Autonomy vs. Risk
Finding the Fit for Rehab Ethics
Peter Allatt, Ethicist

Objectives
• Define autonomy
• Describe the significance of autonomy in health care
• Describe examples of limits to autonomy
• Define and discuss risk and dignity of risk
• Discuss capacity, risk and dignity of risk
• Identify resources for HCP

Conflict of Interest, Interests
• No conflict of interest
• Many interests
  • Researcher or colleague with author of some of the tools mentioned

Cases
A few cases

Vignette #1 – Joan
Lives at risk
Assisted Living

Vignette #1 – Joan cont.
Many risks at home
Vignette #2 – George

Vignette #3 – John

Definitions
Establishing a common terminology

Autonomy
- Self-determination, self rule;
- The right of the individual to determine his own course of action in accordance with a self-selected plan;
- The right of a person to decide what is done with his/her body;

Staff concerns
- DUI
- Injury to
  - Self
  - Patients
  - Staff
Risk

- Subjective notion
- The possibility of suffering harm or loss
- The probability (chance) high or low that somebody could be harmed by these and other hazards, together with an indication of how serious the harm could be

Dignity

- The state or quality of being worthy of honor or respect
- Dignity to express the idea that a being has an innate right to be valued, respected, and to receive ethical treatment.

Risk Assessment

Risk = MAGNITUDE OF OCCURRENCE x PROBABILITY OF OCCURRENCE

Risk – Two Perspectives

Patient Perspective
- Risk magnitude
- Risk probability

HCP Perspective
- Risk magnitude
- Risk probability
Risk Assessment

- There is no formula for drawing a line between acceptable and unacceptable levels of risk, and that risk assessments themselves are highly value laden.

Risk Assessment

- Consider …
  - What if you never got to make a mistake?
  - What if your money was always kept in an envelope where you couldn’t get it?
  - What if you were never given a chance to do well at something?
  - What if you were always treated like a child?
  - What if your only chance to be with people different from you was with your own family?
  - What if the job you did was not useful?
  - What if you never got to make a decision?
  - What if the only risky thing you could do was to act out?
  - What if you couldn’t go outside because the last time you went it rained?
  - What if you took the wrong bus twice and now you can’t take another one?
  - What if you got into trouble and were sent away and you couldn’t come back because they always remember your “trouble”?
  - What if you were never given a chance to do well at something?
  - What if you never got to make a decision?
  - What if you couldn’t go outside because the last time you went it rained?
  - What if you took the wrong bus twice and now you can’t take another one?
  - What if you got into trouble and were sent away and you couldn’t come back because they always remember your “trouble”?

Dignity of Risk

- Dignity of risk – right of individuals to choose some risk in engaging in life experiences

Dignity of Risk

- "The Dignity of Risk acknowledges that life experiences come with risk, and that we must support people in experiencing success and failure throughout their lives. However, it can be a challenge to support decisions that we feel are risky, or with which we don’t agree, without our safety-oriented health care culture.”

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Moral Problems

Moral Dilemma
- Occurs when one knows what is right to do,
make it nearly impossible to pursue the right course of action.

Moral Distress
- Occurs when constraints interfere with acting in the way one believes to be right.

Autonomy
Respect for Autonomy
- Respect for person
- Values
- Beliefs
- Goals
- Authority and responsibility to make decisions in accordance with their:
- Values
- Beliefs
- Goals
- Authority and responsibility for decision made
- Gives person control over
  - their own body
  - body of loved one

Decision Making and Respect for Autonomy
- Capable patients may make decisions others view:
  - Bad decisions
  - Foolish choices
  - Risky decisions

Limits to Autonomy

1. Adapted from Jameton A. Nursing Practice: The Ethical Issues. Prentice-Hall, Inc. Englewood Cliffs, New Jersey; 1984; p.6

Kluge, E. Competence, capacity and informed consent: Beyond the cognitive-competence model. Canadian Journal on Aging. 24(3), 2005

Respect for Autonomy What does it mean?
Risk and Autonomy

• Right to risk is an expression of autonomy

• Removing right to risk is removing autonomy.¹


Risk and Autonomy – cont.

Risk and Dignity of Risk

Professional Duty

• Respect capable patient’s autonomous decision

• Prevent incapable patient from making decision he/she does not fully understand/appreciate

Challenges with capacity, risk & dignity of risk
Challenges to Educating Patients

- Visual limitations
- Hearing loss
- Attention issues
- Health literacy
- Number of issues
- Language differences
- Memory difficulties
- Learning preferences
- Age disparity
- Jargon
- Pressure to make a decision
- Cognition

- Speed information given
- Fatigue
- Stress
- Depression
- Motor function

Autonomy

- John Stuart Mill

- Autonomy and liberty are only achieved by the free exchange of ideas and in trying to persuade one another of the superiority of one view of the world over another.

- Autonomy is not achieved by being protected from disagreements and contrary views.

Vignette #1 – Joan

- If Joan is capable, she can return to the house with Tom
- She can put Tom’s needs above her own
- She can put herself at risk for another fall
- If the house is a hovel, CCAC may refuse to provide services
- It may be more important to Joan that she stay with Tom than to live safely apart

Vignette #2 – George

- HCP may show George photographs of his wounds to aid in his education
- HCP may provide literature, decision aids
- If capable, George can
  - Refuse to follow recommendations to limit sitting
  - Refuse treatment of ulcers ...
  - Refuse NRT and weight loss Rx.
- HCPs may discharge George to CCC or LTC if he is not participating in therapy

Vignette #3 – John

- John can smoke his medical marijuana
- His autonomy does not extend to jeopardizing others (patients/staff)
- HCP can work with John/parents to reduce size of joints
- HCP can work with John to reduce frequency of use
- If John refuses to comply with reasonable requirements, he can be discharged
Suggestions

- Pt. May not feel it is safe to acknowledge risks
  - If I acknowledge risk
  - Not going home
  - Not stay home
- Therefore
  - Understate risks or
  - Do not acknowledge risks
- Need to inform Pt. risk is OK
- Pt. needs to trust HCP

Give Pt./SDM Time

- Patients should not be forced to make immediate decisions
- Within reason
  - $>\text{magnitude of decision} > \text{time and support in making decision}$

Assistance in Decision Making

- Info sheets, pamphlets

- Information
  - If we do not give the patient information
  - They will find it

Risk Acknowledgement

- Pt. May not feel it is safe to acknowledge risks
  - If I acknowledge risk
  - Not going home
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- Therefore
  - Understate risks or
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Information sheets/ handouts

- Key info to augment discussion
- HCP can
  - Use tool to guide discussion
  - Use as a review of discussion
  - Use as a reminder
- Simple language
- Evidence based
- Clinically tested

What is your Role in Health Care Decision-Making in Ontario?

Patient Decision Aids

Patient decision aids are interventions designed to help people make specific, deliberative choices. They make explicit the decision, providing information on the options and outcomes that are relevant to a patient's health status, and clarify personal values. They are intended as adjuncts to counseling.

https://decisionaid.ohri.ca/index.html
Thank You