The Ethics and Practice of Loving Care

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Session Objectives

• To define loving care
• To locate loving care within contemporary practice
• To explore the ethics of loving care, including potential controversies
• To examine tangible examples of loving care in practice
• To begin exploring measurement, QI & research

The Contemporary Context, Rationale and Role for Loving Care

Clinical Ethics Core Values and Principles

1. Preservation of Life
2. Alleviation of Suffering
3. Non-maleficence ("primum non nocere")
4. Autonomy
5. Distributive Justice
6. Truth Telling
7. Integrity of the Profession
Another Tough Day at the Hospice

“My dying wish is that you all take off your clothes and get in bed with me.”

Ethics in Practice

A Question of Balance

Autonomy

Beneficence

Justice

Non-maleficence

Professional Integrity

Truth-telling

Clinical Ethics – Early Themes

<table>
<thead>
<tr>
<th>Subtractive</th>
<th>Additive</th>
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<tbody>
<tr>
<td>Individual</td>
<td>Mutual</td>
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<tr>
<td>Autonomy</td>
<td>Beneficence</td>
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<tr>
<td>Protection</td>
<td>Trust</td>
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<tr>
<td>Contractual</td>
<td>Covenantal</td>
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Problem-Oriented Medicine

Evidence-based Medicine

“Evidence-based medicine has been defined as the conscientious and judicious use of current best evidence in making clinical decisions.”


Evidence-based Medicine

“Evidence-based medicine de-emphasizes intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research. Evidence-based medicine requires new skills of the physician, including efficient literature searching and the application of formal rules of evidence evaluating the clinical literature.”

Evidence-based medicine
“One of the essential qualities of the clinician is interest in humanity, for the secret of care of the patient is in caring for the patient.”

Dr. Francis Peabody
JAMA 1927; 88:877

“Francis Peabody’s dictum... permeated our student days. We learned that the practice of medicine is cold and abrasive unless tempered by love.”

J. Englebert Dunphy
On Caring For the Patient With Cancer
NEJM 1976; 295(6):313-319

“We need detailed information about the causal linkages among the structural attributes of the settings in which care occurs, the processes of care, and the outcomes of care.”

Avedis Donabedian
The quality of care. How can it be assessed?
JAMA 1988  260(12):1743-1748
“Systems awareness and systems design are important for health professionals but are not enough. They are enabling mechanisms. It is the ethical dimension of individuals that is essential to a system's success.”

Avedis Donabedian
A Founder of Quality Assessment
Encounters a Troubled System Firsthand
Health Affairs Vol 20 (1) pp 137-141

“Ultimately, the secret of quality is love. You have to love your patient, you have to love your profession, you have to love your God. If you have love, you can then work backward to monitor and improve the system.”

Deidre Scherer

Precedents for Loving Care -- Pediatrics

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Precedents for Loving Care -- Pediatrics
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Suzanne Toce, MD
Cardinal Glennon Children's Hospital

Precedents for Loving Care -- Hospice

Hospice Descriptors:
"cherished and refreshed"
"special care and honor"
"a place of welcome"
"a loving environment"

"...hospice care is not mere technique; it is a gift and an offering of the best that we have, in our minds and in our hearts."

"Hospice is an intimate transaction between human beings in community."*

Sandol Stoddard
Hospice in The United States: An Overview
J Pall Care 1989 5:3, 10-19

Loving Care
Defining what we mean

Working definition for Loving Care

“One to one interactions intended to convey positive regard, improve comfort, and quality of life and preserve developmental potential by alleviating distress, promoting a sense of well-being, evoking pleasure when possible, and fostering connection to others.”

Phyllis
“Yes, I guess I’m in the mood, but certain restrictions apply.”
### Motherly Love

- Selfless
- Physical
- Sexual
- Scale
- + to ++++
- Well-wishing
- Personal
- Exclusive
- Possessive
- Expectations
- Longing
- Mutual (expectation of being loved in return)

### Love of Parent

- Selfless
- Physical
- Sexual
- Scale
- + to ++++
- Well-wishing
- Personal
- Exclusive
- Possessive
- Expectations
- Longing
- Mutual (expectation of being loved in return)
- Selfless
- Physical
- Sexual

### Love of Sibling

- Selfless
- Physical
- Sexual
- Scale
- + to ++++
- Well-wishing
- Personal
- Exclusive
- Possessive
- Expectations
- Longing
- Mutual (expectation of being loved in return)
- Selfless
- Physical
- Sexual

### Love of Self

- Selfless
- Physical
- Sexual
- Scale
- + to ++++
- Well-wishing
- Personal
- Exclusive
- Possessive
- Expectations
- Longing
- Mutual (expectation of being loved in return)
- Selfless
- Physical
- Sexual

### Neighborly Love

**One Big Happy**

by Rick Detorie

03-26-02

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**Neighborly Love**

**One Big Happy**

by Rick Detorie

03-26-02
### Love of Neighbor – Elder

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### Love of Neighbor – Child

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### Love of Pet

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### Agape – “Universal Love”

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### Love of Patient

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### Potential Controversies
Limits of Loving Care

Practice of Loving Care

“Can the team deliver a patient from anonymity?”

