



Ethical Challenges Around Substitute Decision Making in Clinical Practice

Dr. Janneke Gradstein, MD, Medical Site Lead Cumberland Regional Health Care Center, Associate Professor at Department of Family Medicine Dalhousie University, Nova Scotia.

The following discussion questions are provided as an additional educational tool to accompany this fireside chat video. Please feel free to select the questions that are most relevant to your committee or group, revise and adapt them as needed, etc. As always, we welcome feedback on this or any other NSHEN resource.

Questions:

- In your opinion, what is the biggest challenge associated with substitute decision making in health care?
- Dr. Gradstein talks about biases as a challenge in substitute decision making. She suggests ways of framing questions to substitute decision makers that put the patient's values in focus.
 - Can you think of other strategies health care providers can use to support decision making based on the patient's values and to avoid situations where decisions may be driven by the substitute decision maker (SDM)'s values or wishes rather than those of the patient?
- Sometimes patients make health care decisions for themselves that health care providers disagree with. This may also be the case in substitute decision making.
 - From a health care provider's perspective, do you think it makes a difference to how you would react if the challenging decision is made by an SDM? Why/why not?
- What would you do if an SDM was not acting in what you understand as your patient's best interest?
- Challenges related to substitute decision making in health care often arise due to disagreement between family members and the SDM around values relevant to health care decisions for the patient.
 - Discuss different approaches that a health care team can take to navigate such situations with the SDM and family.
 - When might you contact ethics support for an ethics consultation?
- Dr. Gradstein talks about fluctuating capacity as being a particular challenge.

- What can health care providers, substitute decision makers and patients do to prepare for such situations?
- Based on your experience, what are some of the ways that health care providers can support SDMs in their role?
- People sometimes change their minds. What a patient once said about what they would or wouldn't want may not apply in a new context.
 - How would you address this uncertainty as a health care provider and/or as an SDM?
- Discuss how personal directives and other forms of advance care planning may help the substitute decision making process.

Resources

Dawner, J. et al. (2017). Balancing the interest of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of life-sustaining treatment - Improving the Last Stages of Life. Report commissioned by Law Commission of Ontario (2017).

<https://www.lco-cdo.org/wp-content/uploads/2015/05/Downar-et-al.-Final.pdf>

Dempsey, T.M., E. Sullivan DeMartino (2019) How Should Clinicians Navigate Decision Making for Unrepresented Patients? Case and Commentary. *AMA Journal of Ethics* 2019, 21(7)E559-565. doi: 10.1001/amajethics.2019.559. <https://journalofethics.ama-assn.org/article/how-should-clinicians-navigate-decision-making-unrepresented-patients/2019-07>

Shalowitz, D.I., E. Garrett-Mayer, D. Wendler (2006) The Accuracy of Surrogate Decision Makers A Systematic Review. *Arch Intern Med* 2006;166(5):493-497.

<https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/409986>

Udelsman, B.V., N. Govea, Z. Cooper, D.C. Chang, A. Bader, M. J. Meyer (2020). Concordance in advance care preferences among high-risk surgical patients and surrogate health care decision makers in the perioperative setting. *Surgery* 167(2):396-403. <https://doi.org/10.1016/j.surg.2019.08.013>

Wasserman, J.A. and Navin, M.C. (2018). Capacity for Preference – Respecting Patients with Compromised Decision-Making, *The Hastings Center Report* Vol. 48 (3): 31-39.

Brochures and Tools:

Ethics NSHA Tool: An Approach to Working Through Ethical Questions. Nova Scotia Health, 2017.

https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKewjv3IONzvj1AhV_klEHfnvAyIQFnoECAIQAQ&url=https%3A%2F%2Fwww.cdha.nshealth.ca%2Fsystem%2Ffiles%2Fsites%2F87%2Fdocuments%2Fethics-nsha-tool.docx&usg=AOvVaw2yy-pxgtUyZY1GphYNcmBN

Informed Choice, Subject Guide for health care professionals, Nova Scotia Health

<https://library.nshealth.ca/InformedChoice>

Making Personal Care Decisions for a Loved One Under the Personal Directives Act, Nova Scotia.

https://novascotia.ca/just/pda/docs/Personal_Directive_3-panl_brochure.pdf

[This brochure specific to the Nova Scotia Personal Directives Act, but also relevant for SDMs who are the highest on the statutory list]

Patient and Family Ethics Tool, Help with Ethical Issues.. Patient and Family Guide. Ethics Nova Scotia Health.2020. <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/2056.pdf>

Some articles require access with an institutional login. If you need assistance in accessing an article please email NSHEN administrator Krista Mleczko-Skerry at Krista.MleczkoSkerry@iwk.nshealth.ca