# Ethical Challenges in Gerontology: Preparing Our Future Leaders

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Appendices: See attached Powerpoint slides on enclosed CD-Rom.

# Introduction

***Overview***

Gerontology is the study of the aging process. It includes the study of physical, psychological and social changes in older individuals and the investigation of societal changes resulting from the aging of the population. This field is also concerned with the application of this knowledge to policies and programs. Current population trends in the U.S. show that people are living longer and the number of older adults is rapidly increasing. Expanded career opportunities in gerontology are expected to arise in many disciplines and professions. Gerontology programs such as the certificate and masters program offered at CSULB are designed to prepare students from a multitude of backgrounds to develop aging-related programs, provide direct care via adult day and home care programs, to counsel, manage and to provide instruction in the field of aging. Ethical issues, as such, are a salient piece of this gerontological coursework.

The dramatic aging of our nation's population brings with it an increased need for more focused consideration of issues pertaining to the well-being of this population. The challenges currently present in the field of aging lend themselves strongly to issues that require ethical consideration. Should families be required to care for their aging family members? Do older adults have the right to decide when to die? Should we ration limited health care and other resources based on age and health status? How will budding gerontologists deal with these issues as they move out into the workforce as practitioners and policy makers? Due to the relative "newness" of the field of Gerontology, many of the ethical debates regarding topics mentioned above are not settled, and providing the opportunity for students entering this field to enter the discussion is vital in order to work toward consensus and workable solutions.

***Ethics and Gerontology***

In the *Coming of Age*, Simone de Beauvoir states about aging:

> **It is the meaning that (people) attribute to their life, it is their entire system of values that define the meaning and value of old age. The reverse applies: by the way in which a society behaves toward its old people it uncovers the naked, and often carefully hidden, truth about its real principles and aims.**

With the population growing older, we have a stake in developing a better understanding of gerontology and its related trends and issues. It is our responsibility to ensure that we create a society that values our aging members. ***Ethics***, defined as a set of principles of right conduct, or a theory or a system of

moral values, are critical to reevaluating our treatment and beliefs toward aging individuals.

According to the United Nations, we must appreciate the contribution that older persons make to their societies. We must create a world that provides to older adults **independence** (including access to safe environments, health resources and opportunities for personal growth), **participation** (including the ability to remain integrated in society and have a voice), **care** (care and protection, ability to maximize well-being, and enjoy basic human rights and freedoms), **self-fulfillment** (access to educational, cultural, spiritual and recreational resources) and **dignity** (freedom from exploitation and being valued independently of their economic contribution).

The goal of these modules is to prepare students to think more deeply about what is at stake in the gerontological-related issues presented below, as well as gain insight into how to be responsible leaders in an aging society. This requires an ability to respect the rights, dignity, and worth of all people, while striving to eliminate personal bias. We hope that by providing the facts, students will learn to engage in critical thinking and develop their own personal views, while remaining respectful to opposing opinions. We believe that inherent in this process is the ability to gain **empathy**: or the ability to "walk in someone else's shoes" (Myrick & Erney, 1985) or to "transform personal assumptions about knowing" (Kitchner & King, 1990), in this case about aging and aging individuals.

With knowledge and compassion, we as a society, can make conscious, moral choices that have long lasting impact on both older adults and on the future of our children.

# Family Caregiving Responsibility

## Summary/Literature Overview

Family members and informal (non-paid) care providers (including *friends, partners, and neighbors)* commonly assist with the care of older relatives. Caregiving is often defined as the act of assisting someone who is chronically ill or disabled and who can no longer care for themselves. Family caregiving has become the norm. According to the National Family Caregivers Association, more than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year. Currently, there are over four million family caregivers in California alone. Caregivers care for spouses (5%), and parents (40%) as well as grandparents, parents-in-law, other relatives, and friends (55%). Family caregivers are essential given that over 40% of U.S. primary care physicians think they don't have enough time to spend with patients and that family caregivers provide the overwhelming majority of long term-care services in the U.S. Furthermore**,** the majority of adults living in the community and in need of long-term care depend on family and friends as their only source of help.

While the need for care by older adults is increasing, availability is decreasing; people over 65 are expected to increase at a 2.3% rate, but the number of family members available to care for them will only increase at a 0.8% rate. Unfortunately, availability of care is a major factor in predicting whether or not an older person can remain at home (aging in place) versus being moved to institutionalized care. Furthermore, the services provided by family caregivers represent 80% of all home care services and are conservatively valued at $306 billion a year, more than twice the amount spent on paid home care and nursing home services combined. This is a serious issue given that women, who make up the majority of caregivers (oftentimes part of the "Sandwich Generation" – those caring for both older relatives and young children), are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (SSI) and that caregiving families (families in which one member has a disability) have median incomes that are more than 15% lower than non-caregiving families. Furthermore, family caregivers comprise 13% of the workforce, but often lose wages and time from work due to caregiving and related role demands. In fact, 59% of family caregivers who care for someone over the age of 18 either work or have worked while providing care and 62% have had to make some adjustments to their work life, from reporting late to work to giving up work entirely. Ten percent of employed family caregivers go from full-time to part-time jobs because of their caregiving responsibilities. Overall, American businesses can lose as much as $34 billion each year due to employees' need to care for loved ones 50 years of age and older.

Research shows that while caregiving is assumed to be voluntary, and some do report it as personally fulfilling, at least a third experience stress, burnout and exhaustion, possibly resulting in depression. Specifically, family caregivers

experiencing extreme stress have been shown to have decreased immune systems and increased morbidity. In fact, family caregivers report having a chronic condition at more than twice the rate of non-caregivers. Elderly spousal caregivers with a history of chronic illness themselves have a 63% higher mortality rate than their non-caregiving peers. Also, family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety.

One related question that has been posed is whether or not family members should be caregivers at all, and furthermore, if they should be financially compensated for their time. Conversely, should caregiving be considered familial duty and obligation? This is a heated debate because it has implications for policy and legislation, community health practices, work place productivity, respite care, family systems, technology and elder abuse, among other topics.

PROS OF PAYING FAMILY CAREGIVERS:

1. It will expand capacity and supply of workers
    - Can hire family members not necessarily employable otherwise (deaf, mentally impaired)
2. It will increase gender and family equity
    - Women will be paid for work they already do, "leveling the playing field"
    - Women are most likely to become impoverished in later years (especially low-wage minority woman). Compensation will deter this.
3. It will increase elder's satisfaction as a consumer
    - Outside agencies often impose rigid time schedules, and routines. Elders' will be more satisfied if they have more control over their caregiver.
    - This may increase quality of care. A relative may understand ethnic and cultural preferences, speak same language, or understand food preferences. This may increase a sense of safety and comfort for the older adult. Family members also have longer tenure, providing sense of continuity.
    - Family caregivers have higher motivation; they are committed to providing care.
4. It will decrease administrative and bureaucratic barriers
    - The caregiver is already in place. As such, costs traditionally used to place and screen formal caregivers can be eliminated; overhead costs (management) are decreased, as are turn-over rates. The latter is critical for quality of care.

CONS OF PAYING FAMILY CAREGIVERS:

1. It will increase family exploitation
    - Caregiving should be out of obligation. Paying a family member encourages setting a dollar value on family. How do we do this?

