

Special Challenges in Health Care Decision Making for Patients with Dementia

Andrew B. Cohen, MD, DPhil

Assistant Professor

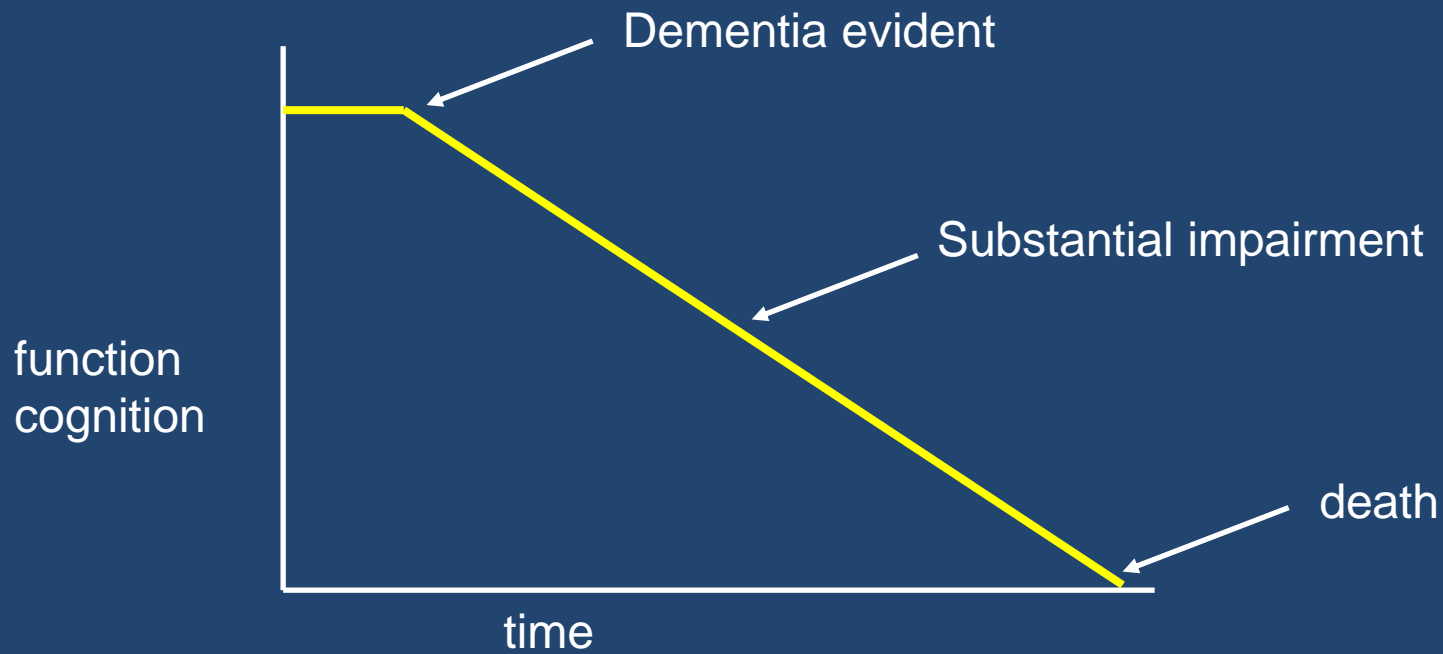
Yale School of Medicine

VA Connecticut Healthcare System

(Supported by K76AG059987, P30AG21342 — both NIA)

