

Social Isolation and Surrogate Decision-Making for Adults Aging in Place with Dementia

Andrew B. Cohen, MD, DPhil

Assistant Professor

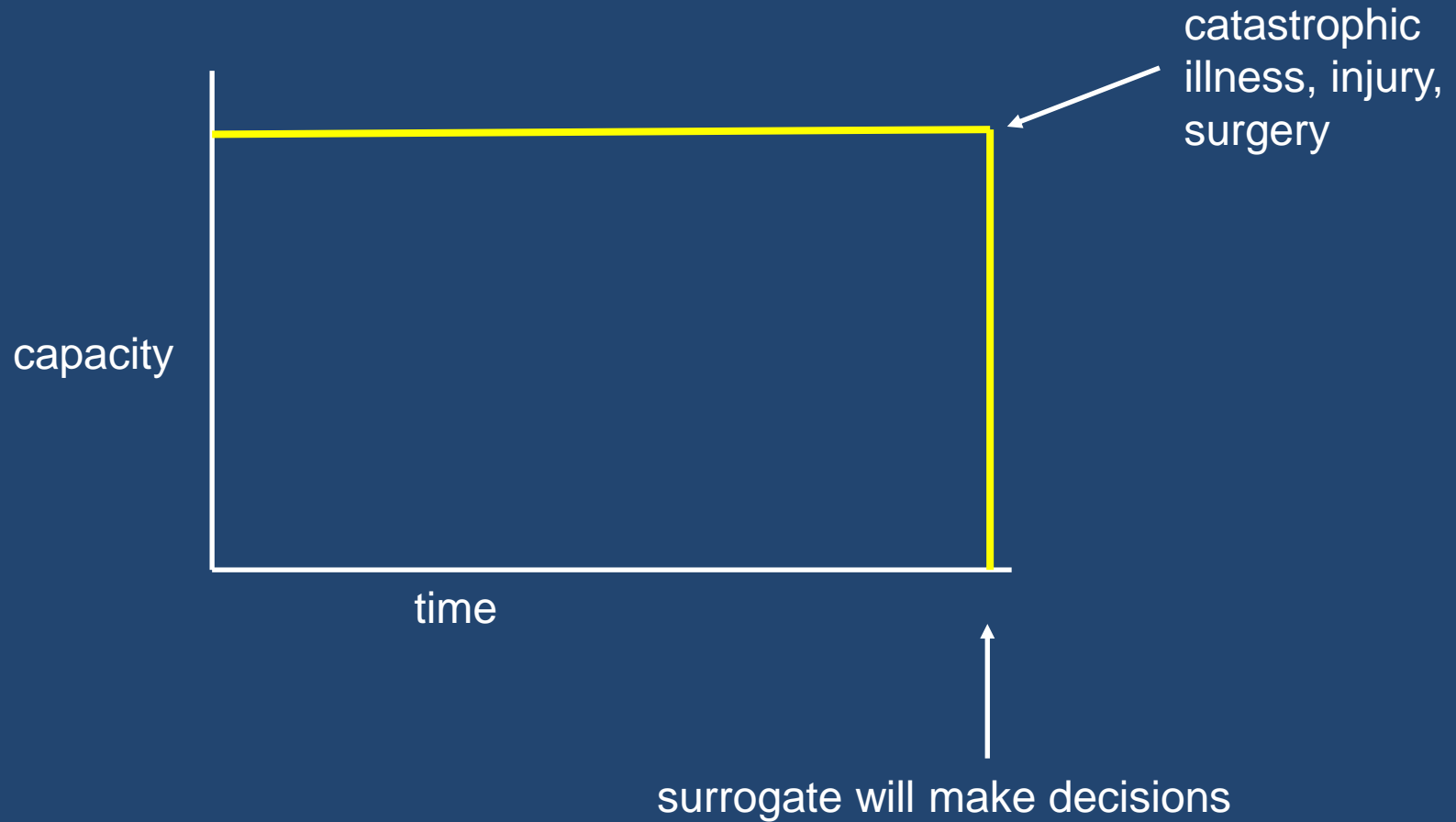