2. It will cause caregiver stress and strain
    - It is a major burden watching a loved one decline and feeling helpless. Caregiving is associated with a variety of negative outcomes-have poorer physical health and psychological well-being. It also disrupts responsibilities to other roles, e.g., parental and work, which causes increased family/society breakdown.
3. It will lead to elder abuse and fraud
    - Strain will lead to elder abuse. Most common is financial. The likelihood that a family member lives off of or takes older person's money is increased. Strain, especially coupled with poor training and skills required for proper caregiving, can also lead to psychological abuse, mistreatment, revenge, and functional incompetency of caregiver (passive neglect).
4. It will incur increased costs
    - There are greater costs to train family caregivers to the level of care needed for long-term elder care. Costs to businesses due to lost time and productivity by their employees who are caregivers are also incurred.

**In summary**, when problems arise in old age, many older adults turn to their family and friends for help. And as stated above, a large majority of care is being provided by informal caregivers. But as the American family changes in conjunction with the increase in the aging population, families are facing new challenges regarding the ability to give care as well as the quality of care provided. As such, there is much debate regarding whether or not family caregivers should provide the care as well as whether or no they should be financially compensated.

# Family Caregiving Responsibility

## Powerpoint Presentation

## Family Caregiving and Financial Compensation

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## Caregivers

- *Informal*: Family members, as well as friends, partners, and neighbors who provide care to aging loved ones.
- *Formal :* paid nurse aids, personal assistants, and home care staff who provide hands-on care in both home and long term settings.

# Family Caregiving Population

- Family caregiving has become the norm!
- In the U.S - 50+ million people provide care for chronically ill, disabled or aged family member or friend during any given year.
- In CA- over four million family caregivers alone.
- Caregivers care for spouses (5%), and parents (40%) as well as grandparents, parents-in-law, other relatives, and friends (55%).

# Family Caregiving: Availability and Challenges

- Availability of care is a major factor in predicting whether or not an older person can remain at home (aging in place) versus being moved to institutionalized care
- While the need for care by older adults is increasing, availability is decreasing.

## Family Caregiving: Availability and Challenges

- Family caregivers essential - over 40% of U.S. primary care physicians think they don't have enough time to spend with patients
- Family caregivers provide overwhelming majority of long term-care services in the U.S.
- The majority of community-dwelling adults in need of long-term care depend on family and friends as only source of help.

FAMILY CAREGIVERS MATTER!

## Economics of Family Caregiving

- Family caregivers give 80% of all home care services and are conservatively valued at $306 billion a year, more than twice the amount spent on paid home care and nursing home services combined.
- 2.5 times more likely than non-caregivers to live in poverty.
- Five times more likely to receive Supplemental Security Income (SSI).
- Caregiving families have median incomes that are more than 15% lower than non-caregiving families.

## Economics of Family Caregiving

- Caregivers 13% of the workforce, but often lose wages and time from work due to caregiving and related role demands.
- 59% of family caregivers (FG) work/have worked while providing care
- 62% have had to make some adjustments to work life, from reporting late to work to giving up work entirely.
- 10% of employed FGs go from full-time to part-time jobs because of caregiving responsibilities.
- Overall, American business loss = as much as $34 billion/year due to employees' need to care for loved ones 50 years of age and older.

## Impact of Family Caregiving

- 1/3 experience stress, burnout and exhaustion, possibly resulting in depression.
- Family caregivers report having a chronic condition at more than twice the rate of non-caregivers.
- Elderly spousal caregivers with a history of chronic illness themselves have a 63% higher mortality rate than their non-caregiving peers.

## Impact of Family Caregiving: Summmary of Sources

**Financial**

- Direct costs of care such as equipment and medicine
- Travel costs of long distance caregivers
- Reduced hours and income from work
- Early retirement
- Disruptions at work
- Reduced productivity at work
- Missed opportunities in career

## Impact of Family Caregiving: Summmary of Sources

**Physical**

- Health problems (headaches, stomach problems, sleep and weight disturbances)
- Increased use of drugs and health services
- Exhaustion and low stamina
- Self neglect
- Increased morbidity and mortality

## Impact of Family Caregiving: Summmary of Sources

**Emotional**

- Grief, loss and hopelessness
- Guilt, anger and resentment
- Giving up time for self, family
- Strained social and family relationships
- Social isolation
- Worry and anxiety
- Depression

## Should Family Members Provide Care? Should they be Financially Compensated?

PROS

- It will expand capacity and supply of workers
- It will increase gender and family equity
- It will increase elder's satisfaction as a consumer
- It will decrease administrative and bureaucratic barriers

## Should Family Members Provide Care? Should they be Financially Compensated?

CONS

- It will increase family exploitation
- It will cause caregiver stress and strain
- It will lead to elder abuse and fraud
- It will incur increased costs

# Family Caregiving Responsibility
## Learning Objectives

The discussion topics and activities are listed here to demonstrate the connection of each with its corresponding course goal. Further detail about these discussion topics and activities will be provided in subsequent sections.

*After completing the Family Caregiving Responsibility Module, the student should be able to:*

| **Objective** | **Discussion Topic** | **Activity** |
|---|---|---|
| Explore personal feelings about long term care placement | What factors can help determine if it's time to place a loved one in a long term care facility? | Reflection journal |
| Quality of care and financial implications of caregiving | Who provides better care: informal or formal (paid) caregivers?<br><br>Should family members who provide care be financially compensated by state/federal policies and programs? | Debate using Pro/Con grid<br><br>View film: *Complaints of a Dutiful Daughter* and discuss financial compensation issue |
| Identify risk factors for caregiver burden | What qualities are most suitable for a caregiver?<br><br>What factors can help us assess potential for elder abuse<br><br>What services are available to assist caregivers? | Case Study<br><br>Compile a resource list for local resources for caregivers (begin with National Family Caregivers Support Program of 2000) |
| The challenges of the sandwich generation and its impact on women, the role of women in families, the workplace and society. | What are caregivers experiencing as a result of their caregiving role? What experiences, both positive and negative exist? How does | Interview a caregiver |

| | | |
|---|---|---|
| | caregiving impact their overall wellbeing? | |
| Availability of caregivers from a political, social, economic and individual caregiver perspective.<br><br>Learn more about The Family Medical Leave Act | Who is ultimately responsible for caregiving? Family or state?<br><br>Should family who don't properly care for their older adults be penalized? | Working in small groups, draft legislation to address this topic. |

# Family Caregiving Responsibility
## Key Terms

*Caregiving:* the act of assisting people with personal care, household chores, transportation, and other tasks associated with daily living.

*Caregiving Families*: families in which one member has a disability.

*Caregiver Burden:* physical, emotional and financial costs associated with assisting persons with long term care needs.

*Caregiver Stress/Strain:* the emotional and physical impact of caregiving.

*Chronic Conditions/Illnesses:* long term (more than 3 months), often permanent and leaving a residual disability that may require long-term care management or care rather than cure.

*Elder Abuse/Mistreatment:* maltreatment of older adults, including physical, sexual, and psychological abuse, and financial exploitation, and neglect.

*Elder Fraud:* frauds and thefts against the elderly by people they know, including identity theft, "borrowing" funds without intending to repay, and denying services to the elderly person – even medical care – to pocket the money

*Elder Neglect:* deprivation of care necessary to maintain elders' health by those trusted to provide care (e.g., neglect of others) or by older persons themselves (self-neglect).

*Equity:* establishment or practice of fairness in families, whereby older adult caregiver is provided opportunities for reciprocal exchange; older adult does not become solely dependent on the family but also maintains his/her valued role in the family system.

*Family Exploitation:* treatment of human beings as mere means to an end — or as mere "objects". It refers to the use of people as a resource, with little or no consideration of their well-being.

*Family and Medical Leave Act:* federal legislation passed in 1993 that provides job protection to workers requiring short-term leave from their jobs for the care of a dependent parent, seriously ill newborn or adopted child.

