Dementia in crisis

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‘The crisis in dementia’

- Growing numbers of people with dementia
- Anxiety about resources to provide support and care

Dening 2013

Classification of crises

Perspectives of

- person with dementia
- informal caregivers
- care providers (health and social care staff)

Vroomen et al, 2013

A classification of causes of crises

- Behaviour
  - aggression
  - psychosis
  - distress
  - wandering/getting lost
  - self neglect/squalor
- Physical health
  - falls, fractures, accidents
  - acute illness
  - delirium
  - not eating or drinking
  - medication problems
- Carer
  - exhaustion or illness
  - death
  - abuse
  - conflict within family
- Care factors
  - e.g. failure of community care
- Social or legal
  - e.g. financial, driving

Dening 2013

Outline

- Why do people with dementia come to hospital?
- Delirium
- Understanding distress
- Why family carers get so unhappy

Current orthodoxy?

Right place, wrong person

Tadd W et al, 2011

Dementia: definition

DEMENTIA

A. Multiple cognitive deficits

1.Memory impairment

2. One or more of:

(a) aphasia
(b) apraxia
(c) agnosia
(d) disturbance in executive functioning

B. Impairment in social or occupational functioning, decline from a previous level of functioning.

C. Gradual onset, progressive decline, at least 6 months.

D. Not due to specified other conditions…

E. … or delirium.

DSM-IV

Variations on a theme

- Alzheimer’s disease
- Vascular dementia
- Lewy body dementia
- Fronto temporal dementia

Dementia in acute hospitals is different

- ½ to ⅔ have added delirium
  - … which is difficult to diagnose and manage
  - … and slows things down
- Vascular dementia predominates
- Physically ill
- Dependent

Why does cognitive impairment matter?

- Common
- Non-specific presentation of illness
- Serious consequences
- Causes distress
- Influences decision making
- Its on the health policy agenda

Medical admissions over 70

- 9% delirium alone
- 19% delirium complicating dementia
- 23% dementia alone

• Total delirium	28%
• Total dementia	41%
• Previously diagnosed dementia	28%

Whittamore et al, 2013

Poor outcomes six months later

- 27% did not return home
- 31% dead within 6 months
- 18% 30-day readmission, 42% 6-months readmission
- 42% recovered to pre-acute illness level of function
- 16% spent >170/180 days at home

Bradshaw et al, 2013

Functional presentations

Presenting problems amongst patients over 70 with cognitive impairment admitted to a general hospital (n=53)

• Falls	34 (64%)
• Immobility	38 (73%)
• Pain	28 (54%)
• Incontinence	24 (46%)
• Breathlessness	12 (23%)
• Dehydration	11 (21%)
• Confusion	11 (21%)

Glover et al, 2013

Variety of acute medical diagnoses

Final diagnoses amongst patients over 70 with cognitive impairment admitted to a general hospital (n=53)

MEDICAL

- pneumonia 4
- urinary tract infection 4
- multi-factorial fall 4
- multi-factorial functional problem 3
- AF with fast ventricular response 3
- dehydration/renal failure 3
- alcohol intoxication 2
- adverse drug reactions 2
- seizures 2 (alcohol excess, brain mets)
- unresponsive episode/syncope 2
- painful hip post fall 2
- unexplained delirium 2
- cancer 2 (gastric, lung)
- fractures 2
- infective exacerbation of COPD 1
- infected leg ulcer 1
- gastroenteritis 1
- stroke 1
- rheumatoid arthritis 1
- progression of vascular dementia 1
- acute urinary retention 1
- anxiety 1

ORTHOPAEDIC

- fractured neck of femur 7
- other fractures 4
- ruptured Achilles tendon 1

Glover et al, 2013

Very dependent

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%
- Barthel <5/20 31%
- help to transfer 65% (hoist 13%)
- help feeding 58% (unable 15%)
- incontinent of urine 67%

Goldberg et al, 2012

Delirium

Full blown episodes are usually easy to diagnose; but it is not so easy to define neatly and comprehensively in a few words …

Its prodrome, subclinical presentation, and potential persistence present unresolved dilemmas regarding the diagnostic boundaries of delirium

Meager and Trzepacz, Oxford Textbook of Psychiatry

Delirium

CORE

1. Inattention or arousal
2. Cognitive impairment
3. Abnormal sleep-wake cycle
4. Temporal course: abrupt change, fluctuates (hours)

ASSOCIATED

1. Psychosis in 50% (visual hallucinations, paranoid delusions)
2. Psychomotor (agitation, restlessness, retardation)
3. Altered or labile affect or emotion (fear, anger, depression)
4. Autonomic features

Confusion Assessment Method

The Confusion Assessment Method (CAM) Diagnostic Algorithm

Feature 1: *Acute Onset or Fluctuating Course*
This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behavior fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?

