# Give Good Care and Avoid "IJ"s:

## Results From an Empirical Study

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10th Annual FSA Compliance and Risk Management Conference

# Conflicts of Interest, and conflicting interests:

- I have no financial conflicts of interest to disclose, but,

- David Hoffman, JD:
- Serves as Clinical Ethics Consultant for VNS of NY, Hospice Program
- Provides legal, ethical and compliance advice to Hospitals and Long Term Care Facilities
- Holds teaching appointments at Columbia University and the Albert Einstein College of Medicine
- Serves on the Board of Directors of The Faith Sommerfield Family Foundation, Inc
- Serves on the Board of Directors of The Completed Life Initiative, Inc

# Why are we here?

Sections

The Washington Post
*Democracy Dies in Darkness*

Health

## Diagnosed with dementia, she documented her wishes for the end. Then her retirement home said no.

Home

Share

455

Susan Saran, a longtime Buddhist, often drives to a nearby monastery to practice her faith. Saran is fighting her retirement community over her right to determine how she will die — even though she has made her wishes known in writing. (Heidi de Marco/KHN)

By **JoNel Aleccia**

# Susan Saran:

When she worked on the trading floor of the Chicago Board Options Exchange, long before cellphone calculators, Susan Saran could perform complex math problems in her head. Years later, as one of its top regulators, she was in charge of investigating insider trading deals.

Today, she struggles to remember multiplication tables.

Seven years ago, at age 57, Saran was diagnosed with frontotemporal dementia, a progressive, fatal brain disease. She had started forgetting things, losing focus at the job she had held for three decades. Then tests revealed the grim diagnosis.

“It was absolutely devastating,” Saran, 64, said. “It changed everything. My job ended. I was put out on disability. I was told to establish myself in an [extended] community before I was unable to care for myself.”

Early signs of dementia that family members may notice

So Saran uprooted herself. She sold her home in 2015 and found a bucolic retirement community in rural New York whose website promised “comprehensive health care for life.”

# Susan Saran:

And now, she is fighting with that community over her right to determine how she will die — even though she has made her wishes known in writing. Similar fights could ensnare millions of Americans with dementia and similar end-of-life directives in coming years.

# And Mary Northern:

## State Dept. of Hum. Serv. v. Northern

**563 S.W.2d 197 (1978)**

STATE of Tennessee, DEPARTMENT OF HUMAN SERVICES, v. Mary C. NORTHERN.

**Court of Appeals of Tennessee, Middle Section.**

February 7, 1978.

Certiorari Denied March 14, 1978.

*201 William B. Hubbard, Patricia J. Cottrell, Asst. Attys. Gen., Gregory M. Galloway, Nashville, for State of Tennessee.

Carol L. McCoy, Nashville, for Guardian Ad Litem.

Ames Davis, Nashville, for amicus curiae.

Certiorari Denied by Supreme Court March 14, 1978.

TODD, Judge.

OPINION

Risk Management ….

OR

risk avoidance?

That is the question

The New York Times

# *Pope Says a Strong U.S. Faction Offers a Backward, Narrow View of the Church*

In unusually sharp remarks published this week, Pope Francis said some conservative American Catholics wrongly ignore much of the Church's mission and reject the possibility of change.



Pope Francis arriving for the weekly general audience in Paul VI hall at the Vatican on Tuesday. Filippo Monteforte/Agence France-Presse — Getty Images


By Jason Horowitz and Ruth Graham
Reporting from Rome and Dallas

Published Aug. 30, 2023 Updated Aug. 31, 2023, 10:17 a.m. ET

# Plan for today – Discuss:

- In this session we will explore the ethical tension between organizational obligations to provide all necessary and appropriate care on the one hand, while simultaneously respecting the right of patients and residents to refuse care, even when it is medically indicated and efficacious.

# Plan for today – Discuss:

Methods for reconciling the competing demands of respect for patient autonomy and the duty of beneficence, which requires that we do what is right for the patient, even if they don't realize it, will be presented through data from an empirical study on resistance by long term care facilities to honoring the advanced directives of patients suffering from dementia.

# Plan for today – Discuss:

Participants will learn to distinguish between withdrawing/withholding care that is legally mandated due to a valid, patient choice, and circumstances that constitute neglect, which can result in findings of Immediate Jeopardy.

# What is VSED??

- VSED is a manner of deliberately hastening death by deciding to stop consuming food & fluids while still physically able to eat & drink
- It is an intentional & voluntary choice by a decisionally capable person who suffers intolerably from an incurable, progressive or terminal illness with the goal of hastening his/her death
- Distinct from frequently occurring diminished appetite often experienced by dying persons
- Rarely 1st choice but often ONLY legal option

# What is a **successful VSED outcome**?

## How is success defined?

- VSED is legally available in all states IF person decisionally capable & makes voluntary (i.e. uncoerced) informed & contemporaneous choice
- A *'successful'* outcome = **peaceful death with minimum of discomfort occurring within a predictable period of days or weeks** (my definition)
- Cause of death is dehydration not starvation

# Four ingredients necessary for successful VSED death?

1. Decisionally capable, suffering pt who is VERY determined to hasten death by fasting

   - must understand the process, know what to expect & have concluded burdens of living consistently out-weigh benefits of continued life (This option is not for everyone!)

