The Ethical Implications of Withholding or Withdrawing Medication Therapy in Patients with Dementia

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Disclosures

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Objectives for Pharmacists

(1) Understand the ethical implications of providing care to patients with dementia.

(2) Describe the ethics of withholding and/or withdrawing medication in patients with dementia.

(3) Explain the value of advance care directive preparation as an ethical vehicle for assessing patient preferences for the provision or non-provision of life-sustaining medication in the patient with dementia.
Objectives for Pharmacy Technicians

(1) Understand the ethical implications of providing care to patients with dementia.

(2) Describe the ethics of withholding and/or withdrawing medication in patients with dementia.

(3) Explain the value of advance care directive preparation as an ethical vehicle for assessing patient preferences for the provision or non-provision of life-sustaining medication in the patient with dementia.
Your spouse has dementia and suffers from recurrent bed sores. He currently has a stage 3 pressure sore and is on antibiotics. This is his fourth sore in 6 months. He seems to be suffering more and more as you observe him lately. Would you allow for the withdrawal of his antibiotic if his provider deems it non-beneficial?
Your mother suffers from late stage dementia. She is rushed to the ER after a fall. She lacks capacity, so the physician asks for your consent to perform a procedure on your mother. If she has the procedure, she will live a few more months. Without the procedure, she will die within a few days? Would you consent to the procedure?
In one word, how would you feel if a close family member received a diagnosis of dementia?
The Case of Kemal Amin Kasem (1932-2014)

Who is Kemal Kasem?

https://video.search.yahoo.com/search/video?fr=mcafee&p=casey+kasem+you+tube#id=2&vid=96d581c176b9f9d0be2f08326e825630&action=view
The Case of Casey Kasem

Facts of the Case

Beloved American Top 40 disc jockey and the voice of Shaggy on Scooby-Doo, Where Are You!

Diagnosed with Lewy Body Dementia in 2007

Died at the age of 82, seven years after diagnosis

He is survived by his wife, their daughter, and three children from a previous marriage

Important Note: Kasem named his three children from his prior marriage as his health care proxies soon after his diagnosis. Kasem did execute a living will soon after his diagnosis.

Did Kasem prepare well for his end-of-life transition?
Ethical Principles and Health Care Decision-making

- **Respect for Autonomy** - Derived from our society’s libertarian ideal of individualism. We should, and must, exercise authority over ourselves. Paternalism is unacceptable. Basis of informed consent.
- **Beneficence** - Provide a benefit to the patient. A benefits vs. risks analysis.
- **Non-maleficence** - Do not harm the patient
- **Distributive Justice** - Fairly distribute scarce health care resources.

Of these four principles, “respect for a patient’s autonomy” is often considered paramount.
Respect for Autonomy - The Competent (Capacitated) Patient

Elements for exercising autonomy in health care decision-making

- Patient must receive adequate information concerning the benefits and risks of medical interventions (treatments and procedures)
- Patient should understand the information given
- A decision must be made without coercion
- Articulation of the decision must be made (intervention is accepted or rejected)
Respect for Autonomy - The Patient Lacking Capacity

- **Advance directives**—Living Wills, POLST, MOLST, DNRO (decisions about care made by patients before becoming incompetent)

- **Surrogate for decision-making**—Proxy, Surrogate, Durable Power of Attorney for Health Care Decision-making) (Person appointed by patient or as defined by statute)

- **Best-interest of the patient**—Default standard (An objective judgment of what is in the best interest of the patient—which may differ from the subjective interests of a person).
Advance Directives

Living Wills - expresses end-of-life preferences such as use of a ventilator, CPR, antibiotics, and feeding and hydration

Durable Power of Attorney for Health Care Decisions

POLST/MOLST

DNRO
Surrogate Decision Maker

1. **Proxy** (F.S. Chapter 765.401)- judicially appointed guardian, spouse, adult child(ren), parent, adult sibling(s), adult relative, close friend, clinical social worker

2. **Health Care Surrogate** (F.S. Chapter 765.202)- written document designating a surrogate to make decisions on behalf of a principal, signed by the principal, and witnessed.

3. **Attorney in fact under a Durable Power of Attorney** (F.S. Chapter 709)- delegated authority to make decisions on behalf of a patient.
Advance Directives

**Advantage**

A way for the “presently” competent patient to exercise his “future” autonomy.

**Disadvantage**

The incompetent can’t change his mind!
Issues with Living Wills

Problems encountered by patients:

- You may not have ever been privy to a critical care experience.
- Do you know the success rate for CPR?
- Do you understand what it will mean to be incontinent?
- Do you think that a certain side effect is unbearable?
- Will your wording cover your exact situation?
Issues with Living Wills

Problems encountered by providers when discussing living wills:

- Are you communicating well with the patient?
- Are you explaining information and statistics in such a way that the patient can understand and appreciate?
- Are you verifying patient understanding?
How is the Dementia Patient Different from other Incapacitated Patients?

Welie (2004) states:

“...certain conditions, and particularly AD [Alzheimer’s Dementia], are poorly understood scientifically...and existentially.”

“[A] living will is written by the patient herself and as such is a chapter in the patient’s own life story, it is never the most recent chapter. To treat the Alzheimer patient according to a living will is like superimposing onto the chapter that is presently being written by the patient one that was written a long time ago.”

The “best interest of the patient” standard should be used for patient’s with dementia.
A counterargument to Welie

Pinch 2004 advocates:

Utilization of additional tools to allow for a semblance of patient autonomy, such as naming a durable power of attorney for health care or proxy and using advance directives such as living wills along with ongoing discussions about preferences and values is best.

“[W]e simply must work from the information we have about the person and from the knowledge that all caregivers bring to the decision-making process. Perhaps someday we will have patients’ stories about their more serious incompetent states when pharmacological agents completely restore memory and they are able to relate such events.”