Feature 2: *Inattention*
This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?

Feature 3: *Disorganized thinking*
This feature is shown by a positive response to the following question: Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

Feature 4: *Altered Level of consciousness*
This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal]), vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable])

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.

Inouye et al 1990

Diagnostic difficulties

- Variability, fluctuation
- Overlap with normality (cat naps, insomnia)
- Overlap with dementia, 6-10 x commoner in dementia
- Co-morbidity
- Recognising things you are not used to when you see them
- Cognition difficult to assess in an ill person

Diagnostic clues?

	‘Vague’ N=28	‘Poor historian’ N=76	‘Poorly motivated’ N=21
Cognitive impairment	57%	58%	38%
Depressed	11%	13%	67%
Either	61%	67%	86%

O’Keeffe et al, 2011

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

Screening and assessment

- Short cognitive tests
- Single Question in Delirium: Do you feel that [the patient] has been more confused lately?
- Single Question in Dementia: has the patient been more forgetful in the past 12 months to the extent that it has significantly affected their daily life?

How to talk to family carers

- History is key - informant
  - cognitive history
  - nature of problems
  - progression
  - functional ability
  - support
  - carers
- Explain what is going on
- Keep them updated
- Involve them in decision making and planning

Diagnosis: underlying cause

- <50% have single cause
- 10-20% no discernible cause
- think in terms of vulnerabilities and precipitants

A useless differential diagnosis

TABLE 3. Putative causes of delirium

- Medications
  - Psychotropics (anxiolytics, sedative-hypnotics, barbiturates, antidepressants, antipsychotics, lithium)
  - Anticonvulsants
  - Analgesics
  - Anticholinergics (antihistamines, antispasmodics, antiparkinsonian agents)
  - Antiarrhythmics
  - Antihypertensives
  - Aminoglycoside antibiotics
  - Miscellaneous (cimetidine, steroids, nonsteroidal anti-inflammatory drugs, salicylates)
- Drugs of abuse (phencyclidine and hallucinogenic agents)
- Alcohol
- Poisons (heavy metals, organic solvents, methyl alcohol, ethylene glycol, insecticides, carbon monoxide)
- Withdrawal syndromes
  - Alcohol
  - Sedatives and hypnotics
- Cardiovascular
  - Congestive heart failure
  - Cardiac arrhythmia
  - Myocardial infarction
- Neurologic
  - Head trauma
  - Space-occupying lesions: tumor, subdural hematoma, abscess, aneurysm
  - Cerebrovascular diseases: thrombosis, embolism, arteritis, hemorrhage, hypertensive encephalopathy
  - Degenerative disorders: Alzheimer disease, multiple sclerosis
  - Epilepsy
- Infection
  - Intracranial: encephalitis and meningitis (viral, bacterial, fungal, protozoal)
  - Systemic: Pneumonia, septicemia, subacute bacterial endocarditis, influenza, typhoid, typhus, infectious mononucleosis, infectious hepatitis, acute rheumatic fever, malaria, mumps, diphtheria, AIDS
- Metabolic
  - Hypoxia
  - Hypoglycemia
  - Acid-base imbalance: acidosis, alkalosis
  - Electrolyte imbalance: elevated or decreased sodium, potassium, calcium, magnesium
  - Water imbalance: inappropriate antidiuretic hormone, water intoxication, dehydration
  - Failure of vital organs: liver, kidney, lung
  - Inborn errors of metabolism: porphyria, Wilson disease, carcinoid syndrome
  - Remote effects of carcinoma
  - Vitamin deficiency: thiamine (Wernicke encephalopathy), nicotinic acid, folate, cyanocobalamin
- Endocrine
  - Thyroid: thyrotoxicosis, myxedema
  - Parathyroid: hypo-and hyperparathyroidism
  - Adrenal: Addison disease, Cushing syndrome
  - Pancreas: hyperinsulinism, diabetes
  - Pituitary hypofunction
- Hematologic
  - Pernicious anemia

A useful differential diagnosis

- meds
- meds
- meds
- brain disease
- infection
- hypoxia
- metabolic
- some combination
- something else

Rockwood 2001

Geriatric Medicine

Geriatric Medicine is general medicine….

