

PEDIATRIC CARE

**From Difficult Patient
to Model Patient:
A Childhood Story
Pg. PS 1**

**On Shared Decisionmaking
In Pediatric Care
Pg. PS2**

From Difficult Patient to Model Patient: A Childhood Story

Now in her 60s, “Sally” (not her real name) recounts her early childhood experiences as a dental patient. According to her parents, her story begins when she was about four years old. Growing up in the days before the fluoridation of our water supply, Sally had numerous dental cavities. Somewhere around the age of four, she was apparently taken by surprise when the dentist pulled a tooth. After this event, her parents told her, she started acting out and went from being a reasonably cooperative patient to being a problem patient.

While she doesn’t recall the details, she does remember going from dentist to dentist because, before long, they all told her parents not to bring her back again. This pattern continued until she was around seven years old. At that time, her current dentist was working on repairing a deep cavity. Because she was as afraid of ‘needles’ as she was mistrusting of dentists, she would not allow the dentist to administer a local anesthetic. When the inevitable happened and the pain became too much for her, she created a scene and refused to allow him to continue. She was immune to her parents’ pleas to let the dentist finish up. The dentist, like those before him, told her parents to take her home and not bring her back unless she would cooperate. At home, she was given a choice between going back to the dentist and letting him finish up or a spanking. She chose the spanking.

Not long afterwards, she was told that an appointment had been made for her with a dentist who was just starting his practice and had opened an office near them. She not only had to go, they said, but she was to go alone. They would not be going with her. She went – reluctantly. With a cavity that still had to be taken care of, she knew she would be in for a lot of pain.

It was clear that her parents had told Dr. “Goodman” (not his real name) of her history, because on the way into the examining room, he stopped and spoke with her. Standing face-to-face and towering over her, he essentially said: “you be good to me, and I’ll be good to you.” He then brought her in to the dental chair and began. What happened after that totally surprised and elated Sally. Instead of working on the unfinished cavity, he simply cleaned her teeth. There was no pain! In her words, she “walked on air” all the way home.

In hindsight, she realized that this new dentist must have been just as nervous as she was, but he had clearly passed her test. She returned the following week during which time she sat still while he completed the work on that troublesome cavity. Thereafter, even though she continued to refuse a needle until she was 16 (when she needed root canal work), she quietly endured all treatments, regardless of the levels of pain. Her positive experiences with this dentist, she reports, only grew – in large part because he related to her as a person. One memory that stands out was that, shortly after she started seeing him, he initiated a practice of having all his child patients place their handprints on his wall. Sally’s was the first and even though it was soon one among many others, he often pointed hers out to her during her visits. Perhaps not surprisingly, she not only continued as his patient long after her family moved away and but also after she married and had children.

Commentary

By visiting Dr. Goodman beforehand, Sally’s parents not only gave him a chance to gather his thoughts about how to deal with Sally, but also initiated a parent-dentist partnership. The decision to send Sally alone may have been their first joint decision – one that helped Dr. Goodman better connect with Sally. By speaking to Sally in a straightforward way and then showing her that dentists do not always bring on pain, Dr. Goodman was able to pave the way for a therapeutic relationship between the two. He then built on that relationship through friendliness. Finally, Sally’s metamorphosis from an especially difficult patient to a model patient, supports the view that the way people act is largely influenced by how they feel. As such, attending to emotional needs may help the process of meeting physical needs.

Although elements of this story validate already accepted concepts about the importance of therapeutic relationships, it is, still, just one story. It is not rigorous research from which generalizations can be made. Nevertheless, practitioners who read this might draw their own conclusions regarding any insights it may suggest and actions they might take to enhance their own encounters with children patients and their parents.□

On Shared Decisionmaking In Pediatric Care

On Shared Decisionmaking

Jaime Staples King and Benjamin Moulton, in their article “Rethinking Informed Consent: The Case for Shared Decision-Making,” report that both of the two standards for information disclosure by physicians – the physician-based standard (what ‘reasonably prudent practitioners’ would disclose) and the patient-based standard (what reasonable patients, intent on making medical decisions, would want to know) – are flawed.¹ First, the many medical decisions that are matters of quality of life, not life-or-death, call for decisions based on patient preferences, rather than the preferences of even reasonably prudent physicians. Second, the great variety of preferences among reasonable patients make it difficult for physicians to know what particular patients would want to know. Whether due to these flaws or something else, many of the decisions made by patients are not fully informed ones.²

