

NEGOTIATING UNCERTAINTY

Ethical challenges of hope, truth-telling, and informed choice in professional caring.

Hope is the physician of every misery.
(Irish proverb)

Part 1: Introduction

- Case 1
 - Ethical decision-making & care in the context of spinal cord injury
 - What is at stake and for whom?
- Themes
 - Hope
 - What are we talking about?
 - Informed choice
 - Where does hope fit in?
 - Truth-telling
 - What are the implications for hope and informed choice?
 - An “ethic of care”
 - How might it help?

Part 2: Application

- Case 2
 - Ethical decision-making in the context of advanced COPD
 - How might do we reconcile hope and truth-telling for informed choice decision-making/care planning in this case?

Part 3: Integration

- Small group discussion – participants’ cases
 - What makes care planning/decision-making difficult in this case?
 - What are the implications of hope, informed choice, and/or truth-telling for decision-making/care planning?
 - Does an ethic of care lens help you discern a way forward?
 - How might you approach this case given the discussion?
- Whole group discussion

Part 4: Conclusion

- Summary
- Some things to think about...

We ridicule those with too much hope and hospitalize those with too little.
(Rona Jevne)

The word which God has written on the brow of every person is hope.

(Victor Hugo)

Using Case 1 as context, the first part of the workshop will be devoted to an exploration of decision-making and care planning as these are shaped by our understandings of hope, informed consent, and truth-telling. The session will be interactive with participants encouraged to comment, question, and/or share from their own experiences related to these themes. The discussion will continue with a consideration of the relevance of Joan Tronto's feminist ethic of care model for developing an approach to decision-making and care planning that attends to hope, informed choice, and truth-telling, particularly in the context of incurable chronic illness (Part 2). In this discussion the facilitator will draw on her doctoral work with patients and families living with advanced chronic obstructive pulmonary disease (COPD) as well as from her experience as coordinator of a hospital clinical ethics consultation service. Using a small group format, the third part of the workshop will provide an opportunity for participants to further apply and integrate their learning by analyzing additional cases. One member of each small group will present the group's analysis and questions to the larger group for further discussion. The session will close with a brief summary of critical points and some further food for thought. A bibliography of relevant readings will be provided.

Participants should come prepared to discuss cases they have struggled with in their own clinical experience. Relevant cases will be those in which participants have been uncomfortable with some aspect of informed choice due to truth-telling and/or hope factors as these affected the patient, family members or substitute decision-maker, members of the care team, or the participant personally. The workshop facilitator invites interested participants to email a case summary (one page or less) of a relevant case prior to Jan 16, 2009, for inclusion in Part 3 of the workshop. Please include what it was that bothered, confused, or perplexed you about this case and what you hope to gain by having the case considered in the context of this workshop. Participants can email their case summaries (with details altered to preserve confidentiality) to: acsimpso@dal.ca.

*Listen to me, talk truthfully to me
...I am angry and sad... support my hope
That tomorrow there may be new medicines
That today you care deeply
That you will do your best
When you come into my hospital room, promise me presence
Promise me a healing partnership keep hope alive
That is all I have*

(Stephen A. Schmidt, EdD, Chicago, IL; patient with long-standing Crohn's disease;
JAMA, Aug 21, 1996; 276(7))

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