Archie Young circa 1990

Geriatric Medicine

Geriatric Medicine is general medicine….

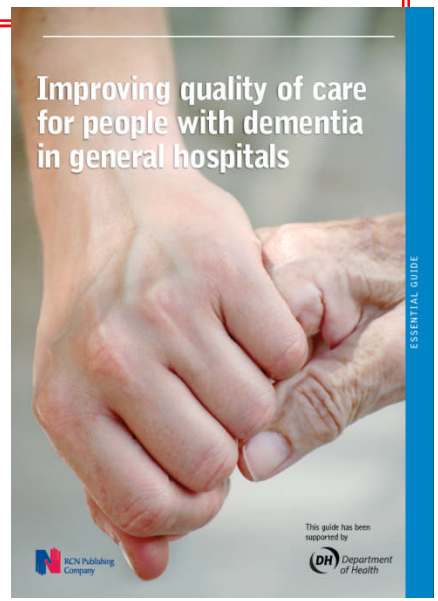
…. done obsessively

Archie Young circa 1990

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

Problems for people with dementia



- 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

RCN Guidelines 2010

See through the eyes of the person with dementia

- What might be threatening?
- What would make it feel more safe?
  - Comfort, identity, attachment, occupation, inclusion
  - Continuity: staff, ward moves
  - Familiarity, family
  - Orientation, signage, explanation
  - Relationships: biography, personality, interests

What is this?

Focus on communication

• Introduce yourself	Say what you are doing
• Assess	Understanding and expression
• Simplify language	Slow down, repeat, avoid questions (?)
• Non-verbal	Crouch down, touch, tone of voice
• Facilitate	Objects, pictures, demonstrations
• Talk through procedures	To alleviate fear
• Interpret	Emotions, meaning

- Don’t contradict, confront, embarrass or humiliate

Adequate pain relief

- Pain may cause distress behaviour
- Person may not be able to communicate pain…

  … you have to look for it
- But remember opiates are toxic (especially codeine)
- And not all distress is caused by pain
  - constipation, bladder
  - hunger, thirst
  - psychosis, emotions
  - environment, temperature, noise, interference

theguardian

Ann Clwyd: my husband died like a battery hen in hospital

Labour MP tells of inhumane treatment and says she fears normalisation of cruelty now rife among NHS nurses

Amelia Hill
The Guardian, Tuesday 4 December 2012 21.03 GMT

Owen Roberts, husband of Ann Clwyd, was treated with 'coldness, resentment, indifference and even contempt' according to the Labour MP. Photograph: Ann Clwyd

Ann Clwyd has said her biggest regret is that she didn't "stand in the hospital corridor and scream" in protest at the "almost callous lack of care" with which nurses treated her husband as he lay dying in the University Hospital of Wales in Cardiff.

Clwyd, the Labour MP for Cynon Valley since 1984 and Tony Blair's former human rights envoy to Iraq, told the Guardian she fears a "normalisation of cruelty" is now rife

Dissatisfaction

- 77% of carers dissatisfied with quality of care
- Areas of dissatisfaction:
  - Recognising and understanding dementia
  - Inactivity
  - Social interaction
  - Involvement in decision-making
  - Dignity and respect

