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Gray Areas in Bioethics: Ethics Minefields Hidden in Aging Trends

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2

MAGEC Website:

<http://www.aging.umn.edu/educational-programs/geriatric-education-modules>

Webinar Available on MAGEC Website: Ethics and Values in Log-Term Care and Aging.

<https://netfiles.umn.edu/sph/hpm/Magec/GEMs/WEthics/Ethics/Ethics.htm>

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3

Focus

- Living after age 65
 - including living at a time close to death.
- Ethical issues intertwined with everyday lives.
 - seniors and their family members.
- Ethical Issues encountered by practitioners
 - health services professionals—all disciplines.
 - LTC workers—all disciplines.
 - mental health.
 - social services, e.g., adult protective services & housing.
 - aging services workers and volunteers (aging network).
 - legal services—e.g., estate planning & guardianship programs.
- Ethical issues encountered by administrators, public officials, & policymakers.

← Back
Next →

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4

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 (i.e., correct) based on scientific evidence.
- Involves “ought” or “should.”
- Often involves competing considerations.
- Usually no single correct solution.
- Not same as practitioners practicing ethically by observing codes of ethics.

← Back
Next →

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5

Ethical Issues Often Mis-Specified

- Some commonly described “ethical dilemmas” may just be poor practices.
 - Family or professionals telling an older person that admission to a NF will be temporary.
 - Communication solely with family members of older people.
 - Sheltering older people from upsetting topics or news.
- Tricks and lies (by omission or commission) poison family relationships.
 - Leaves anger & sense of betrayal for older person and guilt for family even if the deception was seen as kindness.

← Back
Next →

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6

Frequently Encountered Ethical Issues

- Uncertainty about what to do because:
 - Conflict between interests & well-being of consumer and family members.
 - Conflicts in interest & well-being of various family members.
 - Internal conflict of practitioners about what might be best for consumer & family given competing goals.
- Confidentiality & information-sharing.
- Organization policies/practices raising ethical issues.
- Public policies raising ethical issues.

Practitioners who first cannot identify ethical dilemma can generate examples when asked about the issues above.

← Back
Next →

Bioethics Principles

- Respect for the autonomy of persons.
- Beneficence—doing good (and non-maleficence—doing no harm).
- Justice.

Back

Next

Defining Autonomy

- Respect for the autonomy means persons are seen as ends in themselves, and not means to an end.
- Therefore, persons should be free to direct their lives.
 - Nothing should be done to, for, or about a person without his/her consent.
 - Any promises made must be kept.
 - Autonomy of any person is limited by the rights of other persons.
- Confidentiality rights, privacy rights & informed consent follow from autonomy principle.
- A challenge in this principle is defining a “person.”
 - What cognitive skills are necessary to be self-directing?
- Respecting autonomy in persons with limited capability for autonomous decision-making.

Back

Next

Autonomy and Aging, Unpacked

- Distinctions about autonomy.*
 - Delegated vs undelegated
 - Capacitated vs incapacitated
 - ✓ Surrogates for persons without capacity
 - ✓ Applying person’s wishes vs best interest standard
 - ✓ Issues about personhood and dementia
 - Authentic vs inauthentic
 - Long-range vs short-range
 - Decisional vs executorial
- Autonomy can be cold comfort for seniors with intermittent progressive frailty.
 - Positive approaches to help seniors be self-directing rather than just refraining from interference.

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

Back

Next

Beneficence and Aging, unpacked

- Do unto others their own good.
- Personal differences in values & preferences.
 - Safety vs independence or freedom.
 - Views on personal risk.
- Older people vary in their values and preferences.
- Values vary within families.
 - Not just generational but old people in same family.
- Differences between professionals & clients.
- Internal conflict for professions: competing “goods.”

Note: Beneficence principle—doing good—can conflict with autonomy principle, the right to self-direction. The term “paternalism” means doing something against a person’s will for his or her own good.

Back

Next

Justice and Aging, Unpacked

- Treating like people and situations the same way.
 - Treat all alike patients (clients) alike.
 - Foster policies that treat all like citizens/clientele alike.
 - Don’t give to one unless you give to all.
- Justice over the life span.
 - Affording equal access to life’s chances.
 - Not imposing unjust expectations on others.
 - Ageism: enemy of justice?
- An emerging issue: fairness to workers in aging
 - Limits to work expectations?
 - Fairness in wages.