2. Must have both social & care-giving support

3. Must have access to hospice or palliative medical oversight

4. Must be able to be patient with the process

# Clinical challenges to peaceful VSED death

- For those with terminal illness, forgoing food usually not difficult as appetite often diminished
- Forgoing fluids **can** be challenging – but w good oral care, rinsing & spitting, fine spray etc help relieve  feeling of dry mouth
- Also – use of small doses of opioids & anti-anxiety meds → sleepy state
- Usual  length of fast 7–14 days [aver. is 10] if fluids significantly limited & pt terminally ill
- Pt often slip into coma during final days

# More challenges when patient **NOT** terminally ill

- Can be difficult to obtain palliative over-sight

  - sometimes long-time MD will order meds & provide palliative management or refer hospice

- Sometimes pt must fast for several days before considered eligible for home hospice support
- In absence of terminal illness – fasting can be more 'challenging' & last longer - up to 3 wks?
- Must be clear to all that patient's suffering is intolerable & their decision to 'escape' is voluntary, well considered & very determined

# Ethical issues re VSED support

- Some question whether providing VSED support morally equivalent to assisted suicide
- Those who believe always morally wrong for a person to hasten or cause own death may hold that providing information or support for VSED is also immoral
- Health care professionals are not obliged to provide care they find morally objectionable
- Claims of conscience permit withdrawing from case but NOT abandoning patient

# ANA position statement re VSED

- 2017 ANA published "Nutrition & Hydration at the End of Life"
- Statement supportive of patients' rights to make an informed choice to stop eating and drinking in order to hasten death

  (this was a **very big deal**)
- AMA has not yet addressed this practice.

# Dementia Data…

- 6 million Americans now have Alzheimer's - number is expected to ↑ 14 million by 2050
- Advanced dementia (including Alzheimer's) is 6th leading cause of death in US & the 5th leading cause for those > 65 yrs & 3rd for those > 85 yrs
- Although people can live well for several yrs w dementia – many want to avoid the final terminal stages
- There are SEVEN stages of declining abilities

# Functional Assessment Staging Test

- Stages 1-3 mild cognitive decline: decreasing organizational capacity & memory challenges
- Stages 4-5 = Moderate Decline: can't manage finances or complex tasks > can't choose appropriate clothes for season or occasion
- Stage 6 = moderate/severe: unable to dress or bathe or mechanics of toileting w/o assistance & begins to be incontinent of urine & stool
- Stage 7 = advanced/terminal: ↑ loss of speech unable to recognize loved ones, can't ambulate or sit up w/o assistance, CANNOT FEED SELF or smile
- This 'terminal' stage can last for months to years IF patient is hand fed

# Additional Alzheimer's factoids

- 10% of people 65 or ↑ have Alzheimer's disease (AZD) or another dementia disease
- Older African Americans are twice as likely to have AZD as older whites
- Older Hispanics are 1.5 times as likely to have AZD as older whites
- 2/3 of Americans living w AZD are women
- As # of elderly Amer ↑ so does # of those w AZD
- ↑ early diagnosis b/c of development of biomarkers for disease→ make EOL plans sooner

# 1st West Coast Landmark Case

- Margot Bentley of Vancouver BC, Canada
- 1991 - retired RN completed/revised living will & sent to daughters
- Wrote refused "..nourishment & liquids if suffering from extreme mental disability"
- Then suffered from Alzheimer's > 17 years
- Spoon fed in nursing home for years despite family's efforts & multiple unsuccessful court cases
- One judge ruled she had 'changed her mind'
- Finally died 2015 @ age 83

# Margot Bentley

# 2nd landmark case from Oregon

- Nora Harris, a research librarian
- 2009 'early onset' Alzheimer's at age 56
- Completed advance directive "to prevent her life from being prolonged when disease got worse"
- But - no mention of wishes about hand feeding
  & was spoon fed for years in nursing home
- Husband went to court twice stop feedings
- Judge said written directive **not** specific enough
- Finally died 2017 age 64

# Nora Harris

# Further West coast developments

- 2017 EOLWA developed “Instructions for Oral Feeding & Drinking”
- Form stated when dementia is ‘advanced’ - oral feeding to be limited to ‘comfort-focused’
- Assisted feedings provided only while patient seems to enjoy or willingly participates in being fed
- Received with much enthusiasm in WA…

# **WHEN** to implement dementia feeding limitations

**3 Triggering clinical criteria for dementia directive:**

**1**. Health care agent consults w PCP & **agree** patient **now in** '**advanced**' stage of dementia (**stages 6-7** on **F**unctional **A**ssessment **S**taging **T**est) symptoms include: inability to speak comprehensively, ambulate, recognize family or be continent

**And**

**2**. Patient unable to make health care decisions **And**

**3**. Unable to feed self

# **Two** Options to limit assisted oral feeding when dementia advanced

- **Option A:** refuses all life-prolonging measures including CPR & **all nutrition & hydration** (N&H) whether provided medically **or** by assisted oral feeding **AND**
- Specifically - refuses oral feeding **even if** mouth opens when spoon touches corner
- Requests provision of excellent comfort care & symptom management with palliative or hospice care once feedings stopped

# 2nd option limiting assisted feeding

- **Option B**: refuses all life-prolonging measures including CPR & **medically** provided N&H & l**imits oral feeding** to **comfort focused - e.g:**
- Feedings provided only while pt shows enjoyment or positive anticipation re eating
- Only given foods & fluids seems to enjoy
- Feedings stopped once pt no longer appears interested or begins to cough or choke
- Pt not to be coerced or cajoled into eating
- Once feeding stopped – access to comfort measures & medications with palliative or hospice care