Counting the Cost: Alzheimer's Society, 2009

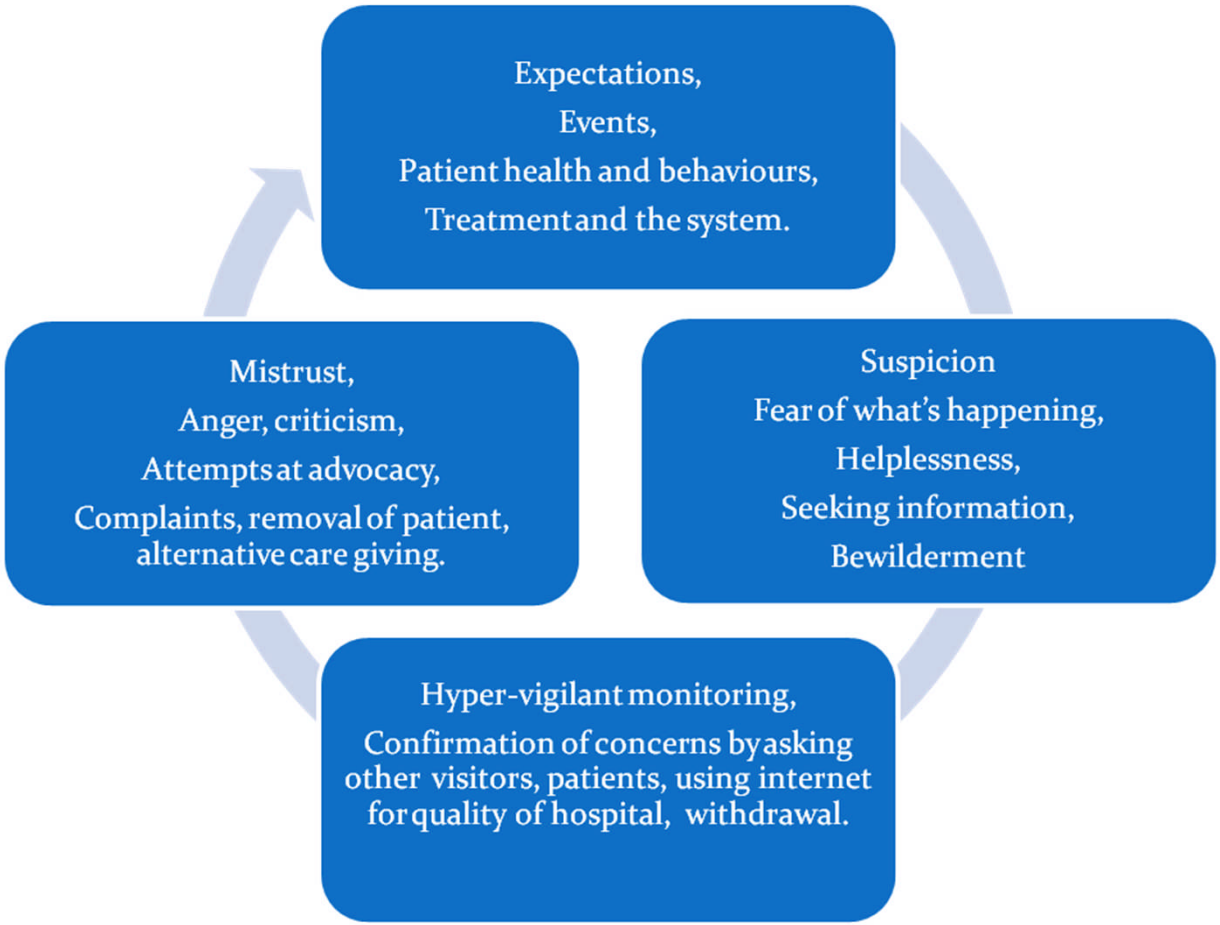
NIHR TEAM Trial: carer very or mostly satisfied

	MMHU (n=234)	Standard care (N=228)
Overall*	91%	83%
Admission arrangements	79%	77%
Car parking	27%	28%
Feeding and nutrition*	86%	77%
Medical management	79%	71%
Kept informed *	77%	64%
Dignity and respect*	94%	87%
Needs of confused patient**	84%	71%
Discharge arrangements*	78%	62%
Prepared for discharge*	79%	70%
Discharge about right time	73%	67%

***p<0.05, **p<0.001**

Goldberg et al, 2013

The cycle of discontent



Jurgens et al, 2012

The cycle of discontent

Jurgens et al, 2012

Make the most of family and friends' expertise

- Factual information
- 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

Breaking the cycle of discontent

- Pre-empt the problem
- Make each hospital contact positive
- Proactively seek opportunities for communication
- View carer as a unit with the person with dementia
- Make systems and processes dementia friendly
- Including Emergency Department, medical admissions unit
- Look out for those with no carers

Dementia summary

- Dementia can be an unpleasant reality
- Good care helps, bad care makes things worse
- People with dementia are people
  - please treat them with respect, help them feel at ease
  - involve and explain, adapt communication
  - try not to humiliate, ignore, infantilise, overwhelm
- Recognise and beware delirium
- Engage and involve families
- Be a good physician

A Radical Suggestion

David Nicholson, chief executive of the NHS Commissioning Board, asserts that 'Hospitals are very bad places for old, frail people' and suggests alternatives must be found.

Here is a radical suggestion – make hospitals good places for older people….

Marion ET McMurdo

BMJ, 16th Feb 2013