

The Ethics and Practice of Loving Care



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Session Objectives

- To define loving care
- To locate loving care w/in contemporary practice
- To explore the ethics of loving care, inc. 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 | 4. Autonomy |
| 2. Alleviation of Suffering | 5. Distributive Justice |
| 3. Non-maleficence
("primum non nocere") | 6. Truth Telling |
| 7. Integrity of the Profession | |

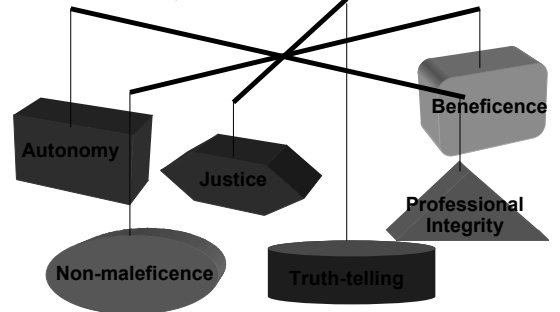
Another Tough Day at the Hospice



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

Ethics in Practice

A Question of Balance



Clinical Ethics – Early Themes

Subtractive

- Individual
- Autonomy
- Protection
- Contractual

Additive

- Mutual
- Beneficence
- Trust
- Covenantal

Problem-Oriented Medicine



Robert Pope collection

Evidence-based Medicine

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

Zarkovich E, Upshur RE.
The virtues of evidence
Theoretical Medicine and Bioethics 2002;23(4-5):403-412.

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
A new approach to teaching the practice of medicine.
Evidence-Based Medicine Working Group
JAMA. Nov 4 1992;268(17):2420-2425.



Suzanne Richardson, NY
Times August 7, 2005

Precedents for Loving Care

“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

Precedents for Loving Care

“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

Continuous Quality Improvement

“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

Continuous Quality Improvement

“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

Continuous Quality Improvement

“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
collection

Avedis Donabedian
A Founder of Quality Assessment
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Health Affairs Vol 20 (1) pp 137-141

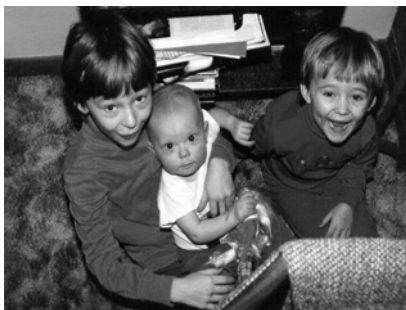
Precedents for Loving Care -- Pediatrics



Precedents for Loving Care -- Pediatrics



Precedents for Loving Care -- Pediatrics



Precedents for Loving Care -- Pediatrics



Mal Warshaw collection

Precedents for Loving Care -- Pediatrics



Suzanne Toce, MD
Cardinal Glennon Children's Hospital

Precedents for Loving Care -- Hospice



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



Phyllis



Phyllis



Yvonne Corbell



Robert



Robert



Mrs. Gold



Deidre Scherer
collection

Ester O'Hara



Ester O'Hara



Ester O'Hara



Ester O'Hara



Romantic Love

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

Scale
+ to ++++

Romantic Love



"Yes, I guess I'm in the mood, but certain restrictions apply."

Fatherly Love

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

Scale
+ to ++++

Motherly Love

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

Scale
+ to +++++

Love of Parent

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

Scale
+ to +++++

Love of Sibling

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

Scale
+ to +++++

Love of Self

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

Scale
+ to +++++

Neighorly Love



One Big Happy
by Rick Detorie

03-26-02

Neighorly Love



One Big Happy
by Rick Detorie

03-26-02

Love of Neighbor – Elder

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

Love of Neighbor – Child

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

Love of Pet

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

Agape – “Universal Love”

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

Love of Patient

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

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...”?



Deidre Scherer
collection

Ned H. Cassem, MD

Consultation Psychiatrist, MGH Professor, Harvard Medical School



St. Paul Pioneer Press Dying Well: The miracle of death, Spring 2000



Bastienne Schmidt & Philippe Cheng



Bastienne Schmidt & Philippe Cheng

Forms of Loving Care

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



Mal Warshaw collection



VITAS corporation



Bastienne Schmidt & Philippe Cheng



Bastienne Schmidt & Philippe Cheng





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."



St. Paul Pioneer Press

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."



St. Paul Pioneer Press

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
Tikkun, Vol. 8, No. 4, pp133-135

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."



St. Paul Pioneer Press
Dying Well: The miracle of death
Spring 2000

William H. Thomas, MD
www.edenalternative.com



*"Hard to tell from here. Could be buzzards.
Could be grief counsellors."*

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

National Service News
Issue 117, Oct 16, 2000
Corporation for National and Community Service



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



Students in Saline, Nebraska's 5th grade class at Wilbur-Edwards are making the telephone calls to the elderly part of their morning routine. Students are working in groups to make the calls and are receiving the same feedback from the elderly. Students are working in groups to make the calls and are receiving the same feedback from the elderly. Students are working in groups to make the calls and are receiving the same feedback from the elderly.

Telecare provides contact between seniors and youth

Saline ElderCare, Wilbur, Nebraska



"Bringing Generations Together"

"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



The New York Times

New York, Sunday, January 25, 2009

In Death Watch for Stranger, Becoming a Friend to the End

By N. B. KENNEDY

The 104-day, 2008 holiday season had been a long one for the volunteer, but the physical and emotional toll was not. In a nursing home bed, still and alone, the 85-year-old man, Mr. Kennedy, was looking for help. He had a large nose and prominent ears. He had a head of white hair and a small, smiling face. He was a stranger to the nursing home, but he was a friend to the end.



Mr. Kennedy, a volunteer, had spent years in the nursing home, and he was a friend to the end. He was a stranger to the nursing home, but he was a friend to the end. He was a stranger to the nursing home, but he was a friend to the end.

The New York Times

New York, Sunday, January 25, 2009



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Hervey Durocher

The Road Not Taken

By Robert Frost

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveler, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear,
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how soon I'd be, and my way
I doubted if I should ever see back.

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
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January 4, 1935 - July 19, 2004

Measurement, Quality Improvement and Research

Types of Measurement and Data

Process

Outcome

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?

Types of Measurement and Data

Process

Outcome

Subjective

Objective

Types of Measurement and Data

Process	Outcome
Subjective	Objective
Qualitative	Quantitative

Types of Measurement and Data

Process	Outcome
Subjective	Objective
Qualitative	Quantitative
Prospective	Retrospective