# Further IMPORTANT instructions

- Once dementia directive completed, discuss with: PCP, health care agent, family members, attorney & all other 'stakeholders' who care about patient
- Give copies of directive to all of above
- Patient should **make videotape** of personal values & **reasons why directive completed** & give copy to all of above
- Remind all you are trusting them to NOT disregard your wishes b/c you 'appear' comfortable or have 'adequate' quality of life

# Long term care considerations

- As dementia becomes advanced, long term care placement often becomes necessary
- In anticipation of such transfer - patients & families should explore whether LTC administrators will honor dementia directive BEFORE entering facility
- In-service education within LTC facilities will be necessary – particular among CNA's who provide most care & often know patients best (video very important for them)
- We anticipate judicial review

# Determining Success of Directive

- May be a some time before we learn if effective in limiting feedings; one current case in Ithaca
- EOLCNY has counseled ↑ number of persons with early dementia who have completed directive (most chose option "A")
- Many have said they don't want to have to wait until dementia becomes 'advanced'
- **VSED** always an option while still decisionally capable & DETERMINED to avoid final dementia stages – none yet

# The Legal Perspective

- Eating & Drinking and the Law
- How did we get here?
- Where are we going?

# Think about 1914

# Think about 1914

# Benjamin Cardozo:

"[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body,"

*Schloendorff* v. *Society of New York Hospital*
211 N. Y. 125, 129-130, 105 N. E. 92, 93 (1914)

# Delio v Westchester

View New York Official Reports version

129 A.D.2d 1

Supreme Court, Appellate Division, Second Department, New York.

In the Matter of Julianne DELIO, etc., Appellant,

v.

WESTCHESTER COUNTY MEDICAL CENTER, et al., Respondents.

June 1, 1987.

**Synopsis**

Wife of 33–year-old patient in chronic vegetative state with no hope of recovery petitioned to terminate patient's care. The Supreme Court, Westchester County, 134 Misc.2d 106, 510 N.Y.S.2d 415, Cerrato, J., denied the petition, and wife appealed. The Supreme Court, Appellate Division, Thompson, J., held that wife, as conservator of patient, was entitled to act in accordance with prior clearly expressed wishes of patient and have use of feeding and hydration tubes discontinued.

Judgment reversed; petition granted.

# Federal Regulation: 42 CFR 488.301

Title 42 Part 488 → Subpart E → §488.301

Title 42 → Chapter IV → Subchapter G → Part 488 → Subpart E → §488.301
Electronic Code of Federal Regulations e-CFR

# Federal Regulation Definitions:

**§488.301 Definitions.**

As used in this subpart—

***

***Abuse*** is the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish. Abuse also includes the **deprivation by an individual, including a caretaker,** of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being. Instances of abuse of all residents, irrespective of any mental or physical condition, cause physical harm, pain or mental anguish. It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology. ***Willful,*** as used in this definition of abuse, means the individual must have acted deliberately, not that the **individual must have intended to inflict injury** or harm.

***

***Immediate jeopardy*** means a situation in which the provider's **noncompliance** with one or more requirements of participation has caused, or **is likely to cause**, serious injury, **harm**, impairment, or death to a resident.

***

***Neglect*** is the failure of the facility, its employees or service providers to provide goods and services to a resident **that are necessary to avoid physical harm, pain, mental anguish, or emotional distress**

***

# State Operations Manual
# Appendix Q - Guidelines for Determining Immediate Jeopardy
# (Rev. 102, Issued: 02-14-14)

| Triggers | |
|---|---|
| **Issue** | **Triggers** |
| D Failure to protect from undue adverse medication consequences and/or failure to provide medications as prescribed. | 1. Administration of medication to an individual with a known history of allergic reaction to that medication;<br>2. Lack of monitoring and identification of potential serious drug interaction, side effects, and adverse reactions;<br>3. Administration of contraindicated medications;<br>4. Pattern of repeated medication errors without intervention;<br>5. Lack of diabetic monitoring resulting or likely to result in serious hypoglycemic or hyperglycemic reaction; or<br>6. Lack of timely and appropriate monitoring required for drug titration. |
| E Failure to provide adequate nutrition and hydration to support and maintain health. | 1. Food supply inadequate to meet the nutritional needs of the individual;<br>2. Failure to provide adequate nutrition and hydration resulting in malnutrition; e.g., severe weight loss, abnormal laboratory values;<br>3. Withholding nutrition and hydration without advance directive; or<br>4. Lack of potable water supply. |
| F Failure to protect from widespread nosocomial infections; e.g., failure to practice standard precautions, failure | 1. Pervasive improper handling of body fluids or substances from an individual with an infectious disease;<br>2. High number of infections or contagious diseases without appropriate reporting, intervention and care;<br>3. Pattern of ineffective infection control precautions; or<br>4. High number of nosocomial infections caused by cross contamination from staff and/or equipment/supplies. |

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| | |
|---|---|
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**E Failure to provide adequate nutrition and hydration to support and maintain health.**

**Food supply inadequate** to meet the nutritional needs of the individual;

2. Failure to provide **adequate nutrition** and hydration **resulting in malnutrition; e.g., severe weight loss, abnormal laboratory values**;