Yale SCHOOL OF MEDICINE

Dementia: Cognition and Function



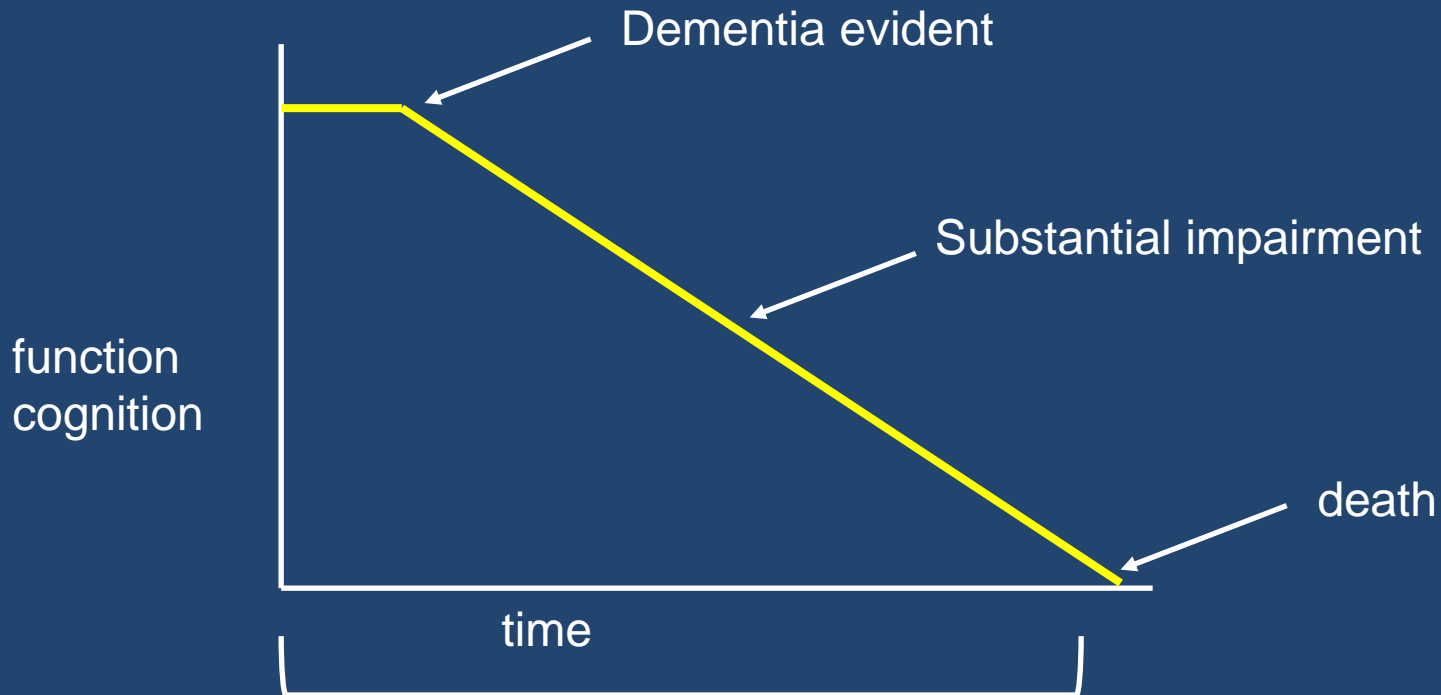
Challenges with Discrete Decisions

- Requires information about benefits and harms
- Benefits different in dementia
 - Common benefits include: maintaining function
maintaining cognition
prolonging life
 - But function and cognition decline inexorably
 - Life expectancy limited
- Treatment harms also often different

Challenges with Discrete Decisions

- An example: anticoagulation in atrial fibrillation
- Decision aids based on CHADS₂VASC, HAS-BLED
- As dementia progresses: less function left to lose,
less life expectancy left to protect
- When to continue anticoagulation and when to stop it?

Challenges with Discrete Decisions



FAST/ GDS



CDR



At each stage:
What is likely benefit?
What is likely harm?

