

Canadian Association of Nephrology Social Workers  
32<sup>nd</sup> Annual Conference

## **ETHICAL MOUNTAINS IN NEPHROLOGY SOCIAL WORK**

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### **Suleman's care**

- Suleman is an elderly male dialysis patient. He is 78 years old. He was admitted to hospital for general weakness. He has many co-morbid medical conditions, and has been on hemodialysis for two years. He was living independently at home prior to this admission, but had been falling at home, and visibly losing weight. While in hospital Suleman had numerous falls and became increasingly confused.
- In renal rounds the nephrologists shared with the team that they felt Suleman was in the end stages of his life at this point. There have been several family meetings on medical floor to discuss Suleman's plan of care. These meetings involved the patient, two of his three daughters (who all share the power of attorney for him), social work and Dr. Gill, Suleman's long-standing family physician.

## Suleman's care

- Suleman has consistently indicated that he wants to return home. In the initial meeting, Dr. Gill spent time explaining to Suleman that he probably would not be returning home, but it was not clear after the meeting whether the patient actually understood this. His daughters have always been supportive of the patient maintaining his independence, but have also been feeling for some time that he was not managing well at home on his own.
- As Suleman's health and cognitive status continues to deteriorate, things are getting confusing.

## Suleman's care

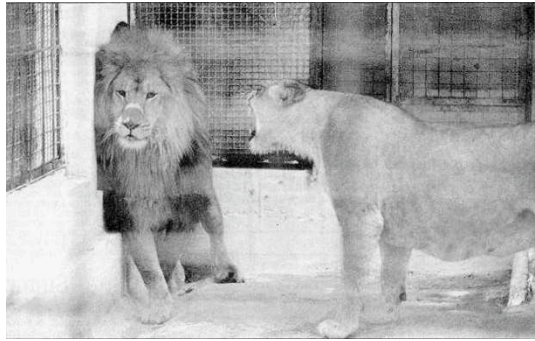
- The discharge planning folks and the social worker, in discussions with the rehab team and Dr. Gill, believe that the plan for the Suleman should be changed to long-term care. Indeed the discharge planner has already moved on this and came to ask Suleman to sign the paperwork. But when she did, Suleman was not doing well, not even able to sit up to do so.
- Meanwhile, the renal social worker has made Suleman's family aware of the nephrologists' opinion of the patient being in end-of-life stages and has begun to facilitate end of life discussions with patient and family, so they could say good-byes etc.
- The discharge planner has called Dr. Gill at this point to advocate for a change to palliative care designation, but Dr. Gill made the decision that Suleman could not be palliative as he still wished to come for his dialysis treatments. Suleman is also being asked to participate in physiotherapy and occupational therapy activities on a daily basis because he is still considered active, and not palliative. The patient is still coming for dialysis treatments, though he is calling out in pain when his is on the treatment.

## Reflect on your conversation

- Who spoke?
- Did you have to struggle to be heard?
- Were you waiting for others to take a breath so you could jump in?
- Were you trying to understand what certain values mean?
- Were you trying to convince each other of what the facts are?



Unhelpful  
understandings



## ETHICS AS JUDGMENT

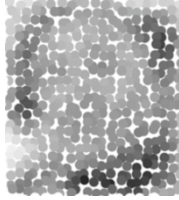
- ◆ God-Squad
- ◆ Ethics Police

Unhelpful  
understandings



## ETHICS AS COMPLIANCE

Ethics as living with...



Integrity

Central to a meaningful,  
happy life

Ethics is in everything we do

All of our attitudes, decisions and  
actions are based on and reflect our  
values and beliefs.

<b>Beliefs about the way the world actually is</b>		
<ul style="list-style-type: none"> <li>• <b>What happens when we die?</b></li> <li>• <b>What is the purpose of life?</b></li> <li>• <b>How are we connected to each other?</b></li> <li>• <b>Why did this happen – what will happen?</b></li> <li>• <b>Where is my car parked?</b></li> <li>• <b>How do I reach you?</b></li> <li>• <b>Is this milk bad?</b></li> </ul>		
<b>Yesterday</b>	<b>Today</b>	<b>Tomorrow</b>

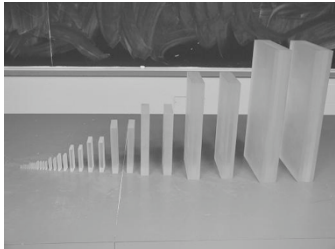
Types of knowledge and beliefs	
<b>Clinic</b>	<b>System</b>
<ul style="list-style-type: none"> <li>➤ Clinical (e.g. pyelonephritis and various antibiotics)</li> <li>➤ Patient history (e.g. progression of patient's pyelonephritis and reaction to antibiotic)</li> <li>➤ Personal identity (the meaning patient attaches to experience of pyelonephritis and hospital)</li> <li>➤ Social (human relations within the system - how to get physician assistance quickly if suspicion condition is getting worse)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Epidemiological (e.g. progression of illness through communities)</li> <li>➤ Epidemiological (e.g. progression of illness through specific communities)</li> <li>➤ Community identity (the meaning communities attach to experiences of illness)</li> <li>➤ System (human relations within the system - how to get institutions and organizations to work together)</li> </ul>

