



## Ethics & Values in Aging & LTC

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### What Will be Covered

- Framework for recognizing & addressing ethical issues in aging services/LTC/LTSS\*
  - definitions, principles, litmus test of an ethical issue
- Common ethical dilemmas in aging services and LTC/LTSS
- How “research” is done in Ethics and Aging
- Identifying & working within consumer values & preferences
- Big ticket topics:
  - Ageism
  - Safety Versus Freedom & Managed Risk contracting
- Possibilities for practitioners
- Resources

\*LTSS stands for Long-term Supportive Services, sometimes called Long-Term Services and Supports. It is my preferred term, and I use it interchangeably with LTC in this presentation.



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### What Will not be Discussed

- Advance directives, living wills, issues on withholding or stopping treatments at end-of-life, or assisted suicide.
- Why not?
  - These are important but well covered topics
  - Little recent work on ethics in aging
  - My focus is how ethical issues are intertwined with the everyday lives of consumers and workers in Aging Services & LTC/LTSS

### Defining an Ethical Issue

- A situation or decision when you are uncertain about what is right to do from a moral or ethics standpoint.
  - Not the same as what is right (correct) based on evidence of effective practice or other outcome
  - Not same as practitioners practicing ethically
  - Involves “ought” or “should”
  - Often involves competing considerations
  - Usually there is no single correct solution



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### Ethical Issues May be Mis-specified

- Some “ethical dilemmas” may really be improper practices not a dilemma
  - Not telling an older person that his/her trip to a NF or AL is meant to be one-way
  - Communication with family members—and then (if they think it best) with the older person
- These are not dilemmas but unfortunate events
  - Can raise dilemmas for those who must deal with such events after-the-fact
- Sometimes ethical issues not recognized
  - Practitioners may say they had 0 ethical issues in a time period

### Frequently Encountered Ethical Issues

- Uncertainty about what should be done because:
  - Conflict among interests and well-being of consumer and various family members
  - Conflicts among interest and well-being among family members
  - Your own internal conflict about what might be best for consumer and family because of competing “good.”
- Issue about confidentiality and sharing information.
- Organization policies/practices raising ethical issues.
- Public policies raising ethical issues.

People who first don't recognize any ethical issues easily generate examples once asked about issues related to the topics listed above.

### From Bioethics 101

- Principles
  - Respect for the autonomy of persons
  - Beneficence (non-maleficence)—do good (do no harm)
  - Justice
  - Fidelity?
- Virtue Ethics
  - Virtues of older person
    - Gets to responsibilities not just rights
  - Virtues of professional, case manager, or other roles
- Procedural vs substantive
- Ethics vs law

### Aging and Autonomy, unpacked

- Definition of respect for persons
  - People are not means to an end
  - People should be able to direct their own lives
  - Therefore, you do not do for, to, or about a person anything without his or her consent
  - And therefore anything you have promised, you fulfill
- Limitation to autonomy principle
  - Exercise of choice and self-direction cannot interfere with another person's autonomy
- Off-shoots from autonomy principle
  - Privacy rights
  - Informed consent rights
  - Confidentiality rights

## Aging and Autonomy, unpacked, con'td

- Distinctions about autonomy\*
  - Delegated vs Undelegated
  - Capacitated vs Incapacitated
    - Surrogates for persons without capacity
    - Substituted judgment vs best interest standard
  - Authenticity
  - Long-range vs short-range
  - Decisional vs Executional
- Autonomy emphasis often cold comfort for people with intermittent or progressive frailty.
- Issues about personhood and dementia.