Challenges with Discrete Decisions

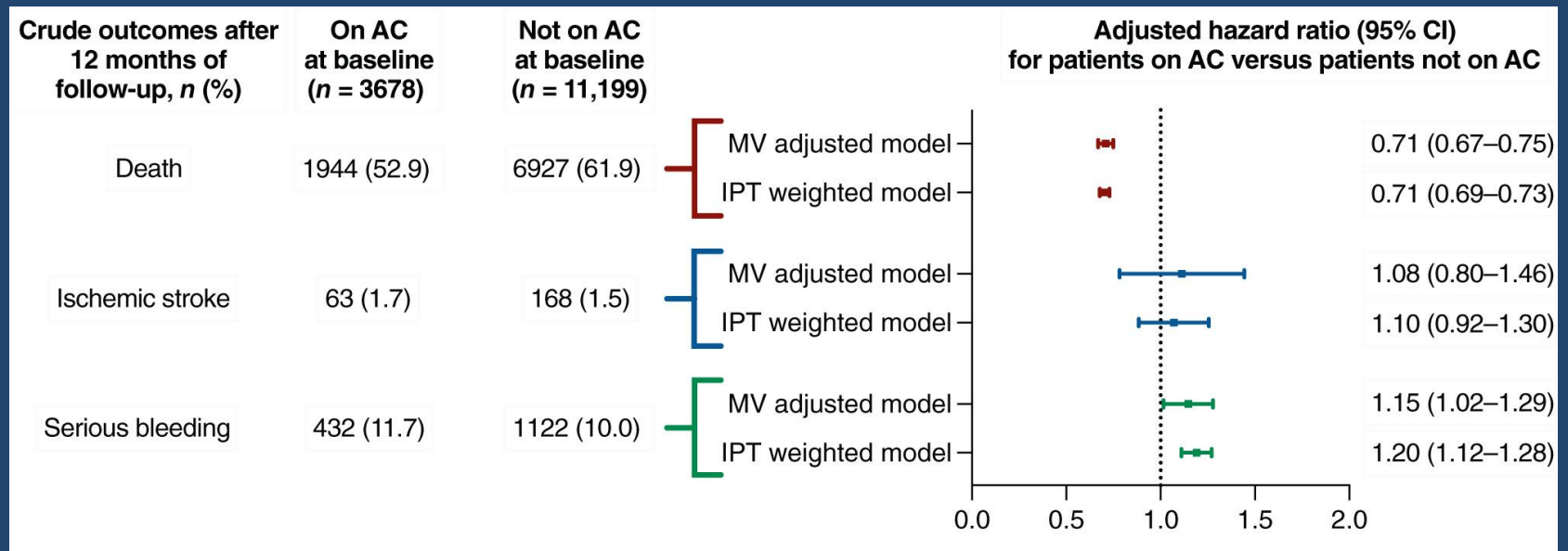
1. Use MDS or OASIS data

Table. Demographic and Clinical Characteristics by Anticoagulant Use

Characteristic	No. (%)		Adjusted OR (95% CI)
	Anticoagulation in the last 6 mo of life (n = 5033)	No anticoagulation in the last 6 mo of life (n = 10 184)	
Age (overall), y			
<80	785 (15.6)	1142 (11.2)	1 [Reference]
80 to 89	2560 (50.9)	4541 (44.6)	0.82 (0.74-0.92)
≥90	1688 (33.5)	4501 (44.2)	0.59 (0.52-0.66)
Other clinical factors			
Rejection of care	454 (9.0)	844 (8.3)	1.03 (0.91-1.17)
Falls	1690 (33.6)	3214 (31.6)	1.04 (0.96-1.12)
Weight loss	1856 (37.0)	3363 (33.5)	1.09 (1.01-1.18)
Pressure ulcer	2052 (40.8)	3228 (31.7)	1.37 (1.27-1.48)
Difficulty swallowing	1136 (22.6)	2008 (19.8)	1.12 (1.02-1.22)
Restraint use	189 (3.8)	433 (4.3)	0.79 (0.66-0.95)
Hospice use	1296 (25.8)	3375 (33.1)	0.76 (0.70-0.83)

