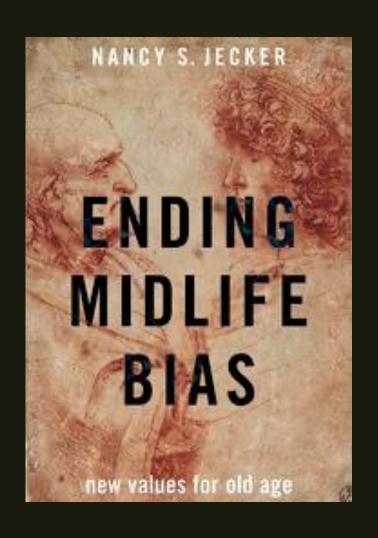
Dignity in Later Life

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Ending Midlife Bias: New Values For Old Age

(Oxford University Press, 2020)

Part I: Philosophical Framework

Part II: Policy and Practice

- 1. Values Across the Lifespan
- 2. What Matters for Individuals in Later Life?
- 3. The Preferred Account of Human Capabilities
- 4. Times Passage
- & the Narrative Self
- 5. Justice between Old and Young

- 6. Healthcare Across the Lifespan
- 7. Who Cares?
- 8. What Cares?
- 9. Ageism
- 10. The Dying, the Newly Dead, & the Long Gone
- 11. Future People
- 12. The Coming of Age of Old Age

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What values matter most across the lifespan?



What values guide bioethics across the lifespan?



What values matter most in later life?



I. WHAT VALUES MATTER MOST ACROSS THE LIFESPAN?

- (1) **Do** we emphasize different values at different life stages?
- (2) **Should** we emphasize different values at different life stages?
- (3) What specific values should we focus on at each life stage?

Do values change from birth to death?

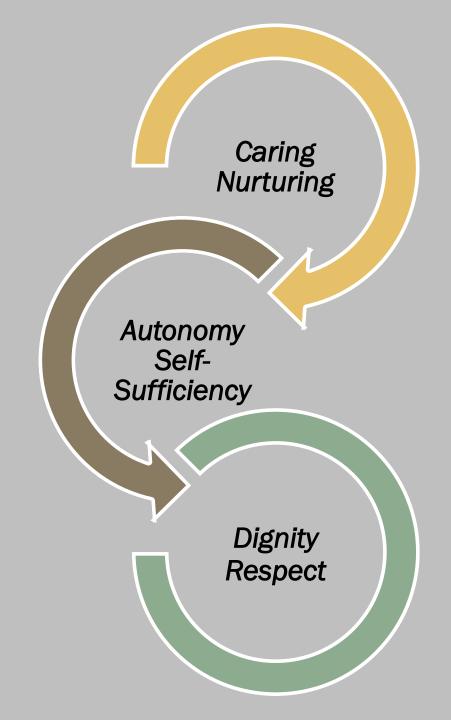
THE LIFE STAGE RELATIVITY OF VALUES

At different life stages, different values emerge as central

The circumstances of our lives

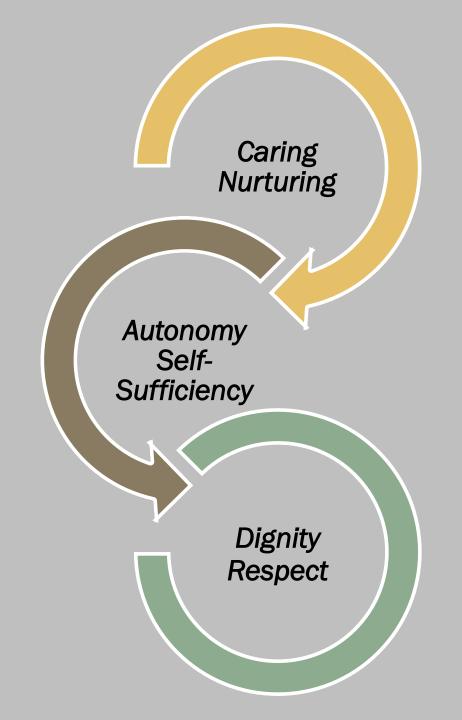
- The values we care most deeply about should be responsive to the circumstances of our lives
- Some important life circumstances are life stage features that reflect the shared human experience of aging
- Virtually all of us are:
 - tasked during infancy & early childhood with bonding to primary caregivers
 - challenged during young adulthood & midlife with figuring out what we want to do with our lives
 - face threats to central functioning & capabilities during old age

