Ethical issues in end-of-life dementia care

Dementia care: the way forward
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Rules at ‘Bliss’

- No dancing.
- No parties.
- No midnight feasts.
- No visiting each other’s rooms.
- No talking after lights out.
- No being late for dinner.
- No falling asleep at the dinner table.
Later that night, Biba and Nina and Dee and Mr Bones watched Matron set off, bristling – past the croquet lawn, past the little summer-house, until she vanished into the darkness.
“We will make this a good, kind home,” said Nina.

“We will have sensible Rules,” said Biba. “We will dance, have midnight feasts! We will visit one another’s rooms, talk after lights are out — even fall asleep at the dining-room table, our heads resting on each other’s shoulders.”
You are barely awake and someone you don’t know is hauling you into a canvas seat that hurts your bones and swinging you through the corridor (in a hoist contraption). You are frightened and you start crying and the person says ‘now don’t be silly!’ . . . The person doesn’t let you test the water or wash your own private parts and swishes a washer over your sore feet. You can’t find the words to express how upset you are.
Ethical issues to be explored

1. Management
   - Qualifications, experience, knowledge of dementia
   - *Attitude* towards older people with dementia?

2. Education & training
   - How are aged care workers *supported*?
   - What *resources* are provided?

3. Care planning & clinical issues
   - End-of-life choices, partnerships with families
   - Infections, nutrition, pain, crisis interventions
Management: capacity to care

The Code of Ethics and Guide to Ethical Conduct for Residential Aged Care’ states:
‘Providers should act in the best interests of residents in determining, particularly before admission, whether or not the organization has the capability of providing them with care appropriate to their needs’
Education & training

- Evidence based practice
- Policies that set *minimum* requirements for employment
- Communication with families
- Education for older people, families and the community
- Support, praise, rewards
Clinical: case study of Mr Jones

Guidelines for a palliative approach in residential aged care, p.59

- Nursing home resident with COPD, epilepsy and advanced dementia
- ‘Absolutely terrified of hospital’
- Acute episodes of dypsnoea
- What interventions are appropriate?
- How is his comfort and dignity addressed?
Crisis plan

- Step by step plan formulated in consultation with family, GP and palliative care physician
- ‘Not to be hospitalised’
- Morphine: the drug of choice for end stage COPD
- Non pharmacological measures
- Support for family
The ‘default’ position

In the absence of clear directives the default position may involve:

- Hospitalisation (against the person’s wishes)
- Intrusive, invasive interventions (without consultation)
- Loss of empowerment and dignity for the person with advanced dementia
- Family distress
Advance care planning

- Communication with resident/patient/client, family, doctor
- Education about end-of-life planning
- Provides resident with choice, e.g., ‘intrusive’ treatments, etc.
- Optimises family satisfaction

Treating infections

- *Guidelines*, p.47, No 14. ‘The use of aggressive medical treatment of infections is not recommended for residents with advanced dementia. Instead, a palliative approach is recommended for the resident’s comfort, which might include short-term antibiotic therapy to ease symptoms and improve quality of life.’
Nutrition

- Consenting to food or refusing food is an expression of the resident’s autonomy.
- Impeccable assessment includes: checking for treatable conditions, e.g., dental caries, mouth ulcers, inflamed gums, etc.
- Family meeting to check goals of care and encourage their cooperation.
- Always continue to offer frequent small amounts of tasty food of the resident’s choice, but do not force.
Guideline No 24: It is considered best practice for residents to receive oral foods and fluids, even in minimal amounts, rather than enteral (nasogastric or PEG) feeding.

Guideline No 28: 1-2 mls of water by mouth every 30 mins can reduce the sensation of thirst and oral discomfort associated with dehydration.

Rehydration can have negative effects: there is no evidence to show it makes people more comfortable.

Impeccable mouth care is the key to comfort.
Resuscitation
(Therapeutic Guidelines Palliative Care, 2005, p.23)

- **Death itself is not an ethical issue! It is the inevitable consequence of having lived a life!**
- **The success rate of CPR is low even in previously healthy individuals. In the presence of serious illness, the outcome of CPR is likely to be universally poor.**
- **The availability (or non availability) of CPR should be discussed with resident/family on (or before) admission**
The ethics of pain management

What the research shows:

- Cognitively impaired older adults are often under-treated for pain
- Doctors identify pain in 43% of communicative n/home residents but only in 17% of non-communicative residents
- ‘Alzheimer’s sufferers feel pain like everyone else’ (International journal Brain, Sept 06)
Pain prevalence in n/homes
(AAG Oct 06)

- 42% have inadequate pain management in RACFs
- 6%-12% of prescribed medication not given
- Only 23% receive round-the-clock analgesia
- Chronic pain in 50% of all older people, 80% in RACFs
- < 50% receive adequate pain relief

GLOBAL YEAR AGAINST PAIN IN OLDER PEOPLE 12/9/06 – 12/10/07
Is it ethical?

- What is in the resident’s best interests?
- Has the resident completed a ‘statement of choices’ form and is it current?
- Does the care team, including resident and family, agree on the goals of care?
- Benefit vs. burden. Is the proposed treatment likely to be a benefit or a burden?
Impeccable assessment

- End stage dementia requires a palliative approach that focuses on impeccable assessment and appropriate interventions to relieve all distressing symptoms.

- It also requires active partnership with families and relevant health care professionals (Guidelines, chapter 5).
Creating trust

- Family meetings to formulate agreed goals
- Allowing concerns to be expressed
- Involvement of GP
- Referral to palliative care experts when needed
- Benefits from evidence-based care (wound management, pain management etc.)
Conclusion

- Advocate for people with dementia who cannot speak for themselves
- On what evidence is the care based?
- Are your policies and procedures founded on sound ethical principles?
- If change is needed, marshal your facts and make recommendations
- You *can* make a difference!
References


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