Caring for Aging Persons in Body, Mind, and Spirit

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Objectives

- What are the elements of caring at the end of life in a Catholic environment?
- What are the challenges?
- How do caregivers remain compassionate and sane?
Avoiding drama

- Staff
- Systems of care: quality
- Residents
- Members of the congregation and family
- Ethics
- You!
DRAMA

- Staff continually on edge, conflict
- Care plans falling short
- Residents unhappy and complaining, appropriately or inappropriately
- Family and members of the religious congregation upset and interfering
- Lots of ethical dilemmas and arguments
- Leadership exhausted, demoralized, fighting, and hating the job
Staff

- Cultivate a team approach
- Educate on aspects of care
- Educate on palliative and hospice care
- Educate on ethics with an emphasis on authentic Church teaching (not rumor!)
- Educate on religious life and charism of sponsor
- Resident centered care, not staff centered
- Minimize per diem assistants: better to pay for staff even with empty beds than have lots of turnover
 Physicians

- You get what you pay for: Medicaid does not pay for good care
- Focus on consistency, availability, empathy
- Educate on end of life care in the Catholic tradition, the charism of the institution
- Insist on belonging to a team
- Attempt to control consults, referrals to hospital and emergency room...realizing that can be tough
Chaplains/Pastoral Care

- Regular schedule for Eucharist and other sacraments
- Training and supervision, not just something for a member of the congregation to do
- Part of the care team
- Cares for the caregivers as well as the residents
Quality care vs. “Homey”

- Tension between over institutionalized environment and failure to maintain high standards: esp. in non licensed facilities
- Personal experience of “Homey”: cleaning staff giving insulin, lack of rigorous infection control, poor charting…
- Quality: falls, psychoactive medications, diabetes control, programming
- Homey and quality can come together over excellent programming: activities, outings, engaging projects, good liturgy, weaving charism related activities into the day of the facility
Systems of Care

- Care plans should be based on reality
- Who do you have who is actively dying vs. who would you not be surprised will die in the next few months?
- Is the care plan appropriate for someone who is declining?
- Recognizing the trajectory of end of life
Sudden death, unexpected cause

- < 10%, MI, accident, etc
Steady decline, short terminal phase
Slow decline, periodic crises, sudden death
Curative / remissive therapy

Presentation

Palliative care

Hospice

Death
Systems of Care

- Thinking through an approach to end of life care
- Developing appropriate protocols, training, standardized orders
- Getting clear on DNH, DNR before a crisis
- Understanding pain control: yes, use opioids to control pain…no, do not deliberately kill…and no, someone who is asleep with Cheyne Stokes respirations is not in respiratory distress…and no, a big Fentanyl patch is not what you start with…
- Making sure chaplains/pastoral care involved: Sacrament of the Sick and prayers at the end of life
Systems of Care: Hospice

- Try to be consistent if you use an outside hospice provider
- Work with them to ensure they understand your philosophy of care and the environment of a Catholic facility
- Make sure your team is on board with the hospice team
- Review care frequently and make sure you and your team are satisfied and be honest with hospice about potential or real concerns
Residents

- Accurate expectations: religious are not all nice, they may be terrified of illness and death, they can be cranky and whiny, they may have very unrealistic expectations
- Dodge Dart Life but want a Cadillac Death
- Confuse Catholic teaching with vitalism
- May well need education on reasons why DNH, DNR, palliative care, hospice care are the best choices in some situations
- Might not be in touch with their bodies, might be disinhibited, might like porn, may be sneaky or not so sneaky drunks
- May have whopping personality disorders or worse!
Accurate expectations and empathy

- If you expect everyone to be St. Therese of Lisieux on a good day, you are going to be disappointed.
- Can you hate your residents? Not quite, but you need to be real.
- Religious life does not make a person perfect, still is life with all the attendant complexities.
- Don’t assume understanding despite education.
- Don’t assume spiritual strength or depth, may well never had it.
- Don’t be surprised at bad behavior and seeming lack of faith.
Congregation members and family

- Can be wonderful and/or terrible
- Religious family and family of origin can be in conflict
- Make clear who decides if resident is not capable
- Keep an eye out for splitting among family/religious with staff
- Don’t confuse HIPPA with stupidity and fear: religious superiors can prudently discuss information with the congregation and family
- Best if advance planning done before comes to care facility but better late than never
- Allow presence appropriately at team meetings (immediate family and religious who are close if ok with resident)
The Hateful Patient

- “Admitted or not, the fact remains that a few patients kindle aversion, fear, despair or even downright malice in their doctors. Emotional reactions to patients cannot simply be wished away, nor is it good medicine to pretend that they do not exist.”
Countertransference and Treatment

- “...feelings regarded not only as a painful visitation but also as a necessary clue guiding...conceptualization and technic...”
- Four classes: Dependent clingers, Entitled demanders, Manipulative help-rejecters, Self-destructive deniers
Feelings as a guide to doing what’s right...

“What the behavior of such patients teach over time is that it is not how one feels about them that is most important in their care. It is how one behaves toward them…”
Using feelings to guide intervention

- Aversion to clingy behavior: set limits on dependency
- Rage and desire to counterattack entitlement: clearly define good medical care
- Depressed with the help rejecters: share pessimism
- Wish that the self-destructive denier would die: recognize the patient probably wants to die and maybe has a severe depression
Why is Groves’ article so important?

- Reveals the secret everyone has: we can’t stand some patients
- Points to such feelings as having diagnostic significance
- Uses the feelings to guide accurate empathy: ways to provide good care and not get trapped in the dislike
Can you hate your patient in a Catholic healthcare facility?

ERD 23

“The inherent dignity of the human person must be respected and protected regardless of the person’s health problem or social status. The respect for human dignity extends to all persons who are served by Catholic health care.”
Yes, but only if it helps you to love.

- “They tie up heavy burdens and lay them on people’s shoulders but will not lift a finger to move them.” (Mt 23:4)
- “I was…ill and you cared for me.” (Mt 26:35)
- “The Spirit of the Lord is upon me…He has sent me to proclaim liberty to captives and recovery of sight to the blind, to let the oppressed go free…” (Luke 4:18)
Ethics

- Most dilemmas aren’t
- People tend to feel strongly and think weakly
- Avoiding common sense is a characteristic of health care environments
- Ethics is about doing right or wrong in a context of what it means to be human: rules help but they require a deeper understanding
- May not need a formal consultant but useful to have someone to review and work with team on tough situations, provide some education
- Care should be consistent with the vows---poverty does not mean squalor but it does imply limits to care and choices
Ethics

- Dying people do not require feeding tubes in the Catholic tradition…
- Feeding tubes do not help Alzheimer’s disease
- People get so nutty about feeding tubes they forget to feed people by hand
- Resuscitation usually does not work in the long term care setting, it is not a jump start of a car on a frosty morning
- Hospitalization and emergency room trips should be made for comfort of the resident…and rare…not to cover the staff’s fantasies and fears.
- HIPPA is not an excuse for failure to work with family and members of the congregation
Caring for the Caregiver

- How do you feel about your job?
- What do you enjoy and appreciate?
- What do you find loathsome?
- Avoiding personal drama, recognizing there will be crazy days…what can be improved?
- Personal education and training
- Learning about the charism of the facility
- Listening to the experience of the residents
- Taking time for prayer and reflection
Summary

- End of life care requires excellence
- Excellence usually does not involve lots of drama
- It may well involve planning, discussion, honesty, some conflict, and lots of education, review of outcomes, attention to measures of quality
- For those involved in caring at the end of life, it can be a graced journey