Whose Choice is it Anyway?
Ethics, Risk and Decision-Making when Patients and Staff Disagree
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The Champlain Centre for Health Care Ethics
Le Centre de bioéthique Champlain

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Learning Objectives

1. Explore ethical issues involved when patient/clients choose to live at risk

2. Present a policy and ethical decision-making framework to facilitate decision-making

3. Demonstrate the value of ethical decision-making in the discharge planning process
Consider these scenarios...
When clients choose to live at risk...

- advocacy
- liability
- resource allocation
- professional responsibility
- health
- well-being
- risk
- safety
- dignity
- decisional capacity
- informed consent
- workload
- duty to care
- client autonomy
Additional Complications

• Different disciplines can’t agree on a plan
• Conflicting views
• Cultural factors and language barriers
• Pressure to discharge
• Lack of consistent directions
In these scenarios, ideally…

- We enhance and respect autonomy
- We agree with patients’ choices
- We practice patient-centered care
- Patients and families agree and comply with our treatment or discharge plan
- Continuity of care and available resources to facilitate transitions and minimize risks
In reality, many challenges...

• Disagreement with patients’ choices and/or with treatment or discharge plans

• Limited resources and increasing pressures

• Fragmented and silo-ed “system”

• Unsure of where our responsibility ends

• Rescue culture – not trained to “let go”
You can’t go home, it’s too risky!

We can’t let you go home, there’s too much risk!

He can’t cope at home, he falls down the stairs. It’s not safe!

How can she be capable? She can’t manage. Get CCAC for LTC.
Are we asking the right questions?

What *tends* to be asked:

- Can they live alone?
- Can they manage?
- Are they safe?
- Is the home suitable?
- What does the family want?

What we *ought* to ask:

- Do they have the capacity for this decision?
- What are the patient’s preferences?
- Can we make the home safer?
- How can we maximize safety, functioning, and well-being?

(From: Kerry Bowman et al., 2010. *The Ethical Considerations in Discharge Planning*. Presentation at Mount Sinai Hospital, Toronto, ON)
How can she be capable?

• We care too much!

• Confusion of rights with best interests

• Functional assessment versus capacity evaluation

• Consent and capacity are foundational, but counterintuitive to staff when there is risk

(From: Mark Handelman, Lawyer Health Law Matters, 2010)
Impact on staff, caregivers, and clients

- Conflict, disagreement, frustration
- Moral uncertainty or distress
- Dissatisfaction
- Burn-out
- Capacity questioned, wishes ignored, non-compliance
- Loss of support
Policy Development Overview

Q1-4 08/09 | Q1 09/10 | Q2 09/10 | Q3 09/10 | Q4 09/10 | Q1 10/11
---|---|---|---|---|---

Board Approval Nov 24
Policy Statement

• Support clients’ rights to make choices about:
  – How and where they live
  – Care or support services they may receive

• Clients have right to live at risk if:
  – No imminent harm to themselves or others
  – “Acceptable” risks

• Inform clients of risks, consequences & options

• Implement risk mitigation strategies
What is “acceptable” risk?

• Risk is not always negative, but limits exist.

• Limits or “unacceptable” risks include:
  – Client or others in immediate and identifiable danger
  – Violation of the law
  – Requirements beyond mandate to provide
  – Serious concerns that will not meet needs or standard of care

• Acceptable risk determined using assessment tools and rigorous review of options.
Policy Tools

- Consent and capacity legislation
- Decision-making flow charts
- Risk assessment tools (e.g., RAI-HC, PIECES, etc.)
- Ethical Decision-Making Worksheet
- Community Code of Ethics and Guiding Principles
- Risk Support Plan
- Risk flagging system
Flow charts Overview

- Use Ethical Decision-Making Worksheet for rigorous assessment of risks and options
- Build in team consultation to facilitate decision-making
- Discuss risks, consequences and options with client (or SDM, if client incapable).
- Develop Risk Support Plan and discuss with client and care team.
- Document plan, file and flag in client record
- Implement, monitor and review regularly
Interprofessional ethics

Ethical decision-making is ideally a collaborative practice – decision-making should be consultative and not adversarial.

Why?

- High stakes
- Different people have different knowledge, expertise and perspectives
- Initial reactions are often knee-jerk emotional
- Initial reactions do not take other perspectives into account
- We naturally jump to conclusions
Ethical Decision-Making Worksheet

• Risk assessment and decision-making tool

• Forum for open and non-threatening discussion

• Assists in deciding what we should do, why and how we should do it

• Only a tool, it cannot make the decision for you!

Available at: http://www.communityethicsnetwork.ca/docs/toolkit2008.pdf
Why Should We Use Ethical Decision-Making Frameworks?