Incorporating patient past preferences is still valuable to health care decision-making in patients with dementia.
Advance Directives give Surrogates Needed Guidance (and Support)

- Being a spouse vs. being a caregiver should be considered when naming surrogate
- Know that emotional support for caregiver may be lacking
- There may be a reluctance of some family members to support decision-maker
- Feelings of guilt may be experienced by surrogate (don’t want to make the wrong decision)
- ADs allow for credence to be given to statements made by surrogate—gives evidence.
- Providers may be biased toward “rescue”

Because the course of dementia is usually progressive and chronic, advance directives should be prepared soon after diagnosis.

Know that the state of having dementia is opposite to societal norms of expected conduct.

Patient will need others, no longer self-sufficient.
Withholding or Withdrawing Medications (Maintenance vs. Life-Sustaining Medications)

Chronic or Progressive Phase (Maintenance)

Medications often withheld or withdrawn from dementia patient:

Acetylcholinesterase inhibitors, mirtazapine and other appetite stimulants, statins, blood pressure medications/diuretics, antidepressants, warfarin, supplements

Terminal Phase (Withholding/Withdrawing medications when death is imminent)

Antibiotics for recurrent infections, warfarin, and any drug requiring monitoring

Is it ever ethical to withhold/withdraw a medication that may be keeping a patient alive?

Doctrine of Double Effect: Intent is important, see Quinlan—lived nine more years after ventilator withdrawal. If intent was for Quinlan to die, providers would have tried another way to cause her death, perhaps.
Withholding vs. Withdrawing Life-Sustaining Treatment: Is there a Difference?

**Withholding treatment?**

CPR (poor success rates, particularly in the elderly and frail)

Antibiotics after several reoccurrences in a bedridden, elderly, frail dementia patient

**Withdrawning treatment?**

Case of Karen Quinlan (taken off of a ventilator)

Terry Schiavo (husband wanted artificial nutrition and hydration stopped for wife in a persistent vegetative state (PVS) for more than 2 years)
Withdrawing or Withholding Life-Sustaining Treatment: Which is “morally safer”? 

Patients and providers often believe that it is always morally safer to withdraw a treatment rather than withhold. At least a treatment was tried.

In most cases, legally, if one “acts,” the person becomes morally responsible for the outcome (driving while drunk).

However, occasionally if one does not act, the person is held responsible (physician does not ask patient about allergies and prescribes penicillin, patient has anaphylactic reaction and dies—physician gets sued).

In medicine, it may be considered morally safer to at least try a course of treatment. However, once either of the two requirements for treatment are absent, the treatment should be withdrawn (or never be given).
Two Necessary Elements for Moral Medical Treatment

1. The treatment has a reasonable chance of benefitting the patient and is unlikely to cause disproportionate pain.

2. Patient gives informed consent. Patient (patient’s proxy) adequately understands and appreciates his diagnosis, prognosis, and proposed treatment options. In emergency, consent may be presumed.

Both elements must be present for ethical treatment provision.
The Case of Casey Kasem: Two Elements for Care Analyzed

1. Benefit of Continued Treatment

Patient’s poor prognosis of advanced disease at 82 years-of-age, bedridden, bed sores should be considered given probable risks such as likely spread of infection, sepsis, and death. To continue a nonbeneficial treatment would be a violation of the principle of non-maleficence. Treatment is likely futile.

2. Consent to treatment

Patient is incapacitated. Proxies and or Living will are available.

Would patient want antibiotics under the present circumstances? The agreement stipulated that he did not want to be kept alive with “any form of life-sustaining procedures, including nutrition and hydration,” if he lost all cognitive function and was given no hope of recovery.

Goals for care will often involve a choice between quality of life and accepting the limits of medicine given patient frailty and mortality vs. causing patient continued suffering or prolonging the inevitable-death.
Withdrawal of Antibiotics from Casey Kasem

https://video.search.yahoo.com/search/video?fr=mcafee&p=casey+kasem+you+tube#id=189&v=id=4e2719c8ff7bbc78ae0e21dc85b1fb84&action=view

FINAL QUESTION: Your spouse, who has advanced dementia, is on his fourth round of antibiotics for bed sores. He seems to really be physically and mentally declining as of late. Would you allow for the withdrawal of his current antibiotic, knowing that he may develop sepsis?

Yes
No
Maybe
The Case of Casey Kasem: How did it End?

https://video.search.yahoo.com/search/video?fr=mcafee&p=casey+kasem+you+tube#id=1&vid=3d641359ec22014e0e6d2f457b6beb05&action=click
Lessons Learned

Appoint a surrogate (may not want your kids or spouse to make such emotional decisions)

Attempt to prepare a living will (next slide will give resources)

Continuously talk to loved ones about your preferences and values. They may change.

Keep all documents in a safe and accessible place. Give to several people—loved ones and friends.
Resources for Advance Directives

Site 1: https://prepareforyourcare.org/

Prepareforyourcare is a good initial site for elderly patients.

Site is easy to navigate.

The text on the screen is relatively large and all videos are closed captioned for those who are hearing impaired.

Site #2:
http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html

The Toolkit for Health Care Advance Planning

Website is more technical, but information allows for a deeper exploration of a patient’s preferences end-of-life care goals.

Patients should go through this toolkit with a health professional or a family member.
Resources for Advance Directives


Caringinfo.org

Gives basic information on what advance directives are, how to select a health care agent, gives each state’s advance directive form, and explains what is necessary (witnesses, etc.) to make the form legal.

Site #4: [https://www.agingwithdignity.org/](https://www.agingwithdignity.org/)

Five Wishes

Most popular living will document

Allows for structured discussions, in layman’s terms, about end-of-life care
References


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