- Who is she?
- Who was she at the top of her game?
- What defines her? Is she more than “lung Ca...dying...crippled...unresponsive...”? 

Ned H. Cassem, MD
Consultation Psychiatrist, MGH, Professor, Harvard Medical School

Forms of Loving Care

- Massage
- Aesthetic grooming
- Story telling & life review
- Cooking
- Music
- Art
- Play
- Presence
- Prayer & Meditation
- Ritual
- Celebration

Bastienne Schmidt & Philippe Chung

Mal Warshaw collection

VITAS corporation
Community Approaches to Loving Care
“Being part of a community is essential for the development of consciousness and individuality and is characterized by communication, mutuality, and the ethical ideals of fidelity, gratitude, reciprocity, justice, and love.”

Vanderpool, Harold Y.
The Ethics of Terminal Care
JAMA, Vol 238, No.9 (Feb. 27, 1978), 850-852

“Our society suggests that caring and living are quite separate and that caring belongs primarily to professionals who have received special training. Although training is important, and although certain people need preparation to practice in their profession with competence, caring is the privilege of every person and is at the heart of being human.”

Henri J.M. Nouwen
Our Greatest Gift A Meditation on Dying and Caring
Harper Collins 1994, New York

“We shouldn’t try to care by ourselves. Care is not an endurance test. We should, whenever possible, care together with others. It is the community of care that reminds the dying person of his or her belovedness.”

Henri J.M. Nouwen
Our Greatest Gift A Meditation on Dying and Caring
Harper Collins 1994, New York

“Cleaving to another, recognizing that the other is the bone of the bone and the flesh of the flesh that is given in common, locating the mutual body as the site of the moral gesture is fundamental to ethical reflection...it requires a radical rethinking of all that occurs to the other. All of the yearning, all of the loss, is in fact, my loss.”

Laurie Zoloth-Dorfman
First, Make Meaning: An Ethics of Encounter for Health Care Reform
Tikkun, Vol. 8, No. 4, pp133-135

“This responsibility for the narratives great and small, for the dreams of the other, for the temptations of the other, for the responsibility of the other, creates a mutual commandedness. The encounter is intensely personal. The death of the other, the illness of the other, her vulnerability, is your own.”

Laurie Zoloth-Dorfman
First, Make Meaning: An Ethics of Encounter for Health Care Reform
Tikkun, Vol. 8, No. 4, pp133-135

“The discourse needs to be continued in a central way by the religious community: The blessings of friendship in the human endeavor, the responsibility for the bearing of collective burden of the ill and the vulnerable, must be borne by the theology and purpose of the faith communities. That each of us will die is inevitable; what must come to be understood as miraculous is our ability to love and bear the weight of the dying in fellowship.”

Laurie Zoloth-Dorfman
First, Make Meaning: An Ethics of Encounter for Health Care Reform
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The Eden Alternative

“The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering in a human community. Loving companionship is the antidote to loneliness.”

William H. Thomas, MD
www.edenalternative.com

“The Eden Alternative

“Life in a truly human community revolves around close and continuing contact with children, plants, and animals.”

William H. Thomas, MD
www.edenalternative.com

Foster Grandparents

“I wish I had a Foster Grandparent for every classroom in my school. The care and loving they give to our children is a joy to see.”

Ellie Willingham
Director of Arbor Hill School, Albany, NY

Hard to tell from here. Could be buzzards. Could be grief counsellors.”

TeleCare

Intergenerational caring

• Started in response to high rates of elder suicide
• Currently approx 50 clients receiving calls
• Volunteers mostly students from 4th to 8th grades.
• Most calls are ~ 3 min long, between 8:30-9:30 am.

Saline Eldercare, Wilbur, Nebraska

TeleCare

Saline Eldercare, Wilbur, Nebraska
“Rainbow Bridge enhances the quality of life for nursing home elders and brings generations together in mutually rewarding relationships by providing life-enriching volunteer opportunities for youth, families, individuals and community organizations.”

www.rainbowb.org

"I'm learning how good it feels to put a smile on someone's face. I knew I had a good side. I'm just glad I can use it."

17 year old at-risk male student

Rainbow Bridge Denver, Colorado
www.rainbowb.org

Natural Helper Program

Natural Helper Program
Types of Measurement and Data

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Measuring Quality

**Process Measures**
- What we do in the course of providing caring interventions

**Outcome Measures**
- The results of our interventions
- How do the patient or family feel?
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