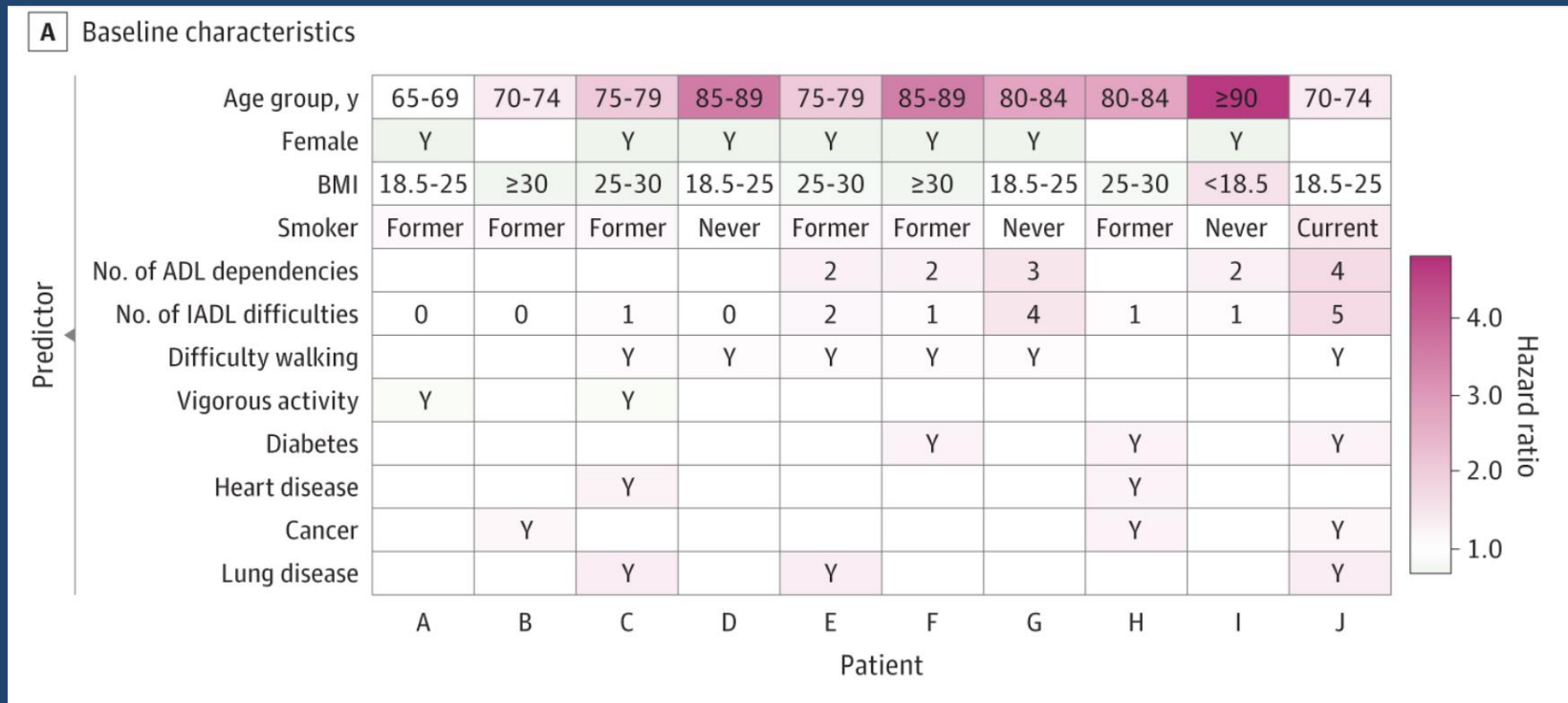
Challenges with Discrete Decisions

1. Use MDS or OASIS data



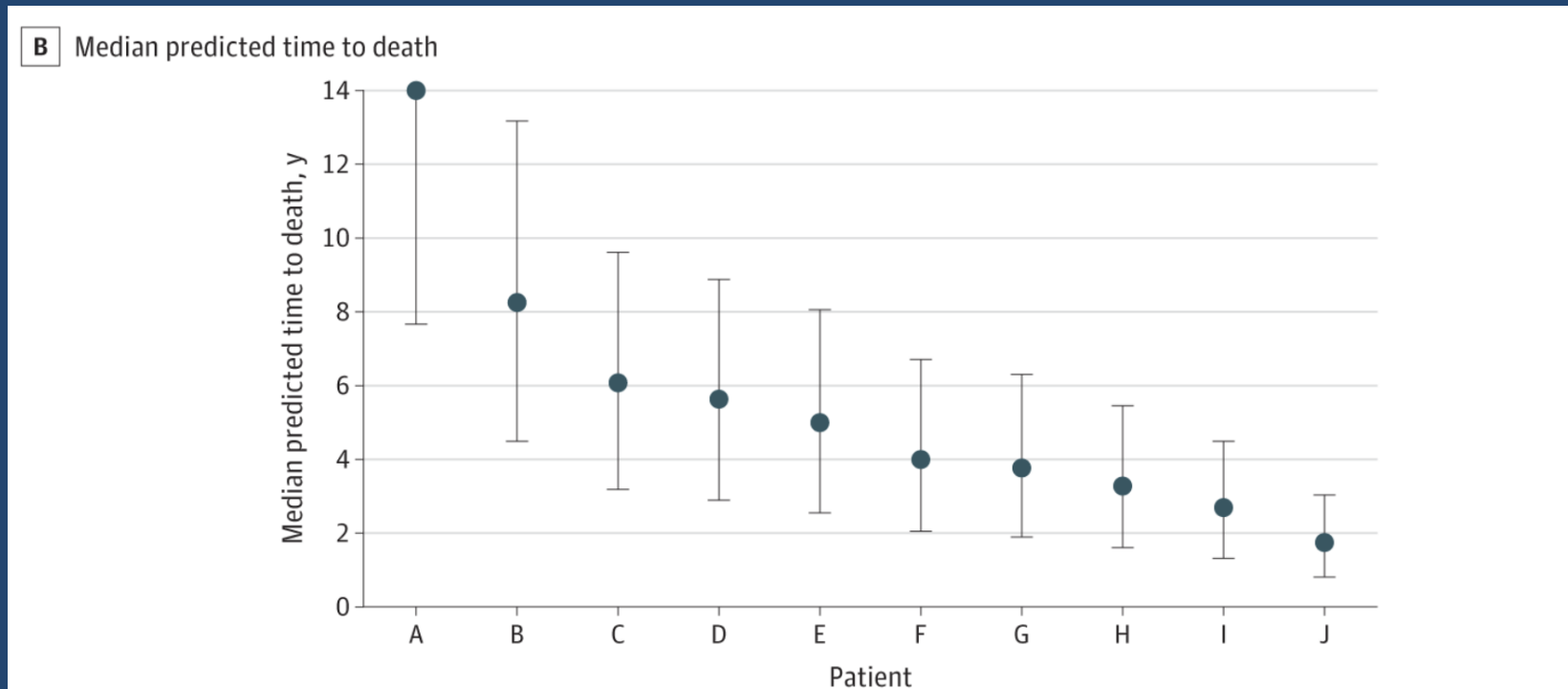
Challenges with Discrete Decisions

2. Use survey data with measures of function, cognition



Challenges with Discrete Decisions

