

What can we learn from the 5 Wishes?

Ethical Issues at End of Life

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Harprit's Story



Harprit is a 71 year old resident in the LTC facility where you are an LPN. Harprit's health had been declining, and she has recently been diagnosed with terminal brain cancer.

While Harprit's cancer is incurable, her oncologist is optimistic because Harprit has a genetic marker which makes her a candidate for a new drug which could extend her life up to 6 months. Harprit cannot get out of bed, lives with chronic pain, and depends on others for all of her daily needs. Harprit does not have full capacity to make all of her decisions, but she is still quite present, and has definite preferences about her life.



Harprit's Story



Harprit has two children – Parm and Davinder. Parm has been at Harprit's side since she moved in to the facility (2-3 years ago), visiting and providing help with care 4-5 times a week. She is skeptical of the new drug and is worried it will only prolong Harprit's suffering.

Davinder is also involved though he can only visit Harprit a few times a month as he works out of town. Davinder wants Harprit to try the new drug as he is hopeful that it will extend her life and allow her to improve to enjoy the time she has left.



Harprit's Story



On a recent evening shift, you stop by Harprit's room to say hello and see how she is doing. You find her flipping through a photo album in her easy chair. She seems especially quiet and thoughtful this evening, and doesn't seem that interested in chatting.

As you turn to leave the room, she says, "Do you know, I don't know why people wait to have a party until after they die. I'd like to have a party before. And my one party rule would be, nobody is allowed to talk about death!" She chuckles, and turns her attention back to the album.



What might be important to Harprit and her family as they make decisions in the end-phases of her life?

How might an Advance Care Plan assist in ensuring ethically optimal care for Harprit?

Health care is a fundamentally **Ethical** activity

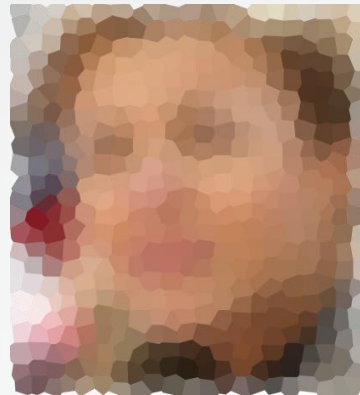
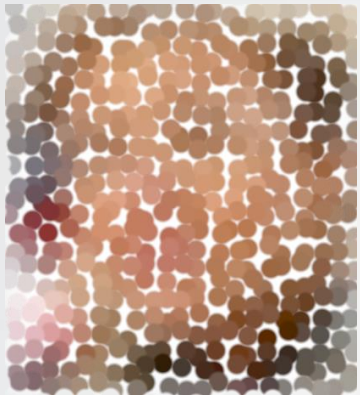


- Health care can be a means of enabling people to, live, flourish and define their lives
- How we do this touches on profound dimensions of personhood, identity, and culture

Ethics



- ...the thoughtful, careful, and **systematic examination of the values** and beliefs that underpin our attitudes, decisions, and actions
- ...asking the question, **what do we owe each other** and how can we live up to that?
- ...figuring out what can be **ethically justifiable** rather than what is **right and wrong**



Ethics as living with integrity

Integrity

- The coherence between principle and action
 - ⋮ Having a coherent and stable set of values
 - ⋮ Articulating these values
 - ⋮ Behaving in accord with these values



Integrity



- Central to a meaningful, fulfilling life
- Requires us to know what matters to us
- Everyone in the story has it on the line
- Allows room for difference