*Financial Compensation:* indirect of direct financial support of informal caregivers. Indirect financial compensation may be in the form of tax relief (i.e., credits, deductions, exemptions), pensions schemes or social security benefits. Direct

compensation, on the other hand, involves the transfer of money through an allowance, stipend, grant or voucher system.

*Filial Duty:* the duty of a child to a parent; in this context, to provide care needed by the aging parent or loved one.

*Formal Caregiving:* nurse aids, personal assistants, and home care staff that provide hands-on care in both home and long term settings.

*Home Care Services:* assistance with daily activities and instrumentals activities of daily living in a person's home.

*Informal Caregiving:* Family members and non-paid care providers (including *friends, partners, and neighbors)* that commonly assist with the care of older relatives.

*Institutionalized Care:* providing care and services to older adults in hospitals, mental institutions or facilities.

*Long Term Care:* A wide range of health and personal care – from simple assisted living arrangements to intensive nursing home care – for elderly or disabled person(s).

*Mortality:* death; a measure of the rate of death from a disease within a given population.

*National Family Caregivers Support Program of 2000:* requires state and area agencies on aging to provide services to support family caregivers.

*Role Demands/Strain:* the duties and expectations required as a caregiver, oftentimes leading to stress or tension due to multiple roles.

*Sandwich Generation:* a generation of people, usually comprised of middle aged women, who care for their aging parents while supporting their own children.

# Family Caregiving Responsibility

## Activities

### Reflection Journal

Have students write their personal feelings about long term care placement. What factors/variables would they need to consider when determining if it is time to place a loved one in a nursing care facility? Have them consider the following when exploring their personal feelings: family honor, obligation, finances, value, commitment to other life roles, childhood and current relationship with loved one, quality of life, and impact on family functioning.

### Debates

Assign students to either pro or con; each side is to come up with 5-6 reasons for/against the topic of whether or not family members should provide care. Have them additionally debate whether or not established family caregivers should be financially compensated. Use attached literature review to guide them in their activity.

One method of conducting a debate is to have the pro side give a 5 minute position statement, then allow the con side a 3 minute rebuttal to the pro side's statement. Lastly, the pro side gets a 3 minute rebuttal to that. Repeat for the con side.

### *Complaints of a Dutiful Daughter*

Show this film in class. Have students break up into small groups of 4-5 students and discuss the caregiving/financial compensation issue as described above.

### Case Study

*Carolyn is a married 44 year old woman with two young children. She works full time as a recreational therapist. Recently, her mom (aged 74) was diagnosed with Alzheimer's disease. Carolyn is concerned for her mom's well being and is beginning to think that her mom should no longer live independently. Her mom lives over an hour away. Carolyn is not sure if she should hire a care manager, move her mom into an assisted living facility or have her mom move in with her family.*

Using the above case study, have students generate solutions to the strain often associated with family caregiving. Next, have students create/share their own examples or scenarios of different types of caregiving families and related challenges.

### Caregiver Resource List

Have students work individually or in dyads to find 10 local resources that can assist family caregivers. Have them begin with the National Family Support Program

of 2000. Students should then compile a summary of the key findings (e.g. name the resource, eligibility criteria, information about accessing the service).

## Caregiver Interview

As a class, come up with 10-15 pertinent questions for family caregivers. Then have each student interview a family caregiver.

## Drafting Caregiver Legislation

To begin, have students learn more about the Family and Medical Leave Act and other related legislature. Then, working in small groups, have students draft new proposed legislation regarding supporting family caregivers and increasing resources. To assist them, visit www.4csl.org, the California Senior Legislature, where you can view examples of current proposals. Further, students can write their local congress person:

> In Long Beach, visit Alan Lowenthal, Senator, 27th District at http://dist27.casen.govoffice.com/ or Betty Karnette, Assembly Member, 54th District at http://democrats.assembly.ca.gov/members/a54/.
> For other districts/states you can visit: http://*insertyourstate*.gov such as http://idaho.gov
>
> *The California Channel*
> http://www.calchannel.com
> The California Channel contains links to streaming video of the governor, CA Assembly and Senate committee meetings, and related policy news.

Students can also visit:

> *The California State Capitol Museum*
> http://www.capitolmuseum.ca.gov
> This site allows the viewer to take a virtual tour of the California state capitol in Sacramento. The Legislation link allows the user to research historical California legislation.

# Family Caregiving Responsibility

## Suggested Resources

<u>Films</u>

*Big Mama* (2000)
California Newsreel, 35 minutes, $195 VHS
This Academy Award-winning documentary is about Viola Dees, age 89, also known as Big Mama, who cares for her 12-year-old grandson, Walter, whose parents are absent. But is she the best person to raise him?

*Grandparents Raising Grandchildren* (2000)
Fanlight Productions, 22 minutes, $179 VHS
This film profiles three grandparents who are the primary caregivers for their grandchildren.

*Breaking Point* (1995)
Wise Owl Productions, Inc., 22 minutes, $110 VHS/DVD
This provocative video documents the story of Nancy, a formerly abusive daughter, as she talks candidly about her repeated abuse of her invalid mother.

*Complaints of a Dutiful Daughter* (1994)
Women Make Movies, 44 minutes, Order No. W99297
With profound insight and a healthy dose of levity, COMPLAINTS OF A DUTIFUL DAUGHTER chronicles the various stages of a mother's Alzheimer's Disease and the evolution of a daughter's response to the illness.

*Elder Abuse* (2002)
Insight Media, 27 minutes, $299 VHS
This film describes various types of elder abuse and details characteristics of abusers. It identifies barriers to getting help and discusses social, cultural and medical factors. It covers the prevention of abuse, treatment of elders who have been abused, and services designed to prevent abuse.

*If These Walls Could Talk 2* (2000)
HBO, 98 minutes (complete film with 3 stories), $9.97 DVD
When Abby dies of a stroke, her surviving partner of 50 years, Edith, must silently face heartbreak and the denial of her status as “family” by the hospital and Abby’s heirs.

*My Mother, My Father: Seven Years Later* (1991)
Terra Nova Films, 42 minutes, $145 VHS
This film presents a sequel to *My Mother, My Father* and updates viewers on the lives of four caregivers as they care for their aging parents.

*When Help Was There: Four Stories of Elder Abuse* (2000)

Fanlight Productions, 19 minutes, $169 VHS/DVD
This film presents four ethnically diverse case studies of elder abuse.

*When the Day Comes…Women as Caregivers* (1991)
Filmmakers Library, 28 minutes, $295 VHS/DVD
This film presents the stories of four women who have served as primary caregivers for loved ones and who discuss the benefits and burdens of caregiving. The caregivers are as in need of social support as those they care for.

*Thou Shalt Honour* (2002)
*PBS (*http://www.pbs.org/thoushalthonor/about/index.html*)*
A documentary interviewing citizens and Washington lawmakers on issues that have daily impact on family caregivers and their loved ones.

Websites
*Area Agency on Aging*
http://www.n4a.org/
The National Association of Area Agencies on Aging (n4a) is the umbrella organization for the 655 area agencies on aging (AAAs) and more than 230 Title VI Native American aging programs in the U.S. Through its presence in Washington, D.C., n4a advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans. The fundamental mission of the AAAs and Title VI programs is to provide services which make it possible for older individuals to remain in their home, thereby preserving their independence and dignity. These agencies coordinate and support a wide range of home- and community-based services, including information and referral, home-delivered and congregate meals, transportation, employment services, senior centers, adult day care and a long-term care ombudsman program.