The Life Stage Relativity of Values



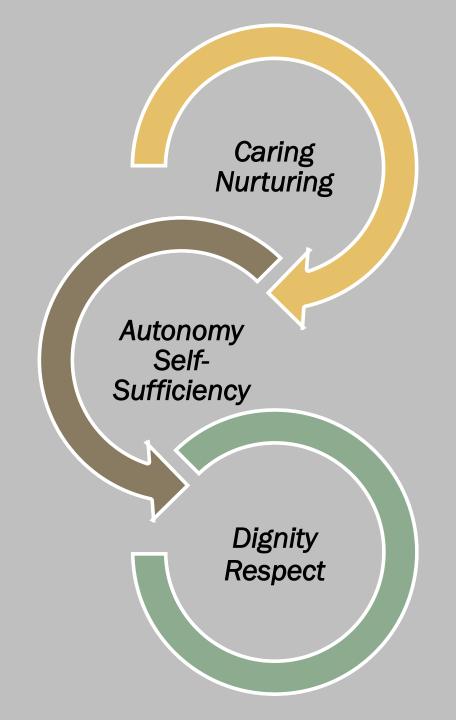
Childhood

- Due to vulnerabilities and needs that characterize infancy and childhood
- Caring, trust, and nurturing ought to figure prominently



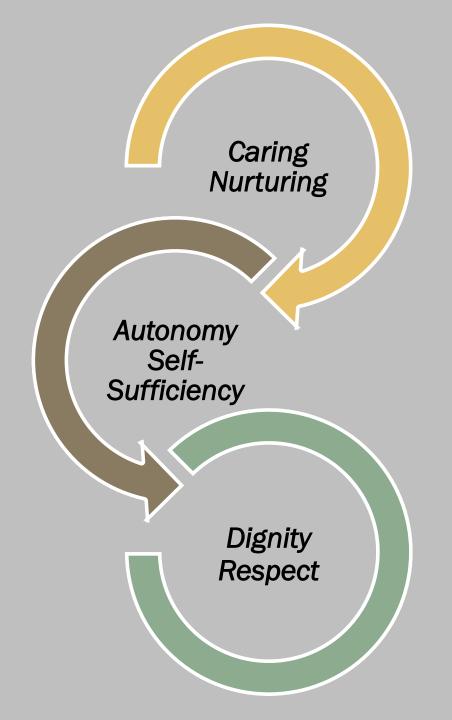
Young Adulthood:

- Due to greater capacities for physical and emotional independence
- It makes sense to place increased emphasis on autonomy



Later Life:

- Due to heightened risk for chronic disease and disability
- It is reasonable to shift our focus to keeping dignity intact and retaining functioning and capabilities



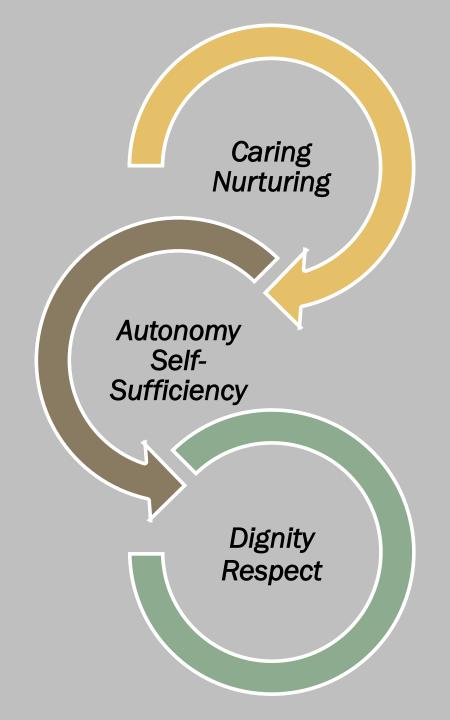
A general claim that admits of exceptions

- For a small child who is the victim of abuse, dignity and privacy might become central
- For a middle age adult undergoing divorce, trusting anew might be a crucial concern
- For an older adult with a terminal Illness, autonomous decision-making might be hugely important

Life stage related values retain significance

- For the child, nurturing care continues to matter
- For the middle age adult, autonomously determining a new plan of life counts a lot
- For the older adult, dignity remains central

