

Can Dementia Care be Person-Centered, Family-Framed, and Age-Friendly?

The Clinical Challenges of Practicing within Divergent Care Paradigms

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Introduction

Finger Lakes Center of Excellence in Alzheimer's Disease (NYS-funded), Director

- To increase the region's capacity to provide state of the art evaluations
- To increase awareness of AD/D and the benefits of early diagnosis
- To train more medical providers in primary care practices to screen for, diagnose, and treat cognitive impairment
- Reduce health care disparities
- To promote participation in clinical trials

URMC Memory Care Program, Clinic Director

- Specialty care; multidisciplinary;
- Assessment/diagnosis/treatment/care management

Embedded LMFT

- Since 2012; Worked with 700+ patients/families

Family Consultation Service in a Long Term Care Facility, Director/Supervisor/LMFT

Experience has taught me that...

There are many models of dementia care

Dementia care approaches and philosophies differ by setting

Most models add value and improve quality of care

Most models are not implemented with fidelity

Models with financial incentives are most likely to be implemented

There are many opportunities for systemic therapists but they are not clearly identified

Learning objectives

Based on the content of this session I am able to

- Provide a general overview of the similarities and differences among person-centered, family-framed, and age-friendly models of care
- Describe how the care settings and profession-specific perspectives influence how models are adopted
- Explain how a relational, systemic perspective can be applied to find the intersection and confluence among care models

What is dementia?

What is Dementia?

...a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life (<https://www.alz.org/alzheimers-dementia/what-is-dementia/>)

- Alzheimer's disease is the most common cause (60-80%)
- Vascular dementia is second

AN ESTIMATED 6.7 MILLION
AMERICANS ARE LIVING WITH
ALZHEIMER'S DEMENTIA.



Dementia is more than memory loss





THE THREE STAGES OF ALZHEIMER'S

The ability to live independently changes with the progression of the disease.

Early Stage

1. Trouble remembering recent events.
2. Difficulty managing finances.
3. Difficulty completing familiar tasks.
4. Losing track of dates, and passage of time.
5. Difficulty with vision and spatial relations. Getting lost.
6. Develop problems with speaking and writing words.
7. Forgetful. Misplacing things.
8. Social withdrawal from family and friends.
9. Changes in mood or personality (confusion, depression, suspicious, anxious).
10. Often repeating questions and statements.
11. Trouble with driving. Confusing pedals and traffic signals.

Caregiver Role: Emotionally supportive. Helpful in getting the person's affairs in order.

Middle Stage

1. Behavioral problems. Anger, paranoia, anxiety, suspicious.
2. Wandering and getting lost.
3. Repetitive. Repeats things often.
4. Anxiety particularly late afternoon and early evening (sun-downing).
5. Eating problems. Loss of table manners.
6. Needs assistance with bathing, dressing, and personal care.
7. Incontinence.
8. Hoarding.
9. Inappropriate behavior.
10. Violent behavior.
11. Increased difficulty with speech and recall.
12. Loss of coordination. Starts to shuffle and have more falls.
13. Stops recognizing family and friends.

Caregiver Role: Expands to full-time. Ensuring the person's safety will become a priority. May need additional assistance.

Late Stage

1. Loses ability to communicate.
2. Loses ability to smile.
3. Inability to recognize people, places and things.
4. Requires full assistance with dressing, bathing, and personal care.
5. Loses ability to chew and swallow.
6. Eventually loses ability to walk.
7. Sleeps a lot.
8. Seizures.
9. Strokes.
10. Incontinence and bowel problems.
11. Weight loss.

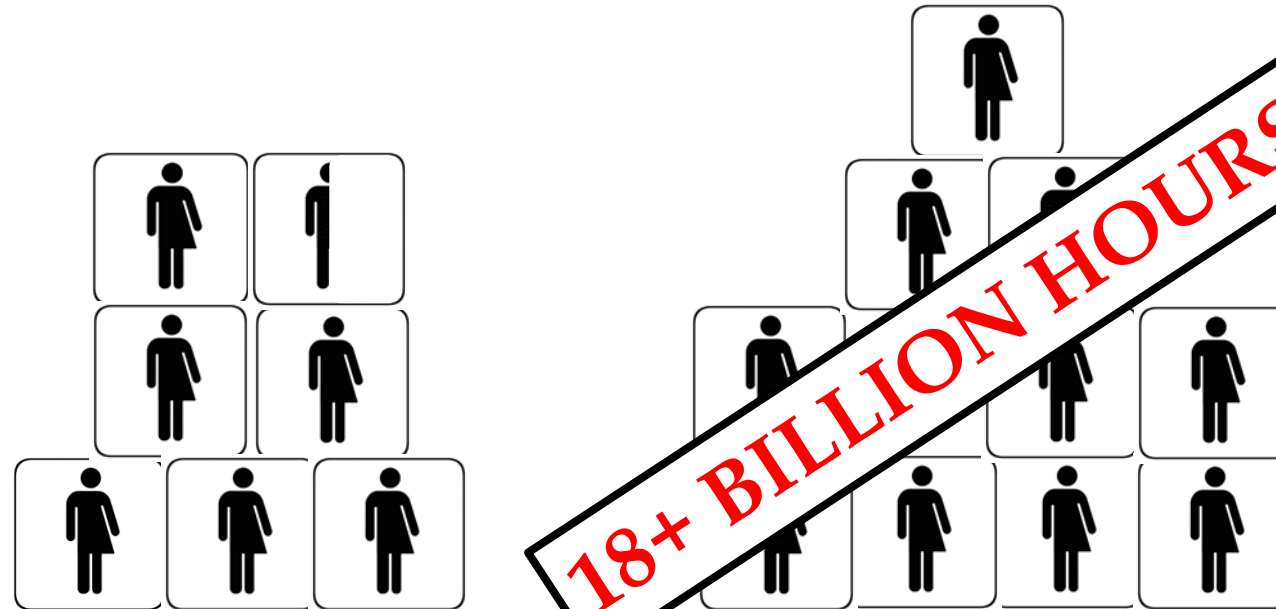
Caregiver Role: May be considering placement options in a skilled care or dementia care facility. End of life planning with hospice care.


Alzheimer's Disease

Those with dementia

Those who care for them

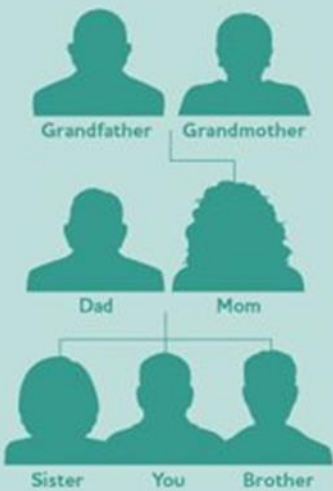
Nearly
\$340 billion
worth of care
is provided by
family members
and other unpaid
caregivers.



 = 1 Million

Dementia is a family disease

Is Alzheimer's Genetic?



Having a parent, brother or sister with Alzheimer's increases your risk but doesn't mean you will develop Alzheimer's.