*Alzheimer's Association*
http://www.alz.org/index.asp
The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Their goal is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. They provide information, education and support

*The Commonwealth Fund*
http://www.commonwealthfund.org/usr_doc/Mead_racialethnicdisparities_chartbook_1111.pdf
This site contains the Racial and Ethnic Disparities in U.S. Healthcare: A Chartbook. The goal of the chartbook is to create an easily accessible resource that can help

policy makers, teachers, researchers, and practitioners begin to understand disparities in their communities and to formulate solutions.

*California Policy Research Center*
http://www.ucop.edu/cprc/
The California Policy Research Center (CPRC) commissions timely research on public policy issues that affect California.

*Eldercare Locator*
http://www.eldercare.gov/Eldercare/Public/Home.asp
A public service of the U.S. Administration on Aging. The Eldercare Locator is the first step to finding resources for older adults in any U.S. community.

*Grandparenting*
http://www.aarp.org/life/grandparents
This page of the AARP site contains information about grandparenting and the role of grandparents and other relatives raising grandchildren in the family.

*Family Caregiving Alliance*
http://www.caregiver.org/caregiver/jsp/home.jsp
Founded in 1977, Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA now offers programs at national, state and local levels to support and sustain caregivers.

*National Alliance for Caregiving*
http://www.caregiving.org
The NAC site provides a report on caregiving in the U.S. and information on caregiving.

*National Association of Geriatric Care Managers*
http://www.caremanager.org/
A volunteer nonprofit association with over 2,000 members and is governed by a 20-member Board of Directors, who are elected to two-year terms and represent a diversity in practices and geographic location. Their focus is to advance professional geriatric care management through education, collaboration, and leadership.

*National Center on Elder Abuse*
http://www.elderabusecenter.org
The NCEA's site provides information, statistics and laws about elder abuse, serving as a clearinghouse for information on this topic.

*National Academy on an Aging Society*
http://www.agingsociety.org/agingsociety/

This website is a non-partisan public policy academy that actively conducts and compiles research on issues related to population aging and provides information to the public, the press, policymakers, and the academic community.

*National Family Caregiver Support Program (NFCS) Resource Room*
http://www.aoa.dhhs.gov/prof/aoaprog/caregiver/carefam/carefam.asp
This page of the U.S. Department of Health and Human Services' site provides elders and caregivers with key information about the NFCS legislation and ways to access support resources.

Additional Resources


American Association of Retired Persons (AARP) (1997). Family caregiving in the US: Findings from a national survey. Bethesda, MD.

Blaser, J. C. (1998). Paid and family caregiving: A practical and ethical consideration. *Generations, 22*, 65-69.

Kane, R. & Penrod, J. D. (1995). *Family caregiving in an aging society: Policy Perspectives*, Vol. 5. Sage Publications, CA.

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Hooyman, N.R. & Kiyak, H.A. (2008). *Social gerontology: A multidisciplinary perspective.* Boston: Pearson A&B.

Moody, H. R. (2006). *Aging: Concepts & Controversies*. Thousand Oaks, CA: Pine Forge Press.

Raschick, M. & Ingersoll-Dayton, B. (2004). Costs and rewards of caregiving among aging spouses and adult children. *Family Relations, 53,* 317-325.

# Euthanasia & Assisted Suicide

## Summary/Literature Overview

While modern medicine and advanced technology have increased our life expectancy, there is much discussion as to the quality of that extended life. In the last 100 years, cause of death has moved from acute, short-term illness such as pneumonia to prolonged chronic illness, such as heart disease. Additionally, medical advances have increasingly placed into our control the timing of death, whether or not we desire to have that choice. For example, feeding tubes and life support are options that may prolong a life, but certainly complicate matters when the prolonged life creates financial and emotional burden to others.

One of the earliest cases regarding an individual's "right to die" was Karen Ann Quinlan (1976), aged 21 and in a coma, whose parents requested that her life support be discontinued. The medical staff of the hospital denied the request and it took a ruling from the New Jersey Supreme Court to allow the disconnection of the mechanical respirator. Karen lived her remaining nine years in a nursing home with the assistance of feeding tubes and antibiotics.

One of the most recent cases (1995) involved Terry Schaivo, who was in a persistent vegetative state since 1990. Her husband requested that the feeding tube sustaining Terry be removed and Terry's parents disagreed with the request. She had not completed an advance directive. However, the court decision was based on testimony from Terry's friends that she had commented that she would not want to live on any kind of life support. Terry lived 13 days after the feeding tube was disconnected.

These court cases exemplify how difficult and complex decisions regarding right to die can be. To make matters more complicated, there are varying levels of assisting an individual with their dying process. Passive euthanasia involves allowing a person to die due to withholding or withdrawing treatment. It is often described as allowing nature to take its course. Assisted suicide typically involves a medical professional providing an individual with the means to end his or her life, but the individual him or herself must administer the fatal dose. Active euthanasia involves a deliberate act to end a person's life. Active euthanasia can be voluntary (the individual asks for assistance), nonvoluntary (the individual is not able to ask for assistance but the request is assumed), or involuntary (the individual has not asked for assistance).

Advance directives are documents that allow an individual to express his or her wishes regarding the dying process in writing. They are helpful in the event that the person is no longer able to communicate his or her wishes. Advance directives also allow individuals to designate another person to make health care decisions on their behalf. In the court cases mentioned earlier, the completion of an advance directive

would have allowed the parties involved to make an informed choice as to the best course of action for the individual receiving life-sustaining treatment. Unfortunately, the rate of completion of advance directives is quite low.

# Euthanasia & Assisted Suicide
## Powerpoint Presentation

**Ethical Challenges in Gerontology: Euthanasia & Assisted Suicide**

**Maria Claver, PhD, MSW**
**Melanie Horn Mallers, PhD**
**Department of Family & Consumer Sciences – Gerontology Program**

**Factors contributing to longer life**

- Modern medicine
- Advanced health technology: Life support, feeding tubes
- Cause of death: acute -> chronic

## “Right to Die”

- Landmark case (1975): Karen Ann Quinlan
  - Age 21
  - Comatose in hospital, mechanical respirator
  - Parents requested disconnection
  - Medical staff denied request
  - New Jersey Supreme Court ruled that respirator could be discontinued
  - Karen died in a nursing home at age 31 with dignity

## “Right to Die”

- US Supreme Court Case – Nancy Beth Cruzan (1990)
  - Injured in auto accident, 25 years old
  - Persistent vegetative state
  - Physicians implanted feeding tubes, could sustain her for 30 years
  - Parents requested removal of feeding tube
  - Supreme Court ruling: only patient can refuse unwanted treatment
  - Follow up: Friends testified as to Nancy’s wish not to live like a vegetable, permission granted to remove tube
  - Nancy died 13 days later

# "Right to Die"

- Terri Schiavo – (2005)
  - In persistent vegetative state since 1990
  - Husband wanted to disconnect feeding tube
  - Parents did not want discontinuation of tube
  - No advanced directive
  - Decision based on few comments by Terri in her 20s
  - Feeding tube disconnected. After 13 days, Terri died March 31, 2005

# Passive Euthanasia

- Allowing to die
- Withholding or withdrawing treatment
- Allowing nature to take its course?

# Active Euthanasia

- Deliberate act to end patient's life by another person
- Involuntary – Individual has not asked for assistance
- Voluntary – Individual asks for assistance
- Nonvoluntary – Individual not able to ask for assistance but request is assumed

# U.S. Laws RE: Active Euthanasia

- In the U.S. voluntary active euthanasia is against the law (patient requests that another person ends the patient's life)
- Physician-assisted suicide (physican provides means to patient, who administers lethal means) is against law in all states except Oregon.