The Life Stage Relativity of Values



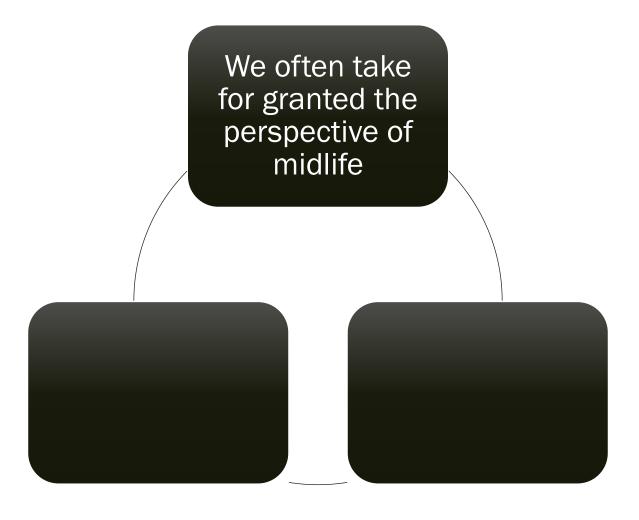
Life stage bias

Occurs when the ethical concerns and questions focal at one life stage are generalized and assumed to be central for all life stages

MIDLIFE BIAS

Midlife values are generalized and assumed central for all life stages

Midlife Bias



Midlife Bias

We often take for granted the perspective of midlife This can lead to a focus on respect for autonomy

Midlife Bias

We often take for granted the perspective of midlife

This can lead to a focus on respect for autonomy

To the exclusion of other values



II. What values guide bioethics across the lifespan?



"No single concept has been more important in the contemporary development of bioethics... than the concept of autonomy..."

Jennings, 2009, Autonomy, In Steinbock, ed., Oxford Handbook of Bioethics

The Prep School Model

- Pictures children as future adults
- Sees our job as "delivering them safe"
- & turning children into adults



1. Critically III Newborns

When caring for critically ill infants in the NICU, we should respect autonomy by assigning preferences to the infant based on the preferences of adults who were previously low-birthweight infants

Saigal et al, 1999, Differences in Preferences for neonatal outcome...

JAMA 281



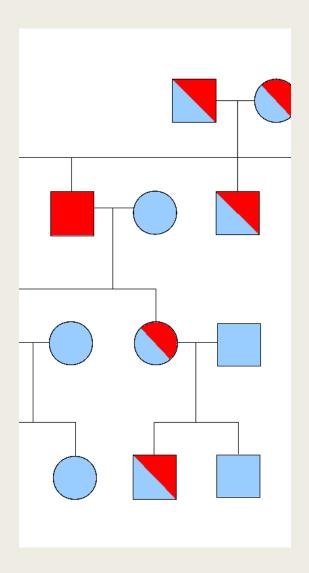
2. Neonatal circumcision

"The child has a right to decide for himself" & neonatal circumcision violates this right

Darby, 2013, The child's right to an open future: Is the principle applicable to non-therapeutic circumcision? J Med Ethics 39

3. Testing for adultonset conditions

We should not test minor children for adult-onset conditions so that they can chose as future adults



4. Cochlear implants

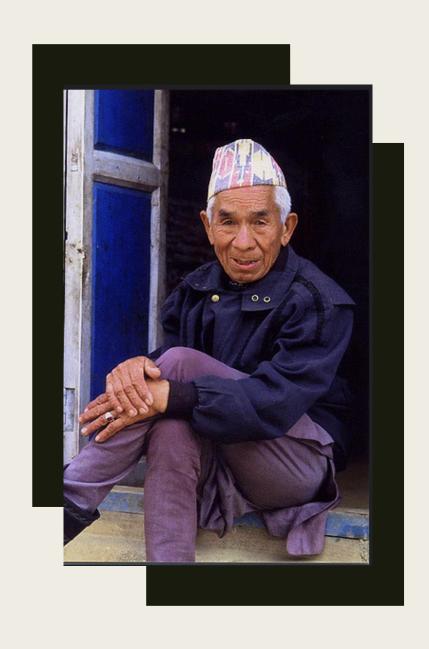
Deaf parents who refuse cochlear implants violate autonomy by confining the child to a narrow group of people and a limited choice of careers



The Hang-in-There! Model

- Pictures later life as holding on
- Sees our job as helping the old stay young
- Privileges midlife values