3. **Withholding nutrition and hydration without advance directive**; or

4. Lack of potable water supply.

# State Operations Manual:

**Example Case #2 (Continued): (Refer to B - Investigation)** During the investigation, the surveyor finds that the chart does not include a copy of the patient's advance directive. The progress note does not contain any documentation of the patient ever stating a wish to have nutrition and hydration withdrawn at the end of life. The patient has a diagnosis of advance dementia with a documented history of refusal to eat in a long-term care facility. The patient had been admitted because of continued weight loss and dehydration related to the refusal to eat or drink. The patient has a daughter who actively

# § 489.102 Requirements for providers.

(a) Hospitals, critical access hospitals, skilled nursing facilities, nursing facilities, home health agencies, providers of home health care (and for Medicaid purposes, providers of personal care services), hospices, and religious nonmedical health care institutions must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving medical care, or patient care in the case of a patient in a religious nonmedical health care institution, by or through the provider and are required to:

(1) Provide written information to such individuals concerning—

(i) **An individual's rights under State law (whether statutory or recognized by the courts of the State) to make decisions concerning such medical care,** including the right to accept or refuse medical or surgical treatment **and the right to formulate, at the individual's option, advance directives.**

- * * *

# § 489.102 Requirements for providers.

- **(3) Not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive;**

- (4) **Ensure compliance with requirements of State law (whether statutory or recognized by the courts of the State) regarding advance directives.** The provider must inform individuals that complaints concerning the advance directive requirements may be filed with the State survey and certification agency;

- (5) Provide for education of staff concerning its policies and procedures on advance directives;

- * * *

# § 489.102 Requirements for providers.

- **(c) The providers listed in paragraph (a) of this section—**

- **(1) Are not required to provide care that conflicts with an advance directive.**

All of which,

lead me to my research project . . .

# Original Study design

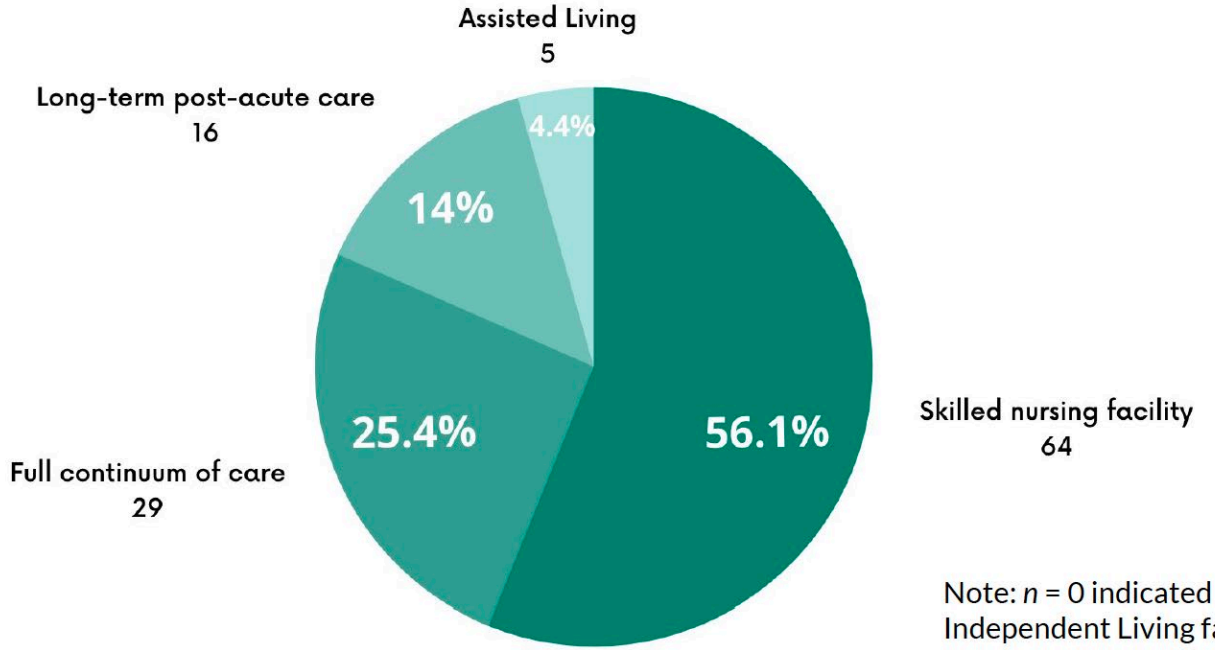
Planned as a randomized

in-person interview study.

Then COVID -19 HAPPENED!

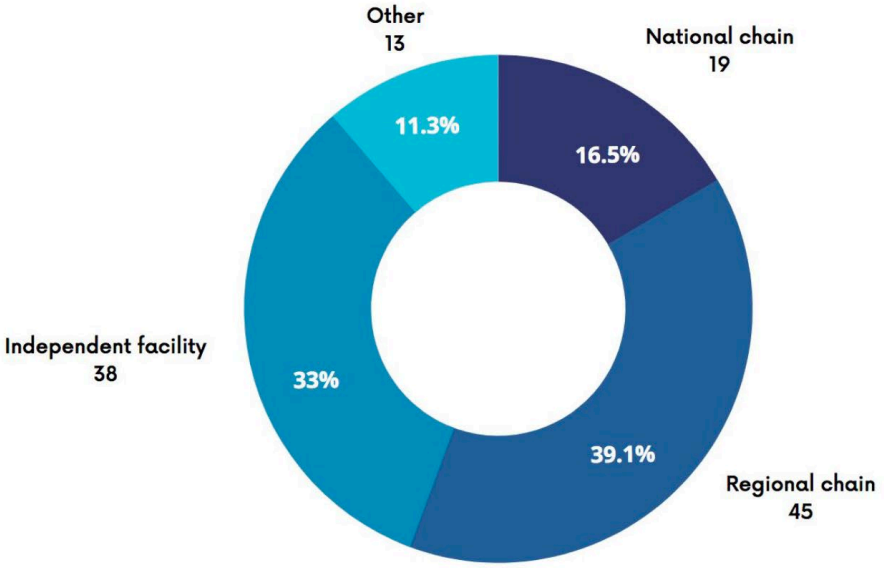
Switched to an on-line survey of AMDA membership.

