

NEGOTIATING UNCERTAINTY

HOPE, TRUTH-TELLING & ETHICS IN CARE

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For your reflection...

“We ridicule those with too much hope and hospitalize those with too little.” Jevne 2004

- Do you agree with this quote? Why, or why not?
- What do you believe is the role of hope in healthcare?



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Session Objectives

Increased familiarity with and insight into:

- Nature and impact of implicit hope messages
- Assumptions we make about hope, especially ‘false’ hope
- Hope “tools” relevant to ethical practice
- Nature and role of truth-telling for hope
- “Doing hope” as an ethical approach to end-of-life hope work
- An “ethic of hope”

Setting the stage...

Healthcare Context

- Psychosocial & spiritual aspects
- “Hope messages”

Health care providers have an obligation to promote hope in patients

Consider what this means...is it worded correctly?

Setting the stage...

*Ethics is basically about the ways we **do** & **should** treat each other; it involves a **systematic** investigation of our values & actions.*

Moral importance of *emotion*

Role of *hope* – implications for person-centred care

▣ Why this obligation? What does it entail?

- Should we address hope? How?
- Where/how does “false hope” fit?

A case to consider...

- Frank has stage 4 lung cancer
- Believes he can be cured
- Has taken part in 2 clinical trials & is pursuing all options, including a new alternative therapy in France - \$\$
- Team worried, views this as “false” hope
Should they reiterate his prognosis? How should they deal with Frank’s false hope?

Notice our language...

Practitioners are urged to:

- *Manage a patient's hope*
- *Re-frame, re-define hope*
- *Establish realistic and reasonable hopes*
- *Nurture "true" hopes and eliminate "false" hopes*

Why?

Part 1: Hope

An **emotional attitude** that:

- ✓ Involves our desires/wants
- ✓ Is related to our values and/or goals
- ✓ Is influenced by what we imagine to be realizable possibilities for us
- ✓ Involves action (ours & others)

(Christy Simpson, 2000, p81)

Scientific basis for hope: neurochemical, acts like endogenous opiates

Hope: Key Features

- Hope is context- and person-relative
- Presence/absence of hope is most acutely felt in times of uncertainty and change
- Hope has a relational aspect
- Hope is multilevel, specific & general, time-related
- Hope involves vulnerability as well as agency

Hope awakens courage. He who can implant courage in the human soul is the best physician.

Karl von Knebel

In the heart of each of us, there is a voice of hope, a small voice that yearns to say "yes" to life. If nurtured and strengthened, it invites, encourages, pulls, pushes, cajoles, and seduces us to go forward. The experience of hope is not tidy. It is not something apart from love and courage and all the dynamics of the human spirit and human relationships. It is ever-present in our lives. Whether viewed as a human need, a biological life force, a mental perspective, or an external pull to transcend self, hope is capable of changing individual lives. It enables individuals to envision a future in which they are willing to participate.

(R. Jevne, The Voice of Hope: Heard Across the Heart of Life, 1994)

Hope & Spirituality


Hope involves a complex dynamic of all these things because it is, more deeply, a unifying and grounding force of human agency.

(quoted in McGeer, 2004)

The soul has an absolute need of something hidden and uncertain for the maintenance of that doubt and hope and effort which are the breath of life itself.

(Eliot, The Lifted Veil)

Hope & Spirituality

- Meaning-making, purpose
- Relational/Personal
- ± religious involvement/expression
- Source of **beliefs, values, identity** – self at deepest level, *self-integrating & transcending*
- Faith/spirituality  Hope

Hope is the word which God has written on the brow of every man.

Victor Hugo

**Four assumptions about “false” hope that
should be critically examined...**

Four Assumptions

1. False hopes exist
2. False hopes can be (reliably) identified
3. False hopes are or create a problem
4. False hopes should be changed, eliminated, and/or avoided

Assumptions 1 & 2...

- Who determines whether a hope is “false” and on what grounds?

Consider...

- *Context- and person-relative nature of judgments about hope(s)*
- *Evidence for the legitimacy or reasonableness of a particular hope?*

Consider...

The contention that hope is a product of the perception of the individual indicates that the use of the same set of facts to calculate probabilities predictably will result in varying degrees of hopefulness or hopelessness among different persons encountering similar circumstances.”

(Rose McGee, 1984:35 *Advances in Nurs Sci*, 6(4);34-44)

Proposed categories of hopes

- False – *revised* description
- Shared/Not shared
- Contested/Uncontested

“Delusive hope still points to distant good.” Euripides

Assumption 3...