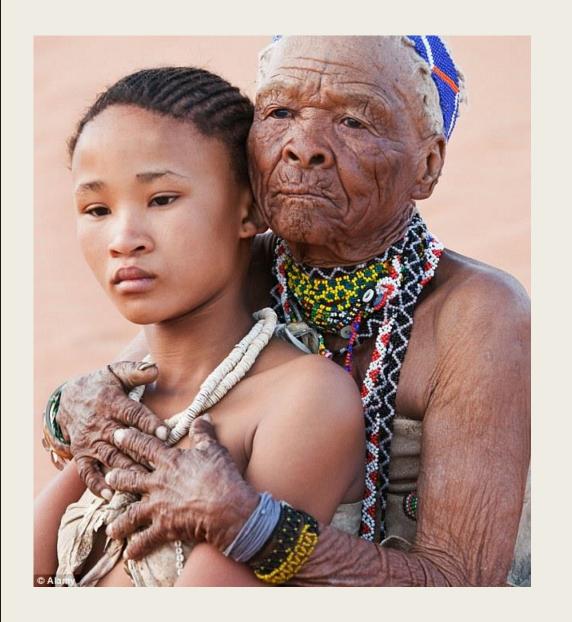


1. Advance Care Planning

Make medical decisions for people with dementia by appealing to prior autonomous wishes

2. "Healthy Aging" (Successful, Active, Vital Aging)

Do what we can to stay young & maintain good health by making the right "lifestyle choices"



3. Age Group Justice

Allocate
resources across
the lifespan
based on
autonomous
choices under
"veiled prudence"

Daniels, 1988, Am I My Parents' Keeper? Oxford



III. What values matter most in later life?

Old age is new

Prior to 1800, no nation enjoyed an average life expectancy at birth beyond 40

1800

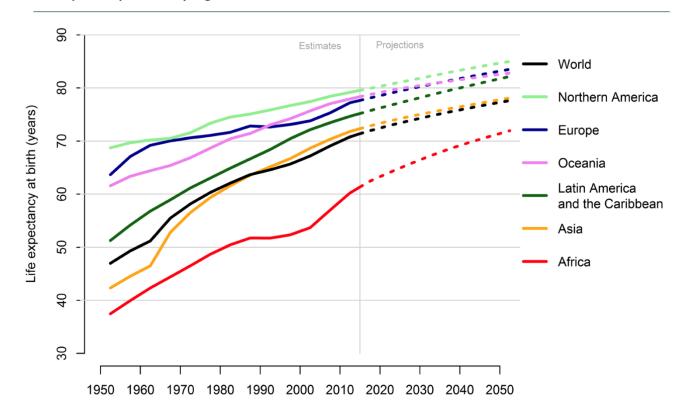
Since 1900, more years have been added to the human lifespan than in all of history combined

1900

Today

Today, there is hardly a country that does not

Life expectancy at birth by region, both sexes combined, from 1950 to 2050



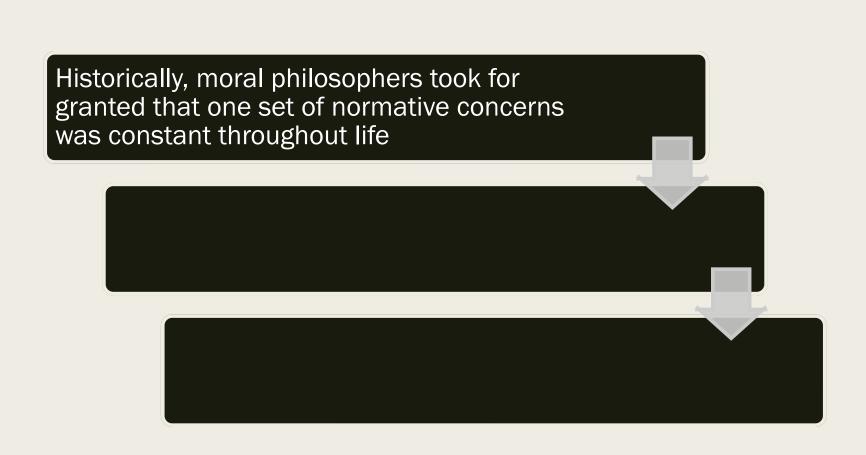
Data source: United Nations (2017). World Population Prospects: the 2017 Revision.