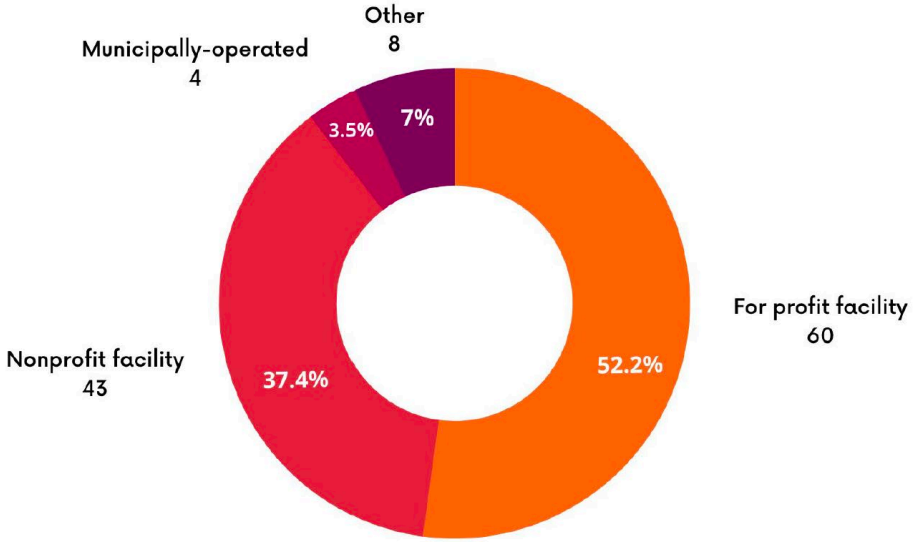
# Facility Type




Note: *n* = 0 indicated working for an Independent Living facility.

