

Ethics and Resource Allocation: How to Respect Human Dignity in the Making of Tough Choices

Hospice & Palliative Care Manitoba 19th Annual Provincial Conference



Bashir Jiwani, PhD
Ethicist & Director
Fraser Health Ethics Services

# Who should get admission to inpatient hospice/palliative care beds?

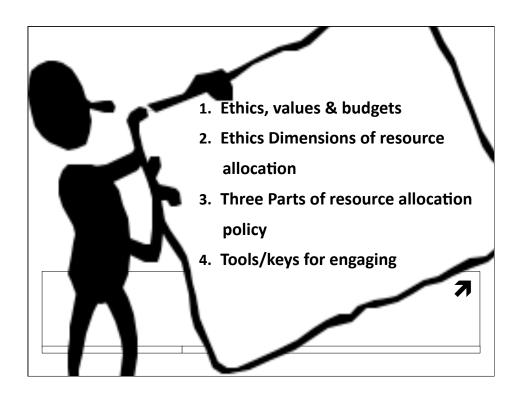
patient	age	Length of time waiting	Anticipated length of stay	Acuity of physical pain	Acuity of psychos ocial distress	Family coping well	Current place	Nursing care needs
James	50	Two weeks	Active deterioration	high	medium	no	Acute care	high
Tina	75	3 months	Longer term stay	medium	high	No family	Assisted living	medium
Akbar	80	1 month	Has approached active deterioration, then improved so hard to say	medium	low	Stretch ed, but not in crisis	home	high

#### How do you respond – to the system?

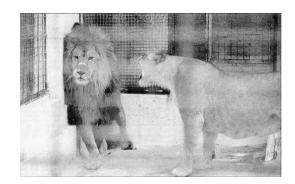
- You are a leader.
- A home care nurse calls you.
- She is going to visit a patient today, whose family is doing the best they can to support their father who is dying.
- She knows that he and they want to stay at home, but may have questions or need support.
- · How do they access support after the business day is over?
- You see this as a broader issue. You are very sensitive to the complexities of healthcare decision-making and the challenges facing leaders and practitioners at all levels, but feel the need to advocate for better care for this population.
- · How do you engage the system about it?

#### Who should get your time?

- You are a home care nurse.
- You arrive at work on Monday morning and see the roster of patients awaiting your support.
- There are 20 patients and families on the list.
- If you were to give everyone the time they needed, it would take 80 hours
- You have only 30 hours to allocate.
- Who should get your time?

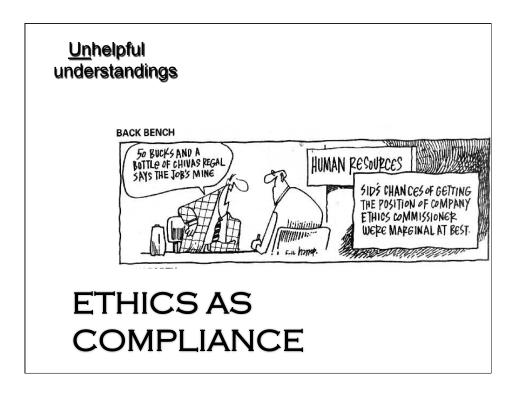


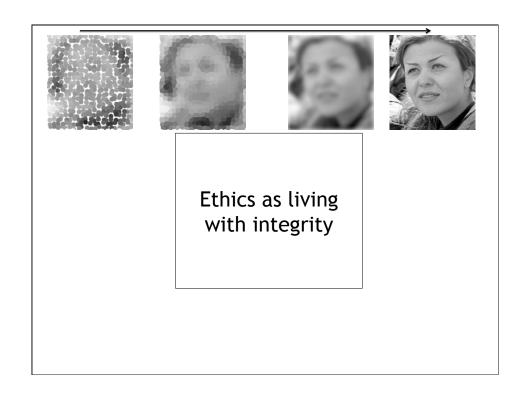
## <u>Un</u>helpful understandings



# ETHICS AS JUDGMENT

- **♦** God-Squad
- **◆ Ethics Police**





#### Budgets communicate values

- **↗** Your decisions, actions and attitudes are all based on your values and beliefs
- **▶** Your budget is a summary of what is important to you and how you will get there
- Values concern
  - **★** the actual decision you make (content)
  - **7** How you make the decision (process)

## Respect

- Unconditional positive regard
- **⊅** Empathetic understanding
- Meaningful engagement of ideas

- **↗** In a <u>fiduciary relationship</u>:
  - guiding decisions based on truster's values and beliefs
- **7** In a <u>relationship of intimate</u> partners:
  - 7 Collaboration
- In a <u>relationship of (what should be) public equals</u>:
  - 7 Transparent decisions based on informed, inclusive, recursive, reflexive deliberation

Substantive Values: Models of Distributive

Justice

- **7** What is our understanding of justice?
  - Treating everyone equally?
  - **↗** Treating everyone equitably?
  - Maximizing overall happiness?
  - Building community solidarity?
  - **★** Respecting individual liberty?