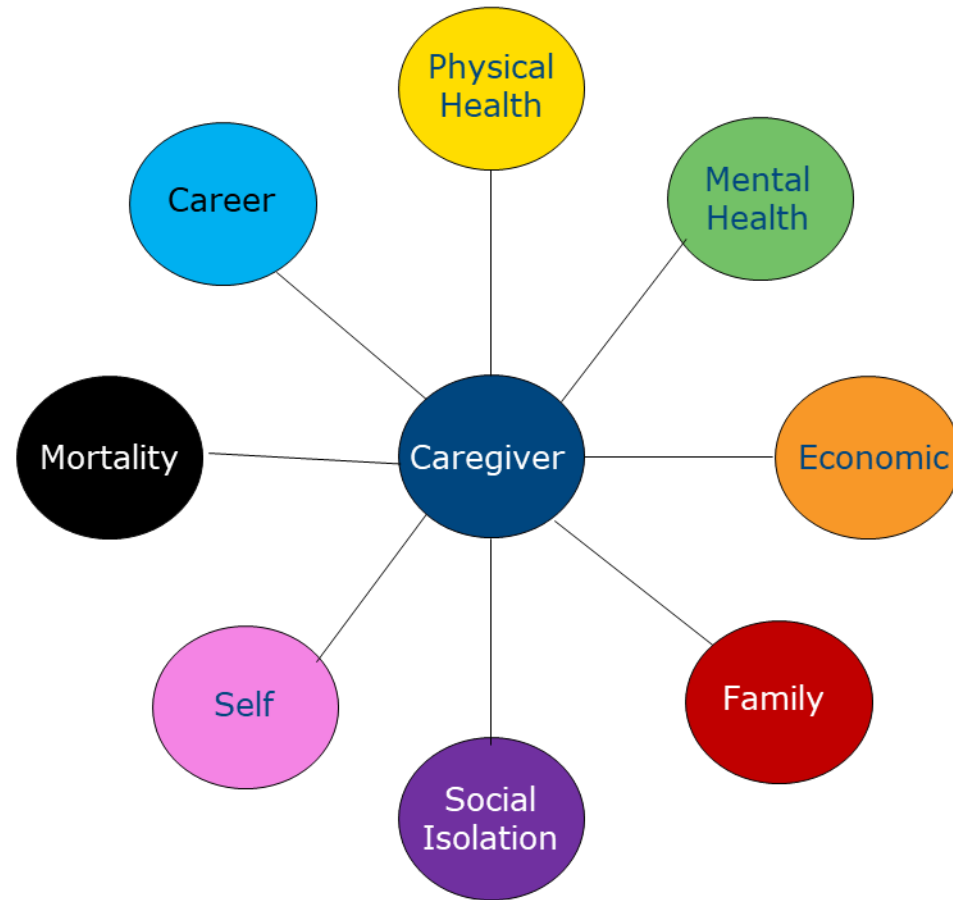
Duration 3-20 years; average 7-9

Most caregivers are family

Ripple effects across the family life cycle

Care decisions affect EVERYONE

Costs of Caregiving



*THE DEMENTIA EXPERIENCE
IS RELATIONAL*

Dementia Care

A TIME OF DISCOVERY, PERSON-CENTERED TREATMENT, AND HOPE

Alzheimer's disease has been...

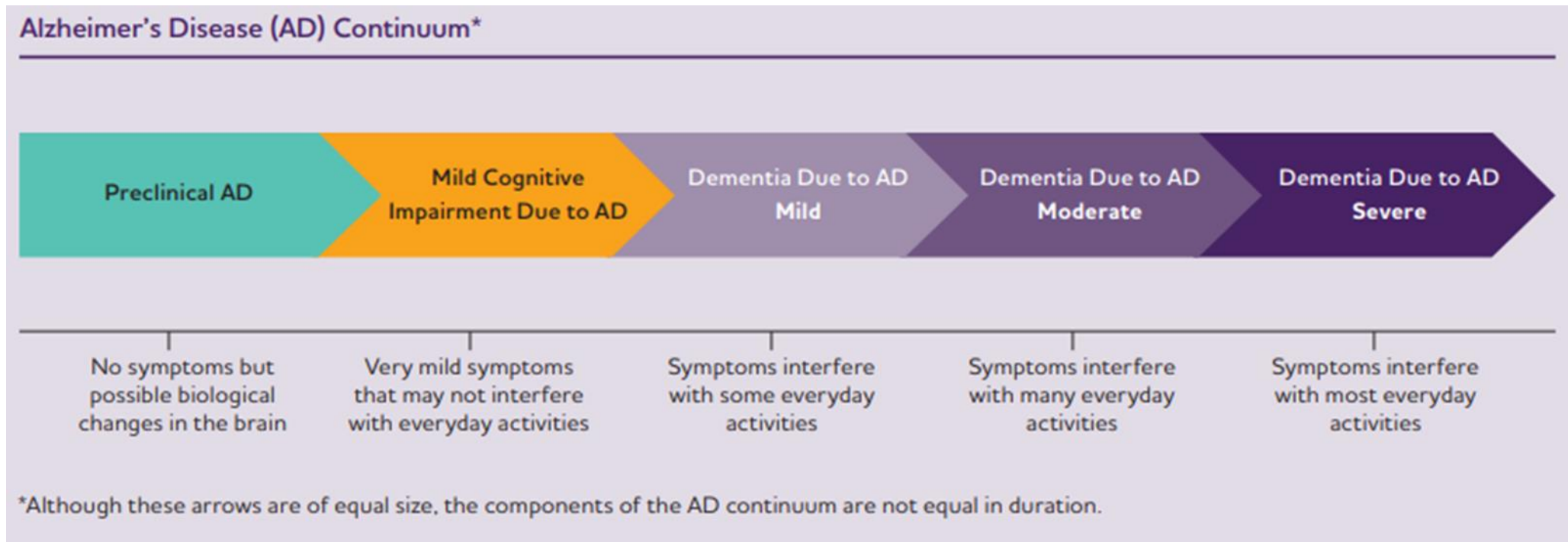
... the only disease in the top 10 leading causes of death that cannot be ...

- Prevented
- Cured
- Slowed

... but there have been advances that offer hope



On the cusp of person-centered treatment



(2020), 2020 Alzheimer's disease facts and figures. *Alzheimer's Dement.*, 16: 391-460. <https://doi.org/10.1002/alz.12068>

Person-Centered Care

Patient-centered care

“Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”

Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. National Academies Press (US), 2001. doi:10.17226/10027

Person-centered care

4 key components:

- Valuing and respecting persons with dementia and those who care for them
- Treating people with dementia as *individuals* with unique needs
- Seeing the world from the perspective of the person with dementia
 - To understand the person's behavior and what is being communicated
 - To validate the subjective experience as perceived by the individual as their reality
- Creating a positive social environment in which the person with dementia can experience relative well-being through care that promotes the building of relationships.

Brooker, D.(2004).What is person centred-care for people with dementia?
Reviews in Clinical Gerontology,13,215–222. doi:10.1017/S095925980400108X

Person-centered care

Key indicators of *individualized care*:

- Developing and regularly reviewing care plans that reflect strengths and needs
- Allowing use of personal possessions
- Accommodating individual preferences and daily routines
- Learning about individual life stories

Brooker, D.(2006).Person-centred dementia care: Making services better. London:Jessica Kingsley Publishers.