More recently, the concept of shared decisionmaking (SDM) – representing patient-professional partnerships – has become part of the philosophical dialogue. Advocates argue that SDM will result in decisions that are more fully informed – that is, decisions that not only take into account medical risks and benefits, but the values and preferences of patients as well – leading to improved health outcomes. Key elements of SDM are an exchange of information between patient and practitioner along with discussion of the exchanged information. The more traditional version of SDM concludes with a jointly made, perhaps negotiated, decision. The SDM model, advocated by Staples King and Moulton, differs in that, after the information exchange and discussion, patients might then decide who they want to make the decision: the patient alone, the doctor alone, or the two jointly. This approach, they say, satisfies the need to inform patients and gives those patients the final say with respect to the decisions – including who makes them. In the end, even if patients delegate decisionmaking to their physicians, it will be their informed choice.

Even so, many valid concerns have been voiced regarding the practicality of SDM. Topping the list is the extra time required to satisfy its requirements. For a detailed outline of those concerns and responses to them, readers are urged to read the Staples King and Moulton article, which can be found online at: http://www.fimdm.org/pdfs/Staples-King_Mou.pdf. (Note: the underscore in the URL is 3 spaces.) What their argument comes down to, however, is this: while the consistent practice of SDM *may* initially result in increased time and expenditures, those increases *may* ultimately be offset by the results of fully informed decisions – namely, greater commitment to the treatment plan by patients, better health outcomes, reduced utilization of medical resources, less resentment of physicians over adverse events, less litigation, reduced insurance premiums and even, perhaps, financial incentives offered by Managed Care Organizations for engaging in SDM.

Efforts to make SDM more practical are already underway. In part, these take the form of decision aids and decision coaches.³ Both hold the promise of not only reducing the time doctors need to spend with patients, but also of making the time spent more productive. This approach has been adopted in several arenas, one of which is the Dartmouth-Hitchcock Medical Center’s Center for Shared Decision Making.⁴ One decision aid for making “tough” decisions, not focused on any particular disease, is offered by the Ottawa Health Research Institute. Its Ottawa Personal Decision Guide, can be found at <http://decisionaid.ohri.ca/decguide.html>. Decision aids for specific diseases and conditions are also available. Decision aids for specific diseases and conditions are also available.

SDM In Pediatric Care

Advocates of SDM in Pediatrics report that parent and child participation in shared decisionmaking can be beneficial even with commonplace conditions such as acute Otitis Media and Asthma.⁵ Measures that practitioners can take to overcome parent and child barriers to participation, as described by Cox et al, include: age-appropriate visual aids (coloring or comic books, photos and so on); turn-taking (encouraging children and parents to take turns in speaking with practitioners, intervening as necessary if parents interrupt the child); eliciting attention/requesting help; clarifying communication with children; and role modeling.⁶ Key to the use of these measures is an assessment of each child’s competency level and inviting participation in age-appropriate ways. One way this might be accomplished is to ask the child simple questions.

Besides better management of childhood conditions, the importance of encouraging children to participate in healthcare discussions, if not decisionmaking, is best summed up by Cox et al:

*...because both parents and children feel ill-prepared to participate in health care decisions...more work is needed to support the development of participation skills during childhood.*⁷ □

¹ Jaime Staples King and Benjamin Moulton, “Rethinking Informed Consent: The Case for Shared Medical Decision-Making,” *American Journal of Law & Medicine* 32 (2006): 429-501.

² See Note 1; Lainie Friedman Ross, *children, families, and health care decision-making*, (NY: Oxford University Press, 2002): 58, 89.

³ See Staples King and Moulton (Note 1) for discussion of decision aids and steps that are taken to assure they are free of bias.

⁴ See

http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486

⁵ Arlene M. Butz, et al., “Shared Decision making In School Age Children With Asthma,” *Pediatric Nursing* 33(2): 111-116 (March-April 2007); Elizabeth D. Cox et al., “Evaluating Deliberation in Pediatric Care,” *Pediatrics* 120: (July 2007): e68-e77.

⁶ See Butz, et al., Note 5.

⁷ See Cox, et al., Note 5: e74