• Common clients, common issues
• Levels the playing field with a common language to ensure that people speak to, and not past each other
• Contributes to shared responsibility, team development, and inter-professionalism.
• “Doing the best we can” without direction or guidance really the best we can do?

Ethical decision-making is deciding what we should do, explaining why we should do it, and describing how we should do it

Barbara Secker, Director of Education, University of Toronto Joint Centre for Bioethics
### Step 1: Identify the Facts — 4 Box method

#### Medical Indications
- Medical issues, history, and diagnosis
- Acute, chronic, critical, emergent, reversible?
- Treatment goals?
- Probabilities of success?
- Plans in case of therapeutic failure?
- Potential benefits of care?
- How can harm be avoided?

#### Client Preferences
- Client’s preferences
- Capacity to decide?
  - If yes, informed consent?
  - If not, who is SDM?
- Does the client have prior expressed capable wishes?
- Advance directives?
- Is client’s right to choose being respected?

#### Quality of Life
- Quality of life in client’s terms
- Views and concerns of care providers

#### Contextual Features
- Family or relationships?
- Any care plans put in place so far?
- Relevant social, legal, economic, or other circumstances?
- Limits on confidentiality? Resource allocation? Conflicts of interest?

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### Step 1: Identify the Facts — 4 Box method

<table>
<thead>
<tr>
<th>Medical Indications</th>
<th>Client Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>State the client's medical condition, such as acute, chronic, critical, emergent, or reversible.</td>
<td>Does the client have any preferences regarding treatment options?</td>
</tr>
<tr>
<td>Probabilities of success?</td>
<td>Is there a family or social support network?</td>
</tr>
<tr>
<td>Potential benefits of care? How can harm be avoided?</td>
<td>Is the client's quality of life impacted by the condition or treatment?</td>
</tr>
<tr>
<td>What are the risks?</td>
<td>What is the client's decision-making capacity?</td>
</tr>
</tbody>
</table>

### TIPS:
- Write down the questions that you don’t know and need to find out.
- This is a good place to identify risks.
- RAI-HC, Risk Assessment tool in CCP or PIECES RISKS framework
  - Roaming or wandering?
  - Imminent risk?
  - Suicidal ideations?
  - Kinship issues or abuse?
  - Substance abuse, Safe driving, Self neglect?

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Step 2: Determine the Ethical Principles in Conflict

Identify ethical issues
What ethical principles are in conflict? Refer to the Code of Ethics for the Community Health and Support Sector on page 16 for further details.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Explain the Issue</th>
</tr>
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<tbody>
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# Values and Ethical Principles

A **value** is something a person/community has identified as important, but *by themselves* don't tell us what we ought to do.

This is why we need corresponding **ethical principles** to guide action.

<table>
<thead>
<tr>
<th>Values</th>
<th>Ethical Principles</th>
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<tbody>
<tr>
<td>Confidentiality</td>
<td>Keep private information confidential</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>Disclose conflicts of interest and avoid disqualifying conflicts of interest</td>
</tr>
<tr>
<td>Dignity</td>
<td>Respect the dignity of morally valuable beings</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Disclose information that people have a right to</td>
</tr>
<tr>
<td>Diversity</td>
<td>Respect diversity</td>
</tr>
<tr>
<td>Integrity</td>
<td>Act with integrity</td>
</tr>
<tr>
<td>Patient-centered care</td>
<td>Provide patient-centered or family-centered care</td>
</tr>
</tbody>
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What values are important to you and why?

How are these values to be defined or understood by your community?

What are the action-guiding ethical principles that correspond to these values?
Community Code of Ethics

- Advocacy
- Client and Employee Safety
- Commitment to Quality Services
- Confidentiality
- Conflict of Interest
- Dignity
- Fair and Equitable Access
- Health and Well-Being
- Informed Choice and Empowerment
- Relationships Among Community Agencies
Step 3: Explore Options

Explore options and consider their strengths and weaknesses
Brainstorm and discuss options either alone or with peers. Be creative and use your imagination. Consider a compromise. Predict the outcomes for each alternative. Does the alternative fit with the client/family values? Question whether the alternative meets the company policies, directives and regulations.

<table>
<thead>
<tr>
<th>Option</th>
<th>Strengths</th>
<th>Weaknesses</th>
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Questions to Consider

- Is the client **capable** to make this decision?
- **Risks** if service is removed or kept in?
- What or who might help **mitigate** this case?
- What does the client want? How is this different from the care team’s goals?
- Options, likely consequences and **benefits**?
- Are there precedents? What precedent might be set?
### Step 4: Act on Your Decision and Evaluate

**Develop an action plan** (The actual plan should be documented in the chart.) Given all the information that you have, choose the best option available. Develop an action plan. Present your suggested alternative and action plan to the client and those involved in such a way that it allows them to accept the plan. Re-examine the alternatives if other factors come to light, if the situation changes, or if an agreement cannot be reached. Determine when to evaluate the plan. Document and communicate the plan.