**Values:**  
Beliefs about what is important...

Instrumental	Intrinsic
<ul style="list-style-type: none"> <li>➤ because they lead to other important values                             <ul style="list-style-type: none"> <li>➤ efficiency,</li> <li>➤ kindness</li> </ul> </li> <li>➤ Conditional</li> </ul>	<ul style="list-style-type: none"> <li>➤ for their own sake                             <ul style="list-style-type: none"> <li>➤ respect for human dignity,</li> <li>➤ kindness</li> </ul> </li> <li>➤ Ends of human life</li> <li>➤ Goods in themselves</li> </ul>

**Instrumental Values: things we take to be important because they lead to other important things**

<ul style="list-style-type: none"> <li>✦ Efficiency</li> <li>✦ Effectiveness                             <ul style="list-style-type: none"> <li>✦ E.g. vaccine                                     <ul style="list-style-type: none"> <li>✦ 1 dose = 85% resistance</li> <li>✦ 2 doses = 100%</li> </ul> </li> <li>✦ What's more efficient?</li> <li>✦ Depends on goals                                     <ul style="list-style-type: none"> <li>✦ giving all some protection?</li> <li>✦ Giving certain groups full protection?</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>✦ Value conditional                             <ul style="list-style-type: none"> <li>✦ Not important if won't lead to the greater good desired</li> </ul> </li> </ul>
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## An ethically justified decision is BOTH

- Based on an understanding of the world that is evidence-based (good facts)
- Based on well-considered understanding of what is important (values)

## Values: What is important...

### Process

- Transparency
- Inclusiveness
- Equality
- Respect

### Content

- Equity
- Respect for autonomy
- Protecting the vulnerable
- Minimizing cost



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<h1>Respect</h1>	
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- Unconditional positive regard
- Empathetic understanding
- Meaningful engagement of ideas
- In a fiduciary relationship:
  - guiding decisions based on truster's values and beliefs
- In a relationship of intimate partners:
  - Collaboration
- In a relationship of (what should be) public equals:
  - Transparent decisions based on informed, inclusive, recursive, reflexive deliberation

Beliefs

Feelings

Values

**3 layers in any conversation**



## Ethics in 3 Questions

1. What values & beliefs *do guide* our actions? (*descriptive* ethics)
2. What values & beliefs *should guide* our actions? (*prescriptive* ethics)
3. *How should we act* based on these values & beliefs in a given situation? (*applied* ethics)

## Suggested change in language

From...

⊕ Does this decision belong in the bucket of ethics?

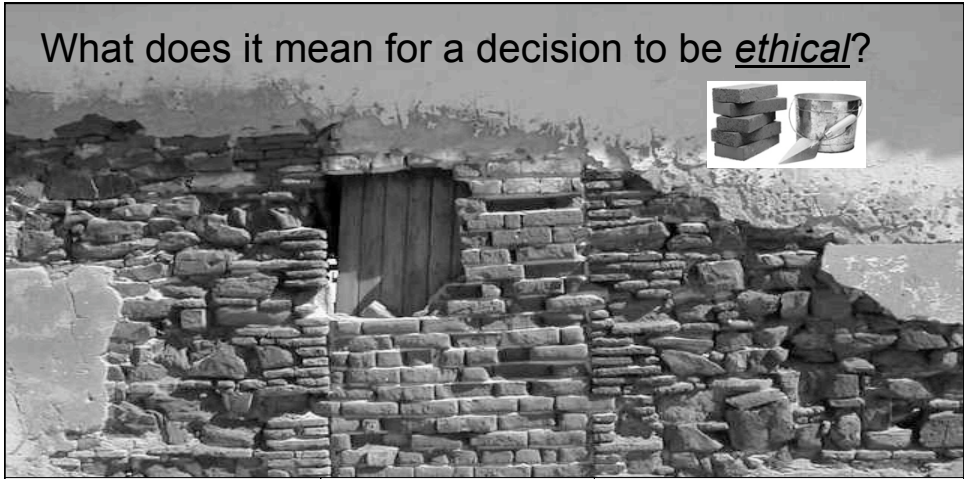
⊕ as opposed to the economics, clinical practice, marketing, risk management etc. bucket

To...

⊕ is this decision ethically justified?

⊕ Recognizing all decisions have an ethics dimension

What does it mean for a decision to be ethical?



Is it based on values we have good reason to cherish - in this order?

Is it based on beliefs we have good reason to think are true?

Have we made the justification for acting on these values and beliefs clear and explicit?