Yale School of Medicine

VA Connecticut Healthcare System

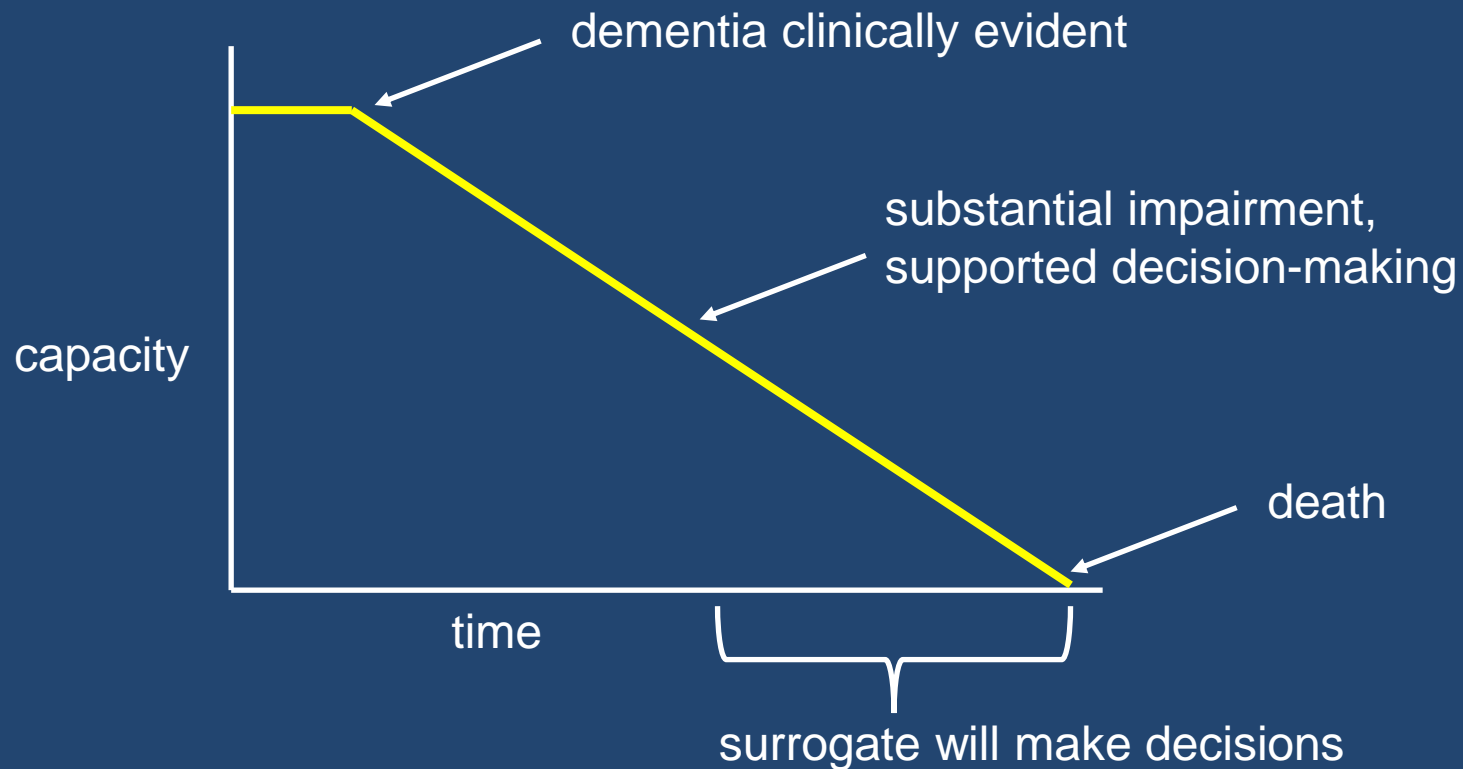
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Decision-Making Capacity