2018 DEMENTIA CARE PRACTICE RECOMMENDATIONS



- Person-centered focus
- Assessment and care planning
- Medical management
- Information, education and support
- Dementia-related behaviors
- Activities of daily living
- Workforce
- Supportive and therapeutic environment
- Transition and coordination of services
- Detection and diagnosis

Model is often used in residential care

Table 1.

Examples of Person-Centered Care Approaches Throughout the Progression of Alzheimer's Disease or Related Dementia

Person-centered care in practice

Sam Fazio, Douglas Pace, Janice Flinner, Beth Kallmyer, The Fundamentals of Person-Centered Care for Individuals With Dementia, The Gerontologist, Volume 58, Issue suppl_1, February 2018, Pages S10–S19, <https://doi.org/10.1093/geront/gnx122>

Early

Tom has always been a very independent man. Although he was diagnosed with Alzheimer's disease, he wants to remain as independent as possible. He goes through his day as he always did, although now his wife Joan is always there for support if needed. Joan sometimes has to assist with a task, help with finding the right word, or give a friendly reminder. She also continues to include Tom in decisions, including treatments, future care and finances.

Middle

Frank was a professional musician and played at all of the local and regional clubs. Since he played late night gigs, he was used to staying up late each night as well as sleeping late each morning. When Frank's care needs became too much for his wife, she looked for a memory care center that would support his lifelong schedule. In his new home, Frank stays up late in his room, oftentimes listening to old records. Staff let him wake on his own each morning and include that information in his care plan. Since there is a piano in the reception area, Frank often plays for other residents and visitors.

Late

Emily was an avid gardener. Her yard was perfectly kept with many varieties of plants, which she grew from seed. He loved fragrant bushes, especially lavender. One side of her yard was filled with beautiful bushes. Throughout the progression, she stayed involved in gardening. In the later stage of the Alzheimer's disease, care providers looked through seed catalogues with her, and talked about different varieties. They kept fragrant cut flowers and plants in her room, especially lavender when available. They kept a small satchel of dried lavender under her pillow, and also used a nice lavender lotion to moisturize her hands and feet.

Evidence-based models of care

CMS Dementia GUIDE Innovation Model

Usually re:
education
and services

COMPREHENSIVE ASSESSMENT

Beneficiaries and caregivers receive separate assessments to identify their needs and a home visit to assess the beneficiary's safety.

CARE PLAN

Beneficiaries receive care plans that address their goals, preferences, and needs, which helps them feel certain about next steps.

24/7 ACCESS

Beneficiaries and caregivers can call a member of their care team or a third-party representative using a 24/7 helpline.

ONGOING MONITORING & SUPPORT

Care navigators provide long-term help to beneficiaries and caregivers so they can revisit their goals and needs at any time and are not left alone in the process.

Care delivered by APPs and BSWs w/ MD supervision

REFERRAL & SUPPORT COORDINATION

Beneficiaries' care navigator connects them and their caregivers to community-based services and supports, such as home-delivered meals and transportation.

CAREGIVER SUPPORT

Caregivers take educational classes beneficiaries receive respite services, which helps relieve the burden of caregiving duties.

MEDICATION MANAGEMENT

Clinician reviews and reconciles medication as needed; care navigators provide tips for beneficiaries to maintain the correct medication schedule.

CARE COORDINATION & TRANSITION

Beneficiaries receive timely referrals to specialists to address other health issues, such as diabetes, and the care navigators coordinate care with the specialist.



CG service
use is often
low

Model intended for
community-dwelling
beneficiaries

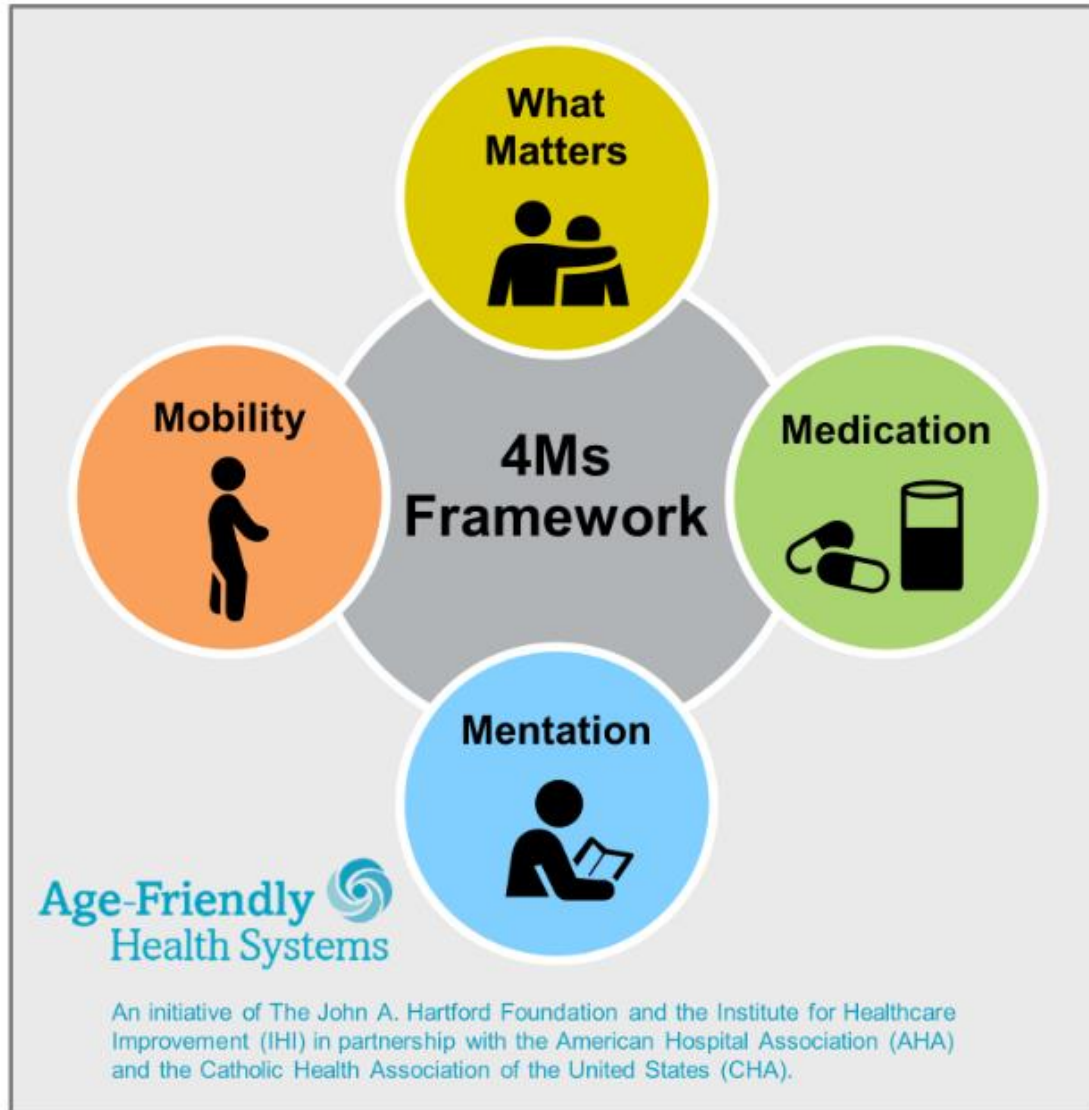
Age-Friendly Health System



AFHS Aims

- Follow an essential set of evidence-based practices
- Cause no harm
- Align with *What Matters* to the older adult and their family caregivers

**AFHS is intended for use
with older adults across
services throughout the
health system**



What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

4 Ms are used to...

Identify core issues that should drive all decision making in the care of older adults

Organize care and focus on the older adult's wellness and strengths rather than solely on disease

Are relevant regardless of an older adult's individual disease(s)

**Special considerations
for dementia?**

Adapted from: Tinetti M. "How Focusing on What Matters Simplifies Complex Care for Older Adults."
Institute for Healthcare Improvement Blog. January 23, 2019.