### Spectrum of ethical justification

**Well justified**

Based on  
good facts

&

Well defended  
values

**Unjustified**

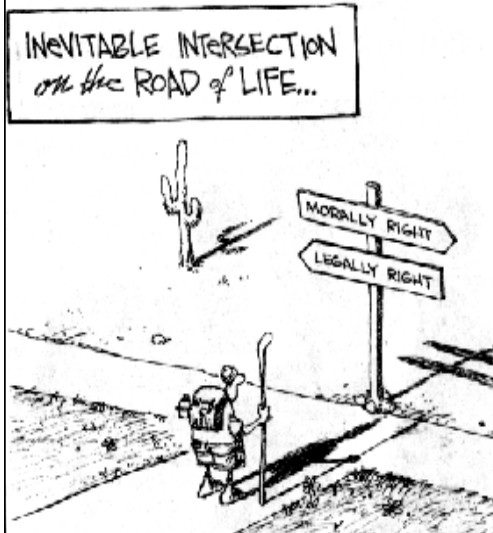
Based on bad  
assumptions

&

Undefended  
values

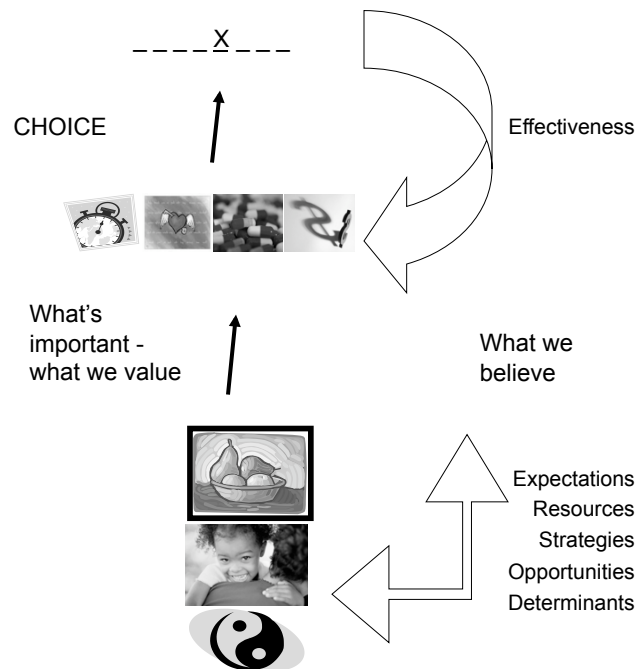
# ETHICS AND THE LAW

NON SEQUITUR



- **Ethics and Law are not synonymous**
  - Moral consensus often precedes legal change
  - The law prescribes moral minimums
  - Unethical laws possible
  
- **Law is relevant to ethics**
  - Source of values
  - Consequences important to consider

How do you spend your time?  
 How do you spend your money?  
 How do you spend your love?  
 How do you treat your loved ones?  
 How do you treat your acquaintances?



## What is Ethics?

Skills of systematic and critical reflection

### Ethics Literacy 1:

#### Listening and understanding skills

- Listen to and understand the values & “facts” others are starting with
- Be self-reflective and understand the values & “facts” they are starting with

Ethics Literacy 2:

**Skills of reflection and assessment**

- Critically reflect on what actually is true about the world, based on what evidence
- Critically reflect on what actually is important in life, including how to balance different values

Ethics Literacy 3:

**Skills of action and articulation**

- Make decisions based on well-considered facts and values and implement these, even when doing so is difficult
- Articulate the justification for their choices

## Ethics Literacy 4: Skills of intervention

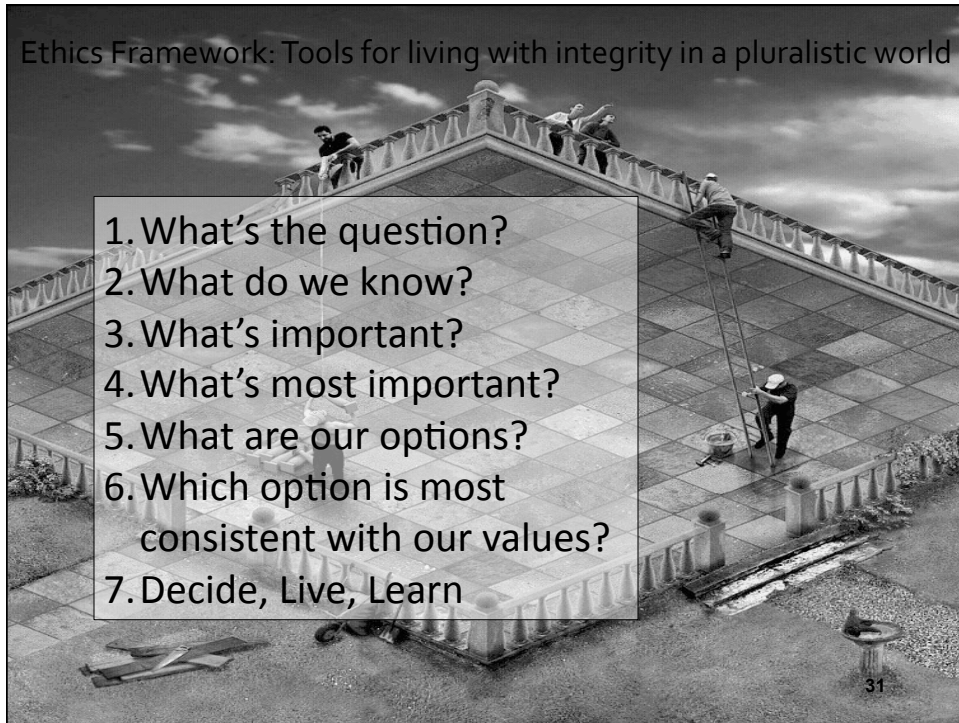
- Facilitate discussion to help others get a clearer and deeper understanding of their own beliefs and values
- Mediate between others to create respectful dialogue and collaborative deliberation with a view to resolving problems in a way that enables all participants to maximally live with integrity

## Why is Ethics Important?

Without critical and systematic reflection on values:

- Inconsistent decisions
- Compromise to integrity (of individuals, teams, organizations)
- Greater moral distress
- Less healthy & happy workforce
- Greater confusion about future right direction
- Decrease support of and compliance


Ethics Framework: Tools for living with integrity in a pluralistic world



1. What's the question?
2. What do we know?
3. What's important?
4. What's most important?
5. What are our options?
6. Which option is most consistent with our values?
7. Decide, Live, Learn

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<h2>Suleman's Story</h2>		
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## Step 1: What's the question?