**Evaluate the plan**

What was the outcome of the plan? Are changes necessary? Document the evaluation.

**Self-evaluate your decision**

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process?
Supporting Clients’ Choices

- Supporting Clients’ Choices Policy and Toolkit

- Process for working with clients, capable and incapable, who choose to live at risk

- Support clients’ rights to choose where and how they live, including risk.
Guiding Principles

- **Capacity:** Honour capable wishes
- **Client-Centred Care:** Identify what’s important from a client’s perspective and try to find appropriate solutions
- **Liberty:** People have the right to live their lives to fullest as long as it doesn’t prevent others from doing the same
- **Accountability:** Responsibility not to agree to a plan if it won’t meet client’s needs or puts them at immediate, identifiable danger.
- **Shared Decision-Making:** Shift from risk aversion with open and transparent decisions
- **Positive Approach to Risk:** rather than a defensive one
- **Empowerment:** Enable choice and control to achieve better outcomes
Risk Support Plan

- Health status summary
- Recommendations
- Risks (actual and potential)
- How we will support the client
- Staff and client sign-off

Adapted with permission from Alberta Health Services – Calgary Health Region Home Care Ethics Committee
Risk Support Plan tips

- Not a legal document or contract – client does not have to sign

- Documents informed decision-making and discussions

- A template – can be changed as the situation requires (e.g., include providers on the sign-off)

- May be shared within circle of care
How does this work in practice?

Using the client choice policy and ethical decision-making framework to facilitate a patient’s transition from hospital to home
Mrs. V is an 82 year old client:

- Spanish speaking, multiple medical issues and past falls
- Lives in brother’s basement, largely using arms to pull herself upstairs
- Admitted with a broken arm after a fall, discharge is approaching
- Staff concerned about risks of returning home and insist on LTC
- May be able to go home with homecare and safety equipment
- According to niece, wants to go home, but brother won’t pay for equipment
Case conference with Care Team

Identify facts and risks
- Recovering broken arm, arthritis, memory impaired, language barrier, accessibility of home, risk of falls
- Capable? SDM? Family/other support? Quality of life?

Determine principles
- Client safety, accountability, commitment to quality services, informed choice, empowerment, fair access, dignity, advocacy, health and well-being

Explore options
- LTC? Home without support? Other community supports available? Alternative care options?
- If capable, right to decide where and how she lives. CCAC services will help mitigate risks.
What happened to Mrs. V?

Act on the decision and evaluate

- Neutral translator used for communication
- Wanted to return home, with only one PSW visit a day
- Her and her brother thought she must be better since she is being discharged
- Staff explained she is recovering and won’t be able to use her arms like before.
- Brother agreed to OT home assessment
- Family purchased safety equipment and moved Mrs. V to ground floor.
What We Learned:

- Knowledge of consent and capacity is critical.

- Leadership support gives staff confidence that they’re doing the right thing.

- An interprofessional team approach to the tool helps clarify the issues and build consensus.

- Need a forum for ongoing discussion.

- Work across continuum to support choices and counter risk-aversion tendency.
Our Future Work

- Address issues identified in implementation
- Continue to implement policy with our staff
- Communicate policy and rationale to service providers and healthcare partners
- Evaluate implementation and outcomes
- Work together to build capacity across continuum to address these challenging cases
Having our cake and eating it too?

- Respect autonomy and rights
- Support choice and appropriate manage risk
- Negotiating agreement on treatment and discharge plans
- Work collaboratively across sectors to facilitate transitions
- “Let go”
Conclusion

• Choosing to live at risk a frequent issue

• Ethical and legal framework as a basis for discussion

• Policy as a vehicle for inter-professional and cross-sectoral practice and communication

• Supporting clients’ choices not only involves changing staff behaviour, but challenging system behaviour.
Conclusion

• Critical analysis of what, why and how we should do this

• Making justifiable decisions forces options

• Series of answers, some of them better than others

• Assessment of relative risk – as imperfect as this is

• Options and weighted options
Acknowledgments and Thanks

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- Kerry Bowman, Ethicist, Mount Sinai Hospital
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  Bioethics

- Alberta Health Services – Calgary Health Region
  Home Care Ethics Committee
Thank You for Your Participation and Engagement!

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