The justice principle can conflict with the autonomy and/or beneficence principle.

Back

Next

Other Terms and Concepts in Bioethics

- Values
 - Enduring preferences on important matters.
 - Differs from transient preferences for given moment.
- Virtues
 - Virtues of an older person receiving care.
 - Responsibilities as well as rights.
 - Virtues in professional roles.
- Ethics and Law
- Procedural and Substantive Ethics
- Narrative Ethics
 - Thick descriptions.
 - Understanding lived experiences.

Back

Next

Research in Bioethics

- Research cannot determine ethical choices.
- Several types of research are nevertheless valuable.
 - Studies of effects of protocols or policies developed as ethics procedures.
 - Studies to identify tensions that occur in practice and result in “thick descriptions” of problems rather than deal in the hypothetical.
 - Studies of values and preferences held by various stakeholder groups.
- Casebooks with commentary can be research products.

Examples: Kane & Caplan (1990). *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*, Springer; Kane & Caplan (1993). *Ethical Conflict in the Management of Home Care*, Springer.



Research Examples

- Ethical issues in “NH Placement.”
- Everyday choices of NH resident from resident and CNA perspectives.
- Ethics issues as perceived by case managers in home-and-community based services (HCBS).
- Values and preferences of elderly HCBS consumers.
- An experiment to test effects of HCBS case managers routinely assessing consumer preferences on the individualized natures of care plans.
- Preferences of LTSS consumers for private versus shared living quarters.



Nursing Home Autonomy

- Part of a series of studies of autonomy in LTC funded by Retirement Research Foundation in 1990s.*
- Interviews with 125 NH residents and 125 CNAs in multiple states to learn area where residents seek control and choice and CNA perceptions of resident preference for control and choice on 10 areas.
- Residents especially valued choice and control over leaving NH for short periods and control of phones and mails. Fewer gave high importance to choice of NH activities.
- CNAs thought residents wanted choice in all 10 areas but thought activities and food would be most important.
- CNAs felt they would be highly unlikely to be able to increase resident control and choice.

*Kane, et al, 1997. Everyday matters in the lives of nursing home residents: Wish for and perception of choice and control. *Journal of American Geriatrics Society*. 45(9): 1086-1093, 1997.



Ethical Issues in NH “Placement”*

- Focus was practitioners in Minnesota who sometimes give advice to seniors & families about NH admission.
 - Included hospital discharge planners, home care workers, housing managers, guardians, and adult protective service workers.
- Many difficult ethics cases were generated using the definition of ethical dilemma in this module.
- Many felt it was not legal or ethical for them to give advice on quality of providers.
 - Further exploration showed the legal analysis was incorrect.
- Ethical issues regarding transfer of information.
- Many competing interests, including patient safety.

*“NH placement” is a dehumanizing term “placement” for the process of advising & assisting regarding NH care.



Case Management Ethics Study

- Sample: 250 HCBS case managers (CMs) in 10 states.
- Reconciling advocacy & gatekeeper roles difficult.
 - CMs control & allocate resources and provide advice & information.
 - CMs asked to keep down per-person costs to serve more in program.
 - Ethical solutions require that CMs disclose those conditions.
- Ethical issues on making referrals.
 - CMs wanted to be fair in allocating business to agencies
 - CMs sometimes over-rode consumer preferences to be sure certain programs—e.g. day care—would remain available.
- CMs risk averse.
 - Bad outcomes risk reputation of public programs

* Kane, RA, Penrod JD, & 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.



Values of LTC Users in Community

- Case managers rarely ask about client values systematically.
- Clues to preferences of a sample of almost 900 HCBS who were asked about values and preference by their CMs:*
 - Client values differed on everyday matters including daily routines, risks, pain, family involvement, what made them feel like themselves.
 - Clients also varied on importance ratings for their values.
 - 1/3 preferred risk-taking for more freedom; 1/3 preferred to be safe even if restricted; and 1/3 were ambivalent or wanted both.
- Consumers were willing to talk about their values and preferences but case managers often skipped asking them.

*Degenholtz 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? *The Gerontologist*, 37 (6), 767-77.



Paying Attention to Client Values

- Quasi-experiment to see if case managers' service plans would be more varied if they learned client values through systematic assessment.*
- Case managers in experimental group assessed values and preferences of their clients as part of comprehensive assessment; those in comparison programs received didactic training about the importance of client preferences.
- Clients and families also given a brochure on the importance of their preferences to their care plan.
- Care plans in experimental group were no more individualized than those in the control group.

