

Navigating Uncertainty in Antenatal Counselling

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- No conflicts of interest to disclose

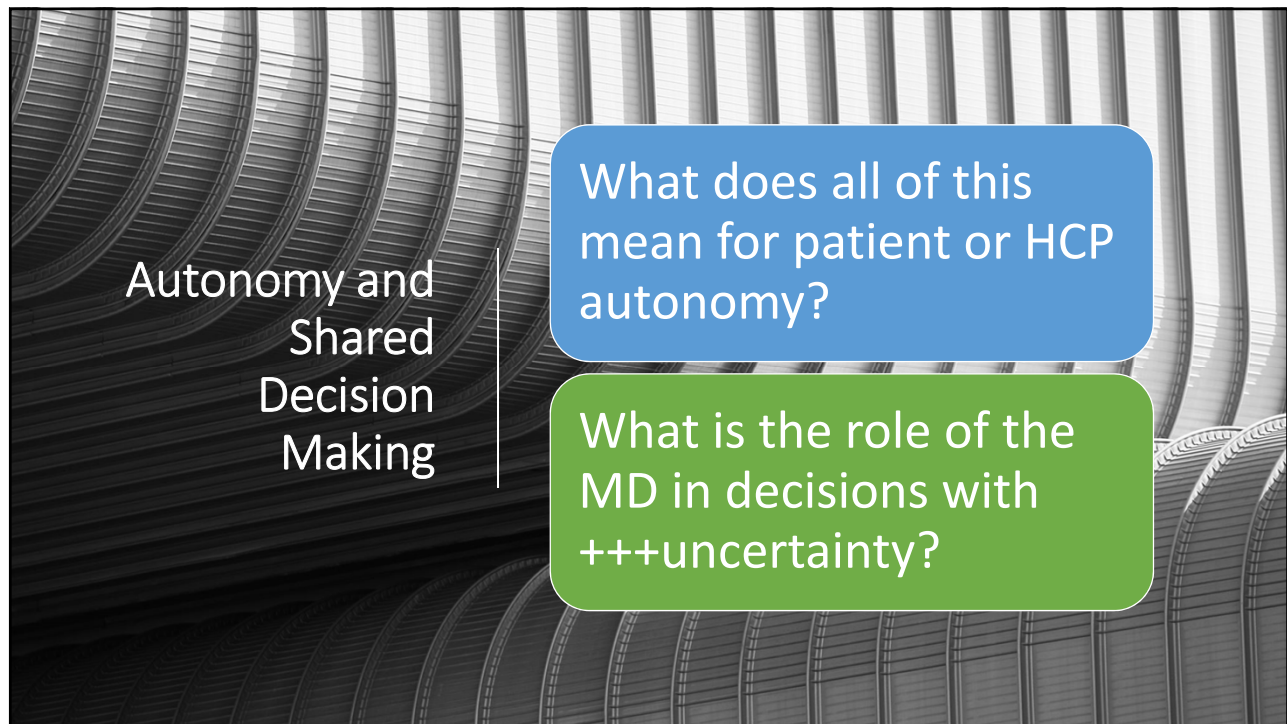
Objectives

- To identify ethical issues in antenatal counselling r/t ++uncertainty
- To explore ethical considerations with shared decision making
- To provide tools to assist providers with counselling



Uncertainty & Antenatal Context

- Value laden decisions
- Varying approaches to shared decision-making
- ++subjectivity re goals and outcomes
- Decision-making paradigm is different in pregnancy vs as parent



HCP Autonomy

- To provide medical information and consideration to decision-making

Patients can only refuse treatments that are offered

Don't ask a question if there is only one acceptable answer

Patient/SDM Autonomy: What is Implied?

- Right to refuse unwanted Rx
- Acting on *values*, self control, respect, freedom from coercion
- Often interpreted as right to demand Rx
- MDs can help bolster autonomy through empathic values based dialogue and titrated directiveness

'Shared Decision Making'

- It *should* be:
 - A complex intervention in which patients and clinicians make decisions **together** (Olthuis et al 2014)
 - Shared responsibility, but responsibility for different domains:
 - Physicians = clinical expertise
 - Substitute decision makers = values and goals
- Often doesn't recognize asymmetry of info
 - Asks patients to act like doctors evaluating highly technical data
 - Asks doctors to act like a friend; not a neutral agent
- Unfair burden on substitute decision makers? On physicians? On teams?

