

Can I help shoulder your burden?
Finding connection through
Shared Decision Making

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Learning Objectives

1. Develop an understanding of the concept of shared decision making and the history from which it emerged.
2. Explore some of the opportunities and barriers that are inherent in the shared decision making model.
3. Discover what palliative care can learn from pediatrics when it comes to shared decision making.

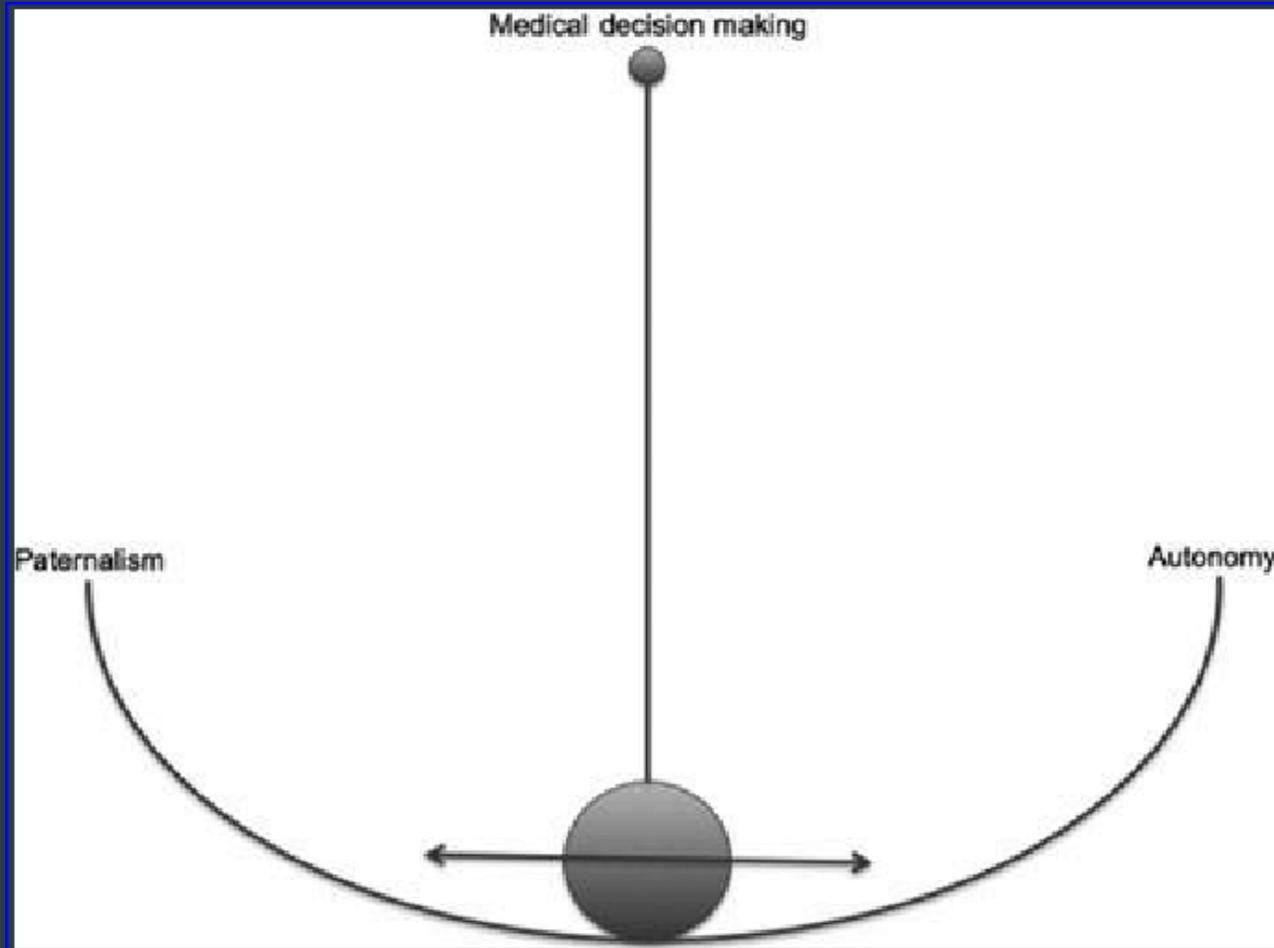
Case: Nell

- ▶ 16 year old with a complex past medical history
 - ▶ myelomeningocele s/p closure at birth, paraplegia, tethered cord s/p release, neuromuscular scoliosis, and shunted hydrocephalus
- ▶ Presented in shunt failure for which she underwent neurosurgical shunt revision
- ▶ Post operative course complicated by significantly depressed neurological function, severely suppressed EEG, and QB MRI with evidence of diffuse hypoxic ischemic brain injury
- ▶ Despite extensive work up and efforts to optimize all aspects of medical care, no clear etiology or progress after 10+ days

Case: Nell

- ▶ Palliative care team first met family during a care conference:
 - ▶ Family acknowledged hearing the information that Nell had suffered a serious brain injury
 - ▶ They were not ready to accept that these changes could be permanent
 - ▶ They would never give up on Nell
- ▶ Palliative care's second encounter was another care conference:
 - ▶ The decision was made to proceed with a compassionate extubation
 - ▶ Unexpectedly, Nell survived the extubation
- ▶ Palliative care's third meeting was a more traditional consultation as consideration turned toward how to proceed...

Medical decision making pendulum



Roeland E, Cain J, Onderdonk C et al., “When Open-Ended Questions Don't Work: The Role of Palliative Paternalism in Difficult Medical Decisions,” *Journal of palliative medicine* 2014; 17(4): 415-420.