False hopes are/create a problem...

- often expressed as concern about the well-being of the patient and/or family
 - e.g., lack of preparation for death, potentially open to manipulation, etc.

...But is there more to consider than this?

Consider...

- If we do not **challenge** or **contest** a particular patient/family's hope, does this mean that we are implicitly endorsing that hope as well as the view of reality that the hope is based upon?

Consider also...

The relevance of our (practioners') hopes, or lack thereof...

- Is it necessary to have the same hope(s) as the client/patient/family in order to care well for them?
- Might this be an aspect of self-protection?

Food for Thought

“...we may also need to recognize that we may be protecting ourselves. We don’t know what to say or do if the hope is not fulfilled. If we allow ourselves to think there is a window of possibility, when it is closed, we too will hurt.”

(Jevne 1996)

Assumption 4...

- Is a focus on changing, eliminating, or avoiding contested hope(s) the best approach?

Consider...

- Concern - vulnerability/fear
- Importance of recognizing that hope(s) can fluctuate and change
- Value of self-reflection before intervening

So...

How can we
find/nurture/support hope?

Consider...

- How do you nurture hope? What do you draw on? Do you need to have hope in order to convey it?
- Is hope part of your practice?
- Do your feelings about a patient (e.g., like/dislike) influence whether and how you address hope?

Part 2: Hope Work

How do/can we work more purposefully and effectively in the area of hope?

- *embedded hope “stories”*
- *collusion*
- *cultural aspects*
- *opening the hope chest*

Some Possibilities...

- “Hope for the best, prepare for the worst” (?)
- Be curious, ask, and *listen*
- Focus on the *meaning* of the hope to the patient/family
- Identify sources of hope for patient/family, e.g., faith-based, relational, etc.



Caring

Care is the “cement” for hope.

Consider **maximizing** hopefulness and
minimizing hopelessness...

And counteracting...

- the alien effect
- the skidding effect
- the bruising effect

(Edey, Jevne, Westra 1998)

Community

“Hope happens more easily
in community.”

Who is your hope-full community?

Creating

Role of imagination in hope...

Symbols of hope?

What would you do in a 'hope
emergency'?

Hope is

...my life jacket in illness

...my light in despair

...my comfort in uncertainty

Courage

Having hope can make us vulnerable

"I have spread my dreams under your feet,
Tread softly because you tread on my dreams"

(WB Yeats)

Possibilities can...

Dis-courage

En-courage

Celebrating

What can we celebrate in the context of
illness and health?

“Hopeful people celebrate life in its entirety. They learn to accept a rhythm of life that ebbs and flows between success and failure, between stability and uncertainty.” (Jevne 1997)

Communicating

Proponents suggest:

- Hope can be nurtured in environments where communication is strong, open, and honest.
- *How do we talk about hope?*

Part 2: Truth-telling

Remember the implicit and explicit messages related to hope and “false” hope”...

- *Manage a patient’s hope*
- *Re-frame, re-define hope*
- *Establish realistic and reasonable hopes*
- *Nurture “true” hopes and eliminate “false” hopes*

What are the implications re: truth-telling ?

Historical perspective

“Historically, the health professions expressed little concern for truthfulness in their ethical codes...in medicine, deception has been widely practiced, if not prescribed...In the hierarchy of values, truthfulness was assigned a subordinate place in relation to benefiting the patient and preventing harm.”

Michael Yeo, Concepts and Cases in Nursing Ethics, 1991

Today's perspective

In contrast, the general presumption today is in favour of openness and the disclosure of information to patients.

This change is captured, for example, in professional codes of ethics...

WHY?

Truth

A primary value...

– ‘Something we value
for its own sake’

- As individuals
- As a society

Things to Consider...

▣ **Truth and the Health Context**

- Informed choices
- Appropriate treatment
- Accurate information supports autonomy

▣ **Significance of health information**

- Truthfulness encourages trust

▣ **Vulnerability**

- In the moment
- Long-term

Truth-telling

- Should this be an absolute principle?

At any cost?

Digging Deeper: Disclosure and 'Deception'



Is not telling the truth justified when...

- It does more harm than good for patient?
- It makes things easier for the health care provider or caregiver?
- The patient lacks ability to understand or process the information?
- The patient has indicated she doesn't want to know the truth?
- Other?

Telling the Truth

Evaluate benefits & harms

- Who is judging harm?
- How is harm measured?
- How much harm is too much?

- Stereotypes re: 'bad news'
- Short versus long term effects
- Different values, expectations
- Cultural variations

Consider “telling the truth”...