# Facility Type & Funding

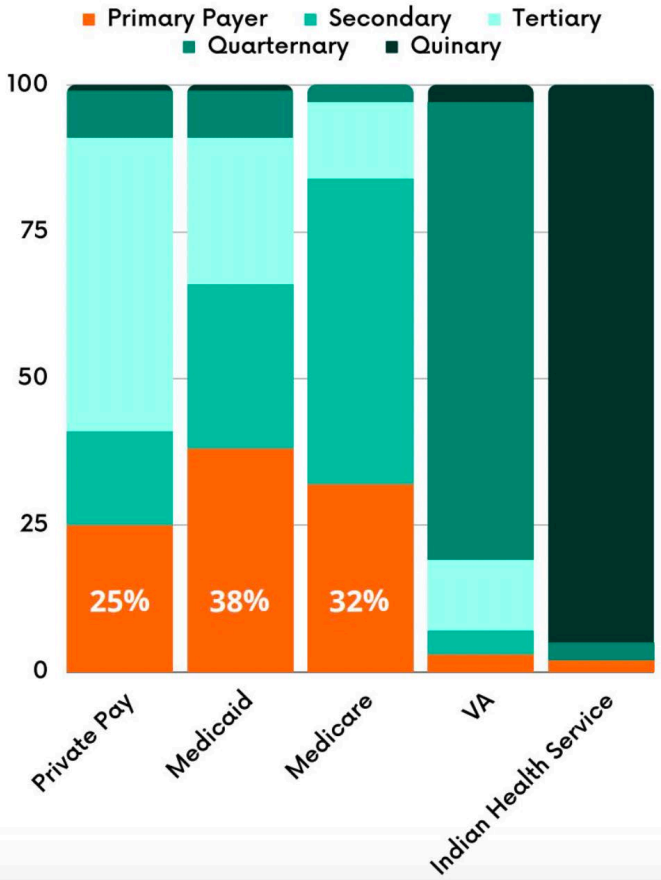


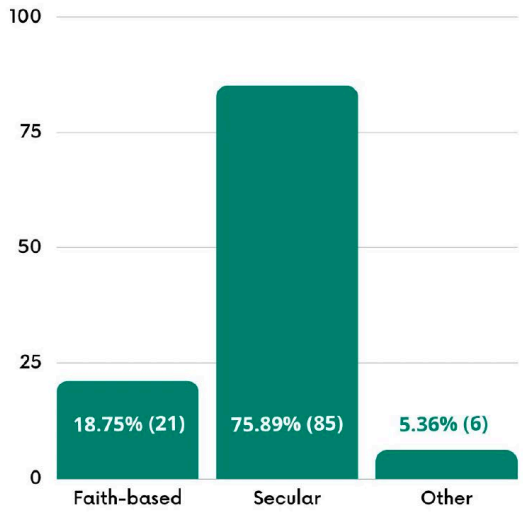
# Payer Structure

**25%** of respondents indicated that private pay made up the largest proportion of their payer base.

**38%** and **32%** indicated the same for Medicaid and Medicare, respectively.



# Facility Detail



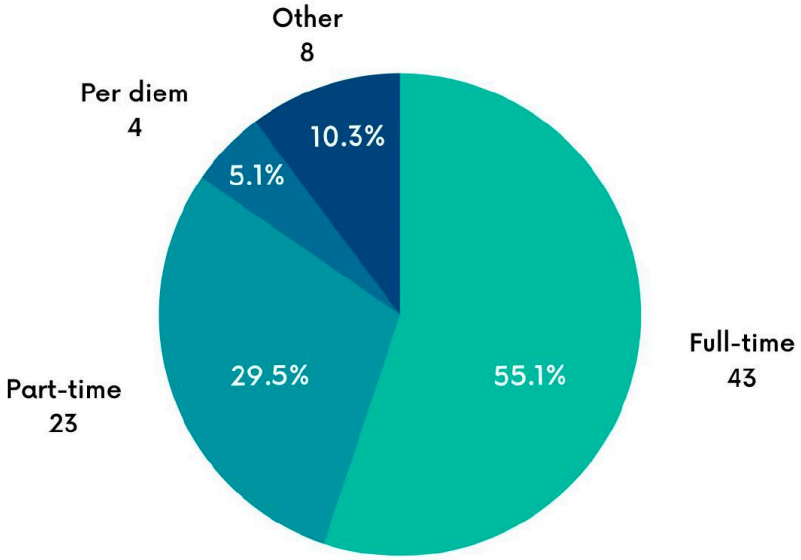

**Total # of beds:**
**Average: 171.79, Range: 24-500**
Standard deviation: 120.05

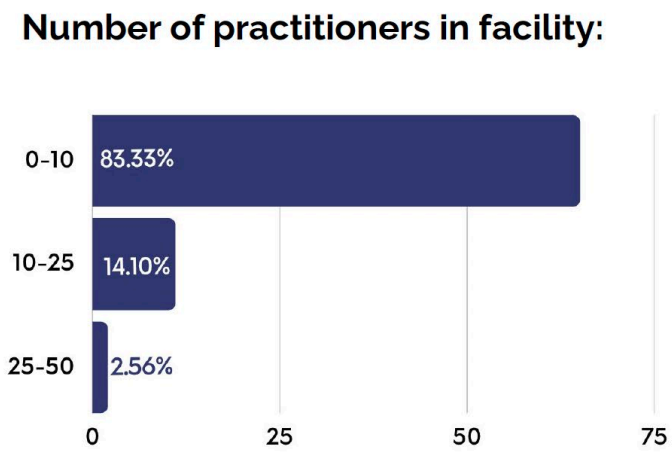
| Bed Type | Minimum | Maximum | Mean | SD |
|---|---|---|---|---|
| **Independent living** | 0.00 | 400.00 | **25.06** | 79.31 |
| **Assisted living** | 0.00 | 349.00 | **17.22** | 43.73 |
| **Memory care** | 0.00 | 150.00 | **16.45** | 28.13 |
| **Skilled nursing** | 0.00 | 500.00 | **111.17** | 81.49 |


Enter facility with dementia


Develop dementia at facility

# Personal Job Role + Practitioner Staffing



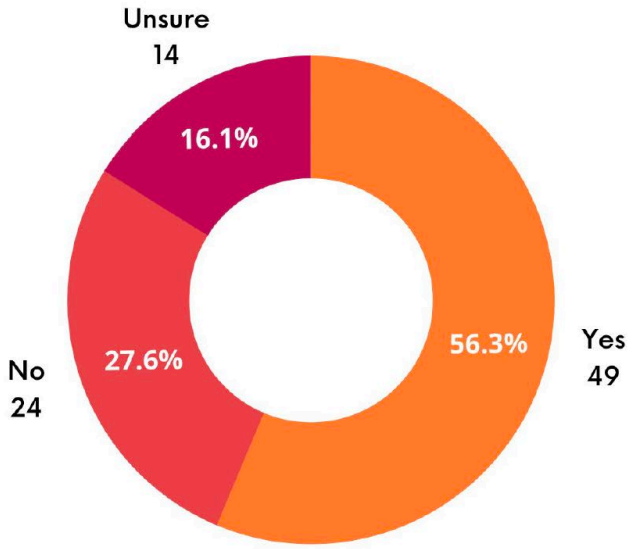
# When do staff ask patients and their families about advance directives/care wishes?


**The bulk of facilities assess on admission.**

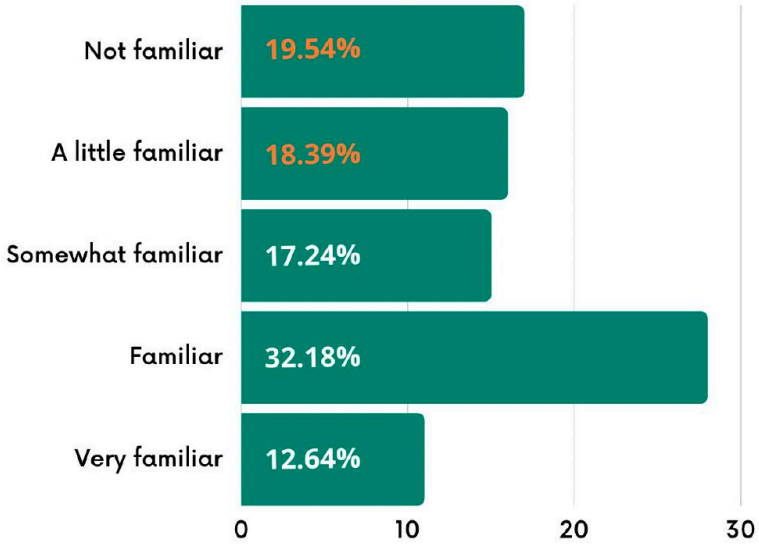
Among 87 respondents, **advance documentation rates at their facilities ranged from 5-100%.** The **mean rate was 59.49%** with a standard deviation of 24.33%.