Multiple Advance Care Planning Tools

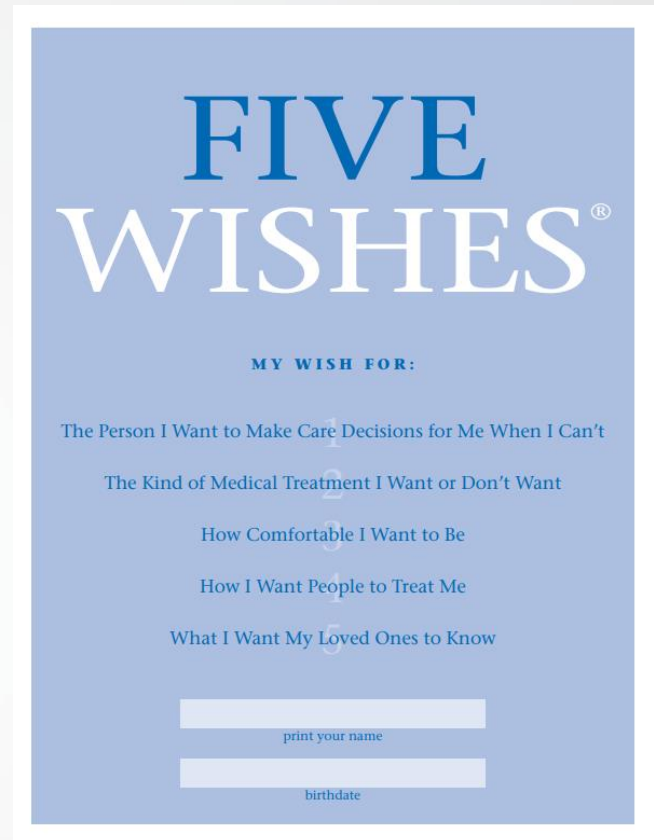


- Alberta Health Services – **Conversations Matter**
<http://goals.conversationsmatter.ca.s3-website-us-east-1.amazonaws.com/>
- BC Ministry of Health – **My Voice**
www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf
- Canadian Hospices & Palliative Care Association –
Speak Up - www.advancecareplanning.ca
- Others..

The 5 Wishes



- Advanced care planning tool developed in US
- Intended to cover personal, emotional, and spiritual needs, as well as medical wishes
- May have legal standing under some jurisdictions though standing in Canadian jurisdictions varies.
- Selected for this talk because of its simplicity



Wish 1: The person I want to make care decisions for me when I can't

- Assigns a health care surrogate decision-maker (SDM) who makes decisions on the maker's behalf if they are unable to speak for themselves.
- Gives direction about who would be eligible to be a SDM
- Identifies the domains of decision-making for which SDM would have authority.



Wish 1: The person I want to make care decisions for me when I can't

The Ethics

- **Promotes patient centredness**
 - Names individual who can be an “expert” on the patient
 - Maximizes chances care decisions will align with patient’s wishes, values, and beliefs
- **Promotes harmony** - Helps to avoid/resolve conflict if family members/loved ones disagree about decisions

Wish 2: The kind of medical treatment I want or don't want

- Clarifies what “life support treatment” means to the maker, and when the maker would and would not want it.
- Invites maker to give direction in particular circumstances:
 - Close to death
 - In a coma and not expected to wake up or recover
 - Permanent and severe brain damage and not expected to recover
 - Other conditions under which maker would not want to be kept alive



Wish 2: The kind of medical treatment I want or don't want

The Ethics

- **Patient Centredness:** Maximizes chances care decisions align with patient's wishes, values, and beliefs
- **Patient Centredness + Benefit:**
 - Allows for patient to define what they believe would be beneficial to them
 - Gives some hints about how patient defines quality of life

Wish 3: How comfortable I want to be

- Addresses matters of comfort care
- Invites maker to give direction on:
 - Whether/how to manage symptoms (pain, nausea, etc.)
 - Which comforts to provide (lip care, massage, touch)
 - Desired personal care (shaving, nail clipping, etc.)
 - Auditory input (music, readings)
 - Any options considered (hospice, others)



Wish 3: How comfortable I want to be



The Ethics

- **Patient Centredness:** Maximizes chances care decisions align with patient's wishes, values, and beliefs
- **Patient Centredness + Benefit:**
 - Allows for patient to define what they believe would be beneficial to them
 - Gives some hints about how patient defines quality of life
- **Human Dignity:** Reinforces need to be treated with dignity (in general, and in daily care)
- **Promote a Good Death:** Gives specific direction about atmosphere during final days

Wish 4: How I want people to treat me



- This section speaks to personal matters.
- Invites maker to give direction on:
 - Who should be around during final stages of life
 - Attitudes in the room (positivity vs sadness)
 - Desired interaction (hand-holding, prayer)
 - Efforts to retain dignity
 - Desired location of death (if choice is possible)



