Challenges and opportunities in dementia

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‘Right place, wrong person’

A key message echoed by staff at all levels in the organisations involved in this study was that the acute hospital is not the ‘right place’ for older people.

The prevalence of this view has resulted in the physical environment, staff skills and education and organisational processes acting as barriers to delivering dignified care to older people.

Interviews with 76 patients, family carers, staff, middle managers and executive in 4 Trusts

Tadd W, Dignity in Practice 2011
Medical admissions over 70 years

- No mental health problem 30%
- Total cognitive impairment 51%
  - Delirium alone 9%
  - Delirium complicating dementia 23%
  - Dementia alone 19%
- Total delirium 28%
- Total dementia 41%
- Previously diagnosed dementia 28%

Whittamore et al, 2013
The problem with dementia

- Activities of daily living
- Behavioural and psychological symptoms
- Decision-making
- Carer strain
- Prone to acute illness, injury and delirium
- Progression to end-of-life care
### Crises in dementia

**Crises**
- Delirium
- Physical illness or injury
- Functional crisis
- Mental health, behavioural problem
- Social crisis or care system crisis

**Hospital presenting problems**
- Immobility 73%
- Falls 64%
- Pain 54%
- New incontinence 46%
- Breathlessness 23%
- Dehydration 21%
- Confusion 21%
Disorder of cognition, and attention or arousal (drowsy, distractible) with identifiable physical cause(s).

Look for:
- Disordered thinking - rambling speech, incoherent, irrelevant, illogical flow
- Hallucinations (often visual), delusions (usually paranoid)
- Hypoactive, lethargic or depressive forms

Recovery can be quick, very slow (several months), or not at all.
How to miss delirium

• Keep any talk with patients to a minimum
• Do not assess cognitive function
• Assume cognitive impairment is long-standing
• Never talk to nurses, especially night staff
• Don’t talk to families either
• If patient is withdrawn, start an antidepressant
• If patient is noisy, start a benzodiazepine

Thanks to Shaun O’Keefe
If your patient is forgetful, make a diagnosis

• History, and collateral history
• Examination, including mental state
• Cognitive tests
• Investigation, including imaging
• Observation of abilities and behaviour
• Follow-up, progression over time
Mr NH: MRI brain
Noisy, busy, environments

Fast pace of work

Intensive questioning

Multiple new faces

Moving through different departments and wards

Inability to express wishes

Taking account of other patients’ needs
See behaviour as communicating need

People with dementia ...

... are not by nature difficult, willful, attention-seeking, aggressive

But may

- feel threatened, frustrated, anxious, lost, afraid
- be overwhelmed by questions, noise or activity
- try to communicate pain, discomfort, thirst, need for the toilet
- be bored
Distress and difficult behaviour

Dementia experience =

Neurological impairment (amnesia, aphasia, apraxia, agnosia, executive function)

+ physical and mental health

+ personality

+ biography (life story)

+ social psychology (communication and relationships)

Kitwood 1992
Person-centred dementia care

- Value people with dementia and those who care for them
- Individualised care
- Understand perspective of person with dementia
- Use relationships to reduce distress and enhance well-being

Kitwood 1997; Brooker 2007
Individualise care

- Physical and mental health
- Identify and use residual abilities
- Recognise unique history, personality, social and economic resources
- Preferences, routines, familiarity
Aspects of physical health

- Acute illness, injury and fractures
- Delirium
- Chronic multi-morbidity
- Look for and treat pain
- Vision, hearing
- Teeth, hydration, nutrition
- Constipation
- Lower urinary tract symptoms
- Mobility and activities of daily living
- Medication
Mental state examination

A process of observation and questioning:

- Alertness, arousal, attention, behaviour
- Understanding and expression
- Mood and emotion
- Delusions and hallucinations
- Cognition (use a scale)
- Insight, risk, mental capacity
A lot of psychopathology

Prevalence amongst patients over 70 with cognitive impairment admitted to a general hospital, of at least moderate severity (n=195)

- delusions 14%
- hallucinations 11%
- agitated 18%
- depressed 34%
- anxious 35%
- apathetic 38%
- disinhibited 10%
- sleep problems 34%
- MMSE <9/30 25%

Goldberg et al, 2012
Make the most of family and friends’ expertise

- Factual information – ‘collateral history’
- Causes of distress and comfort
- Background, biography, routines
- For occupying, sitting, hands-on care
- Beliefs or values when assessing best interests
- Keep them informed and involved
  - avoids dissatisfaction and complaints
Medical and Mental Health Unit

- Specialist mental health staff
- Training in person centred dementia care
- Purposeful activity
- Environment
- New approach to family carers
- Medical staff interested and expert in delirium and dementia

www.nottingham.ac.uk/mcop; Goldberg BMJ 2013
Recognise the end of life

- Half of people with delirium or dementia admitted to hospital will be dead within a year
- Communicate. Identify priorities, solve problems, and make plans
- A patient who is mute, immobile or struggling to swallow is approaching the end-of-life.
Trajectory of decline at the end of life in dementia is like that in heart failure

Episodes of acute illness or delirium
Eclectic care

Medical model
- Diagnose
- Treat
- Discharge

Principles of palliative care
- Meticulous management of symptoms
- Open communication
- Psychological, emotional and spiritual support of the patient and those close to them
- Advance care planning

Rehabilitation
- Focus on optimising function
- Reability, resettlement, readjustment
- Problem-orientated, multi-disciplinary approach
- Identification and remediation of diseases/injuries, impairment, activity limitation, participation restrictions
- Agreed achievable goals

Person-centred care
- Value people with dementia and those who care for them
- Individualised care
- Perspective of person with dementia
- Social environment and relationships

Comprehensive Geriatric Assessment
- Diagnosis
- Function
- Mental Health
- Social
- Environmental

Recovery model
- Focus on hope
- Positive attributes and abilities
- Achievable goals
- Taking risks and accepting failure

Social model (disability movement)
Disability is an oppression by the majority in society on those with different abilities

Oliver 1990

Brooker 2007
Clash of cultures

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<tr>
<th>ACUTE</th>
<th>PERSON-CENTRED</th>
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<td>Palliation, experience</td>
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<td>Function, behaviour</td>
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<td>Continuity, follow-on</td>
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Requirements for optimal hospital care

• Staff *knowledge* and *authority* to respond to an unmet need
• Role-relevant training
• Clinical experts and senior staff role modelling best practice
• Taking opportunities to spend time with patients
• Appropriate risk management
• Valuing dementia care as skilled work

Handley et al 2017
Summary

- People living with dementia frequently come to hospital
- They are usually there with good reason
- They need to maintain abilities and minimise distress
- Physicians must work out the medical bit
- Function, family, social, mental, psychological, palliative aspects
- 25% are approaching the end of life (but which 25%?)
- Well-adapted care is possible, but requires leadership, skills and resources