

BOOK REVIEW

## Shared decision making in an unequal world

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**John D Lantos, Editor. *The Ethics of Shared Decision Making*. Oxford University Press, New York, 2021, 211 pages, \$74, ISBN 978-0-19-7598573.**

A frail 83-year-old lady, living with her husband in a village, had fallen and fractured her right hip. The optimal treatment was surgery to replace the broken hip, but both she and her husband refused the surgery out of fear and their cultural beliefs. After a lot of counselling and convincing, she underwent the surgery, but died of surgical complications a week later. I played the role of her primary care physician, in organising her surgery, counselling the family, and then providing comfort care at the end of her life. During this entire process, there were several instances when the line between my decisions about “what is best for her” and a decision based on the family’s values and preferences was blurred. Such stories — where shared decision making between the patient and the physicians remains illusory — abound in medical practice. The idea of operationalising shared decision making in typical low- and middle-income settings like India, with poor health literacy even among the educated, a weak public health system, and over-crowded health facilities, with very little time available for physician-patient interaction, leaves much to be desired.

It is against this background that I read this volume edited by John D Lantos. It gave me a fresh, grounded perspective of shared decision making (SDM) from the point of view of paediatricians in the United States. The most important thing I learned was that paediatricians and probably all physicians, world over, grapple with the concept of SDM and it is not just a problem in India. The honest narration of seasoned clinicians from their own experiences gave me a sense of familiarity due to several instances where I have had the responsibility for

major decisions in the treatment of patients.

They say we shouldn’t judge a book by its cover. That wouldn’t fit this book because it has a beautiful, bright, and beckoning cover in a vivid red that suits the clear, concise, and interesting style of the book. While browsing through the names of the 21 contributing authors to the book, I noticed that most of them were clinicians — paediatricians, critical care experts, anaesthesiologists, oncologists — providing care for children in the US. This created an expectation that the complex topic of SDM would be handled with a hands-on, practical perspective, which was more than fulfilled by the time I finished reading the book.

In his introductory chapter, Lantos brings out the landscape of clinical decision making in paediatrics, especially difficult decisions such as end-of-life care. In the second chapter, Feudtner, Schall and Hill focus on the dilemmas of the surrogate decision-maker in cases of children or persons with limited capacity to decide. It is written in the captivating style of a theatre act with a prologue and epilogue and brings out the concept of the “personal sense of duty” of the surrogate in making decisions in such situations. In Chapter 3, Siegler draws a historical timeline of the birth of Clinical Medical Ethics as a specialty, and how it contributed to the idea of SDM.

Halpern and Owen, in their chapter “Scaffolding Autonomy”, throw open the dilemma of sharing bad news with adolescents and children in the spirit of full disclosure versus “scaffolding” the information with emotional support. This chapter uses two interesting case studies, one in which bad news was communicated without any emotional scaffold to an adolescent; and another in which the exact opposite was done, and the person was not involved in the decision making at all. This chapter helps delve deeper into the idea of SDM.

As mentioned at the start of this review, in many instances in physician-patient communication, the line between paternalism and SDM becomes blurred. In Chapter 6, Clark, Lewis-Newby, Kon and Morrison highlight the idea of “Clinician Directiveness” across a spectrum of how directive clinicians can be while practising SDM. Sometimes, they may have to be more directive and nudge the patient towards the decision that is in their best interest, and sometimes they must be less so. Walter and Fiks, set out a ten-step pragmatic approach to practise SDM. This chapter is a must read for all paediatricians and doctors interested in implementing SDM in their own practice.

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Miller and Cousino handle a very complex issue, involving children and adolescents in difficult clinical decisions such as those at end-of-life. I am not a paediatrician and so this whole chapter was an eye-opener for me. The stepwise framework espoused by Sawyer and Opel, for implementing SDM in the care of children, includes assessing whether there is more than one medically reasonable treatment choice, whether one option has a favourable benefit-burden ratio, whether the options are preference sensitive, along with a calibration of the SDM approach in a spectrum of physician-guided to parent-guided decisions. This theoretical framework is very helpful for paediatricians who plan to adopt the SDM model in their practice.

Derrington and Paquette's chapter on the role of culture and cultural sensitivity of paediatricians in implementing SDM is very relevant to the diverse cultural contexts of paediatric practice in India. In Chapter 11, Blumenthal-Barby highlights the various biases and heuristics that influence the decision-making of parents as well as physicians. This useful chapter helps us understand and reflect on the biases in our thought process while making shared decisions. In the concluding chapter, Lantos sums up the operational challenges of SDM in the paediatric context, using fiction, poetry, and a case study. This brings all the concepts in the book together in a seamless flow.

The greatest strength of this book is its strong grounding in clinical practice. There are examples and case studies used in all the chapters that bring ethical concepts to life. There is also a judicious balance of theory and empirical work. The style of writing is simple and succinct, and it seems that a lot of work has gone into establishing a smooth flow between the chapters. Sometimes multi-author edited volumes tend to distract the reader due to widely disparate writing styles. This does not happen in this book and the narrative flows freely throughout. Though the focus is on SDM for the paediatrician,

the lessons and theory can be applied widely even by other clinicians.

There are some minor but glaring typographical errors in the book, which may be corrected in future editions. On Page 16, in Figure 2.3, the phrase "Socially end Self Defined" must actually read as "Socially and Self Defined". On Page 17, in Box 2.1, the list of "Examples of Good-Parent beliefs" is repeated. On Page 15, in the last paragraph line 1, "Individuals' identities grow out of their 'well' roles as professionals, spouses, parents, or friends.....", the word 'well' is out of place.

SDM is a two-way street. As much as a clinician needs to be sensitised to its nuances, the success of SDM also depends on the preparedness of the patient or the parent of the child to share and take part in the decision-making process. I expected the book to have at least a chapter dedicated to preparing parents, children and patients to participate in SDM, and strategies to enhance their preparedness. While the various aspects of SDM as a communication skill are covered well in the book, I feel that the ethical reasoning and ethical analysis is lacking in depth. Autonomy as a core ethical principle in SDM is covered, as is respect for persons. Besides these, SDM also has important justice and equity aspects. SDM gives voice to the vulnerable and the weak and protects the vulnerable from exploitation. These aspects are not discussed in detail in the book.

We live in an unequal and unjust world with several power hierarchies, especially in the physician-patient relationship. Shared decision-making is one attempt at bridging the power hierarchy and handing a semblance of control to patients and their families. This very well-edited collection of essays goes some way towards laying out the complex concept of SDM for all physicians who are interested in reflecting on the ethics of SDM and implementing it in their own practice, and I strongly recommend it.