*Kane, Degenholtz HB., & Kane (1999). Adding values: An experiment in systematic attention to values and preferences of community long-term care clients. *Journal of Gerontology: Social Sciences*, 54B (2): S109-S119.



Privacy in Living Quarters

- 16 focus groups in MN and FL of prospective and actual AL residents, families of residents and prospective residents with dementia; some Hispanic and African-American groups.*
- Strong value for private quarters (room and bathroom) held across all groups.
- Participants indicated many activities they would prefer not to do in the presence of a roommate.
- They also indicated activities that they would not want their roommate to do in their presence.
- Participants would prefer smaller private space to larger shared space.

* Kane et al., 1998. *Consumer Perspectives on Private Versus Shared Accommodations in Assisted Living Settings*. Washington, DC: AARP 1998.



What Does All this Research Tell Us

- Ethical issues are real—practitioners face them all the time.
- Multiple interests need to be reconciled.
- Practitioners are often undecided about what is right to do.
- Safety concerns interfere with respect for autonomy.
- Lack of awareness of the values and preferences of older people interfere with beneficence.
 - But practitioners do not always ask.
- Surveys and case studies of ethical issues provide detail for the context of ethical decision-making.



Ethics Minefields

- Many areas of aging services raise ethics issues.
 - Previous slides had examples from NH Care, Case Management, Hospital Discharge Planning, and Home Care.
- Other areas raising similar issues and conflicts include: guardianship and conservatorship programs; adult protective services; housing programs; elder abuse prevention and identification programs; primary health care; and behavioral health programs for seniors.
- Tension between promoting seniors' preferences and acting to protect their safety occurs in most practice settings.



The Problem of Safety

- Perfect safety is an absurd goal
- A new operational definition of safety is needed that allows for consumer choice.
 - Is reasonable safety a viable goal?
- Establishing the priority goal between:
 - Maximum QOL and autonomy as consistent with health & safety.
 - Maximum health & safety as consistent with personal autonomy and choice.
- Often two things cannot be maximized.
 - Which is primary and which is the side constraint?



Real Examples of Safety Issues

- Older NH resident has a 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 a stroke can no longer take her own meds. Doctor says fine but state regulations say no.
- Family members worry that their relative will be unsafe at home though that is where the older person wants to stay.



Safety Considerations are Complex

- Must consider safety of all alternatives
 - home may have dangers but alternatives are not danger free
- Must consider likelihood of event as well as its seriousness if it occurs.
 - example of fall risk
 - predictions often inaccurate
 - must consider likelihood of injury as well as of falling
- Must consider psychological and social risks as well as physical risks of various alternatives.

Back

Next

Negotiated Risk Agreements

- Negotiated risk agreements (a.k.a. negotiated risk contracting), managed risk agreements) have been proposed as a mechanism for informed acceptance of risk by clients.
- These are agreements between a consumer (or consumer's agent) with providers that consumer may accept risks so as to achieve other goals of consumer after risks are explained.
- Began in Assisted Living and spread to other settings. *
- Managed risk agreements are both a process & a document resulting from the process.
- Probably would not stand up in court.
- Most useful as care planning & communication devices.
- Negotiated risk agreements help generate alternative ideas.

* <https://aspe.hhs.gov/basic-report/study-negotiated-risk-agreements-assisted-living-final-report>.

Back

Next

Issues in Managed Risk Agreements

- Who explains the risks and how?
- What is the informed consent process?
- Can a family member or other surrogate accept risks on behalf of someone with dementia?
- Is an agreement revoked in the case of later dementia?
- How often is an agreement updated?
- How can we distinguish between providers permitting consumers to choose risk and negligent care?
- How to react when a negative event occurs?
 - Must someone be blamed?
 - Can mid-point corrections be made?

Back

Next

What of Safety if Dementia is Involved

- Cases are more difficult but the principles are the same.
- Many people with dementia can make many decisions.
- Usually they cannot make complex financial decisions.
 - Can often make or assist in many health decisions.
 - Usually can make everyday choices.
- Ask the persons with dementia whenever possible
 - Get assent if consent is impossible
 - Best practices in conversations with people with dementia
 - Choose right time, speak slowly, use pictures
- Family or other agents can give proxy consent & assume risks.
 - What standard for the proxy decision-maker?
 - Previously expressed preferences of person or substituted judgment based on best interests?
 - What weight to give written advance directives?