At least **31%** of respondents (*n* = 23) indicated their facility does not conduct swallow tests on admittance, and at least **35%** (*n* = 26) do not discuss handling of oral feeding and hydration with families.

## Use of CMS Code 99497

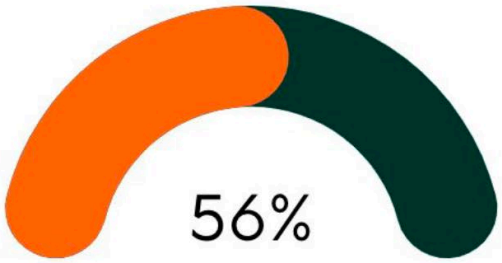



## VSED Awareness

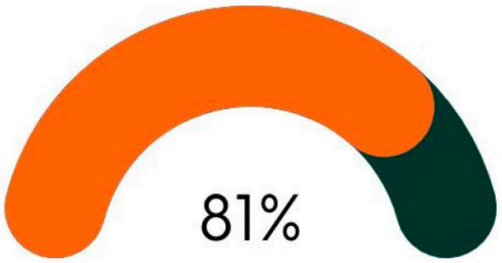



84 respondents estimated that of the patients entering their facilities with advance directives, **8.76% on average specified VSED at some juncture** (standard deviation of 18.62%, with a range between 0-90% – so a lot of variability here).

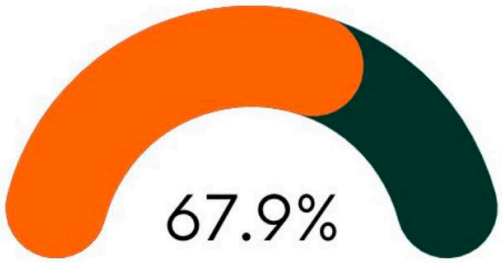
## *What would assist your facility in managing end of life issues for those of your patients with dementia?*




Desire more clarity from CMS on standards for food and nutrition



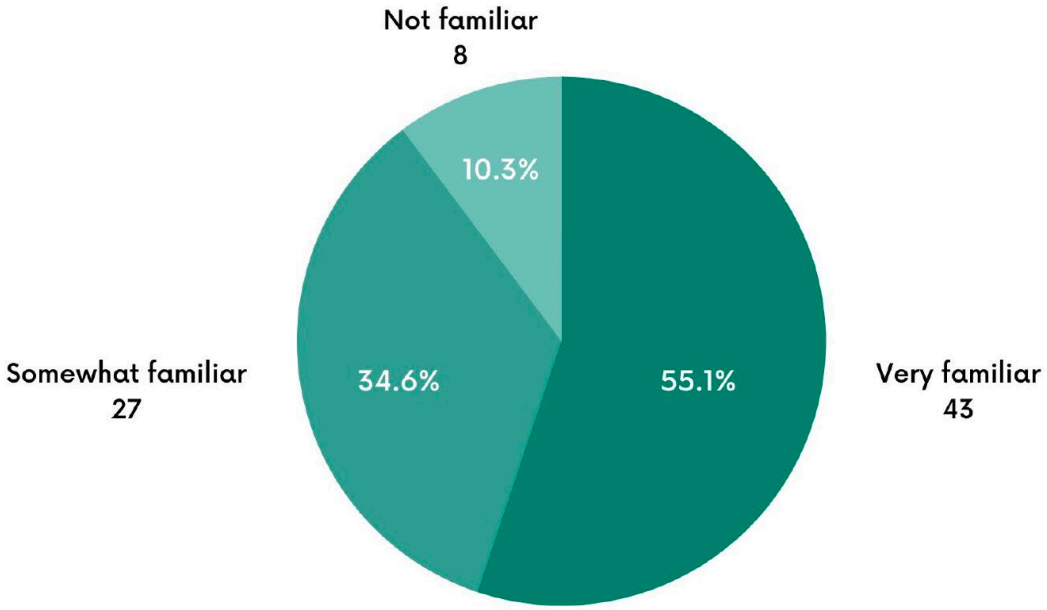

Desire more clarity from patients and families on their care wishes in advance




Desire more flexibility for physicians in judgments of medical futility

**88.46% (*n* = 69)** of respondents indicated that their facility did have specific procedures and practices for assisting patients with dementia in oral feeding.

# Immediate Jeopardy Concerns

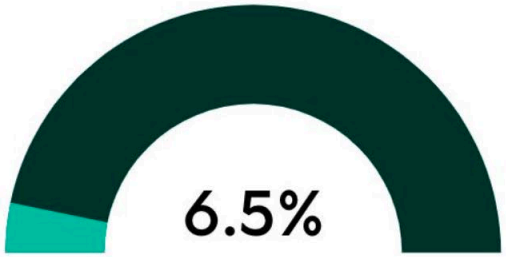



**64.10%** (*n* = 50) of respondents indicated that their facility had specific protocols/rules in place for preventing IJ.