Sharing Decisions

The image features a central photograph of a network of pins connected by thin, silver wires on a dark, textured surface. The pins are arranged in a roughly circular pattern, with some in the foreground and others receding into the background, creating a sense of depth. The wires connect the pins in a complex, web-like structure. The background is blurred, showing more pins and wires. The image is overlaid with a dark blue, semi-transparent geometric shape on the left side and a bright green, semi-transparent geometric shape on the right side. The text 'Sharing Decisions' is written in a bright green, sans-serif font on the dark blue shape.

Patients and Families

What do they contribute?

- ▶ Life story (narrative)
- ▶ Values and preferences
 - ▶ And in turn goals



Health Care Professionals

What can they provide?

- ▶ Medical facts of the case
- ▶ Professional experience
- ▶ Research/ EBM



Shouldering burden



SDM: Some Benefits

- ▶ Validate the person who is the patient
- ▶ Restore the art of medicine
- ▶ Culturally humble model



SDM: Some Challenges

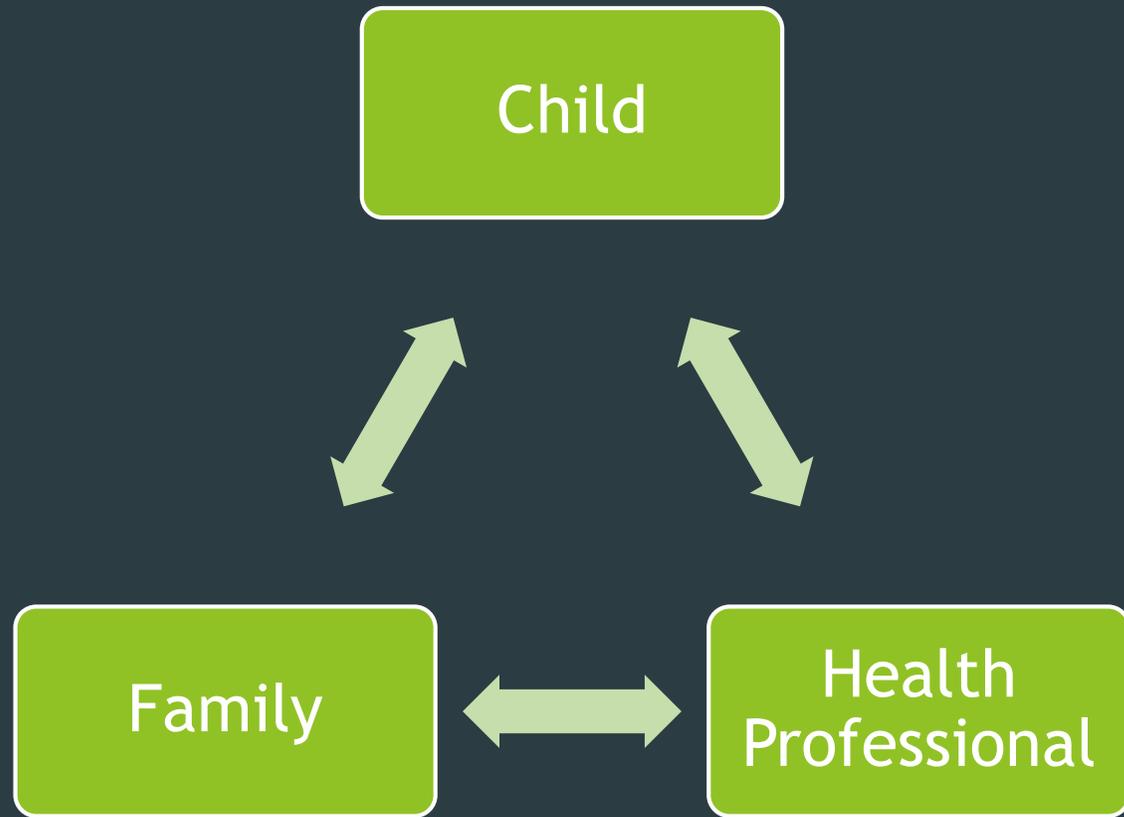
- ▶ Time
- ▶ Adapting to family needs
- ▶ What if we disagree?



Pearls from Pediatrics



The Pediatrics Triangle



Some tools and constructs we use

- ▶ **Decision making involvement**
- ▶ **Recommendations and reflections**
 - ▶ *“Doctor, what would you do?”*
- ▶ **Time limited trials**
- ▶ **The off-ramp**

Return to our case:

Nell - A review of the medical facts

- ▶ 16 year old female with significant medical complexity, including shunted hydrocephalus
- ▶ Presented in shunt failure and underwent neurosurgical procedure
- ▶ Course complicated by severe neurological injury of unclear etiology, though consistent with anoxic injury with no meaningful improvement over 10+ days
- ▶ Survived compassionate extubation
- ▶ Need to decide how to proceed

Return to our case:

Nell in broad strokes
Her story in 10 points



Implications of shouldering burdens

- ▶ "Wins" may be shared, but now losses are shared too..



Tools for SDM Self-Care

- ▶ Personal care
- ▶ Opportunities to reflect
 - ▶ Journaling
 - ▶ Art making
 - ▶ Parallel chart
- ▶ Opportunities to debrief



Do you want to read more?

- ▶ Sara Taub, Natalie Lanocha; Shared Decision-making in Pediatrics: Toward a More Participatory Model. *Pediatr Rev* January 2023; 44 (1): 50-52. <https://doi.org/10.1542/pir.2021-004984>

We want to hear more!

- ▶ What has been your experience with shared decision-making?
- ▶ What practices do you employ to get to know the patient's story? And how do you weave it back into the decision making process?
- ▶ How do you take care of yourself in the setting of challenging decision making?