## Death with Dignity Act

- Passed by Oregon voters in 1994
- Reaffirmed (after judicial challenge) in 1997
- Allows physicians to prescribe lethal medication to terminally ill patients
- In first 5 years, 129 patients died by PAS

## Advance Directives

- Documents allow individual to express wishes
- Allow designation of a healthcare proxy
- Used in case individual cannot communicate
- Rate of completion low

# Euthanasia & Assisted Suicide

## Learning Objectives

The discussion topics and activities are listed here to demonstrate the connection of each with its corresponding course goal. Further detail about these discussion topics and activities will be provided in subsequent sections.

*After completing the Euthanasia & Assisted Suicide Module, the student should be able to:*

| **Objective** | **Discussion Topic** | **Activity** |
|---|---|---|
| Explore your own attitudes about death and the meaning of death | What happens to us after we die?<br><br>Which questions from the Attitudes about Death Questionnaire were most difficult to answer?<br><br>What do you want people to remember about you when you are no longer living? | Writing activity: If I had 6 months left to live…<br><br>Attitudes about Death Questionnaire<br><br>Write your own obituary<br><br>Personal Meaning Grid |
| Identify the role of media's portrayal of death and the influence of Western attitude about death | How do the media influence our beliefs and attitudes about death?<br><br>How do you feel about the portrayal of death in media? | Find a TV show, film, commercial, greeting card or children's book that contains the concept of death and present it to the class |
| Explore the concept of the right to die and understand life sustaining technologies | Should a person have the right to choose when to die?<br><br>Who should have decided Terry Schiavo's fate: her husband or her parents?<br><br>What should be required of a person who requests euthanasia? | Read current legislature and summarize the goal of the policy.<br><br>Court cases: Terry Schiavo, Nancy Cruzan<br><br>Oregon's Death with Dignity Act |

| | | Around the Room Debate |
|---|---|---|
| Understand the significance of advance directives and barriers to their use | Why are advance directives important? How can we increase their completion and usage? | Write own advance directive using Five Wishes form |
| Cultural variations regarding dying, death and bereavement | How does culture influence our bereavement, mourning and grief rituals? | Group presentation of a culture's death rituals using role play, music, props, based on the literature |

# Euthanasia & Assisted Suicide
## Key Terms

*Active Euthanasia*: positive steps to hasten someone else's death, such as administering a lethal injection; assisted suicide, perhaps by a physician or nurse

*Advance Directive*: documents such as living wills, wills, and durable power of attorney for health care decisions that outline actions to be taken when an individual is no longer able to do so, often because of irreversible illness

*Assisted Suicide*: providing an individual with the means to end his or her own life

*Bioethics*: discipline dealing with procedural approaches to questions about death, dying and medical decision making

*Conservator*: person designated by a court to manage the affairs, either personal or financial or both, of persons unable to do so for themselves

*Death with Dignity*: dying when one still has some independence and control over decisions about life

*Durable Power of Attorney*: legal document that conveys to another person designated by the person signing the document the right to make decisions regarding either health and personal care or assets and income, or both, of the person giving the power; it is a durable power that does not expire, as a power of attorney normally does, when a person becomes incompetent

*Dying Process*: stages as advanced by Kubler-Ross; five stages experienced by the dying person; 1) denial and isolation, 2) anger and resentment, 3) bargaining and an attempt to postpone, 4) depression and a sense of loss, and 5) acceptance

*Euthanasia*: the act or practice of killing (active euthanasia) or permitting the death of (passive euthanasia) hopelessly sick or injured individuals in a relatively painless way; mercy killing

*Hospice*: a place or a program of care for dying persons that gives emphasis to personal dignity of the dying person, reducing pain, sources of anxiety, and family reconciliation when indicated

*Medical Power or Attorney*: similar to "durable power of attorney," but focuses on a health care surrogate to make decisions about medical care

*Passive Euthanasia*: voluntary elective death through the withdrawal of life-sustaining treatments or failure to treat life-threatening conditions

*Patient Self-Determination Act*: federal law requiring that health care facilities inform their patients about their rights to decide how they want to live or die; for example, by providing them information on refusing treatment and on filing advance directives

*Right to Die*: the belief that persons have the right to take their own lives, especially if they experience untreatable pain, often accompanied by the belief that persons have a right to physician assistance in the dying process

# Euthanasia & Assisted Suicide
## Activities

### If I Had Six Months Left To Live….
If you knew you had only one month to live, how would you spend it? Would you live differently from now? Are there things you'd feel an urgency to do?

### Attitudes about Death Questionnaire
The Attitudes about Death Questionnaire is a multiple choice survey that allows the student to explore one's perspective about death-related topics such as: personal experiences with death, life after death, terminal illness, suicide and funerals. "You and Death: A Questionnaire" by Edwin S. Shneidman et al., published in *Psychology Today* (August 1970).

### Write Your Own Obituary
Find an obituary in the newspaper as an example. Write your own obituary, including facts you would like others to know about you.

### Personal Meaning Grid
For this activity, students are asked to create a grid with four columns and four rows. Have students label each column with the following headings: **People**, **Roles, Things** and **Activities**. Under the *people* column, have them write down 4 people who provide meaning/who they feel emotionally connected to. Under the *roles* column, have them list 4 meaningful roles that they occupy (such as daughter, student, wife, mom, etc). For *things*, have them list 4 items that are important to them. And finally, under the activities column, have student's list hobbies and actions/behaviors that give their life meaning (such as reading, hiking, playing with children, etc). Throughout your lecture on death and dying, have students cross off one or two boxes. By the end of lecture, one box should remain. This activity is intended to get students to begin to reflect on what they hold dear and what gives their life value, as well as serve as motivation to find meaning in life and not take for granted people and experiences.

### Media Search
Have students find a TV show, film, commercial, greeting card or children's book that contains the concept of death (or provide some examples to students) and address the following questions: What was the plot or story? Which character(s) died? How did the character(s) die? How was death determined? What were the survivors' reactions to death? Was there a funeral ritual or commemoration of the

death? If children were depicted in the story, how were they told about the death, and what were their reactions? What portion of the program content included issues of cultural diversity in dying, death or grief? Were the characters that died mentioned again? In what manner or context? What did this program teach viewers about death? How could the presentation of death-related actions or topics have been improved?

## Legislative Summary

Read current legislature and summarize the goal of the policy (e.g., Oregon's Death with Dignity Act).

## Court Case Examination

Find information about landmark court cases (e.g., Terry Schiavo, Nancy Cruzan). Present key facts about the case to the class and discuss reactions to the court decision.

## Around the Room Debate

Post five signs around the room: Strongly Agree, Somewhat Agree, Not Sure/Neutral, Somewhat Disagree, Strongly Disagree. Read the following statement and ask students to stand under the sign that describes their opinion about the statement. Choose students to defend their position and let students know that they can move positions at any time during the conversation.

Statement: Individuals should have the right to choose when to die.

## Five Wishes Advance Directive

Access the Five Wishes advance directive form (www.fivewishes.org) and complete your own advance directive. Follow-up discussion: Which decisions were easiest to make? Which were most difficult?

## Culture Presentation about Death

Ask students to sign up for a cultural group (4-6 members per group) to focus on for this project (e.g., Native American, African/African-American, Mexican/Mexican-American, Buddhism, Judaism, Asian/Asian American/Pacific Islander). Each group will have 20 minutes total for presentation and Q&A. Group presentations should describe the death beliefs, rituals and traditions of their assigned cultural group. Successful presentations with provide handouts, audio/visual examples, role plays and overall creativity!