2. Use survey data (e.g., HRS, NHATS)



Challenges with Discrete Decisions

3. Improve severity ascertainment in claims

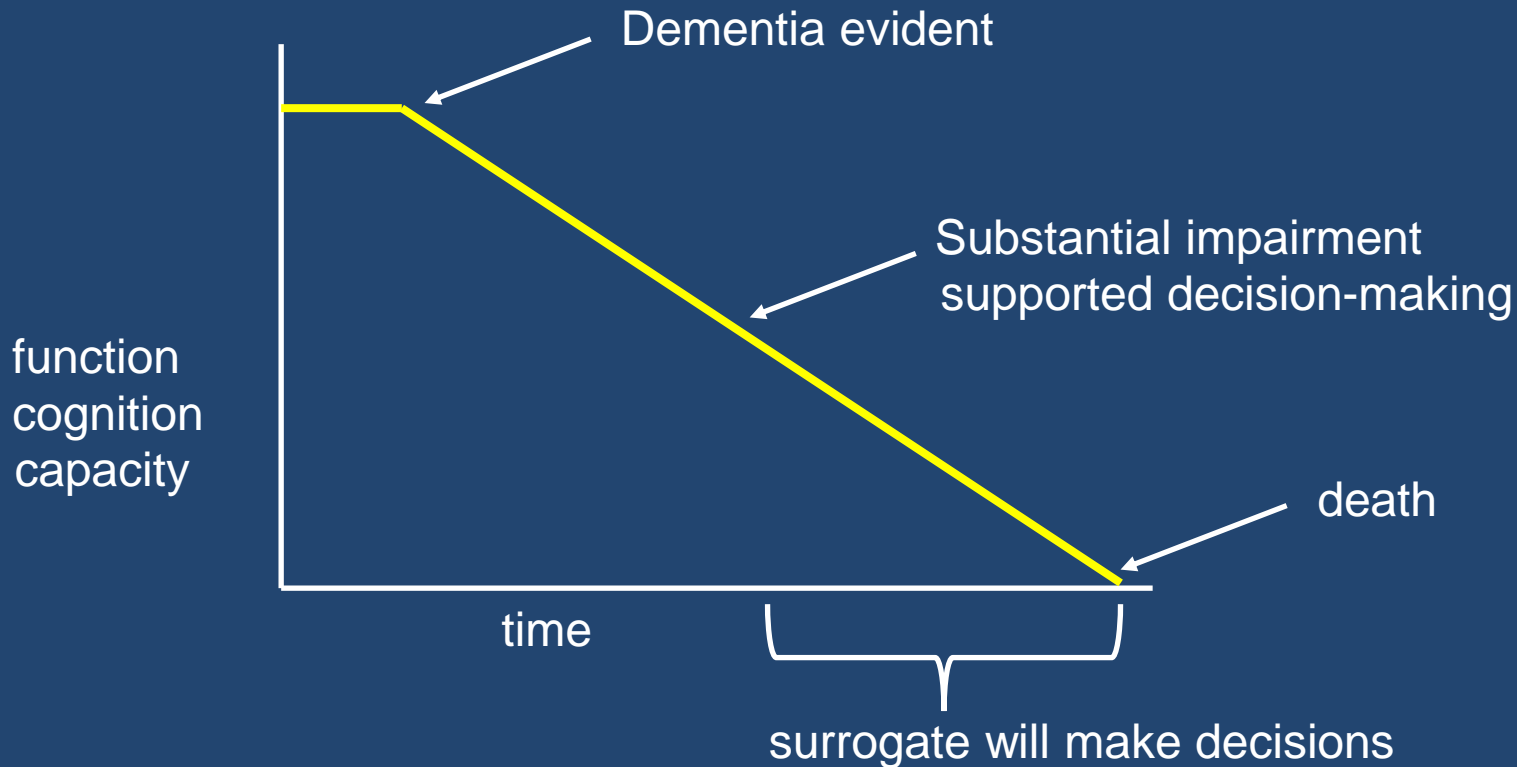
Claims-Based Frailty Index as a Measure of Dementia Severity in Medicare Claims Data