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POSITION STATEMENT



Counselling and management for anticipated extremely preterm birth

Posted: Aug 11, 2017

*“The parents’ expectations regarding their own role in decision making can never be assumed. **Some parents are reluctant to carry the burden of decision making**, while others want to be involved but do not know how.”*

*“Shared decision making (SDM) is the best approach for preference-sensitive decisions, which include those made when no clear evidence supports one treatment over another, options have different inherent benefits/risks, or parental values are involved. SDM can mitigate parental grief around end-of-life decisions, enhance knowledge of and satisfaction with care, aid decision making that is consistent with **parental values and foster collaboration with medical teams.**”*

“Moral Schism”

Where a significant internal struggle with personal values causes uncertainty as to the right course of action to pursue, resulting in distress

1. Manifests prior to a decision & can persist after
2. An internal conflict; uncertainty about what is best and accompanied by significant turmoil and angst
3. Qualitatively unique → emotional sequelae

Foe, G., Hellmann, J. & Greenberg, R.A. Parental Moral Distress and Moral Schism in the Neonatal ICU. *Bioethical Inquiry* **15**, 319–325 (2018). <https://doi.org/10.1007/s11673-018-9858-5>

Addressing Moral Schism

Role of HCP

- Prevent fragmented care
- Provide holistic care
- Engage in shared decision making
- Involve bioethics, social work, palliative care, and spiritual care, as appropriate

Role of Bioethics

- Enhance awareness and identification of ethical issues, sources for moral distress and moral schism
- Provide education and resources to staff and families about moral distress and moral schism
- Provide bioethics consultations to families – even when there is no conflict with team
- Proactively address causes of moral distress and moral schism

Goal-Centric Shared Decision Making

- Shift from determining what treatments patients want → what they hope treatment will accomplish
 - **Identify values**
 - Identify goals
 - Prioritize
 - Map treatments options on to values and goals

Titrating Clinician Directiveness in Serious Pediatric Illness



Morrison W, Clark JD, Lewis-Newby M, Kon AA. Titrating Clinician Directiveness in Serious Pediatric Illness. *Pediatrics*. 2018 Nov;142(Suppl 3):S178-S186. doi: 10.1542/peds.2018-05161. PMID: 30385625.

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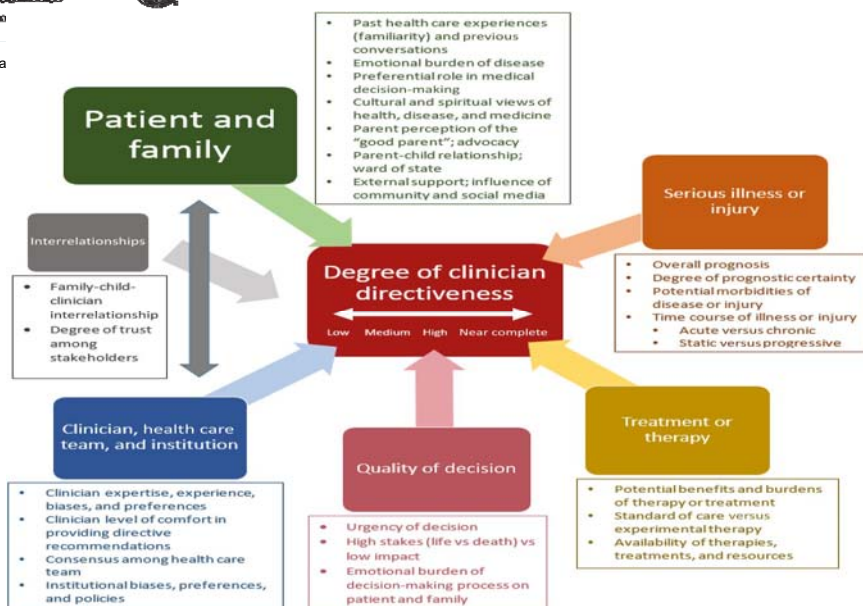
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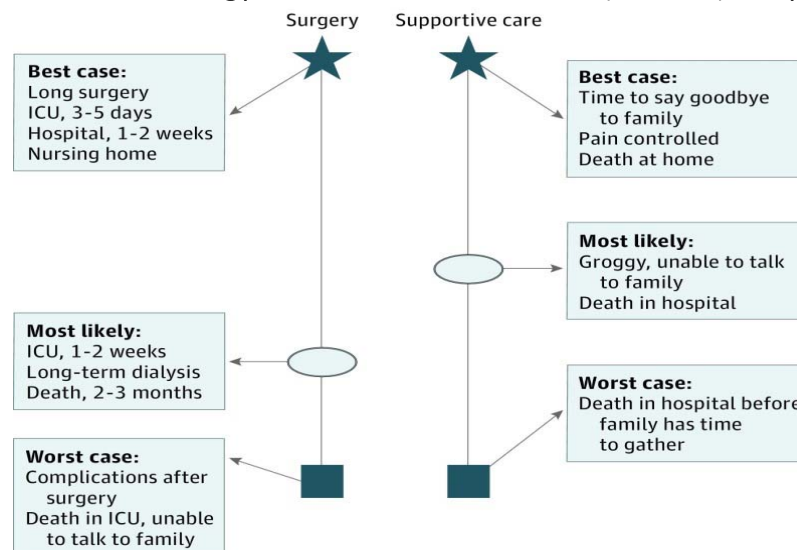
Communication Strategy: Best Case/Worst Case (BC/WC) Framework