<http://www.ihl.org/communities/blogs/how-focusing-on-what-matters-simplifies-complex-carefor-older-adult>

	What Matters	Medication	Mentation: Dementia	Mentation: Depression	Mobility
Aim	Know and align care with each older adult's specific health outcome goals and care preferences, including, but not limited to, end-of-life care, and across settings of care.	If medication is necessary, use age-friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.	Prevent, identify, treat, and manage dementia across settings of care.	Prevent, identify, treat, and manage depression across settings of care.	Ensure that each older adult moves safely every day to maintain function and do What Matters most.

Physician-led but all disciplines play a role

So...what can matter to a person with dementia?

Some of “what matters” is specific to the stage of dementia and living setting

- Where they live
- Who cares for them
- Not burdening family
- Which activities they do
- Which decisions they make
- Minimizing pain
- Feeling safe
- Feeling connected
- Foods they enjoy
- Quality versus quantity of life

Ask the older adult *what matters*

Think about how many preferences here may rely on the resources of others

If you do not have existing questions to start this conversation, try the following, and adapt as needed:

"What do you most want to focus on while you are in the hospital/emergency department for _____ (fill in health problem) so that you can do _____ (fill in desired activity) more often or more easily?"^{3,4,5}

For older adults with advanced or serious illness, consider:

"What are your most important goals if your health situation worsens?"⁶



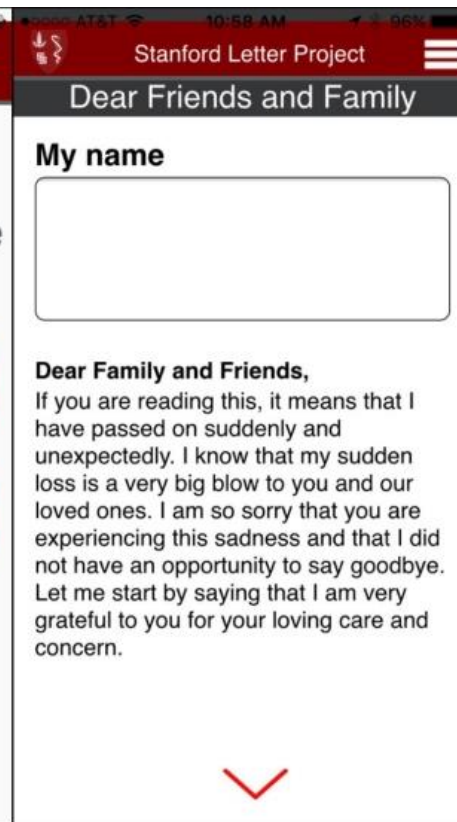
Stanford Letter Project



VJ Periyakoil, MD
Professor of Medicine
Stanford University

"2.6 million Americans die every year, and very few of them get to talk to their doctor about their end of life wishes."

She urges every adult to tell their doctors about how they want to spend their last days; she suggests engaging in end-of-life discussions each time you reach a milestone in your life such as getting married, having a baby or being diagnosed with a chronic illness.



Dear Doctor,

My Doctor's name

RE: What matters most to me at the end of my life

I have been reading and thinking about end-of-life issues lately. I realize how important it is that I communicate my wishes to you and my family. I know that you are very busy.

You may find it awkward to talk to me about my end-of-life wishes or you may feel that it is too early for me to have this conversation. So I am writing this letter to clarify what matters most to me.

My name

What Matters Most to Me

Examples: Being at home, doing gardening, going to church, playing with my grandchildren

My important future life milestones:

Examples: my 10th wedding anniversary, my grandson high school graduation, birth of my granddaughter

Here is how we prefer to handle bad news in my family

Examples: We talk openly about it, we shield the children from it, we do not like to talk about it, we do not tell the patient

Here is how we make medical decisions in our family

Examples: I make the decision myself, my entire family has to agree on major decisions about me, my daughter who is a nurse makes the decisions etc.

Here is who I want making medical decisions for me when I am not able to make my own decisions

1.

2.

3.

What I DO NOT want at the end of my life

- I do not want to be on a breathing machine
- I do not want artificial liquid feeding
- I do not want dialysis
- I do not want to spend my last days in a hospital
- I do not want to die at home
- Other

What I DO WANT at the end of life

- I want to be pain free
- I want to spend my the last days in the hospital
- I want you to help me die gently and naturally
- I want to die at home
- I want hospice care
- Other

If my pain and distress are difficult to control, please sedate me (make with sleep with sleep medicines) even if this means that I may die sooner

- Yes
- No

What to Discuss in a “What Matters” Conversation

“What Matters” conversations are more effective and actionable if they: 1) explore the older adult’s life context, priorities, and preferences and connect them to the impacts of care, self-management, and care decisions; and 2) are anchored to tangible health or care events in an older adult’s life. It may be appropriate to have an initial conversation in an outpatient setting that is focused on understanding an individual older adult’s life context, then follow up with treatment-specific questions or start a conversation from a diagnosis and specific treatment decisions, and then broaden the discussion to the older adult’s life preferences.⁸



Institute for Healthcare Improvement

TOOLKIT

“What Matters” to Older Adults?

A Toolkit for Health Systems to Design Better Care with Older Adults

This content was created especially for:

Age-Friendly Health Systems

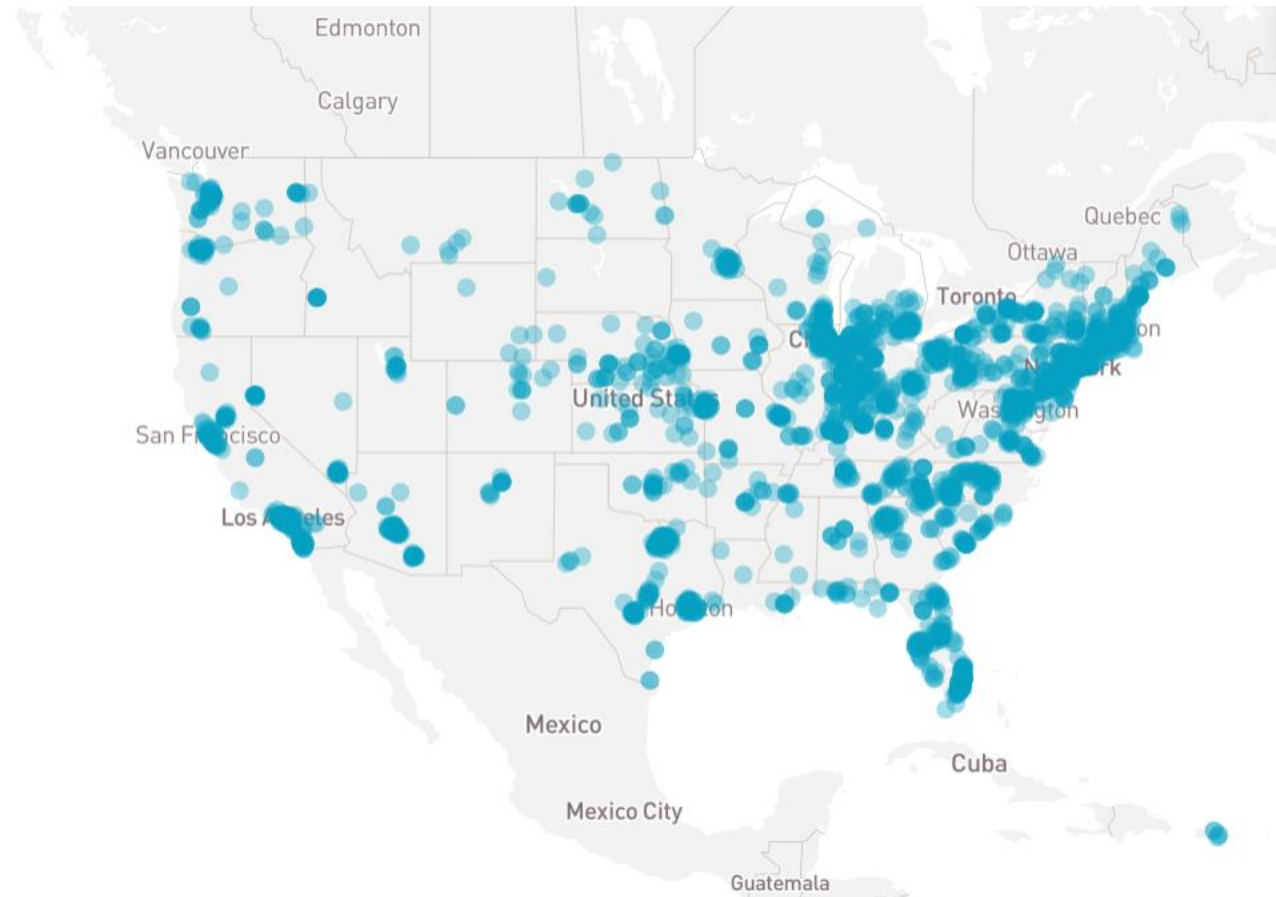
An initiative of The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States (CHA).



Significance of the AFHS

There are currently over 3,000 health care entities registered as participants in the AFHS initiative.

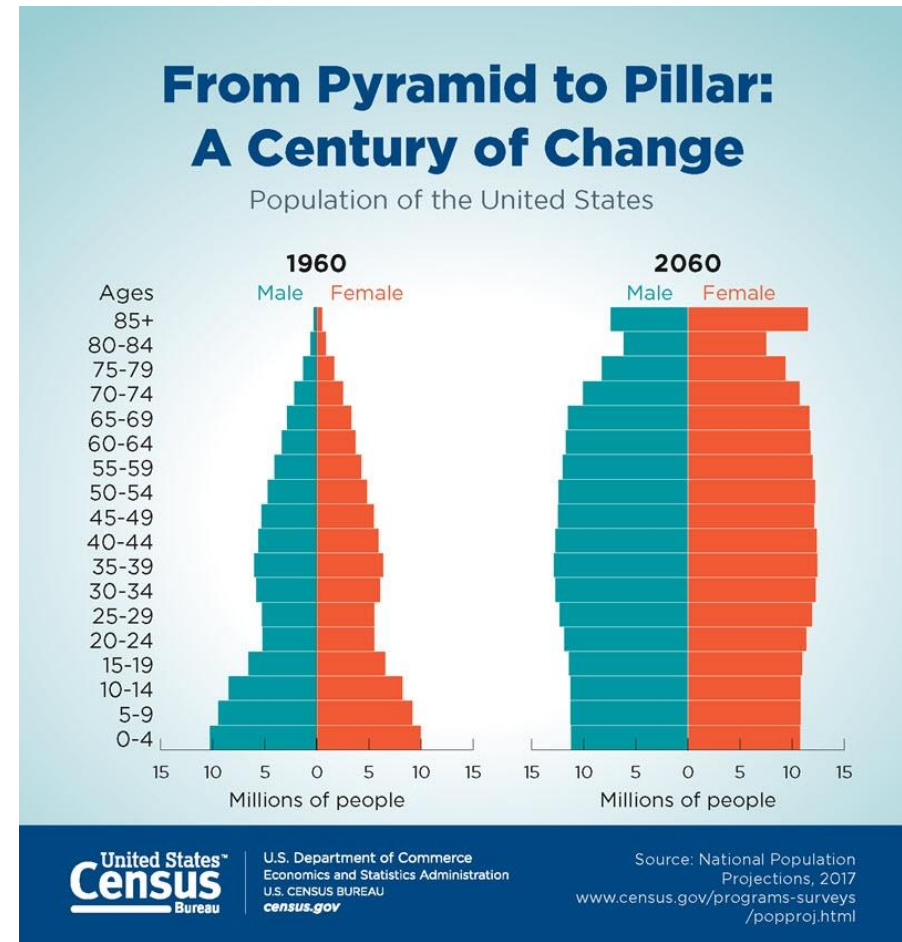
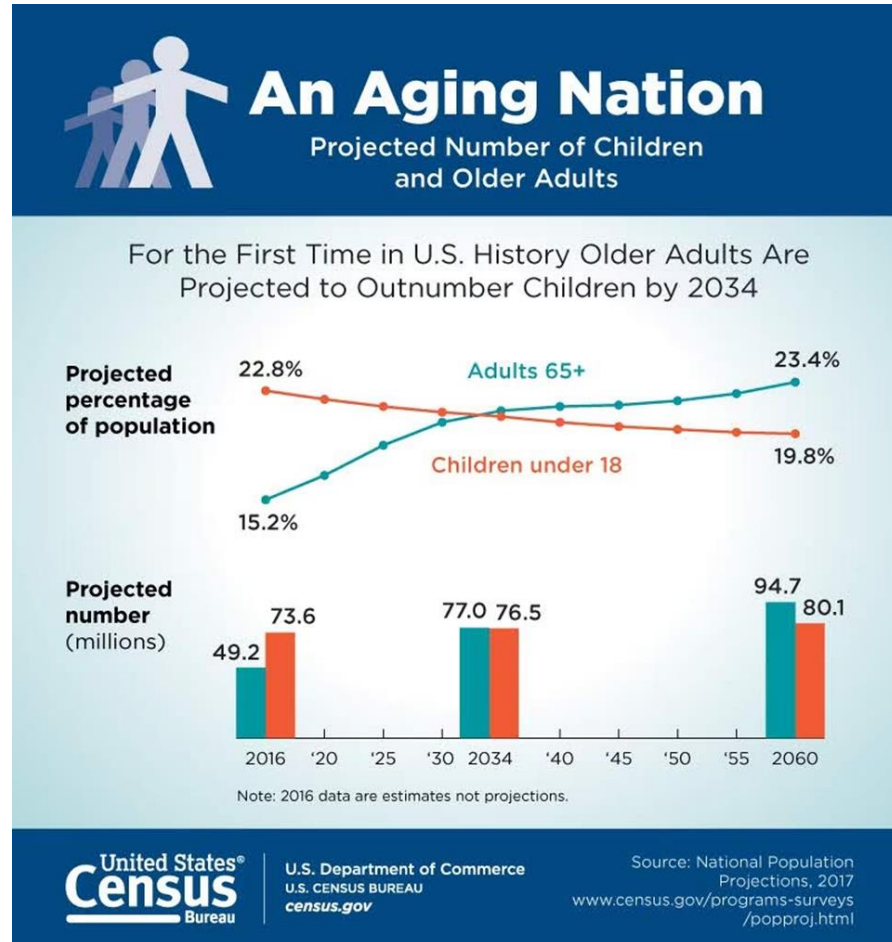
*North
Pacific
Ocean*