Wish 4: How I want people to treat me



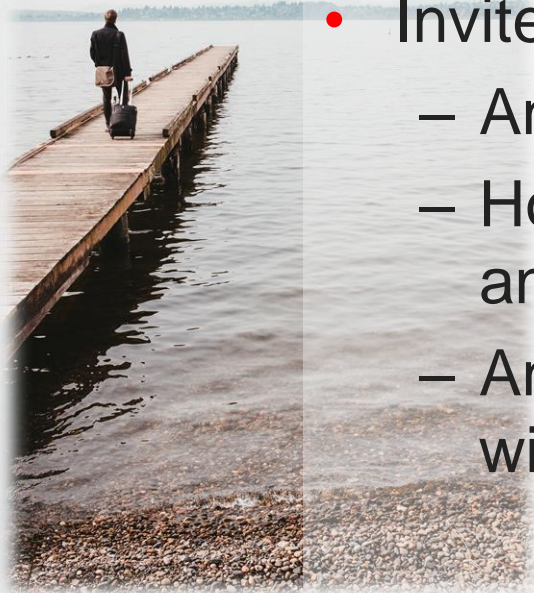
The Ethics

- **Patient Centredness:** Decisions align with maker's wishes, values, and beliefs
- **Patient Centredness + Benefit:**
 - Maker defines what is beneficial to them
 - Gives guidance about how maker defines quality of life
- **Human Dignity:** Reinforces need to be treated with dignity (in general, and in relation to daily care)
- **Promotes a Good Death:** Gives specific direction about atmosphere at very end stages of life
- **Supports family/loved ones:** Removing uncertainty about how best to be with maker

Wish 5: What I want my loved ones to know



- This section deals with matters of forgiveness, remembrance, and final wishes regarding funeral or memorial plans.
- Invites maker to provide information about:
 - Any hopes for reconciliation within family
 - How patient perceives the meaning of death and the dying process
 - Any requests that people respect their wishes even if they don't agree



Wish 5: What I want my loved ones to know



The Ethics

- **Patient Centredness:** Maximizes chances care decisions align with patient's wishes, values, and beliefs
- **Human Dignity:** Reinforces need to be treated with dignity (in general, and in relation to daily care)
- **Promotes a Good Death:** Gives specific direction about atmosphere at very end stages of life
- **Supports family/loved ones:**
 - Removing uncertainty about how best to be with patient
 - Promoting harmony for loved ones after patient death

What does the **5 Wishes** tell us about what is ethically important at end of life?

- Promote patient centredness (align care with wishes)
- Maximize Benefit (where maker defines benefit)
- Preserve Harmony among maker, family, loved ones
- Respect and Promote Human Dignity
- A Good Death
- Supports the well-being of family/loved ones

Anything Missing?



- Direction about *how* decisions should be made. Are culture/ faith dimensions relevant?
- Situations where there may be appropriate limitations on what care providers can do
- Decisions when the person is not exactly at end stages, but where they still need help to make decisions
- Decision-making when the person for whom decisions are being made has preferences and requests that differ from the ones in the advanced care plan.

Important Values at End of Life



- Promote patient centredness (align decisions with wishes)
- **Respect patient wishes for how decisions should be made**
- **Make decisions with good information and expertise**
- Maximize Benefit (where maker defines benefit)
- **Balance preferences/interests of who the patient was, with who they are now**
- Preserve harmony among family and loved ones
- Respect and Promote Human Dignity
- A Good Death
- Supports the well-being of family/loved ones

What about Harprit?



- Has she already done Advance Care Planning? Does she have an SDM?
- Involve her as much as possible regarding
 - How decisions should be made?
 - What she prefers with regards to medical care
 - Her thoughts about end of life (she is already thinking about it!)
- Confirm potential of new drug
- Support family to consider any prior wishes which may be relevant
- Follow Harprit's lead about what supports her dignity
- Work to create a story which family can live on from

Summary

- Advance care plans are ‘value-laden’ in their structure and content
- Tools like the **5 Wishes** can enable more ethical care
- ACP tools are not perfect
 - do not solve all dilemmas (can add to confusion)
 - not anticipate all possible ethical issues that can arise
- Understanding the ethical rationale behind ACPs can help us to plan for, receive, and deliver ethically optimal care

Thank You! Comments?



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