Principles of Palliative Care in Dementia

Dr Adrian Treloar

A bit of latin

- Ego in cubiculare eruditorum sum.
- Sed Nick in horto est
- Quod cena in horto est
- Sed morbus prope cena non est
- Ergo morbus perpessiet et teniat dolore

- Cenorum canis
- Cena canorum

- Grabadoc mitte amoxycillin per telefonico celluare, sed morbus viset non est.

Primum non nocere

- What does that mean?
- Who said that?

Answers

- First do no harm
- Interestingly it was not Hippocrates but seems to have been coined in the 17th - 18th centuries

First do no harm

- There are some issues with this in palliative care, chemotherapy, treatments with side effects

- In dementia we cannot avoid potentially harmful treatments which will help that person
- While we must never intend to harm, we must intend to treat and reduce suffering when we can, but we must also accept that almost everything we do may be harmful.

Hippocratic oath

- I will prescribe regimens for the good of my patients according to my ability and my judgment and never do harm to anyone.

- Our first aim is to do the good of our patients
- But there are then some absolute exclusions including giving a lethal drug.
- Hippocrates was more absolute, simply saying he will never harm

Why is that important?

- Because those with dementia and incapacity seem often to be neglected because they resist treatments
- Are not taken to hospital when needed for fear of assault (avoid doing harm at all costs)
- With the result of neglect occurring

Double effect

- Accept risk of harm for a clear benefit
- Classic example = opiates in pain, although in appropriate doses these may not be associated with shortening life
- Better examples =
  - Chemotherapy
  - Antipsychotics in dementia;- known to be harmful but may be the only way to alleviate severe distress

Burdensomeness

- A crucial concept
- Helps us to be sure we act reasonably

Good clinical care

- Proper understanding of the symptoms of distress
  - Anger/ Frustration
  - Aggression/Agitation
  - Fear/ Anxiety
  - Tearfulness/ misery
  - Pain when still
  - Discomfort on moving
  - Restlessness
  - Insomnia
  - Calling out/ vocalisation

Are these symptoms different from pain in the physical sense?

Causes of severe distress

- **Depression**
- **Psychosis**
- **Pain**
- **Poor understanding,**
- **Fear and anxiety**
- **Insomnia**
- **Hunger and diet**
- **Boredom, isolation and spiritual care**
- **Poor Environments**
- **Environmental interventions**

Approach to palliative care in dementia

- Cherish and value life
- Accept natural death
- Distress reduction is key
- Be willing to limit care to that which is not burdensome etc
- Talk to and discuss with relatives etc
- Remember that palliative care of dementia can provide excellent results

How do we know when palliative care is indicated in Dementia

- Arguably from diagnosis
- But patients and carers want more treatment/ cure / health preservation early on
- Definitively in the terminal phases
- But probably at some point during the illness where distress reduction and limitation of ineffective and burdensome treatments are important.

The Gold Standards method

- The gold standard method
  - Would you be surprised if this patient died in the next year
- Is simple, but hard to predict and probably will not work all that well

A criterion based approach

- Works well in testing
- Leads to helpful conversations with carers and patients
- Allows discussion of palliation at an appropriate time.

Criteria

1. A diagnosis of moderate/ severe dementia
2. And
    a. Severe distress
    b. Severe physical frailty
    c. Another indicator for palliative care

- **Indicators that transition towards Palliative and End of life care in Dementia should be considered.**
- We believe that the following will provide clinicians with a better guide as to when a patients ought to move towards a mainly palliative approach to their care. It is absolutely the case that some of these symptoms may exist and not mean that a mainly palliative care approach is needed, but as the number of such symptoms increase, so we believe will the likelihood that such an approach is indicated. ***Important note***
- ***This is not a tool which, by getting a certain score states that a person should have palliative care, merely a tool which indicates that this should be considered and discussed. At times, the criteria might be met but palliative care not appropriate, and at others palliative care may be appropriate despite criteria not being met***
- **1a** **A diagnosis of dementia with severe cognitive decline** (FAST stage 6) At stage 6 individuals may
- Lose most awareness of recent experiences as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pyjamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or faecal incontinence
- Experience significant personality changes and behavioural symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviours such as hand-wringing or tissue shredding
- Tend to wander and become lost
- **or**
- **1b** **A diagnosis of dementia with very severe cognitive decline.** (FAST Stage 7) At stage 7
- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.
- **With either**
- **2a** **Enduring and Severe mental or physical pain** as might be demonstrated by some or all of the following
- Anger/ Frustration
- Aggression/Agitation
- Fear/ Anxiety
- Tearfulness/ misery
- Pain when still
- Discomfort on moving
- Restlessness
- Insomnia
- Calling out/ vocalization
- Wandering and persistent challenging behaviors when these appear to be driven by distress or fear
- Autonomic arousal, sweating, tachycardia, hypertension
- Note in situations where distress fluctuates (perhaps most often mental distress), some distress may be appropriately tolerated, in lieu of better days.
- **And/or**
- **2b** **Severe physical dependency** as might be demonstrated by some or all of the following
- Significantly disabled and very highly dependent on others.
- Poor mobility;- unable to mobilise without the support of two
- Disability that puts skin care and pressure areas at risk

An aside

- Best care and best place of care
- Current problems with requirement for those with dementia to be only managed in Dementia specialist homes;- a loss of liberty and imposition of less good care for some
- CSCI have implemented the Care Homes Act in a perverse way