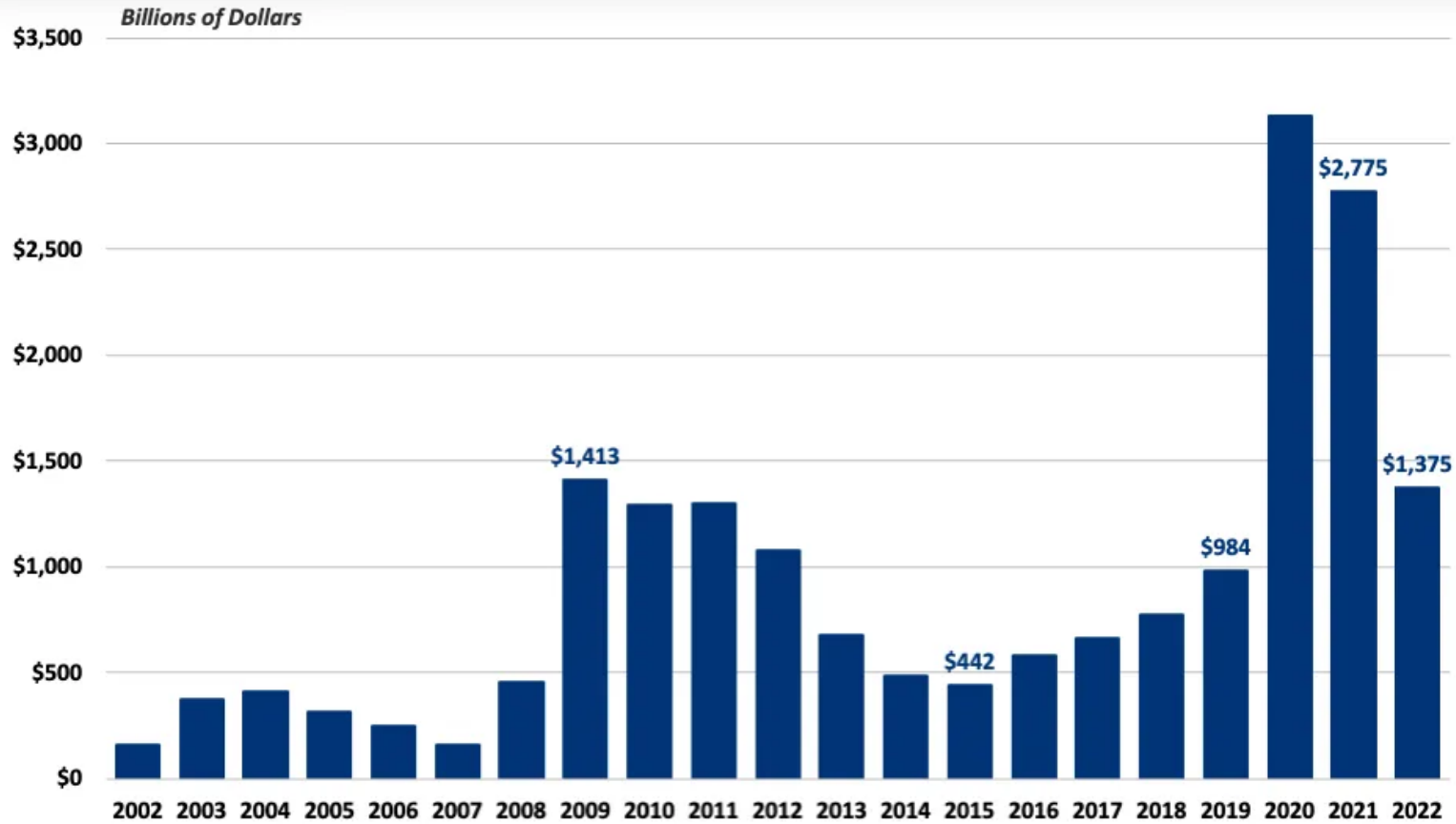
What drives the proliferation of new models of dementia care?



US Aging Population



FY 2022 Deficit Totaled \$1.4 Trillion



Sources: Congressional Budget Office and U.S. Department of the Treasury.



Realization that Family Caregivers Matter

Recognize, Assist, Include, Support, & Engage (RAISE)
Family Caregivers Act
Initial Report to Congress

Prepared by: RAISE Family Caregiving Advisory Council
With assistance from: Administration for Community Living,
an operating division of the U.S. Department of Health and Human Services



2022 National Strategy to Support Family Caregivers

Developed by:
The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council
&
The Advisory Council to Support Grandparents Raising Grandchildren



RECOGNIZE | **ASSIST** | **INCLUDE** | **SUPPORT** | **ENGAGE**

Technical assistance provided by the Administration for Community Living | September 21, 2022



HOWEVER....The perceived value of family caregivers differs by stakeholder group and care setting

Government mandates/incentives



- Use of psychotropic medications
- Minimum staffing levels
- Hospital readmissions
- Quality metrics

Increased awareness of disparities



These factors have changed workforce considerations (e.g., CHWs, patient navigators, etc.)