# Euthanasia & Assisted Suicide
## Suggested Resources

Films

*Care for the Dying (The Series)* (2000)
Terra Nova Films, 4 tapes, each tape 20-37 minutes, $159 single VHS/$499 four tape set
This four tape series explores the issues and decisions that older adults need to discuss and make as they approach the final stages of their life.

*Facing Death* (2002)
First Run Icarus Films, 57 minutes, $248 VHS
This remarkably intimate film was produced in 2002, when Kubler-Ross lived secluded in the desert and was awaiting, as she says, her own death, on the verge of the transition she researched so passionately.

*A Family Undertaking* (2003)
Fanlight Productions, 56 minutes, $229 VHS/$249 DVD
This video documentary explores the complex psychological, cultural, legal and financial issues surrounding an important and growing new trend: the home funeral movement.

*Full Circle* (1997)
Terra Nova Films, 29 minutes, $165 VHS
This film tells the story of a middle-aged woman bringing her elderly mother home to die.

*The Sea Inside* (2004)
New Line Cinema, $19.95 DVD
Based on the profoundly moving true story, *The Sea Inside* is about Spaniard Ramon Sampedro, who fought a 30-year campaign to win the right to end his life with dignity.

*The Self-Made Man* (2006)
New Day Films, 57 minutes, $250 VHS/DVD (with extra features – 64 minutes)
This film, about a 77-year-old man diagnosed with a terminal disease who decides to take his own life, explores "rational suicide," the "right to die" and the difficult end-of-life choices faced by an aging population.

*To Live Until I Die* (1999)
Fanlight Productions, 56 minutes, $229 VHS
This film presents the lives of six terminally ill older adults in its exploration of living and dying.

Websites

*End of Life Choices (The Hemlock Foundation)*
http://www.hemlock.org
This site serves the Hemlock Foundation's home page and provides information on the organization and their work to promote "freedom of choice at the end of life."

*Aging with Dignity*
http://www.fivewishes.org
This site presents its Five Wishes advance directive, which addresses the personal, emotional and spiritual issues that people say matter most to them during times of serious illness.

*Hospice Foundation of America (HFA)*
http://www.hospicefoundation.org
This site defines and describes hospice as well as serving to announce HFA's teleconferences and other resources.

*The National Hospice and Palliative Care Organization (NHPCO)*
http://www.nhpco.org
The NHPCO site provides information on hospice, including statistics, answers to frequently asked questions, videos, and discussion of public policy.

Additional Resources

Crow, L. & Werth, J. L. (2005). An overview of end-of-life concerns. *Healthcare and Aging, 12*(4), 1, 6.

Dickinson, G. E. & Field, D. (2002). Teaching end-of-life issues: Current status in United Kingdom and United States medical schools. *American Journal of Hospice and Palliative Care, 19,* 181-186.

Gunter-Hunt, G., Mahoney, J. E., & Sieger, C. E. (2002). A comparison of state advance directive documents. *The Gerontologist, 42*(1), 51-60.

Hooyman, N.R. & Kiyak, H.A. (2008). *Social gerontology: A multidisciplinary perspective.* Boston: Pearson A&B.

Lambert, H. C., McColl, M. A., Gilbert, J., Wong, J., Murray, G. & Shortt, S. E. D. (2005). Factors affecting long-term-care residents' decision-making processes as they formulate advance directives. *The Gerontologist, 45*(5), 626-633.

Moody, H. R. (2006). *Aging: Concepts & Controversies*. Thousand Oaks, CA: Pine Forge Press.

Sofka, C. J. (2004). What kind of funeral? Identifying and resolving family conflicts. *Generations, Summer,* 21-25.

# Rationing Health Care

## Summary/Literature Overview

Health care costs for older Americans account for one-third of all national healthcare expenditures; a major portion going to Medicare. And the average expenditure for health care services for adults 65 and over is nearly four times the cost of those under 65 and increases more among the oldest old. As such, some predict a health care crisis in the near future. This crisis refers to the costs, the growing number of individuals who are uninsured, and the unknown status of the future of our health care system (Hooyman & Kiyak, 2008).

Policy makers and service providers have begun to entertain several possibilities for addressing the expected lack of resources. For example, cost-containment changes in private health care, such as managed care, are intended to slow down the rate of acute health care costs, because expenses are rising faster than the cost of living. Medicare and Medicaid spending (which comprises 26 percent of the federal budget) is expanding faster than the economic growth rate, adding to demands in policy movements for reform. Reform is especially critical given that individuals and their families continue to pay a significant amount out of pocket; in fact, older adults pay a higher proportion of their incomes on health care services than before Medicare and Medicaid were established (Federal Interagency Forum on Aging, 2006).

A number of factors underlie the growing health care costs. This includes improved modern medicine (resulting in increased utilization of health care providers as well as more sophisticated/expensive technologies and procedures) and prolonged life (causing a schism between a health care system oriented towards acute care and the increasing chronic care needs of older adults). Fortunately, a growing number of initiatives and possibilities are being proposed to offset such challenges in health care, including age-based programs (or programs only available to people of a certain age), specifically, rationing especially costly medical procedures (such as organ transplants).

Rationing health care may be accomplished in a variety of ways: ability to pay for the care, anticipated benefits of the care, waiting lists, or first-come first-served, and productivity to society or social worth. The latter is grounds for further controversy given that, at least in the United States, there is emphasis towards individual social value defined by financial productivity, as opposed to unpaid productivity via civic engagement, volunteerism and other unpaid contributions to society. Rationing health care on the basis of age is complicated given the larger questions of economics it raises*: If prolonging life is desirable, who will pay? Who will get access to expensive health care resources?* Interestingly, while people do not blame older adults for the rising costs of health care and would not withhold care based on age (Zwiebel, Cassel, & Karrison, 1993), other studies indicate that when people are

forced to decide who should be treated between children and older adults, most select the former.

Thus, though age-based rationing is not supported, people do tend to favor younger over older adults for treatment (Kuder & Roeder, 1995). Some, however, argue that chronological age is the best criterion to use (Callahan, 1994) because each of us has a natural life span that should be accepted. Callahan supports the notion set forth by Ellesiates 3:1-2 that states "To every thing there is a season, and a time to every purpose under the Heaven. A time to be born, and a time to die…"

From a pragmatic point of view, those in favor of rationing health care argue that it would be efficient to administer, older adults are less financially productive, and the benefit derived from medical care would be less for older adults than their younger counterparts. Furthermore, medical expenses to rise as people get older and health care spending is greatest among the oldest old. In addition, some argue that rationing health care eliminates all attempts to "do everything possible" which may decrease quality of life anyway. Overtreatment would no longer be a relevant issue.

However, there are also powerful reasons against rationing health care that need to be considered. First, the older adult population is highly diverse in functional level and health status. Age, once these factors are considered, is really a mere number with little relevance to quality of life, longevity and risk of morbidity. On a related note, we must also consider vitalism--that everyone is morally entitled to unlimited longevity and good health. Further**,** a policy of withholding treatments from members of a social group involves elements of discrimination, both of which would intrude on the doctor-patient relationship, undermine the autonomy of elderly patients, and invoke the slippery slope towards involuntary forms of euthanasia.