- How should the renal team work together with family physicians and other hospital teams?
- What should Suleman's goals of care be?
- What should our process be for dealing with situations that become particularly challenging?
- What should our policy be for providing dialysis to patient who resist/refuse treatment?
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- 

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## Step 2: What do we know?

- About Suleman’s clinical condition?
- About Suleman as a person, his values and beliefs?
- About how Suleman wants this phase of his life to go?
- About the possibilities for improvement in Suleman’s physical ability?
- About Suleman’s daughters’ perspectives?
- About Suleman’s various caregivers’ perspectives?
- About what resources are available?
- About how different teams and people work together?

## Step 2: What we know must be backed by evidence!

What we know	Our <u>evidence</u> for this
About Suleman’s clinical condition	
About how Suleman wants this phase of his life to go?	
About the possibilities for improvement in Suleman’s physical ability?	
About how different teams and people work together?	

### Step 3: What is important?

#### Whatever we do, it is important that...

<ul style="list-style-type: none"> <li>➤ We discharge our professional obligation</li> <li>➤ We treat our patients with respect</li> <li>➤ We make decisions in a manner consistent with Suleman's values and beliefs</li> <li>➤ We maximize the resources available for providing care to all those who need it</li> <li>➤ We minimize exposure to legal liability</li> <li>➤ We minimize exposure to professional censure</li> <li>➤ We minimize healthcare costs</li> <li>➤ We respect the values and beliefs of families</li> </ul>	<ul style="list-style-type: none"> <li>➤ We treat our colleagues with respect</li> <li>➤ We respect the professional autonomy of our staff</li> <li>➤ We minimize harm to our patients, residents, and clients</li> <li>➤ We act on good evidence</li> <li>➤ We demonstrate compassion to our clients</li> <li>➤ We support the relationships of those we care for</li> <li>➤ We meet the needs of all of our patients equitably</li> <li>➤ We advocate for those patients who are particularly vulnerable</li> </ul>
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### Why is safety important?

- ❑ Core value of the system: advancing the well-being of those in our care
- ❑ If we want to make things better, causing harm would go in the opposite direction
- ❑ The first principle then: do no harm

## Respect:

### Engaging the world with kindness, compassion

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- Unconditional positive regard (kindness)
  - Regardless of what I think of your opinion, I will treat you well
- Empathetic understanding (compassion)
  - I will work hard to open my mind to understand why you think what you think
  - I will work hard to open my heart to understand what you are feeling
- Collaborative thinking (engagement)
  - I will share my reasons, and work together with you to develop a broader perspective

## Respecting autonomy in health care

- We're here to serve
- We have different understandings of what's meaningful
- Our residents are vulnerable
  - Health status
  - Knowledge
  - Power
- We have a fiduciary responsibility
- Respect begins with active listening
- We can respect autonomy beyond the point of expression



## Step 4: What is MOST important?

- |  |  |
|--|--|
| <ul style="list-style-type: none"><li>➤ We discharge our professional obligation</li><li>➤ We treat our patients with respect</li><li>➤ We make decisions in a manner consistent with Suleman's values and beliefs</li><li>➤ We maximize the resources available for providing care to all those who need it</li><li>➤ We minimize exposure to legal liability</li><li>➤ We minimize exposure to professional censure</li><li>➤ We minimize healthcare costs</li><li>➤ We respect the values and beliefs of families</li></ul> | <ul style="list-style-type: none"><li>➤ We treat our colleagues with respect</li><li>➤ We respect the professional autonomy of our staff</li><li>➤ We minimize harm to our patients, residents, and clients</li><li>➤ We act on good evidence</li><li>➤ We demonstrate compassion to our clients</li><li>➤ We support the relationships of those we care for</li><li>➤ We meet the needs of all of our patients equitably</li><li>➤ We advocate for those patients who are particularly vulnerable</li></ul> |
|--|--|

## Step 5: What are our options?

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## Step 6: Which option fits best with what's most important?

Values ↓	Options →	Do nothing		
Minimizing Suleman's pain and suffering				
Advocate for vulnerable patients				
Support Suleman's relationships				

## Step 7: Decide, implement, and learn

Construct a solution that will help live up to as many values as possible, beginning with the most important

Key steps:

- Respectful engagement with Suleman and his family
- Clarification of the facts, and the evidence that supports these
- Conversation amongst the team

## Ethics dimensions of clinical decisions

How the decision is made

- who is involved
- what's the conversation like

How those involved are supported

- maximizing integrity

What decision is made

- substantive values

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## How a decision is made

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

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## **Deliberative Engagement**

- leads to...
  - ◆ Legitimacy
  - ◆ Best practice
  - ◆ Trust
  - ◆ Compliance

## **Key team decisions**

- Core process values
  - ◆ Respect
  - ◆ Clarity about authority to make decisions
  - ◆ Facts and evidence
  - ◆ Dealing with difference
  - ◆ Resolving disagreement
  - ◆ Commitment to engagement
  - ◆ Support in times of tension (distress)
- Core content values



## What decision is made

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## Substantive Values: Models of Distributive Justice

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

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## Principles or values?