Autonomy's significance may be waning...

Populations are becoming

- older
- more dependent
- more vulnerable to cognitive/physical impairments





Historically, moral philosophers took for granted that one set of normative concerns was constant throughout life

That resulted in moral theories in which life stage related values were largely ignored and undertheorized

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That resulted in moral theories in which life stage related values were largely ignored and undertheorized

As societies age, remaining relevant requires giving an account of the moral life that makes sense to people in later life



Autonomy
presupposes a
capacity to make &
carry out a plan of life

Dignity



Older adults are more likely to face obstacles to making and carrying out a plan of life

Dementia doubles every 5 years for people 65+:

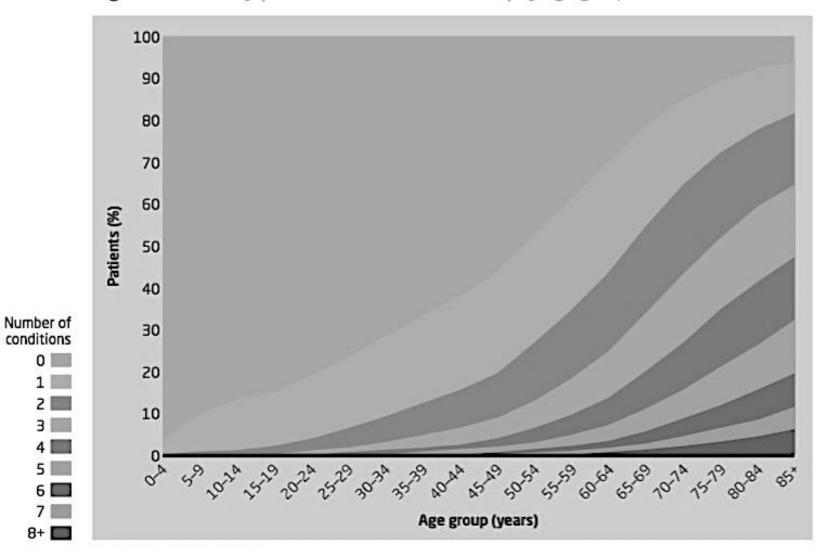
- <3% of 65-69</p>
- **30%** of 85-89

People >65 are more likely than people <65 to experience:

- Stroke
- Heart disease
- Cancer
- Diabetes
- Depression

Cognitive & physical functioning

Figure 5 Morbidity (number of chronic conditions) by age group



Impact over time

<u>ADLs</u>

- Toileting
- Eating
- Dressing
- Bating
- Grooming
- Getting out of bed
- Getting out of chair
- Walking

<u>IADLs</u>

- Shopping
- Meals
- Housekeeping
- Laundry
- Medications
- Phone calls
- Traveling
- Finances

Threats to dignity

- Threats to dignity in later life have not received the attention they deserve
- Dignity has not been linked directly to later life
- Dignity has gotten a bad rap...



Macklin, "Dignity is a useless concept"

- Dignity is useless because it is redundant with autonomy
- It "can be eliminated without any loss of content"

Macklin, 2003, Dignity is a useless concept, BMJ

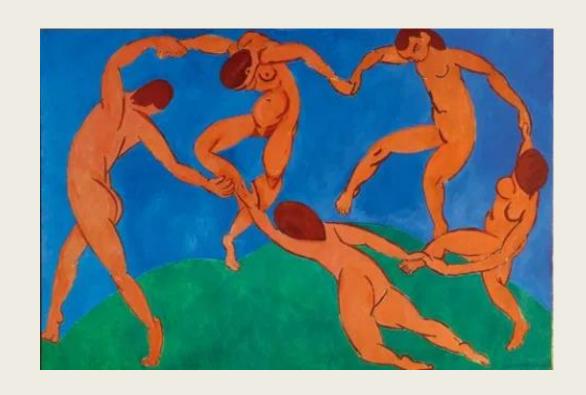
Pinker, "The Stupidity of Dignity"

- Dignity is "a squishy, subjective notion"
- It is "hardly up to the heavyweight demands place upon it"

Pinker, 2008, The stupidity of dignity, New Republic

What is Dignity?

- Latin, "dignitas"
 The state or quality of being worthy of honor or respect
- We possess dignity because of the kinds of beings we are



Central Human Capabilities

Life

Having an unfinished narrative

Health

Being physically and mentally healthy and well nourished

Bodily Integrity

Being able to use one's body to realize one's desires & goals

Contd.