From a sole economic perspective, opponents point out that even if age were used as a criterion, what age do you select? If the age was raised from 65 to 70, this would still only result in less than a 15 percent reduction in Medicare costs. McKusick (1990) argues that more significant changes need to be considered given the financial crises our health system faces. Furthermore, opponents point out that health care costs are not solely due to longevity; other factors, such as increased utilization, new medical technologies, general inflation, and fraud, waste and abuse are factors and need to be addressed first. On this note, others argue that even after the above costs are eliminated, rationing health care may still be unavoidable given the impact of the population aging along with technological innovation (Schwartz, 1987).

# Rationing Health Care
## Powerpoint Presentation

# Rationing Health Care

**Maria Claver, PhD, MSW**
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**Department of Family & Consumer Sciences**
**Gerontology Program**

## Health Care Costs

- Health care costs for older Americans account for one third of all national healthcare expenditures
- Average expenditure for health care services for adults 65+ is nearly four times the cost of those under 65 and increases more among the oldest old.

## Health Care Crisis

Health care professionals/analysts predict health care crisis due to:

- Costs of Health Care
- Growing number of uninsured individuals
- Unknown status of the future of our health care system

Relevant factors:

-Expenses are rising faster than the cost of living

-Medicare/Medicaid spending (26% of the federal budget) expanding faster than economic growth rate

-Individuals and their families continue to pay a significant amount out of pocket

## Factors Contributing to Health Care Costs

- *Improved modern medicine*→ increased use of health care providers and more sophisticated/expensive technologies and procedures)
- *Prolonged life*→ causing a schism between health care system oriented towards acute care and the increasing chronic care needs of older adults.

## Possible Solution: Rationing Health Care Costs by Age

The Issue: Demand for health care is nearly limitless, but funds are finite. How do we decide which patients get expensive treatments and which do not?

- Age-based programs: programs only available to people of a certain age.
- Rationing health care: reducing health care resources, access and opportunities.

## Rationing Health Care

Rationing health care methods:

- ability to pay for the care
- anticipated benefits of the care
- waiting lists
- first-come first-served
- productivity to society or social worth

## The Controversy

- If prolonging life is desirable, who will pay?
- Who will get access to expensive health care resources?
- Do you support rationing health care based on age?
- CASE STUDY: 5 yr. old vs. 75 yr. old

## Proponents

- Chronological age best criterion to use
- Natural life span should be accepted
- Efficient to administer
- Older adults are less financially productive
- Benefit of medical care would be less for older adults than their younger counterparts.

## Proponents, cont’d

- Rationing health care may unavoidable given the impact of the population aging along with technological innovation.
- Medical expenses rise towards the end of life.
- Overtreatment occurs
- “Doing everything possible” decreases quality of life anyway.

## Opponents

- Older adult population highly diverse in functional level and health status.
- Raising age is irrelevant: if the age was raised from 65 to 70 = less than a 15% reduction in Medicare costs. More significant changes need to be considered given the financial crises our health system faces.
- Health care costs not solely due to longevity; consider increased utilization, new medical technologies, general inflation, fraud, waste and abuse.

# Opponents, cont'd

- Vitalism--everyone morally entitled to unlimited longevity and good health.
- Older adults are to be cared for; deserve dignity
- Discrimination/Ageism
- Intrusion on the doctor-patient relationship
- Undermines the autonomy of elderly patients
- Invoke the slippery slope towards involuntary forms of euthanasia.

# Rationing Health Care
## Learning Objectives

The discussion topics and activities are listed here to demonstrate the connection of each with its corresponding course goal. Further detail about these discussion topics and activities will be provided in subsequent sections.

*After completing the Rationing Health Care Module, the student should be able to:*

| Objective | Discussion Topic | Activity |
|---|---|---|
| Financing long term health care | Who is responsible for financing long term health care? The private sector? The government? | Role play activity: You are a lawyer… |
| Discrimination toward the poor/elderly regarding health care accessibility | How does health care accessibility differ for older adults versus younger adults, men versus women and between members of various ethnic groups?<br><br>Is age-based rationing a form of discrimination? | Examine health care disparity charts and describe the trends in health care access. |
| Understand the role of policy in the allocation of health care resources | What role does (should) policy play in determining access to health care? | Summarize a current piece of legislation regarding health care and contact legislator about the bill |
| Life sustaining technologies and medications | Should there be an upper age limit for costly health care procedures such as organ transplants?<br><br>Should medications be withheld from older adults even if they are proven to prolong life regardless of the increased cost of caring for a seriously ill older adult? | Case study: Who gets the health services |
| Quality of life | What constitutes quality | Determine at what age |

| | | |
|---|---|---|
| | of life? | rationing should occur. What issues should be considered? Type of care? Quality of life after the health care technology/medication? |
| The role of public knowledge and opinion in rationing health care | Should rationing be public knowledge? | Pretend you are a journalist. Write up an interview… |

# Rationing Health Care
## Key Terms

*Activities of Daily Living*: summary of an individual's performance in personal care tasks such as bathing or dressing, as well as such home-management activities as shopping, meal preparation and taking medications

*Acute Conditions:* short-term disease or temporary conditions, such as infections or the common cold, which are often debilitating to older persons.

*Age-Based Programs:* services that provide resources or care based on a specified age criteria.

*Age-Based Rationing:* method for limiting health care resources or access to health care services using age as a criterion.

*Ageism:* stereotypes about or prejudices towards old age/people;

*Capitation:* A method of payment for health care services in which the provider accepts a fixed amount of payment per subscriber per period of time, in return for providing specified services.

*Chronic Condition*: long-term (more than three months), often permanent, and leaving a residual disability that may require long-term management or care rather than cure

*Consumer-Directed Care:* Consumer-directed services are a way of thinking about and providing services that assumes caregivers have the right and ability to determine what they need, how their needs will be met and by whom, as well as, judge the quality of the services they receive.

*Cost benefit analysis:* a decision-making technique to develop quantitative information on how to allocate resources

*Cost effective analysis:* Cost-effectiveness analysis is a specific type of economic analysis in which all costs are related to a single, common effect. Decision makers can use it to compare different resource allocation options in like terms

*Disability*:  impairment in the ability to complete multiple daily tasks

*Discrimination:* unfair treatment of a person or group on the basis of prejudice, in this case due to age.

*Good Health*: more than the mere absence of infirmity, a state of complete physical, mental, and social well-being

*Health Status*: the presence or absence of disease as well as the degree of disability in an individual's level of functioning

*Health Maintenance Organizations (HMOs):* A state-licensed health maintenance organization that delivers physician and hospital services to members directly or through contracts with affiliated providers. The plan requires members to choose a network provider (a primary care physician) to coordinate their health care.

*Instrumental Activities of Daily Living*: daily activities involving the use of the environment

*Quality of Life*: going beyond health status alone, this concept considers the individual's sense of competence, ability to perform activities of daily living, and satisfaction with social interactions, in addition to functional health.

*Long-term Care:* A wide range of health and personal care – from simple assisted living arrangements to intensive nursing home care – for elderly or disabled person(s).

*Managed Care:* a health plan in which Medicare beneficiaries receive care from a network of providers employed by, or under contract to, an HMO.

*Medicare:* Health insurance for people age 65 or older, under age 65 with certain disabilities, and any age with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a kidney transplant). It is covered under the United States federal government program, via the Social Security Act. It has four parts: Hospital Insurance (Part A), Supplementary Medical Insurance (Part B), Medicare Advantage Plans (Part C), Prescription Drug Coverage (Part D).

*Medicaid:* Government-funded program in the United States that provides medical expense coverage for eligible people under age 65 who are indigent and meet certain other criteria.

*Medigap:* Health insurance in the US that is intended to supplement Medicare benefits and presumably to fill the gaps in healthcare coverage.