- Key questions
 - What needs to be told?
 - Why is the information being shared?
 - How should the information be shared?
 - Possible hope effects?

Disclosure

- Truth-telling requires accuracy and honesty
 - Information needs to be shared in an understandable manner
 - Goal is “shared” or “negotiated” understanding

*How to paint as clear a picture as possible in line
with a patient's style preferences?*

Remember...

***The truth may be brutal,
but “the telling of it
should not be.”***

[Philip Hebert, Barry Hoffmaster, et al, Bioethics for Clinicians: 7. Truth-telling, *CMAJ*, 156(2) 225-228, 1997; A Jonsen, M Siegler, and S Windslade, *Clinical ethics* 3rd ed, New York: McGraw Hill, 1992: 53]

- May require multiple conversations
- Established relationship helps

Underlying questions

- Can a patient refuse information or refuse to know?
- Is disclosing (some) information different from not lying to patients?

Not telling the truth: “Deception”

- Involves leading another to adopt a belief that one holds to be untrue
 - By act?
 - By omission?
 - Intentionally?
 - Unintentionally?
- May indirectly confirm (or not refute) a patient’s hope

Survey says...When is lying ok?

- 51% - When it spares someone's feelings
- 28% - Never
- 15% - White lies are always fine
- 6% - When the question concerns my weight or age

Chatelaine, April 2006, p. 26

Notice...

- The wording of the question:
- “Should the healthcare provider tell?”

- How is this different from:
- “Should the patient tell? (or is it?)”

Fiduciary Relationships

- Usually involve power imbalances
 - Knowledge
 - Status
- Based on trust
 - Truth-telling is a vital component of this

Revisiting Ethics Frameworks

An “ethic of care” (Tronto, 1993)

4 phases, 4 moral elements

- Phase 1: caring about –
 - Moral element: **attentiveness**
- Phase 2: taking care of
 - Moral element: **responsibility**
- Phase 3: care-giving
 - Moral element: **competence**
- Phase 4: care-receiving
 - Moral element: **responsiveness**

Palliative care approach as an applied example of this “ethic of care”

A related view...

- **Relational Care ethics** (Gadow, 1999; Bergum & Dossetor, 2005)

“How should you and I be treated?”

- mutual respect for self and others
- relational engagement
- embodied knowledge
- environment

Dialogue

To be truly dialogical requires:

- authenticity (interpretation)
- openness (trust)
- integrity (accountability & discipline)
- responsiveness (intentionality)

(Bergum & Dossetor, 2005)

Part 3: Putting It Together

- Ethics
 - 4 principles
 - relational care
- Truth-telling
 - process & content
- Hope
 - context, person specific
 - relational
 - vulnerable
 - agency

“Doing Hope”

“Doing Hope”

- Radical listening – *empathy*, open mind- open heart
 - Witnessing (accompaniment, *presence*)
 - Sensitive exploration of uncharted territory
 - reflection, options, sense/meaning-making
 - Minimizing expectations, barriers, and/or constraints - rebalancing
- “...no one gives or provides hope to another, but rather one creates the conversational space for hope to arise from the forms of conversation one shares.”* (Weingarten 2010)

Ethic of Hope

Cellarius: *Considering the Ethics of Hope* (2008)

- Negotiation
- Competence
- Responsibility

Undertaking hope work with a patient requires that the patient and health care practitioner negotiate the activity, that the practitioner be competent in hope work, and that the practitioner live up to the responsibilities of engaging in hope work. Despite the imposition of ethical structure on hope work, the proposed ethical fundamentals are not foreign medical standards imposed on human interaction, but are standards congruent with the ethics of everyday life. (p116)

Finally...

- “The suffering human being needs a place where he/she can rest, a place which breathes genuine hospitality, where fear and hope are permitted to exist side by side...a place where the naked face appeals for compassion and finds response.”

(Eriksson & Lindstrom 2003)

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Case: Diagnosis

Ben Burroughs is a 12 year old with widespread metastatic bone cancer and a poor prognosis. His parents are asking the health care team not to reveal to him the full details of his condition and prognosis. Should the health care team respect their wishes?

If you were the chaplain working with this family and team, how would you approach it?

Case: Test Results

Norah McDonald is a new patient in Dr. Lee's practice. While reviewing Norah's file, Dr. Lee discovers that Norah had a previous PAP smear with irregular cells but that there was no follow-up. Norah has come in for an appointment due to gynecological complaints. What should Dr. Lee tell Norah?

Question

- What about placebos?
 - Truth-telling
 - Hope effects
 - Ethics