#### Differences in health

- Justified (though unequal)
  - Overall health between young and old
  - Prostate cancer rates between men and women
- Unjustified (unequal and inequitable)
  - Nutritional status between girls and boys
  - Immunization status between girls and boys
  - Access to care based on race

Inequity in Health

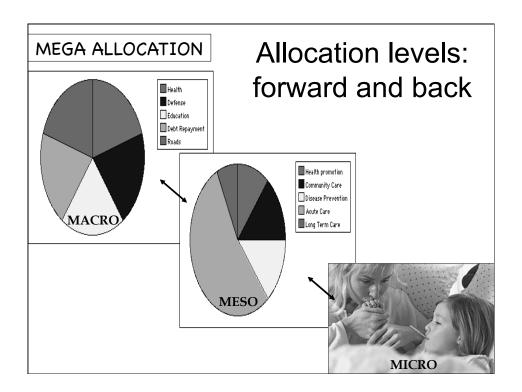
- **↗** Inequalities in health that are unjust/unfair
- → Unjust/unfair if systematically put groups of people already socially disadvantaged at further disadvantage
- **♂** Systematic inequality in health between more and less advantaged groups in society

Groups at risk in Canada

- **7** Poor
- 7 Homeless
- Aboriginal communities
- 7 Immigrant & refugee population
- People with physical and mental disabilities

#### Meritocracy and vulnerable populations

People with dementia... "have no knowledge left to convey to their children, they no longer are intertwined with the community but rather have lost the memory of relationships; and they are therefore easily transgressed and abandoned." (Post, 1995)



Is equity a Canadian value?

- **7** If so, this has implications
  - **7** Within individual care programs
  - **→** Within the health system
  - Within macro governmental policy
  - **◄** For our outlook on foreign affairs

2. Salient ethics dimensions of decisions...

- Mandate of and relationships between decisionmakers
- Consultation of others
  - Experts
  - 7 Those impacted
- Decision itself
- Decision follow-up

19

#### How a decision is made

- **₹** Who speaks?
- 7 How is difference dealt with?
- **→** How are decisions made?
- → What standards will be used to decide what counts as evidence?

### The process of decision-making

#### Implicit rationing

- Discretion of professionals
- Subjective
- **⋾** Sensitive to patient needs?
- **7** Focus on the quality of the story
- More sensitive to culture of facility than individual patient needs?

#### **Explicit rationing**

- Use of formal criteria
- 7 Transparent
- Accountable
- **7** Fair?

21

#### Decision-making in a democracy

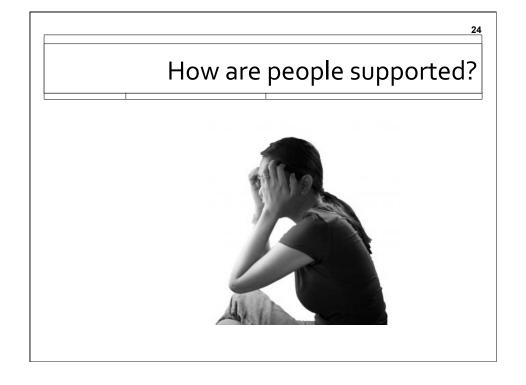
- **7** The role and authority of...
  - **7** Elites
    - **7** those in positions of power
    - **7** But in a democracy
  - Experts
    - Clinical experts
    - Experts about their own lives
  - Publics
    - 7 The communities that the decisions are meant to serve

22

#### Respectful system-level decision-making

- Unconditional positive regard
- **⊅** Empathetic understanding
- Meaningful engagement of ideas
- In a <u>relationship of (what should be) public equals:</u>
  - Transparent decisions
  - based on deliberation that is
    - informed,
    - inclusive,
    - recursive,
    - reflexive

#### What decision is made Criteria for admission Probable longer term stay Age Deservingness Terminal care – active deterioration Seniority - how long waiting Respite care - Risk to family stress Acuity of pain, symptom severity, need for symptom control Continuing care Rehab Psychosocial care/crisis Clinician's personal knowledge of Risk to physical safety patient Political significance Dependency level Patient best interests Nursing care needs



25

#### 3. 3 parts of a resource allocation policy

- 7 The criteria used
- Who uses the criteria
- **7** The process by which the criteria are used

# Geoff, Tony, and Betty Ann agree to go on a holiday

**★Geoff:** family castle in Italy

\*\*Tony: Montana

**∗**Betty Ann: Hawaii

26

#### How about these criteria?

- **\***Definite option
- \*Maybe
- **∗**Not an option
- **\*Where does this take us?**

27

# Ok, how about this criterion...

\*Have a good time...

28

### OK, it's important that...

- \* Access to fine wine
- **\*** Email access
- **\*** Access to family
- \* Within budget
- **\*** Good business facilities
- \* Access to mountain biking
- **\*** Exposure to new culture

29

### Prioritized, it's important that...

**\*** Most important

- **\* ITALY**, it is!
- \* Access to fine wine
- \* Access to mountain biking
- \* Access to family
- \* Within budget
- **\*** Imortant
  - **☀** Email access
  - **\*** Good business facilities
  - **\*** Exposure to new culture

30

#### But wait...

- **★Geoff always gets his way!**
- **\***NOT Italy!

31

## 4. Steps forward

#### The skills of ethics

- Understanding our own values and beliefs
- **↑** Listening to others to understand the perspectives they are coming from
- Engaging in deliberation respectfully
- Articulating the rationale behind decisions
- **7** Acting on decisions, even when difficult

For leaders

- Make decisions transparent
- Use systematic processes
- Create a culture of appropriate consultation & engagement
- Support those impacted

Steps ahead – for all of us

- **◄** Use systematic processes for analyzing issues
- Use available ethics resources
- Push authority where appropriate
- **↗** Look after yourselves

