



Preemie Voices

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Book Review

As neonatologists, many of us have been asked about our chosen profession, “How can you do that?” And what have we responded with – “it is satisfying work”, or maybe “children are special”, and “I just try to give every baby a chance.” When the public hears from the media, or

perhaps from one of our patients’ parents, of the smallest and most premature infants we care for, their facial expression often changes. They wonder if we are “doing good” or simply creating more problems, adding to individual and family suffering, and burdening society. On occasion I recount to those who ask such questions that the vast majority of babies who are admitted to a NICU go home healthy; that long-term ‘disability’ visits a small number of patients and their families – clearly less than 15% overall, and rarely as much as 25-30% when addressing the smallest of our patients.

Contributing to such knowledge, in a most amazing manner over 40 years, is the work of Dr. Saroj Saigal from McMaster University and McMaster Children’s Hospital in Hamilton, Ontario, Canada. Hers has been a career devoted to monitoring, measuring, and understanding long-term outcomes of the classic ELBW and, given the state of neonatology in the late 1970’s and early 1980’s, those at the borderline of viability. We have to remind ourselves that her cohort of ELBW infants from 1977-1982 were cared for before surfactant and synchronized or high-frequency modes of ventilation. They were monitored with arterial blood gases and an occasional transcutaneous oxygen monitor – pulse-oximetry had yet to be developed. They received IV nutrition, but not via PICC lines. And their neurological conditions were ascertained by excellent neurological examinations, an occasional CT scan, or the relatively new technology of 2D ultrasonography. That these children were seen in follow-up over such a long period of time is a testament to excellent leadership, research support and funding, institutional priority, and will on the part of Saroj and her research partner, developmental pediatrician Dr. Peter Rosenbaum. It is also a great credit to the parents of these children and, ultimately, to the children themselves.

In a venue designed for the lay public – but equally apropos to NICU clinicians, pediatricians, and obstetricians/maternal-fetal medicine staff – Saroj crafts a text of volunteered perspectives...the preemie voices...from 41 of her now 30+ year-old patients. The text includes these letters, written by [now adult] patients and accompanied by photographs and inspirational messages. It is then followed by a brief introduction to neonatology, photographs, and glossary of terms and acronyms used in

the NICU. The next few chapters recount the history of neonatology, the Canadian experience, survival and ethical matters, and long-term outcomes in general. The book also addresses the McMaster’s program for longitudinal follow-up and matters around quality of life – with contrasting perspectives of parents and providers, and even attention to the impact of prematurity on other siblings within an affected family.

In Chapter 9, Dr. Rosenbaum gives insights addressing “Issues in Childhood Disability: A Forty-year Perspective on a Changing Field.” I found this chapter most illuminating, and a pleasure to read and reflect upon, especially Figure 2 where he denotes the “F-words of Childhood Disability” from the WHO’s 2001 International Classification of Functioning, Health and Disability. Finally, in the Epilogue, written by Maryse Glaude-Beaulieu, a gifted student who has overcome many obstacles in her life, we hear a resounding message that this book provides the reader – perhaps one that could be captured in the word “resiliency” - as she states, “I never saw myself as a preemie, or as a disabled person. I was just like everyone else, with challenges to overcome.”

I would heartily recommend this book to practicing NICU clinicians of every discipline, fellows in training, and suggest it be given due consideration for NICU parents. Thank you, Saroj, for your tireless efforts, your probing approach and openness to varying perspectives, and the gifts you have provided so many patients, families and clinicians.

**Premie Voices*, by Saroj Saigal, MD (Victoria, BC, Canada; Friesen Press, 2014. Available in hardcover, paperback and ebook)

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