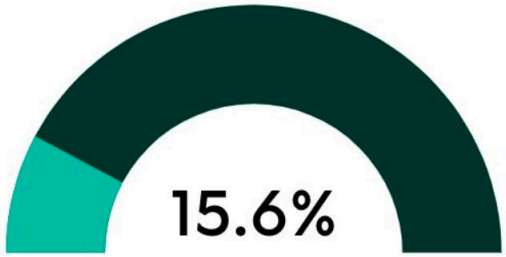
Only **28%** of this subgroup (*n* = 14) could definitively say that these policies include guidance on withholding assisted oral feeding.

**67.53%** (*n* = 52) respondents said they had not had the chance to discuss VSED concerns around immediate jeopardy with any colleagues.

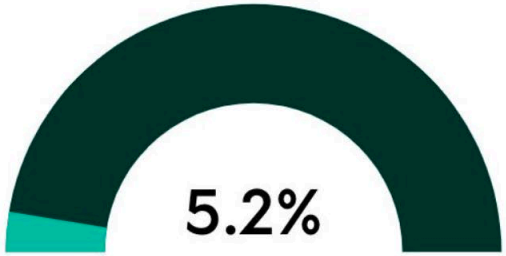
# Immediate Jeopardy Attitudes




Were aware of any institution that was penalized for withholding nutrition or hydration pursuant to an advance directive




Cited Immediate Jeopardy as a primary institutional concern over implementing VSED by advance directive




Think Immediate Jeopardy is a correct designation for facilities that accommodate VSED by advance directive

**11.69%** (*n* = 9) were unsure.

# Immediate Jeopardy Experience

**25.97%** of respondents (*n* = 20) affirmed their institution had held trainings or briefings on avoiding Immediate Jeopardy in clinical practice, and **45.45%** (*n* = 35) reported having had meetings with their facility administrators on the topic.

Of the 35 participants who responded to the question, **45.17% (*n* = 16) indicated their facility had faced an Immediate Jeopardy investigation.**

**5.6%** (*n* = 4) later indicated that their facility had been the subject of an investigation into patient neglect. (Next step: investigate these subgroups?) **23.94%** (*n* = 17) cited the potential for investigation of neglect as a significant concern in considering VSED (larger than the proportion who were concerned about immediate jeopardy).

# VSED Attitudes

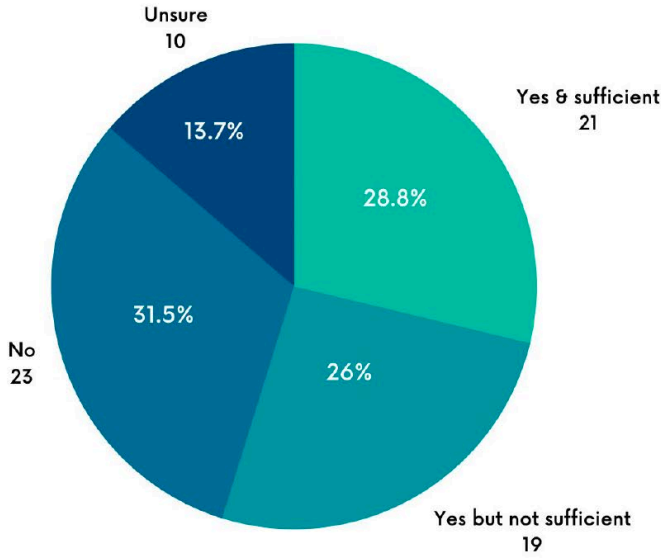
**37.7%** (*n* = 26) see informing patients and surrogates about the option of VSED as part of their institution's clinical responsibility.

**31.9%** (*n* = 22) do not, and **30.4%** (*n* = 21) are unsure.

*Opens us up to the possibility of subgroup analyses.*

# Training Needs

Does the institution provide trainings on managing symptoms from patients declining assisted oral nutrition and hydration?




Participants were most interested in:

- Trainings on **VSED Policy 50.7%** (*n* = 37)
- Trainings on **palliative care and oral care during VSED 41.1%** (*n* = 30)
- Trainings on advance directive screening at intake **32.9%** (*n* = 24).

- *Comparable numbers also indicated interest in the ethical obligation to respect advance directives, though others indicated this question was a sign of our researcher bias, a valid concern.*

# Managing Conflict

Participants were no stranger to family conflict, with **70%** (*n* = 49) indicating experience at their facility with managing family conflict around provision of nutrition and hydration to patients.

**53.6%** (*n* = 37) have a process for resolving disputes between prior expressed patient wishes and surrogate wishes.

**60.9%** (*n* = 42) reported rejecting surrogate instructions based on knowledge of advance care planning wishes.

# Where do we go from here?

Residents must appoint an agent who knows, **and will follow**, your wishes regarding oral feeding.

And appoint an alternate agent or two!

<u>And leave behind clear written instructions that describe your values and preferences</u>

# David's advance directive:

- I do not want to be a potted plant.
- If I am unable to express myself **and** show signs of experiencing joy, I want all but pain care withheld, so that my passing can come quickly.
- Organs to the living, body to science, then to the sea.
- Smile and Breathe.

D.N.H.

# Why does this matter?

# Like your teeth,

If you ignore your rights

They will go away!

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