\*Collopy, B. (1988). *Autonomy in Long-Term Care: Some Crucial Distinctions. The Gerontologist, 28 (Suppl), 10-17.*

## Aging and beneficence, unpacked

- Do unto others their own good
- Personal differences in values & preferences
  - Safety vs independence or freedom
  - Views on personal risk
- Older clients differ from each other
- Differences occur in families
- Differences between professionals & clients
- Intrinsic difficulties: competing “goods”

**Note: Beneficence principle—doing good—can conflict with autonomy principle, the right to self-direction**

## Justice and Aging, unpacked

- Treating like people the same
- Justice over the life span
- Justice within families
  - Avoiding unjust expectations of various family members
- Justice across clients
- Relevance of age
  - Avoiding ageism—i.e., bias against old people
  - Ageism occurs among people of all ages
  - Seniors can internalize biases against old people
  - Test: ask if opinions would be the same about fairness in a case if the main actors were middle-aged rather than elderly

## LTSS for Elderly Rich in Ethics Challenges

- LTC embedded in personal values
- LTC involves personal dignity
- LTC client often dependent on others to exercise their autonomy
  - Giving help creates more dependence
  - Paradox of dependency
- LTC clients often at risk
- LTC clients can be limited in decision capacity
- LTC involved end of life issues

**Research shows that many of ethical dilemmas and ethics cases for seniors involves questions of acceptable risk and risk-taking.**

## Research in Bioethics

- Impossible to study what should be done ethically
- Research of several types is still valuable
  - Possible to study effects of protocols or policies developed as ethics procedures—and to improve those procedures
  - Studies can identify tensions that occur in practice and result in “thick descriptions” of ethical problems rather than deal in the hypothetical
  - Possible to study values and preferences held by various groups
  - Orderly development of examples from research, construction of cases, and iterative case commentary



## Ethics Research with Multiple Groups

- My research on ethical issue:
  - Nursing home social workers and nurses aides
  - Decision advisors in multiple fields and settings
    - Home care, hospitals, housing, guardianship, case managers, guardians, housing managers
  - Hospital and NH discharge planners
- Many difficult cases were generated
- Many respondents felt it was not legally or ethically permissible to give advice on quality of providers or even differences among providers
  - Proved to be based on erroneous assumptions



## Case Management Ethics Study

(Sample, 250 case managers in 10 states\*)

- Tension between consumer safety and choice
- Reconciling advocacy and allocation roles
  - Case managers also may control resources & allocate them
  - They may be asked to consider overall costs for people serves and keep down per-person expenses
  - Ethical solutions require disclosure of those conditions
- Issues on making referrals
  - Deference sometimes want to be fair to agencies
    - Concern over influencing organization business
  - Keeping particular programs full—e.g. day care
  - They needed to question whether they were violating consumer autonomy in hard sell of programs

\* Kane, RA, Penrod JD, and Kivnick, HQ. (1994). Case managers discuss ethics: Dilemmas of an emerging occupation in long-term care in the United States. *Journal of Case Management*, 3(1):3-12, 1994.



## Values in LTSS

- Values: i.e., enduring preferences on important matters.
- Research on values of older people usually on end-of-life issues.
- Values differ on everyday matters, including daily routines, risks, pain, meaningful life
- Professionals often do not know the values of people they serve\*
- Professionals often don't ask about preference
  - False promise issue—raising expectations unrealistically.
  - Standardized approaches to discussion of values and preferences help. \*\*

\*Kane, RA, Caplan AL, Liu-Wong EK, Freeman IC, Aronson MA, and Finch, MD. (1997). Everyday matters in the lives of nursing home residents: With and without perception of choice and control. *Journal of American Geriatrics Society*, 45(9): 1086-1093.

\*\* Deegenholts HD, Kane, RA and Kivnick-HQ. (1997). Care-related preferences and values of elderly community-based LTC consumers: Can case managers learn what's important to clients? *Gerontologist*, 37(6), 767-777.



## The Problem of Safety

- Perfect safety an absurdity
- How to allow for consumer choice
- Reaching a new operational definition of safety

Is goal:

1. Maximum QOL and autonomy as consistent with health & safety?
  2. Or maximum health & safety as consistent with personal autonomy and choice?
- Often two things cannot be maximized
    - Which is primary and which is side constraint

## Real Examples of Safety Issues

- Older person has faulty gag reflex and aspirates his food sometimes—can he make choice to eat regular food & beverages
- Older NH resident wants to go outside to take a walk unaccompanied.
- Assisted living resident wants to remain where she has been for 11 years but after stroke can no longer take her own meds. Doctor says fine but state regulations say no.