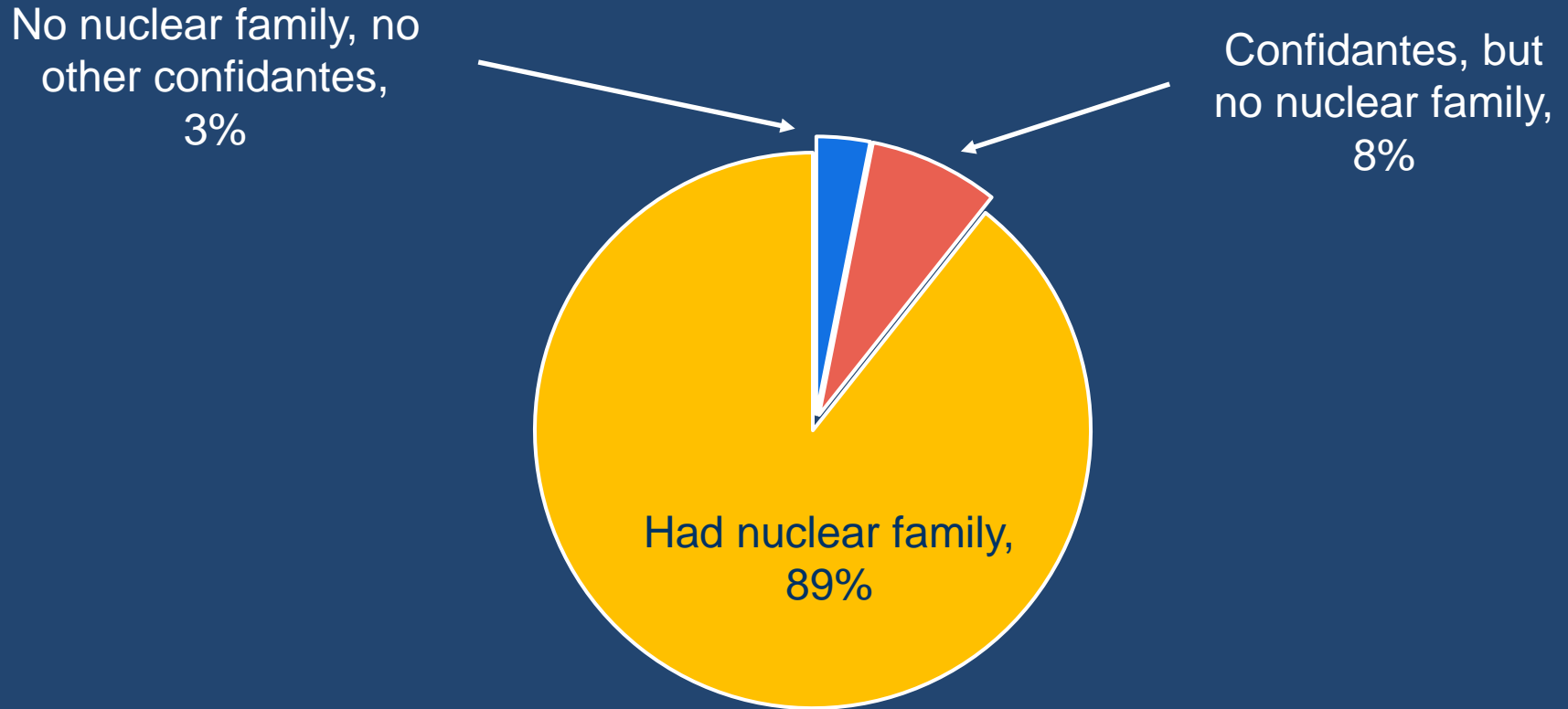
Decision-Making Capacity



Implicit Assumption in this Paradigm

- Surrogate will be a family member
- Increasing number of older adults without nuclear family
- There are older adults with family who do not want their family members to make decisions for them

This Paradigm Doesn't Fit Some Older Persons



Cohen et al, J Amer Geriatr Soc 2020

This Paradigm Doesn't Fit Some Older Persons

Participant: I think that, if you don't die readily, my sister is the type of person who wants to exhaust every possibility of keeping you alive, and I don't prescribe to that. I don't want to be trapped in a body that I can't use. So her making decisions for me, I guess I would just hope she didn't pick up her phone that day.

Interviewer: If there was some option on a form to indicate people who might be asked to do this and you didn't want them, would you be open to filling out that type of form?

Participant: Yes, I would definitely sign that form, yes.

Cohen et al (unpublished)

Unrepresented Adults with Dementia

- “Unrepresented” (“unbefriended”) —
impaired capacity, no suitable surrogate
- Challenges if unrepresented with dementia —
incapacity is prolonged
- Guardianship is the default mechanism

Professional Guardianship

- Mostly involves patients who live in nursing homes
- Fewer than half have no nuclear family
- Professional guardians receive little training
- Their medical decisions are similar to those for patients who have family surrogates

Professional Guardianship

	With guardian (n = 217)	Without guardian (n = 868)	Adjusted OR
ICU admission, %	17.5	13.7	1.33 (0.89, 1.99)
Intubated, %	7.4	6.1	1.21 (0.67, 2.19)
CPR, %	1.8	1.0	1.77 (0.54, 5.88)
Feeding tube, %	6.9	8.1	0.82 (0.46, 1.46)
≥3 admissions, %	12.9	15.9	0.77 (0.50, 1.20)
Death in hospital, %	25.8	29.3	0.83 (0.59, 1.17)

Default Expectation for Surrogates

- We assume that surrogates know how to be surrogates
- Surrogate decision-making in dementia is difficult
- Particularly difficult around questions about aging in place

Questions Going Forward

- How and when should to identify people who do not have a desired surrogate?
- What can we can do about this before capacity becomes impaired?
- How do we train professional guardians and other surrogates to do the best possible job?