Reflections on dementia care

The experience of dementia differs for each person and each caregiver

A person's/family's early experience with dementia can shape the future trajectory

Health and human service professionals typically see family members primarily as in service to the person with the impairment

Caregivers do not stop being caregivers when a loved one enters residential care

A family systems, relational perspective is sorely lacking in dementia care

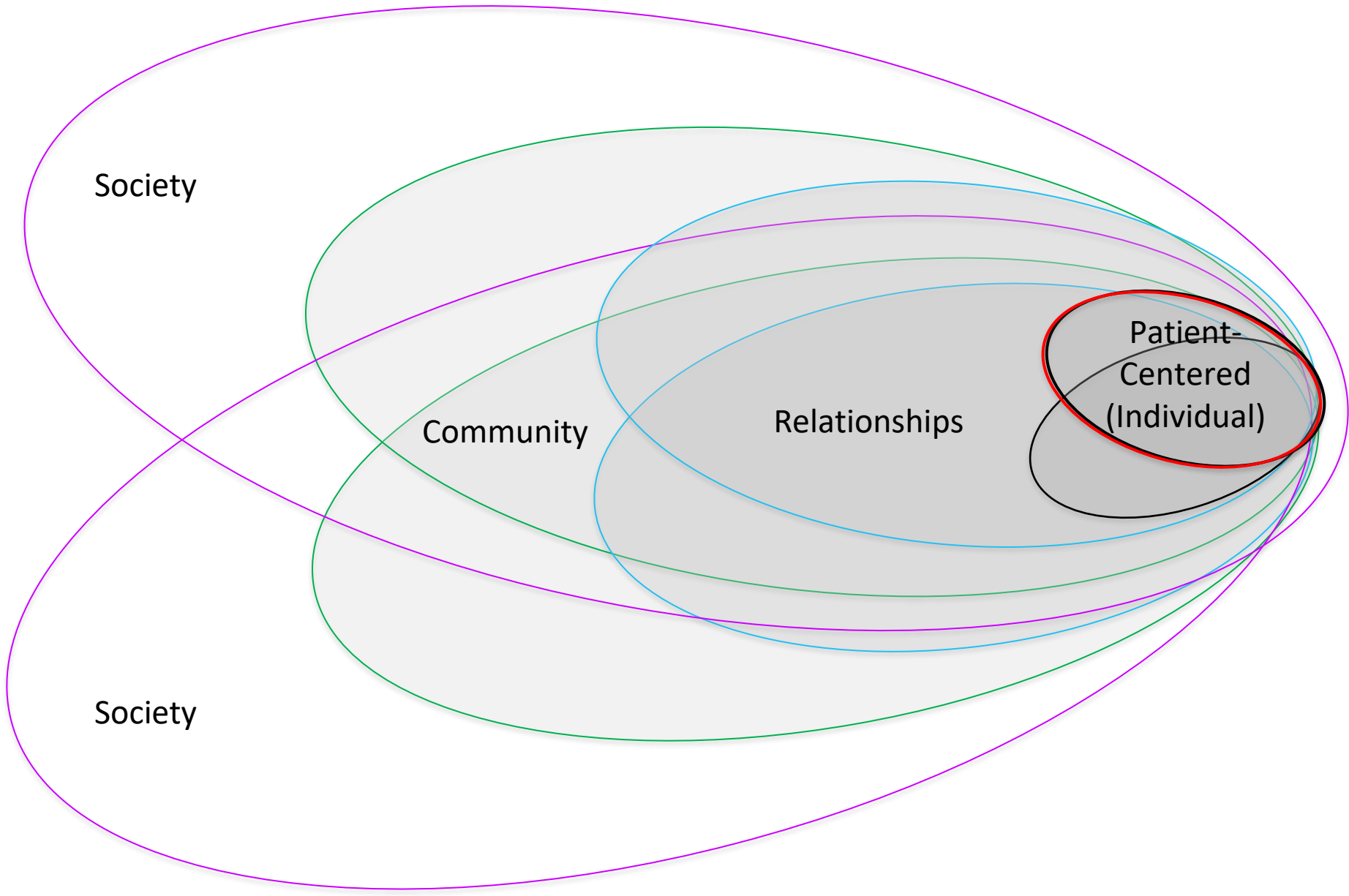
RELATIONAL, SYSTEMIC CARE



Finding a
lane for the
relational,
systemic
therapist

Photo by [Denys Nevozhai](#) on [Unsplash](#)