## The assisted-living dilemma

*Residents and regulators strain to balance freedom with protection*



## Managed risk contracts a.k.a. negotiated risk contracts

- Agreements between a consumer (or consumer's agent) with provider that consumer may accept risks so as to achieve other goals of consumer after risks are explained
- Managed risk agreements are both a process & a document
- They have been used more as a care planning & communication device than legal vehicle
- They can help generate alternative ideas

## Safety Often Viewed Narrowly

- Must consider safety of all alternatives--not just the alternatives to nursing homes
- Must consider likelihood of event as well as seriousness if it occurs
- Must consider psychological and social risks as well as physical risks of various alternatives

## Questions Re Managed Risk Contracts

- Who explains risks?
- Can family or other agent accept risks for someone with dementia?
  - Best interest or substituted judgment standard?
- How often is agreement updated?
- Is agreement revoked if person later has dementia.
- How to distinguishing between provider's permitting consumers to choose risk from negligent care
- How to react when negative event occurs?
  - Can this be done without bestowing blame?
  - How to make mid-course corrections?

## Negotiated Risk Contracts in Operation

- What risks count?
  - Physical, psychological, social
- What about risks of most protective alternative?
- Likelihood of risk vs severity of risk?
- Informed consent process
- Proxy risk taker for cognitively impaired
  - Is it allowed
- Dealing with bad consequences.

## Dementia Issues

- All cases more difficult—but same principles apply.
- Many people with dementia capable of many decisions much of the time
  - Perhaps not complex financial decisions but many health and family and everyday choices
  - Need to be asked—assent if not consent, and also asked opinions
- Contributions of feminist and humanists to this area has been providing the “thick descriptions” and content to demonstrate the importance of knowing people with dementia as persons and communicating with them.

## Ethics Committees

- Roles
  - Self-education
  - Case discussion and advising
  - Policy and practice examination
- Structure
  - Cross-disciplinary
  - Outside members
  - Sometimes a network
  - Trade associations can sponsor

## Steps for Practitioners or Agencies

- Begin discussing ethics issues at all levels of staff.
  - Learning circles to explore issues
- Discuss values and preferences with clientele
  - Get to know consumers/residents—one by one
  - Discuss insights & how to act on consumer preferences
    - Getting to yes.
    - Don't worry that "everyone might want this"—everyone won't
- Examine policies and processes in organization
  - Are there any that make consumer choice harder?
  - Can more information be provided in ways more easily processed?
- Would an ethics committee work in the setting?
  - If not a committee, could there be a process to raise and discuss ethical issues?

## Increasing Awareness Generally

- Try Thought Exercises
  - What do I want for self? For parents?
- Read first-hand stories by LTSS users
- Try novels and movies
  - Humanities help inform bioethics
- Look for role models in LTSS
  - Illustrates art of the possible
  - Could be in your family or among your clients

My parents and main LTSS models—Pearl and Max Smolkin



## Resources

- A separate document on resources is included with webinar materials.
- Numerous first person books by older people getting care, and family members—email Rosalie for examples.
- Novels and films on aging—email Rosalie for examples.
- Ed Ratner MAGEC Geriatric Education Module (GEM) webinar on end-of-life  
<https://webfiles.umn.edu/gdn/hgm/Magec/GEM%20Modules/Ratner%20Ed%20of%20Life/Ratner%20Ed%20of%20Life.htm>
- Rosalie Kane is preparing a forthcoming Geriatric Education Module (GEM) that will expand on content in this webinar and use case examples. Look for it on the MAGEC website in a few months.
- Human values and Aging Newsletter, AARP
  - Harry H Moody, editor will put you on email lists.
- For PDFs of some of research cites, email Rosalie

Discussed at webinar

- Resource person who has worked on issues of legal liability and ways that providers can encourage consumer choice while not getting sued:

Marshall B Kapp—publications and contact information below:

<http://med.lsu.edu/?fuseaction=directory.full&usemenu=&usetemplate=column&directoryID=15073>

## For further information or comments

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## Minnesota Gerontological Society Center on Aging MAGEC

Questions?

Contact [info@mngero.org](mailto:info@mngero.org)

Next Webinar – November 20 at noon  
Yoga with Older Adults  
with Corgena Cheung, St. Catherine University