- Worries with principle based approaches:
  - ♦ Language not intuitive at the most practical level
  - ♦ Often differing understandings of language
  - ♦ Only take you so far when comparing programs of entirely different types

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## Shift to values language

- Specification of principles
- Much more everyday
- Easier to get share understand around
- Still need to be very clear
- Need develop list of decision criteria that is
  - ♦ Exhaustive
  - ♦ Mutually exclusive
  - ♦ prioritized

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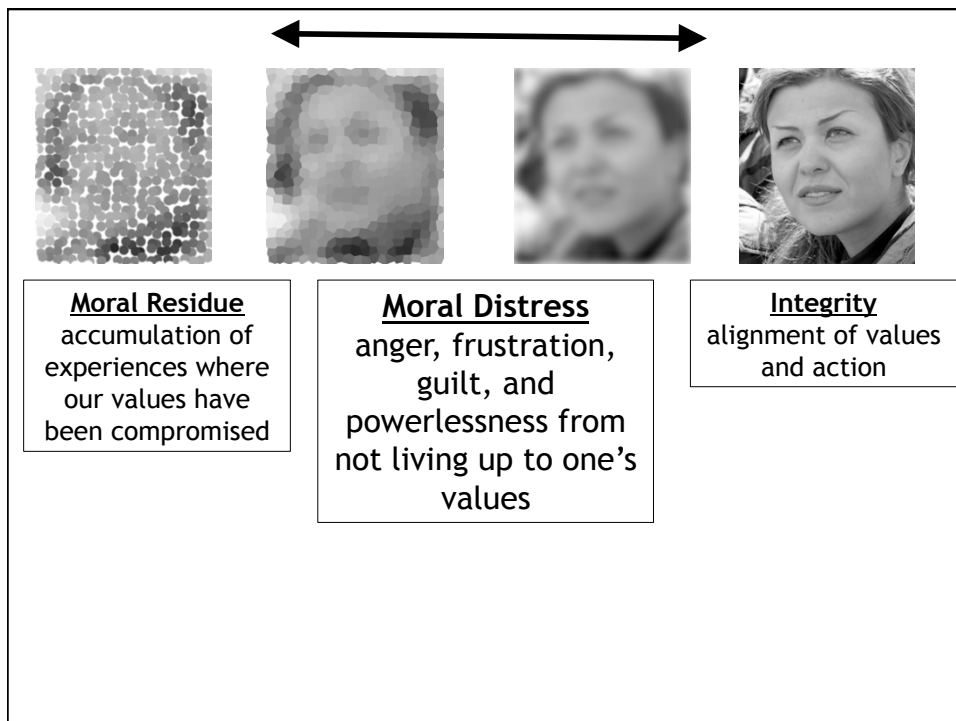
## How are people supported?

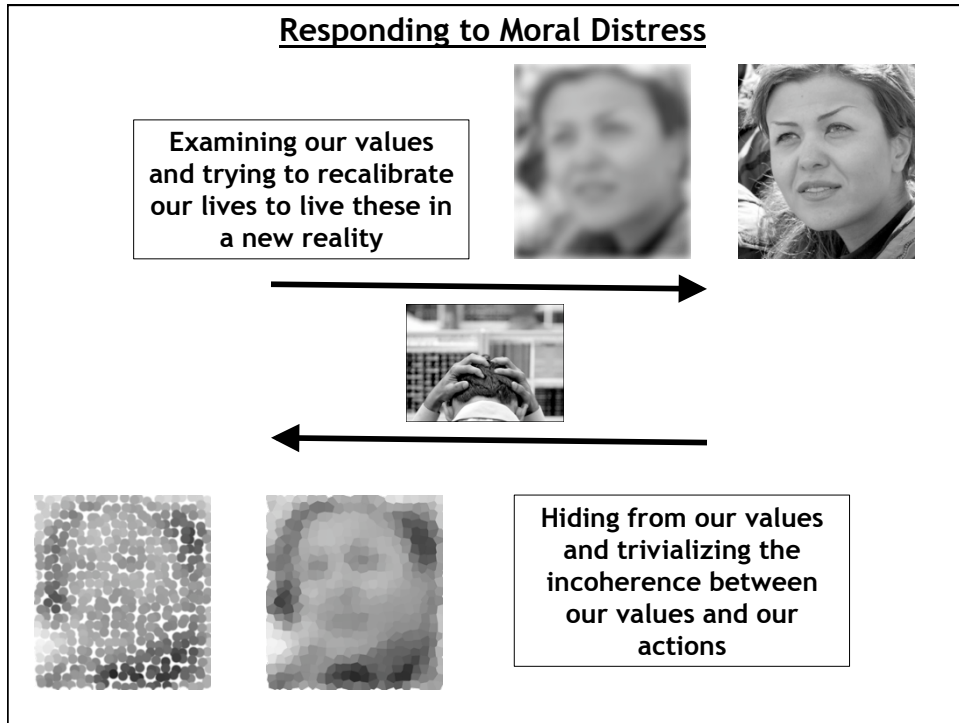
- Our decisions impact others' ability to live with integrity
- We have a responsibility to recognize this and support these individuals
- Recognition is support