Family-Framed Approach

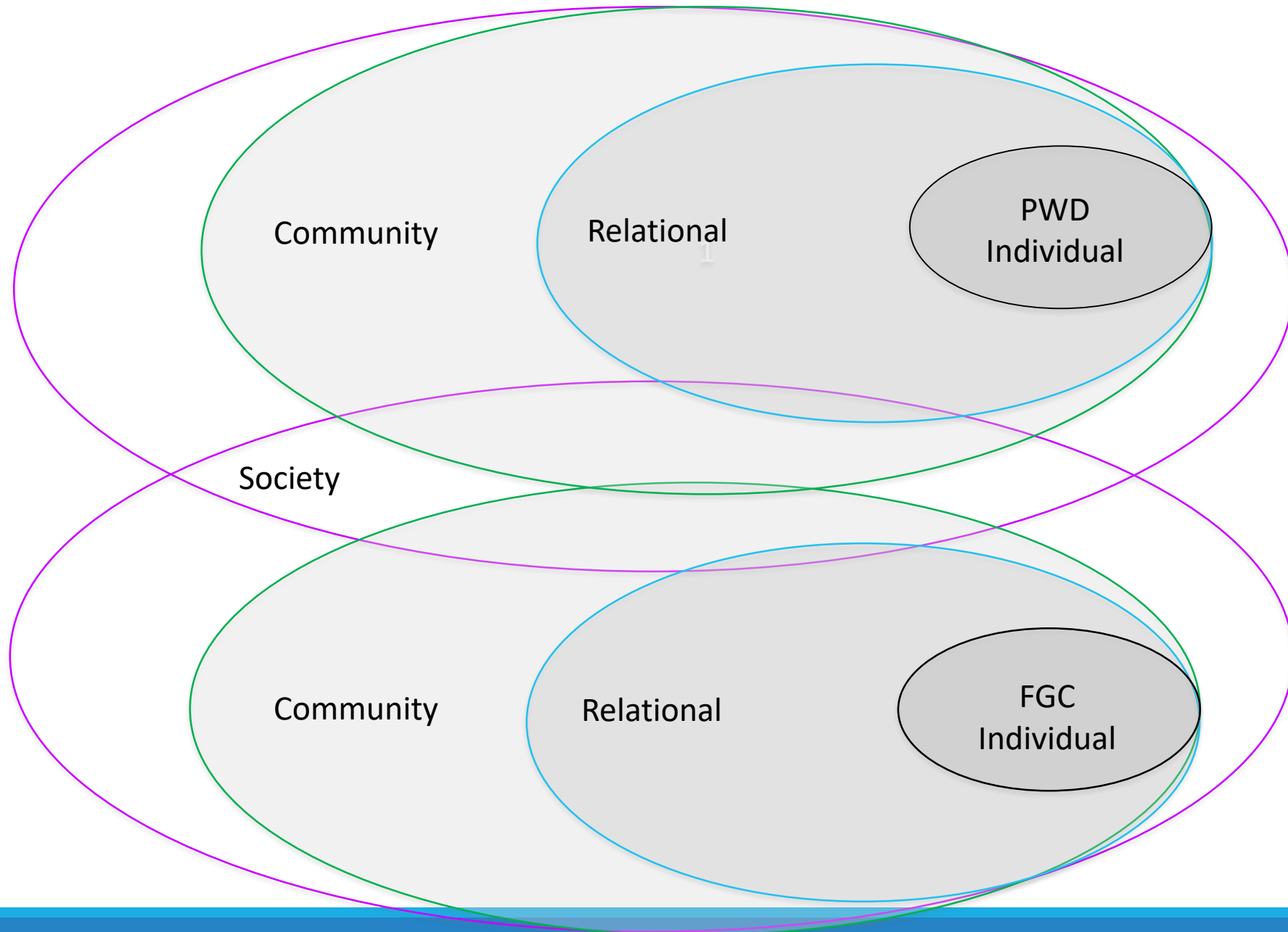


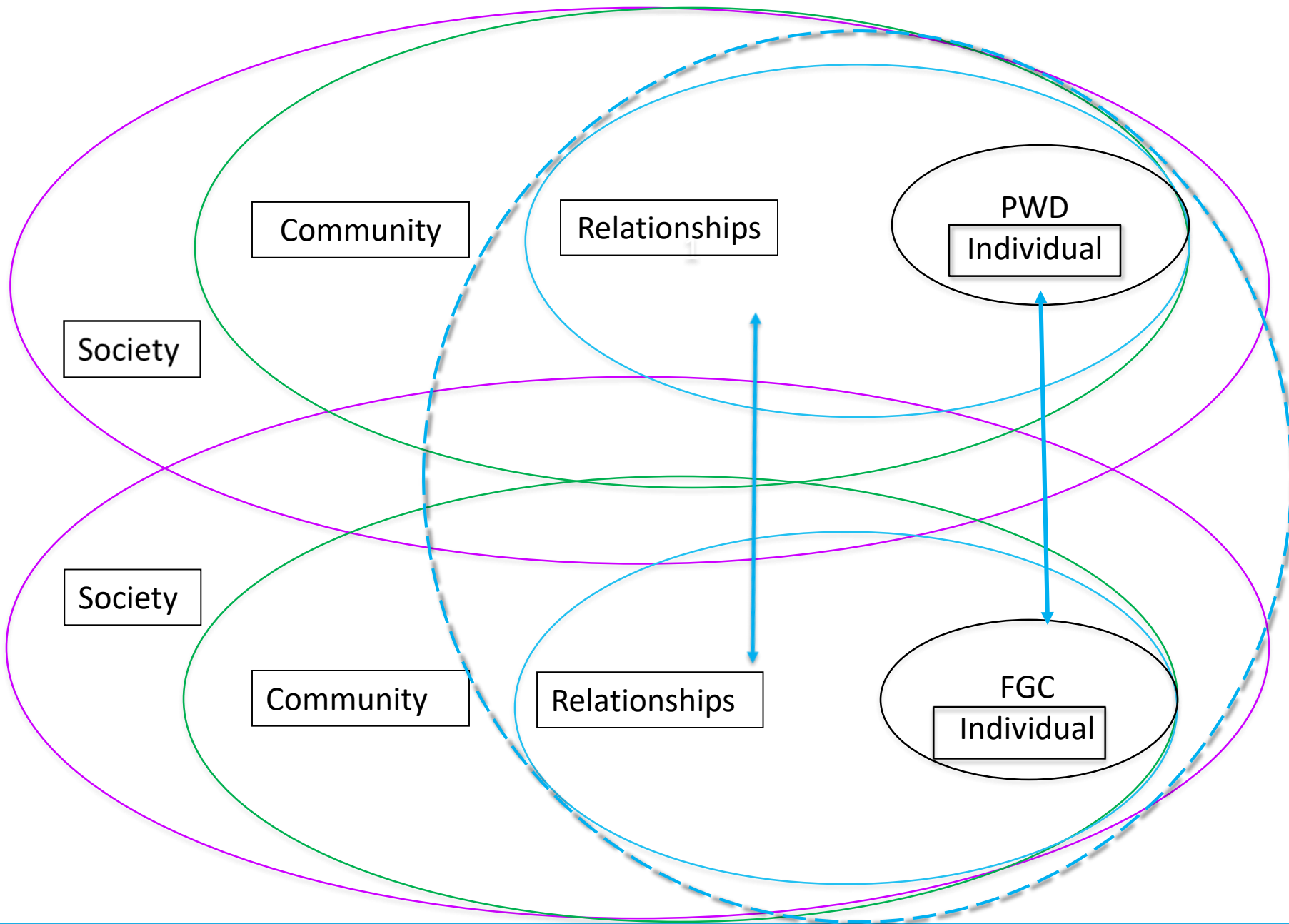
What's missing?



**ACKNOWLEDGMENT OF
THE FAMILY CAREGIVER'S
BIOPSYCHOSOCIAL NEEDS**

**ASSESSMENT OF HOW
FAMILY RELATIONSHIPS,
BEHAVIORS, HEALTH,
RESOURCES, ETC. MAY
AFFECT THE PWD'S WELL-
BEING**





Family-Framed Dementia Care *Goals*

For medical, healthcare, and human service providers to know and understand the PWD and FCG(s) within the context of their family relationships in order to develop a plan of care that:

Meets the biopsychosocial needs and wishes of the PWD

Considers the needs, wishes, and resources of the FCG(s)

so that the care plan will:

Be feasible

Likely to be implemented

Promote the safety and well-being of the PWD and FCG(s)

Family-Framed Dementia Care *Principles*

Because dementia is progressive, degenerative, and has a duration of approximately 10 years the needs of the PWD, FCG(s), and other family members develop and change over time.

As a result those in need of intervention can include:

- PWD
- FCG(s)
- Other Family Members or CGs
- PWD and FCG(s)
- The whole family

Family-Framed Dementia Care *Skills*

A general understanding of how family systems, relationships, and dynamics affect the lived experience of dementia for those with the diagnosis and those who care for them

→ Don't assume close, trusting relationships

Proficiency in administering a comprehensive family assessment to understand the strengths, and resources

→ Family/social history is more than smoking status

Knowing when to refer the patient and/or family caregiver(s) for behavioral health services or family therapy

→ Clarify reason for referral

Evaluating the needs of the family caregiver(s) to determine if they are willing, capable, and have the resources needed to provide the required support while maximizing their own health and well-being

→ Don't assume the "informant" is the "caregiver" or "HCP," etc.

Need for systemic therapists

Through integration, collaboration ...

- Perform biopsychosocial assessments of persons with cognitive impairment and those who care for them
- Share relevant information for inclusion in care planning
- Support caregivers throughout the course of dementia and advocate for their needs as appropriate
- Facilitate important patient/family conversations (e.g., what matters, advance directives, addressing discrepancies between what matters and what is possible)

BREAKING NEWS!

MFTs in Medicare efforts has been included in the proposed omnibus package currently making its way through Congress. It is anticipated that both houses of Congress will take action on this bill in the coming days.

Stay tuned to the AAMFT Blog and social media accounts for updates.



**AAMFT
Announcement**

December 20, 2022

MFTs will be
eligible to become
Medicare
providers in 2024

FOR IMMEDIATE RELEASE

December 2, 2022

Contact: HHS Press Office

202-690-6343

media@hhs.gov

HHS Roadmap for Behavioral Health Integration

<https://www.aspe.hhs.gov/reports/hhs-roadmap-behavioral-health-integration>





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Questions for reflection

Is person-centered care sufficient for those with dementia throughout the disease?

Can an AFHS promote dementia care that is “person centered” *and* relational and systemic (i.e., “family framed”)?

How can we promote efforts to reconcile patient care preferences with the preferences and capacity of the patient’s family to honor the patient’s wishes?