Back

Next

Guardianships

- Guardianships & conservatorship defined by state law.
 - Sometimes a state chooses one or the other term.
 - Former may refer to person and latter to property.
 - Legal guardians have the last word
 - Some legal authorities suggest avoiding legal guardianships because they are hard to revoke and research suggests they often do not benefit wards.
- Power of Attorney (POA) is a revocable status and does not over-ride the older persons choices.
- Power of attorney for health decisions only asked if the person cannot consent (e.g. unconscious, in emergency surgery, suffering from advanced dementia or temporary delirium).

Authors to look for on details of guardianship:
Madelyn Iris; Kate Wilbur; Elias Cohen

Back

Next

Ageism

- Ageism is biased attitudes towards people based on age.
- In gerontology, ageism is sometimes defined as bias based on being old.
- Ageism, unlike racism and sexism, entails bias against a status that everybody reaches if they survive long enough.
- Ageism may be expressed in subtle ways or subtle ways or involve overt discrimination.
- How does it play out in practice:
 - Protection of people because of their age.
 - Older people themselves can be ageist towards people who are even older.
 - Older people may internalize negative societal attitudes about old people, including themselves.

Back

Next

Is Ageism a Factor?

Test of ageism: would opinions be the same about a case if the main actors were middle-aged rather than elderly.

Examples:

- Would a 40 or 50 year old be asked to stay in a NH under the same condition?
- Would a younger person living alone be encouraged to stay at home when an older person would not?
- Would this new friendship of the client be viewed with suspicion even if the client were younger?



Ethics Problem Solving Framework

- Is autonomy being improperly compromised?
- Are you sure you are doing no harm by opposing preferences of the older person?
- Do you know what the older person in this situation values. Has anyone tried to find out?
- Do any of the 3 bioethics principles raise conflicts?
- Stakeholder considerations:
 - Who besides the older person has interests in the situation? One or more family members? Professionals, paid caregivers, others?
 - What are the particular interests of each party?
 - Can you sort out which interests can be reconciled?
 - If not, which interests should take priority?
- Is ageism a factor?



Process Check

- Some processes are closely related to ethical issues.
 - Informed consent.
 - Competency evaluations.
 - Care-planning or service planning.
 - Allocation of services.
- Such processes may surface questions of autonomy, beneficence and justice because:
 - They involve exchange of information.
 - They involve receiving a status (a benefit) or a label (wanted or unwanted).
 - There is often a power imbalance.
 - Processes become routinized and automatic.
- Can the processes be improved?
 - Slowed down enough to listen to consumers?
 - Speeded up to avoid long waits?



Ethics Committees

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



Getting There: Practitioners and Agencies

- Begin discussing ethics at all levels of staff
 - Learning circles to explore issues.
- Discuss values and preferences with clientele.
 - Get to know consumers/residents.
 - Brainstorm how to act on consumer preferences
 - Figure out how to get to yes.
 - Don't worry that "everyone might want this."
- Consider whether an Ethics Committee would work in the setting.
 - If not an Ethics Committee, what process could be developed?



Systemic Issues

- "Ought Implies Can."
 - No ethical duty to do the impossible.
 - But if policies and rules keep getting in the way, it is time to re-examine those policies.
- Self-study of the organization
 - Are there built-in ways to get consumer feedback?
 - Are there practices or policies in place that make consumer choice more difficult?
 - Can information be provided to consumers in ways more easily processed?
 - Should we create a process?



Getting there: Increasing Awareness

- Conduct thought exercises?
 - What would I want for myself? For my parents?
- Read first-person stories by people receiving LTC.
- Read or view (and discuss) novels, memoirs, journalistic & anthropological work. (Humanities inform bioethics.)
 - Selected novels: Doris Lessing, *Diary of a Good Neighbor*; Penelope Lively,
- Steve Miles: Unadorned Advance Directive

<http://www.bioethics.net/2016/02/unadorned-my-testament/>

← Back

Next →

I have completed nearly three score and ten years and enjoyed health, family, career, travel and accomplishments. My wonderful profession gave me an extraordinary vantage point from which to view medical and long term care institutions for persons in the last decades of life. I believe that the health resources used on my behalf are most wisely used to alleviate pain and disability rather than employed to prolong my life.

