), poet, writer, teacher of creative nonfiction, and mother of Fiona who has WHS, encapsulates the aim stated above in our striving "to comprehend and learn of these experiences" of parents. A

deep reading of her treatise raises many of the precepts championed in the discipline referred to as narrative medicine. In this journal, Nowaczyk (2012) reviewed the topic of narrative medicine and showed "how geneticists can further improve their abilities to hear and honor patients' stories by writing and sharing stories with patients and with each other…" In this context, I recommend reading her article which astutely applies the principles of narrative medicine to medical genetics. On a similar note, Nowaczyk and I invited the genetics community to share stories and accounts "that enlighten or confuse and in the process shine new light on the practice of clinical genetics" when introducing a new article type in the *American Journal of Medical Genetics* called *Frameshifts: Narrative in Medical Genetics* (Nowaczyk & Carey, 2013). The idea here was that often in our clinical encounters an event, comment, or insight will stop us in our tracks, make us think, reflect, shift our focus—just like a DNA variant producing a frameshift and eventually a stop in transcription. These are stories that "humble us" and connect us to the empathetic endeavor needed for the care of a family. The work by Lanier accomplishes just that: My perusal, including writing notes in the margin of the book, frequently "stopped" me, made me ponder a particular theme, and invited an active listening to the story of Lanier and her husband, Justin, experiencing the birth of Fiona and the events surrounding her rearing during the first 7 years of her life. Fiona has WHS due to a deletion (not a "defect") in the distal end of the #4 chromosome. The natural history and the genetic knowledge of the distal 4p deletion syndrome are quite familiar to this readership, and I will not expand on them here. For those interested, Battaglia et al. (2015) provided a current review of the condition.

What Lanier accomplishes in her work is the disclosure and recognition of a number of themes and narratives that those of us involved in genetic care should know well: the giving of the news of a diagnosis, the importance of the choice of words we use in counseling, and the fallacy of the normal or "perfect child." Additionally several themes that—at least in my experience—regularly occur in the early discussions of a diagnosis of a child with developmental disabilities surface in her accounts.

One such theme and alluded to above is the construct of the "normal child." Lanier, who masterfully weaves the narrative of the disability community throughout the book, cites an authority on the topic of normalcy stating, "the problem is not the person with disabilities … the problem is the way that normalcy is constructed to create the problem of the disabled person." The disability narrative that I am referring to is comprehensively covered in the many stories in the book edited by Catapano and Garland-Thomson (2019), *About us: Essays from the disability series of the New York Times*. This book is recommended as a resource and certainly worth reading in the context of this discourse. The pieces will "enlighten or confuse" us, certainly "humble us."

Another theme that emerges in Lanier's *Memoir* and is familiar to our community is the delivery of unexpected or difficult news to a family. Here, Lanier recalls the story of the pediatrician who informs the family early in the newborn period that he had concerns about Fiona because of her growth delays. We are reminded of the potential effect of the words we use in talking to our patients that can stigmatize and by their impact add to the already challenging aspects of the experience. I cringed when I read on page 18 of the doctor's discussion of Fiona's low birth weight. He states, "….'you see, he said, before dropping a bomb,' it is either bad seed … or bad soil." This early experience was contrasted (and I would say thankfully) by the meeting of the author and her husband at the genetics clinic a few weeks later in their encounter with the "genetics resident." She comments, "…looking back I see the brilliance of the resident's language." He referred to the change in the chromosome as a genetic deletion (which it is) "rather than a genetic defect." This underscores that particular words that we use have an impact- they are vividly recalled. Here, Lanier again brings up of the narrative of disability community and the concern with the view of "diminished personhood." The resident, Lanier says, chose words that were remembered and helpful, "in the poker game of doctor's words, we were dealt aces." "We will not put limits on her," the resident said, "we will help her be all that she can be." Lanier follows, "the resident did a powerful thing that day: through the language and framing, he took my daughter's life back from a culture that might label her as less than and he returned that life to us." What an insight for us (and kudos to the resident).

This experience of the informing interview, the delivery of unexpected news, is one that I have contemplated regularly over the years: the notion that when first making a diagnosis we need to be aware of not taking value away from the child in our giving of the news; we need to carefully plan and think about the words we choose to use. This is a place where Hamlet's words ring true for me: we do not always recognize the underlying impact that certain words may generate. Lanier refers to this as the isolation of difference: "Normal is not just a range on the bell curve. To be Normal is to partake in a certain kind of belonging with others. This was one thing that made parenting Fiona unexpectedly hard-the isolation of difference." In referring to a diagnosis, expressions such as "these children" or "Down syndrome children" can be isolating. Lanier repeatedly brings out a theme that most of us know: "the child is not the diagnosis." She clearly wants to debunk any notion that the child is "a tragedy."

An additional narrative that emerges in the book is embedded in the title, that is, the *Raising a rare girl*, that is, the rare disease narrative. Here, the experience of parents can again be one of isolation. Nevertheless, this experience can be assuaged by helping make connections with other parents early on in diagnosis; these connections to fellow-travelers nowadays occur in the participation in Facebook and/or support groups. There is no reason for me to say more on this topic to our readers: introducing families to other parents and to advocacy groups—I believe—has become a routine part of anticipatory guidance in these settings. Lanier relates their positive experience in attending the annual conference of the 4p- support group (page 157 ff) when Fiona was still an infant.

A theme that resonated with me personally as I read the book is one that I suspect many readers are aware of, but it struck me poignantly in reading Lanier's book. This is the idea that when we are in clinic, we are only seeing a child and her family for a snapshot—only for a few moments. In reading *Raising a rare girl* you—as the reader—experience much of the day-to-day life including episodes of feeding, observing early communication milestones, and interactions with early

intervention program professionals in the home. You celebrate the acquisition of milestones with the family. Although I have heard accounts like these in clinic over the years, to read about and experience them, to "hear and honor (the) stories" was stirring.

After finishing the book and rereading my notations, I was reminded of a similar work in this genre that I read 7 years ago, Rachel Adams' *Raising Henry* (Adams, 2013). I would recommend it as well in contributing to learning of the experiences "that enlighten or confuse and in the process shine new light on the practice of clinical genetics." Henry is a boy with Down syndrome, and Rachel Adams, also a writer and professor like Lanier, tells her story of both learning the diagnosis of Down syndrome and caring for him. The accounts of various professionals who helped and hindered and the challenges in seeking the most ideal academic environment for a preschooler—again witnessing the day to day challenges—is a "frameshift," a story similar but different to the one I heard and honored in my reading of *Raising a rare girl*.

In summary, close reading of these books provides insights into the lives of families experiencing these events and gives us an authentic hands-on experience in narrative medicine. As written by Nowaczyk (2012), "Our lives are stories, and to make sense of our lives, we tell stories."

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CONFLICT OF INTEREST

The author declares no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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