## moral distress & moral residue

- Integrity: when principle and action align
- Distress: anger, frustration, guilt, and powerlessness when one's values & actions don't line up
- Residue: builds with experiences where we have had to compromise ourselves





## Productively responding to moral distress

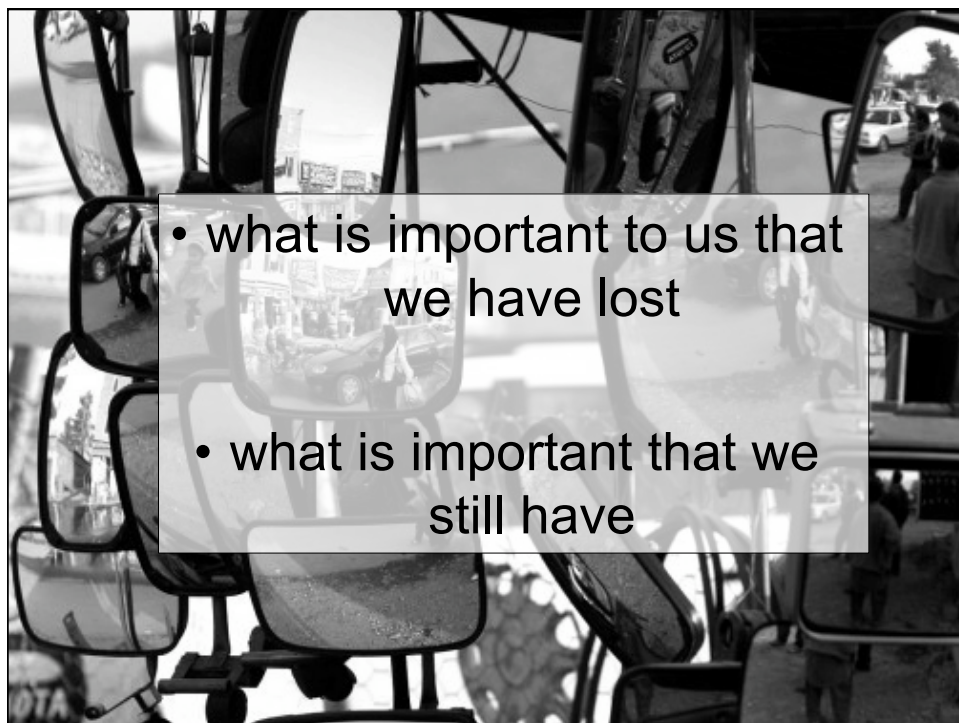
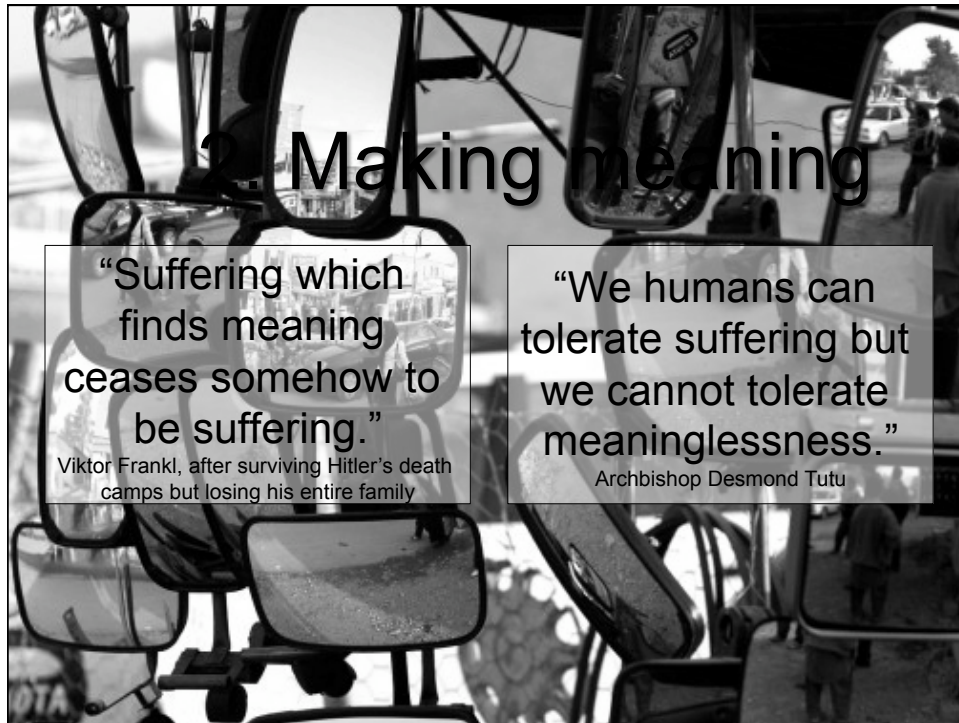
1. Name what we are experiencing
2. Make sense of the situation
3. Reintegrate self into life
4. Act with others to bring values to life
5. Work to rebuild trust through open, honest dialogue