There are many treatments that are commonly used on persons after sixty years of age that I do not want to receive. I make this directive to express my preferences and to relieve my family of the burden of reflecting on these complex decisions. Joline, my wife, is my health care agent for these decisions but this document is to guide her in exercising that power on my behalf. I do not wish to receive cardiopulmonary resuscitation, cardiac massage, countershock for ventricular fibrillation or agonal rhythms, pressors to raise my blood pressure or intracardiac injections of medications under any circumstances. I decline endotracheal intubation other than for elective medical procedures to which I have consented. In the event that an emergency medical provider inserts an endotracheal tube into me, I ask that it be removed within seventy-two hours. I entirely refuse enteral alimentation by nasogastric or percutaneous tubes or intravenous hyperalimentation. I refuse dialysis and bone marrow, kidney and liver transplants. With regard to other major interventions such as chemotherapy for cancer or surgery, I decline treatments of marginal utility: experience (not speculation) must have shown that an offered intervention has a high probability of resulting in at least three years of low disability life. I am entirely comfortable with early enrollment in hospice or palliative care programs as well as with palliative or terminal sedation.

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Given that the principle of respect for my personal autonomy is robust enough to empower me to refuse various life-prolonging therapies, respect for my values rightfully extends to allowing me to insist that my preferences for living conditions also be honored. I want decent art rather than institutional décor on the walls. I want fresh flowers in my room. I want equipment to play talking books. My bed must be large enough to accommodate another person who wants to lay or cuddle with me. I do not want such encounters governed by medical orders, monitored according to nursing plans or channeled by pre-appointment to some special room for 'conjugal visiting.' Hope, spontaneity, and intimacy are the antidotes to being crushed by the loneliness created by professionally devised care plans. At my discretion, I want access to up to two servings of palatable wine or bourbon per day. I do not want medical orders that override my dietary preferences with regard to salt or the texture of my food. I want to be able to choose to own a dog and to pay for staffing and facilities to enable him/her to stay in my room. I have no illusion that accommodating these preferences will make institutional life delightful but I believe they will make it somewhat more human. As a person contemplating living in an institution, these preferences may have the added benefit of reminding the staff that I am not to be managed as simply a client, a case or a patient. I fear and reject any place that finds such human requests and needs to be bizarre or impossible.

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Case Study #1

- Denny is an 82 year old who lives with his 55 year old son who has a developmental disability. While the son has lived with Denny his whole life, he is high functioning and mostly independent.
- Denny was hospitalized for a condition that has left him unable to stand or ambulate. The healthcare team was concerned about his ability to function at home safely. The son told the team that he was unable to meet his father's physical needs.
- The healthcare team convinced Denny to transfer to a SNF despite his insistence that he wanted to go home. He emphasized that his son needs him at home. Upon arriving at the SNF, he indicated that he was leaving. The SNF staff contacted the hospital discharge planner regarding Denny's plan to leave. At this point, Denny was informed that if he did not stay at the SNF, he would be put on a 72 hour hold for his own safety.

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Case Study #2

- Judy is a 68 year old woman with renal failure and receives dialysis three times a week at a unit an hour from her home. Judy has some physical limitations, but is cognitively alert and oriented. She has Medicare and Medicaid.
- She lives in a rural area with her husband who works full time. Judy receives several hours per day of home care to assist with ADLs and IADLs. Due to the rural nature of where she lives, there is only one home care agency serving her area and a shortage of home care workers. The home care agency hired her 19 year old granddaughter with a criminal and substance abuse history as Judy's PCA.
- One day, Judy arrived at the dialysis unit via a transportation company. She presented with slurred speech and physical weakness (significantly more than normal for her).

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Case Study #3

- John is an 88 year old widower who is moving into an apartment in a senior living community. He lived in his own home for two years after his wife's death. Recently, some of his friends have moved in this community and he has gotten to know some more of the people. He thinks it is time to make a change and thinks it will be fun.
- John's daughter who lives in California fully supports Johns move. However, she is pressuring him to utilize all of the technology available to him to give her the piece of mind that he is OK. The technology includes sensors around the apartment including the bed, toilet, refrigerator, and more that would text message his daughter if there are anomalies in his behavior. The facility also highly encourages the residents to give access to this information to a family member for safety purposes.
- John does not want his daughter or anyone else to have access to this information as he has recently started an intimate relationship with another member of this senior community.

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