- Strategy to communicate with patients and help them manage uncertainty
- Uses stories and a handwritten graphic aids
 - describe how patients may experience a range of possible outcomes including the best case, worst case, and most likely scenarios
- Physician's Role:
 - to present the stories of how patients may experience the treatment and the outcome;
 - to present what is known and what is uncertain;
 - ask the patient/decision maker to evaluate treatment and outcomes based on personal goals and values
- Meant to assist with "high-stakes" treatment decisions
- Focus is on what matters to the patient and which story (i.e. treatment path) best fits with the patient's perspective, goals, and values

Taylor, L. J., Nabozny, M. J., Steffens, N. M., Tucholka, J. L., Brasel, K. J., Johnson, S. K., Zelenski, A., Rathouz, P. J., Zhao, Q., Kwekkeboom, K. L., Campbell, T. C., & Schwarze, M. L. (2017). A Framework to Improve Surgeon Communication in High-Stakes Surgical Decisions: Best Case/Worst Case. *JAMA surgery*, 152(6), 531–538. <https://doi.org/10.1001/jamasurg.2016.5674>

Humbyrd C. J. (2022). Virtue Ethics in a Value-driven World: Seeking the Story. *Clinical orthopaedics and related research*, 480(2), 241–243. <https://doi.org/10.1097/CORR.0000000000002100>

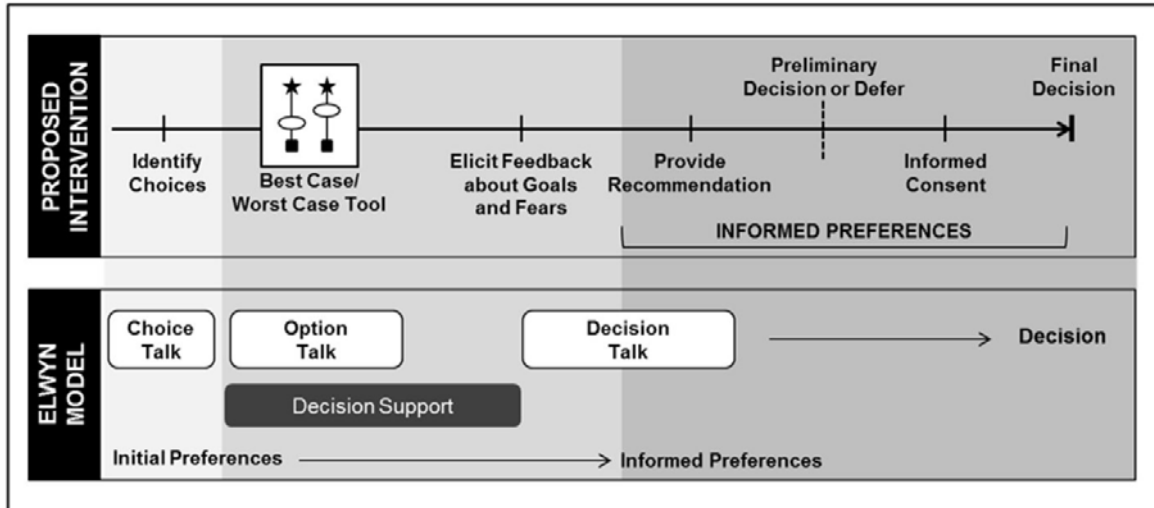
Communication Strategy: Best Case/Worst Case (BC/WC) Graphic Aid



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Best Case/Worst Case (BC/WC) NEPHROLOGIST Communication Tool - Whiteboard Video (University of Wisconsin) https://www.youtube.com/watch?v=oXFr7koz_A

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