

Best Practices 2016 Day
 May 2, 2016 • Chestnut Conference Centre, Toronto, ON

Autonomy vs. Risk

Finding the Fit for Rehab Ethics

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Best Practices Day

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



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Cases

A few cases



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Vignette #1 – Joan



Lives at risk



Assisted Living



Vignette #1 – Joan cont.



Many risks at home



Tom



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Vignette #2 – George



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Vignette #2 – George



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Vignette #3 – John



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Vignette #3 – John

Staff concerns

- DUI
- Injury to
- Self
- Patients
- Staff

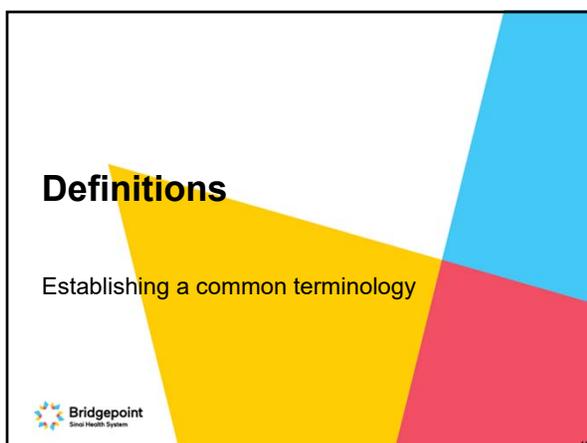


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Definitions

Establishing a common terminology



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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;



Individual
Autonomy

Relational
Autonomy

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Risk

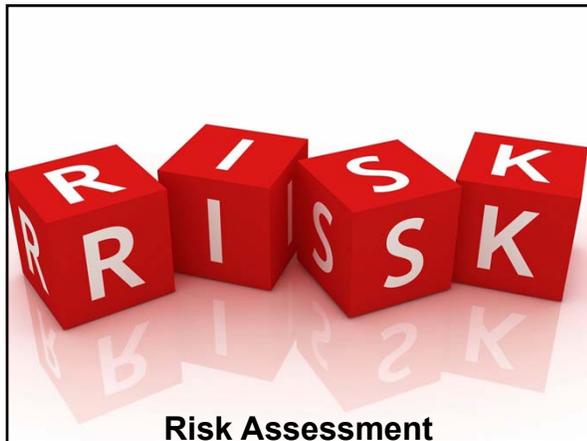
- **Subjective** notion
- The possibility of suffering harm or loss
- The probability (**chance**) high or low that somebody could be harmed by these and other hazards, together with an indication of how serious the harm could be




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 =

MAGNITUDE OF OCCURRENCE
X
PROBABILITY OF OCCURRENCE



Risk assessment

- A **systematic** process of **evaluating (qualitative & quantitative)** the **potential** risks that may be involved in a projected activity or undertaking.

		Magnitude of Risk				
		Minimal	Minor	Major	Serious	Catastrophic
Probability of Risk	Near Certainty	Green	Yellow	Orange	Red	Red
	Highly Likely	Green	Yellow	Orange	Red	Red
	Likely	Green	Yellow	Orange	Red	Red
	Low	Green	Yellow	Orange	Red	Red
	Rare	Green	Yellow	Orange	Red	Red

- Green: Acceptable Risk Low
- Yellow: Acceptable Risk Medium
- Orange: Unacceptable Risk High
- Red: Unacceptable Risk Extreme



Canadian Centre for Occupational Health and Safety https://www.ccohs.ca/oshanswers/hsprograms/risk_assessment.html

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**.



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Michel Silberfeld (1992), The Use of 'Risk' in Decision-making. *Canadian Journal on Aging*, pp 124-136.

Dignity of Risk



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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 once 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 worked and got paid \$0.46 an hour?
- What if you had to wear your winter coat when it rained because it was all you had?
- What if you had no privacy?
- What if you could do part of the grocery shopping but weren't allowed to do any because you weren't able to do all of the shopping?
- What if you spent three hours every day just waiting?
- What if you grew old and never knew adulthood?
- What if you never got a chance?

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The Dignity of Risk. http://www.site.uconn.edu/docs/The_Dignity_of_Risk_Tom_Pomeranz.pdf

Dignity of Risk

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

Dignity of risk = right of failure

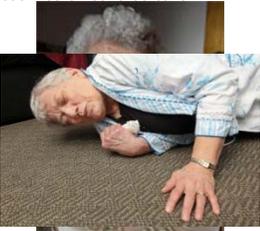
- "the notion that one has **options** from **which** to **choose** is often **more important** than the particular **option** one initially selects."¹

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1. Anthony, W. (2000). A Recovery oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal* 24(2), 159-168.

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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Dignity of Risk Project. What is the Dignity of Risk? <http://dignityofrisk.com/what-is-the-dignity-of-risk>

Dignity of Risk

I suggest to you that that which makes us most human is our ability to enjoy our successes by having the ability to own our own failures.

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Chris Lyons. Self-Determination: "Dignity of Risk." <http://mn.gov/mnddc/parallels2/one/video08/dignityofRisk.html>

Moral Problems

Moral Dilemma

Moral Distress

- Occurs when one knows what is right but is unable to do so, often because of constraints that make it nearly impossible to pursue the right course of action.¹
- Moral distress occurs when constraints on one's actions, when those constraints interfere with acting in the way one believes to be right.²




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- Adapted from Jameton A. *Nursing Practice: The Ethical Issues*. Prentice-Hall, Inc. Englewood Cliffs, New Jersey, 1984; p.6
- Canadian Nurses Association. *Ethical distress in health care*



Respect for Autonomy
What does it mean?

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Respect for Autonomy

- Respect for person
- 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

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Decision Making and Respect for Autonomy

- Capable patients may make decisions others view:
 - Bad decisions
 - Foolish choices
 - Risky decisions



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Kluge, E. Competence, capacity and informed consent: Beyond the cognitive-competence model. *Canadian Journal on Aging*. 24(3), 2007

Respect for Autonomy



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Limits to Autonomy

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Risk and Autonomy

- Right to risk is an expression of autonomy



- Removing right to risk is removing autonomy.¹



1. Nay, Rhonda. The dignity of risk. *Australian Nursing Journal*. 9(1), 2002.

Risk and Autonomy – cont.



Risk and Autonomy



Risk and Dignity of Risk



Challenges with capacity, risk & 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 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
- Pain
- Depression
- Motor function
- ...



Bridgepoint
Speros, C. H. (Sept. 30, 2009) "More than Words: Promoting Health Literacy in Older Adults" OJIN: The Online Journal of Issues in Nursing, Vol. 14, No. 3. Manuscript 5. http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TablesOfContents/Sept09/HealthLiteracyinOlderAdults.html

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**.

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Lantos, J. et al. Clinician Integrity and Limits to Patient Autonomy. JAMA. 2011;305(5).

Return to Cases



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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

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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

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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

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Suggestions



Risk Acknowledgement

- 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



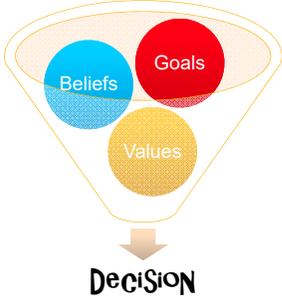

Give Pt./SDM Time

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




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Assistance in Decision Making




Info sheets, pamphlets



Information

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





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

e-EB&B

- Simple language
- Evidence based
- Clinically tested







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




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




Patient Decision Aids




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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**.



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Patient Decision Aids

e-EB&B




<https://decisionaid.ohri.ca/index.html>

650 Patient Decision Aids



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