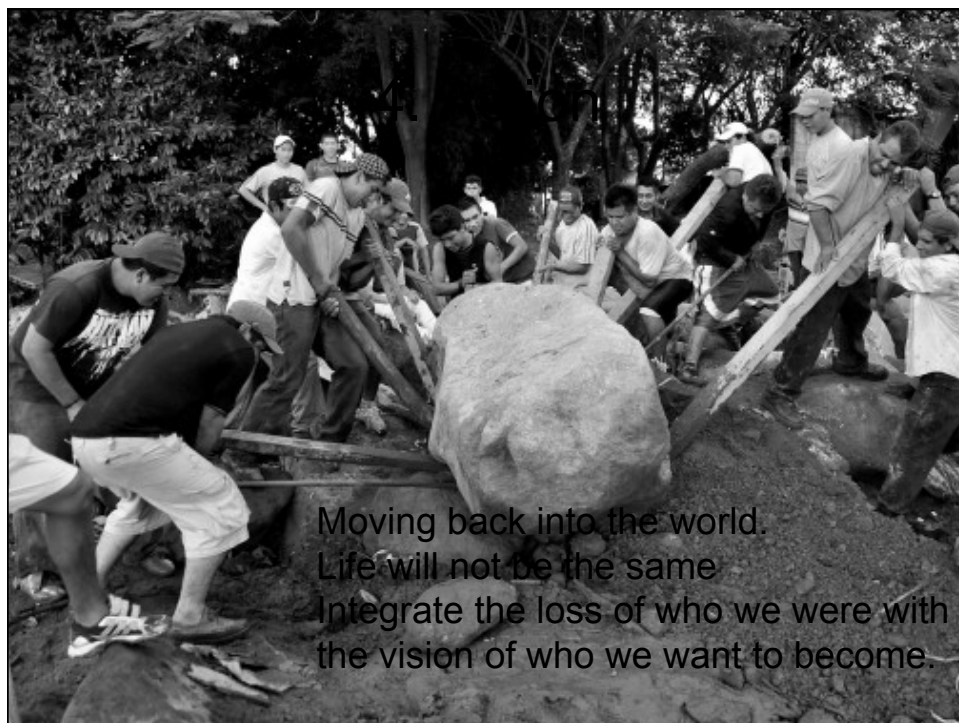
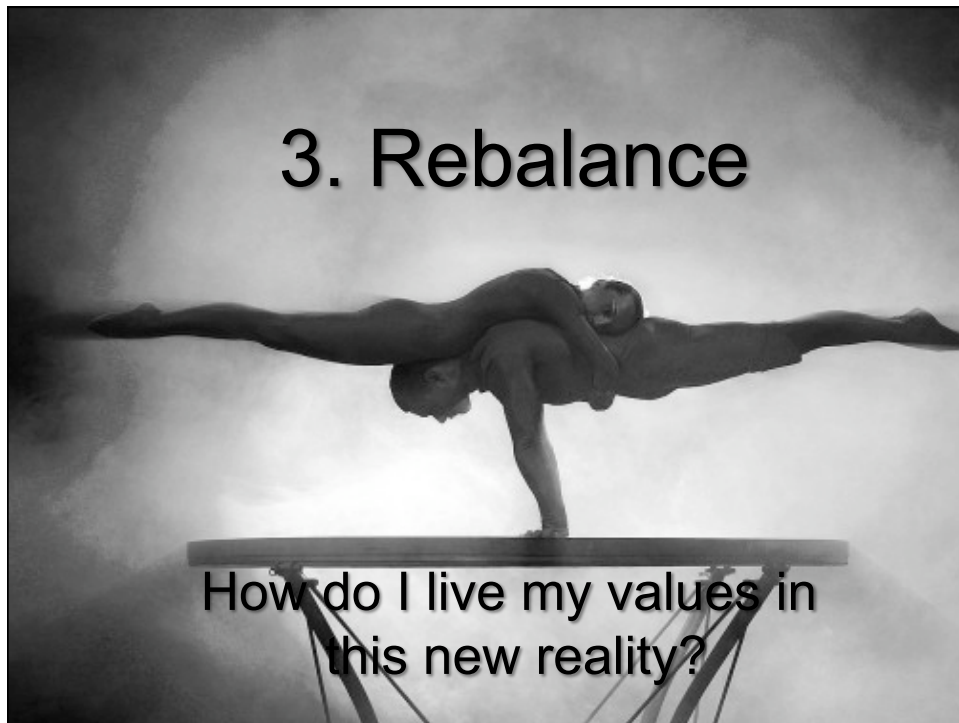
1. The telling itself is part of the work of mourning and of healing