Chan Mi Park, MD, MPH ✉, Stephanie Denise M Sison, MD, MBA,
Ellen P McCarthy, PhD, MPH, Sandra Shi, MD, MPH, Natalia Gouskova, PhD,
Kueiyu Joshua Lin, MD, MPH, ScD, Dae Hyun Kim, MD, MPH, ScD Author Notes

The Journals of Gerontology: Series A, Volume 78, Issue 11, November 2023, Pages 2145–2151, <https://doi.org/10.1093/gerona/glad166>

(GEMSSTAR, 2022)

Challenges with Goal-Oriented Care



Challenges with Goal-Oriented Care

- Surrogate is supposed to exercise substituted judgment
- Unique challenges for substituted judgment in dementia

OPINION
GUEST ESSAY

My Father Didn't Want to Live if He Had Dementia. But Then He Had It.

Oct. 23, 2023

Some years back, in 2004, my father had written a letter to my brother saying that if he or my mother were to get “very sick,” neither would want extraordinary measures taken to keep them alive. “We want to live only if we have a meaningful life,” he wrote.

OPINION
GUEST ESSAY

My Father Didn't Want to Live if He Had Dementia. But Then He Had It.

Oct. 23, 2023

But despite his weakened state, my father didn't seem unhappy. Over the course of his illness, he'd never expressed a sincere wish to die. What was meaningful to my father in 2004 was very different from what had become meaningful to him in the past few months, when watching TV, spending time with his caregiver and children, and even just eating a spoonful of ice cream had clearly given him genuine pleasure.

OPINION
GUEST ESSAY

My Father Didn't Want to Live if He Had Dementia. But Then He Had It.

Oct. 23, 2023

and I faced a terrible dilemma: Whose wishes for his medical treatment were we to honor? Those of my father back when he was a healthy, highly functioning geneticist? Or those of the simpler, weakened man my father had become?

Challenges with Goal-Oriented Care

- Echoes an older debate:

Autonomy and the Demented Self

Dworkin, Milbank Q 1986

Dworkin on Dementia
Elegant Theory, Questionable Policy

Dresser, Hast Cent Rep 1995

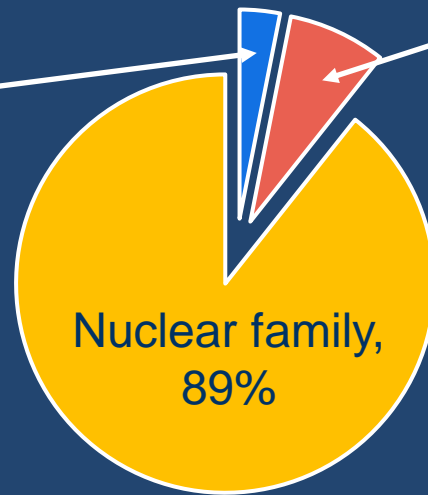
- In practice, surrogates have to figure this out on their own
- More broadly: surrogates expected to know what to do

Challenges with Goal-Oriented Care

- Some persons with dementia do not have surrogates (1-2%)

Some do not have *desired* surrogates (7-8%)

No nuclear family, no other confidantes, 3%



Confidantes, but no nuclear family, 8%

Summary

- Inherent challenges to discrete decisions, goal-oriented care
- Need for:
 - Data to inform discrete decisions
 - Preparation for role of surrogate
 - Improve care in situations where there is no surrogate
- Work already happening by people in this room
- Looking forward to discussion with all of you!