Senses, Imagination, Thought
 Being able to imagine, think, reason & use the senses

Emotions

Being able to feel and express a range of human emotions

Practical Reason

Being able to form a conception of the good & engage in planning

Contd.

Affiliation

Being able to live for & in relation to others

Nature

Being able to live in relation to animals & nature

Play

Being able to laugh, play & recreate

Environment

Being able to regulate ones 's immediate physical environment

Human Capabilities

Life

Health

Bodily Integrity

Senses, Imagination, Thought

Emotions

Practical Reason

Affiliation

Nature

Play

Environment

- As people move through the stages of their lives, what they can do & be changes
- A capabilities account of dignity reflects this and makes reasonable efforts to safeguard threshold capabilities at each stage of life

Respecting Dignity

 Respecting dignity requires reasonable efforts to ensure a threshold level of each of the central human capabilities







- A dignity informed approach offers a fuller picture of humanness
- It includes, yet is not limited to, the capacity for rational agency



What might a dignity-guided bioethics look like?



The Case of Annie

- Annie was a 78 yo woman w/severe lumbar back pain, unable to get out of bed for 3 days. On day 4, her pain improved enough to allow her to seek care.
- Diagnosed w/ lumbar compression fracture, secondary to osteoporosis, and stage-2 pressure ulcer over the coccyx. Instructed to minimize time in bed. Due to the pain, she was non-compliant.
- At 2 mo follow-up, Annie had stage-4 sacral decubitus ulcer and low-grade fever. She was admitted to the hospital and an infected bone at the base of spine (sacral osteomyelitis) was diagnosed. She received local wound care and was discharged to a skilled nursing facility.







IDENTIFY PARADIGM

IDENTIFY AT-RISK CAPABILITIES

FORMULATE GUIDANCE

Dignity-Guided Ethics



IDENTIFY AT-RISK CAPABILITIES

Geriatric syndromes:

- Occur with high prevalence among older adults
- Defy single-disease model
- Involve multiple organ systems & pathways
- Recalcitrant to standard clinical practice guidelines
- Associated with substantial morbidity & poor outcomes
- Examples include frailty, incontinence, falls, dementia, pressure ulcers



IDENTIFY AT-RISK CAPABILITIES

At-Risk Capabilities

- Life
- Health
- Bodily Integrity
- Affiliation
- Environment

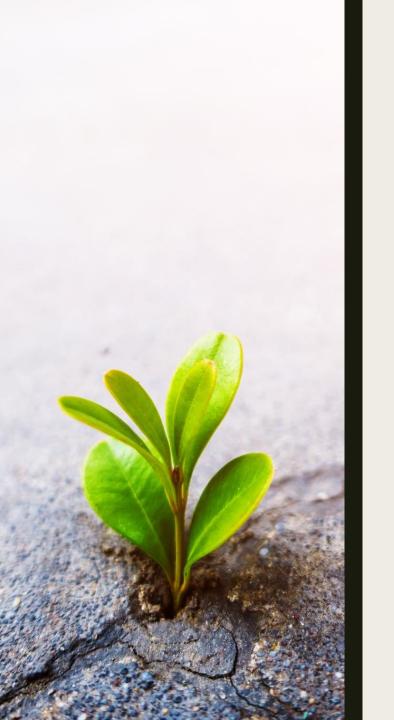


FORMULATE ETHICS GUIDANCE

We ought to make reasonable efforts to support each at-risk capability at a threshold level

- Life
- Health
- Bodily Integrity
- Affiliation
- Environment

AT-RISK CAPABILITIES	ETHICS GUIDANCE
Life	 Supporting activities central to the patient's life narrative
Health	 Staying out of the hospital for 12 mo.
Bodily Integrity	 Leaving the confines of bed
Affiliation	 Keeping ties with family, showing caring
Environment	 Making available mattress overlay, foam wedge, etc.



Respecting Annie's dignity hinges on whether we make the effort to help her in all the areas where her capabilities are at risk of falling below floor level

Take-Aways

- <u>Life Stage Relativity of Values</u>: values change across the life span
- <u>Midlife Bias</u>: midlife tends to be overrepresented in bioethics & moral philosophy
- <u>Later Life:</u> a direction for future theorizing





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