***Give sorrow words.  
The grief that does not speak,  
whispers the o'erfraught heart  
and bids it break.***

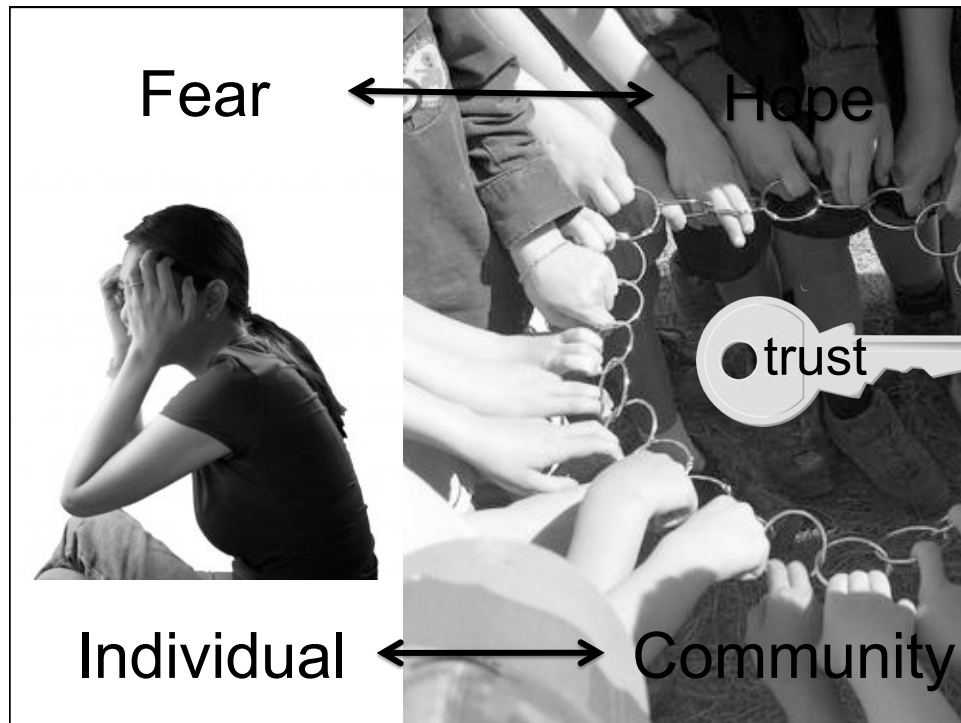
- Shakespeare, Macbeth











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## Agency, Autonomy, Authenticity

- Agency
  - making a reasonable choice from available alternatives
- Autonomy
  - About making choices and reflecting on the circumstances and relationships that affect one's ability to make choices
- Authenticity
  - having an identity - a commitment to certain values and beliefs
  - articulating and demonstrating that identity in word, deed and attitude

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## The Relational Matrix (Rodney)

- Key to success: collaboration
- Keys to successful collaboration:
  - Being authentically present for each other
    - Involved in the here and now of the patient situation
    - Being respectful
    - Listening
    - Willing to be available for help
  - Being able to trust that colleagues are approachable and knowledgeable
- Trust
  - “reliance on others’ competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care.” (Baier)
  - “the ‘glue’ that holds the relational matrix together” (Rodney)

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## Barriers to collaboration

- Different knowledge of different disciplines
- Different understanding of ethical practice across disciplines
- Context of uncertainty with diagnostic and management work split
- Short staffing
- Loss of clinical leadership
- Inadequate services for patients and families



- Residents/ clients/ patients
  - Those we lead
    - Colleagues
  - Those who lead us

## 5. Creating and maintaining trusting relationships

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### Getting centered for the exercise

- Sit comfortably in a chair with closed eyes.
- Empty your mind, intend to do nothing but being present, having your attention extroverted.
- Don't think "Be there" or anything like that, just relax and do nothing.
- Notice the space you are in and the sounds in the room.
- If thoughts are going through your mind you just let them die out and get back to just being there.
- Don't try to strain and force yourself to not think, simply relax into a quiet space of just being there.
- Likewise with any physical reactions you might have. If you twitch or yawn, just notice that and get your attention to just being there.

<h2>The exercise</h2>	
1. Choose a professional story (everyone)	➤ "What are you going to tell me about?"
2. Assign numbers 1 & 2	➤ Listening for:
3. Pair up – a 1 with a 2	➤ How they are feeling
4. 12 min.: 1 listens to 2's story	➤ What is important to them & why
5. Switch partners (still 1 & 2)	➤ What they think the facts are
6. 12 min.: 2 listens to 1's story	➤ Seeking to understand
7. 2 min: write each "what is important" on a separate sticky	➤ Not..
8. 2 min: post stickies on wall	➤ Solving problem
9. 5 min: thematize	➤ Sharing own story
	➤ Judging

<h2>The exercise</h2>	
➤ "What are you going to tell me about?"	➤ Seeking to understand
➤ Listening for:	➤ Not..
➤ How they are feeling	➤ Solving problem
➤ What is important to them & why	➤ Sharing own story
➤ What they think the facts are	➤ Judging

## The art of conversation

- Willingness to participate as equals
- Meaningful respect:
  - Unconditional positive regard
  - Empathetic understanding
- Sincere interest in honouring the integrity of all involved
- Freedom of thought
- Commitment to critical reflection:
  - Focus on reasons
  - Reflexive
  - Recursive
- Inclusiveness and mutual support:
  - The thinking and comfort of all participants matters

## To Listen

- Having an open heart
- Having an open mind
- Giving reasons



Chinese character for the verb: To Listen

## 4 keys to living well

For Teaching, for living...

1. Don't make assumptions
2. Do your best
3. Don't take things personally
4. Be immaculate with your word



## Ethics as

- ☑ We are guided by values, whether we recognize it or not
- ☑ To think about and act on the values we have reason to cherish, as opposed to values that have been subtly inculcated in us is to take control of our lives - to be free