*Need-Based (or Means Based) Entitlement Programs:* social programs delivered to persons who meet defined criteria of eligibility based on economic need or ability to pay for the benefits.

*Oldest-old:* people 85 and older.

*Science of Scarcity:* a prime factor in the rationing debate is economics; due to lack of resources in the past, impetus has been made to make way for the young.

*Spend Down:* The amount of health care costs an individual must incur in order to qualify for Medicaid. That amount is determined on a case-by-case basis; results in older adults who "spend down" or decreased their financial worth by reducing their income and other resources.

*Two-Tiered System of Health:* notion that two forms of health care systems exist; one for those with private health care insurance or with the means to pay for expensive medical treatment, and one for those forced to rely on Medicaid or Veterans' assistance.

*Vitalism:* everyone is morally entitled to unlimited longevity and good health.

# Rationing Health Care
## Activities

### You are a Lawyer
You are an attorney and your client believes she has not been given health care because of her age. Make a case for or against this situation to present to a "jury."

### Health Care Disparity Chart Examination
Using the Racial and Ethnic Disparities in U.S. Health Care: A Chartbook (www.commonwealthfund.org/usr_doc/Mead_racialethnicdisparities_chartbook_1111.pdf, have students break into small groups. Each small group should come up with 5 key findings from each of the chartbook's six chapters. The key findings should represent meaningful facts about health care disparity. A second activity using this resource could be to have students create mini prevention plans utilizing the strategies for closing the gap (last chapter) to offset disparities.

### Summarize Legislation
Have students find recently passed legislation or policy. Summarize the goal of the policy, what problem it aims to alleviate and analyze how well the policy will address the issue.

### Case Study: Who Gets the Health Services?
Separate the class into small groups and give each group the following list of possible health care recipients. The small group must come to a consensus as to who most deserves the limited resources and rank the potential recipients from most deserving to least deserving:

-10 year old child with asthma needing costly and on-going medications
-45 year old woman with spinal cord injury needing medical equipment
-75 year old marathon runner needing hip replacement
-90 year old man with cancer needing radiation treatment

### Pretend You Are a Journalist
Pretend you are a journalist whose assignment is to interview a medical professional who has had to make the decision described above in the case study activity. How much information should be given to the public and the health care recipient's family as to how the decision was made to grant the health care resources?

# Rationing Health Care
## Suggested Resources

Films

*Can't Afford to Grow Old* (1990)
Filmmakers Library, 55 minutes, $295 VHS/DVD
This analysis of the impact of the aging of America on our strained health-care system combines poignant human stories with informed testimony by lawmakers and public policy experts. The debate centers around whether the government or the private sector should ultimately pay for long-term care. We are shown innovating programs, one private and one publicly funded, that give seniors some options as they experience frailty in old age.

*Medicine at the Crossroads* (1993)
Terra Nova Films, 60 minutes, $95 VHS
This film profiles the health care systems in India, Ireland, and Arizona to illustrate how social and cultural forces influence health care systems.

*Who Cares: Chronic Illness in America* (2001)
Films for the Humanities and Sciences, 57 minutes, $129.95 VHS/DVD
This film is a Fred Friendly Seminar which discusses the limitations of the health care system, especially as it pertains to chronic illnesses.

Websites

*Office for the Study of Aging*
http://www.sph.sc.edu/osa/programs_consumer.html
Consumer-Directed Care is part of a culture change in long-term care. Consumer Direction is the wave of the future. In the upcoming decades, aging individuals will be more educated and will desire more input and control in their healthcare and long-term care services. One of OSA's leading efforts in promoting culture change in long-term care is training staff in the philosophical shift from case management to facilitation.

*Federal Interagency Forum on Aging*
http://www.agingstats.gov/agingstatsdotnet/main_site/default.aspx
A website that provides data from numerous agencies including the Administration on Aging, Agency for Healthcare Research and Quality, Bureau of Labor Statistics, Census Bureau, Center for Medicare & Medicaid Service, Department of Housing & Urban Development and more.

*International Federations on Aging*
*http://www.ifa-fiv.org/en/accueil.aspx*
This website is a membership based network of organizations, bodies and individuals with a mission to improve the quality of the lives of older people around

the world through policy change, grassroots partnerships and strengthening bridges between public and private sectors concerned with ageing issues.

*Medicaid*
http://www.cms.hhs.gov/home/medicaid.asp
Provides information on government-funded program in the United States that provides medical expense coverage for eligible people under age 65 who are indigent and meet certain other criteria.

*National Academy on Aging*
http://www.agingsociety.org/agingsociety/
As a non-partisan public policy institute, the Academy actively conducts and compiles research on issues related to population aging and provides information to the public, the press, policymakers, and the academic community.

*National Association of Area Agencies on Aging*
http://www.n4a.org/
The National Association of Area Agencies on Aging (n4a) is the umbrella organization for the 655 area agencies on aging (AAAs) and more than 230 Title VI Native American aging programs in the U.S. Through its presence in Washington, D.C., n4a advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans. The fundamental mission of the AAAs and Title VI programs is to provide services which make it possible for older individuals to remain in their home, thereby preserving their independence and dignity. These agencies coordinate and support a wide range of home- and community-based services, including information and referral, home-delivered and congregate meals, transportation, employment services, senior centers, adult day care and a long-term care ombudsman program.

*National Center for Policy Analysis*
http://www.ncpa.org/
The National Center for Policy Analysis (NCPA) is a nonprofit, nonpartisan public policy research organization, established in 1983. The NCPA's goal is to develop and promote private alternatives to government regulation and control, solving problems by relying on the strength of the competitive, entrepreneurial private sector. Topics include reforms in health care, taxes, Social Security, welfare, criminal justice, education and environmental regulation

*Rough and Tumble: A Snapshot of CA Public Policy and Politics*
http://www.rtumble.com
This site features a variety of current newspaper articles about policy issues ranging from upcoming elections to hot topics of the day.

*Social Security Administration*
http://www.ssa.gov/
The official website of the US Social Security Administration.

Additional Resources

Fact sheets from the Consumer Directed Resources. U.S. Department of Health and Human Services Administration on Aging National Family Caregiver Support Program Resources on Consumer Directed Resources accessible at:
http://www.aoa.gov/press/nfc_month/2004/fact_sheets/Fact%20Sheet%20-%20Consumer%20Directed%20Care1.pdf

Excerpted report (1992) by John Goodman and Gerald Musgrave on *Patient Power.* Washington DC: Cato Institute
http://www.ncpa.org/w/w50.html

Policy Brief (December, 2005) from the Brookings Institute, #147, *Health Care Rationing*: What it Means, by Henry J. Aaron.
http://www3.brookings.edu/comm/policybriefs/pb147.pdf

Article (2008) by Health Care Policy: Does ageism affect health care rationing?
http://www.healthandage.com/html/res/healthpolicy/content/page3.htm

Binstock, R.H. & Post, S. (1991). *Too old for health care? Controversies in medicine, law, economics and ethics.* Baltimore: John Hopkins: University Press.

Callahan, D. (1987). Setting *limits: Medical goals in an aging society.* New York: Simon & Schuster.

Hackler, C. (1994). *Health care for an aging population*. Albany: Suny Press.

Hooyman, N. R. & Kiyak, H. A. (2008). *Social gerontology: A multidisciplinary perspective.* Boston: Pearson A&B.

Moody, H. R. (2006). *Aging: Concepts & Controversies.* Thousand Oaks, CA: Pine Forge Press.

Smeeding, T. M. (1987). *Should medical care be rationed by age?* Totawa, NJ: Rowman & Littlefield.