'No rehab potential'

Functional recovery after acute illness among people with dementia

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- Dementia with Lewy bodies for 6 years
- Lives with wife, supported by son
- Wandering, up at night, poor safety awareness, falls
- Unwell in respite care

- Hypotensive, dehydrated, septic (CRP 250), renal failure (Urea 50, Cr 320)
- Drowsy, immobile, distressed crying out

- Little improvement in behaviour or function despite treatment
- Wife insistent she wants him home
- MDT don't think it can work
- Referred for community hospital rehabilitation

- Assessed and declined
- 'No rehab potential'

Outline

- Disability amongst people with dementia in hospital
- Delirium
- Recovery models
- Can people with dementia rehabilitate?

Dementia: definition

DFMFNTIA

- 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.

Dementia subtypes

Alzheimer's disease	31%
Vascular	22%
Mixed	25%
Lewy body	11%
Fronto-temporal	8%
Rarities	3%

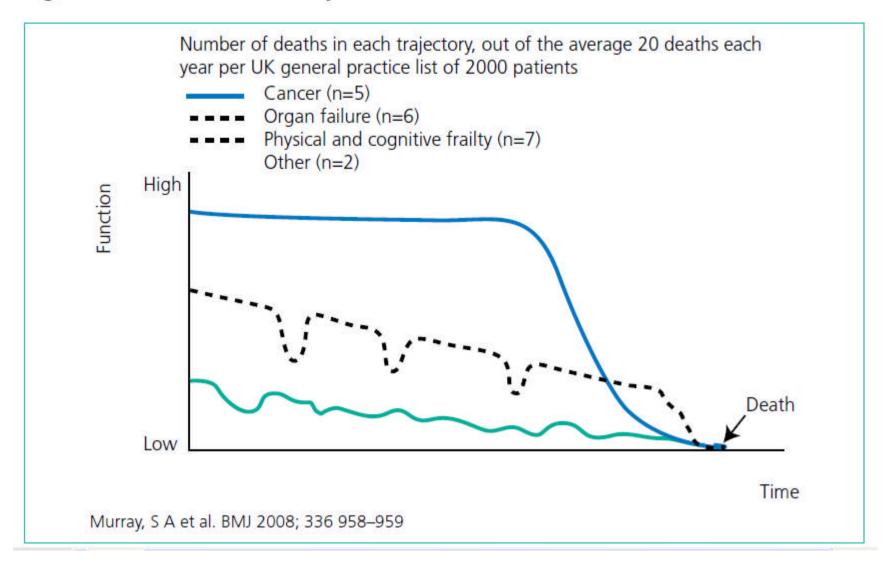
The problem with dementia

- Activities of daily living
- Communication, reasoning, decision making
- Safety awareness
- Behavioural and psychological symptoms
- Carer strain
- Progression to end of life care

Medical admissions over 70

•	Delirium alone	9%
•	Delirium complicating dementia	19%
•	Dementia alone	23%
•	Total delirium	28%
•	Total dementia	41%
•	Previously diagnosed dementia	28%

Figure 1: The three main trajectories of decline at the end of life



Functional presentations

Presenting problems amongst patients over 70 with cognitive impairment admitted to a general hospital

Falls	64%
Immobility	73%
Pain	54%
Incontinence	46%
Breathlessness	23%
Dehydration	21%
Confusion	21%

Psychopathology

Prevalence of at least moderate severity symptoms amongst patients over 70 with cognitive impairment admitted to a general hospital

•	delusions	14%
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hallucinations 11%

• agitated 18%

depressed 34%

anxious 35%

apathetic38%

disinhibited 10%

sleep problems 34%

• MMSE <9/30 25%

Severe and worsening disability

Barthel Index	Prior to acute illness	At admission
0-5 (very severe)	7%	31%
6-10 (severe)	17%	32%
11-15 (moderate)	20%	27%
16-20 (mild)	49%	10%
Incontinent	23%	53%
Major help transfer	13%	48%
Help feeding	23%	58%

Poor outcomes six months later

- 27% did not return home
- 31% dead within 6 months
- 18% 30-day readmission
- 42% 6-months readmission
- 25% new care home admission
- 16% spent >170/180 days at home

Recovery of function over six months

Change in Barthel Index	Admission to follow up	Pre-acute illness to follow up
Improved (≥2 points)	44%	10%
Same (±1 point)	27%	32%
Deteriorated (≥2 points)	29%	58%

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

Diagnosis: underlying cause

- Any illness, injury, drug, drug withdrawal
- <50% have single cause</p>
- 10-20% no discernible cause

Slow recovery

Persistence

- 61% after 24h
- 45% at discharge
- 33% at 1 month
- 26% at 3 months
- 21% at 6 months

Outcomes 6 months after delirium

	Delirium n=107	No delirium n=140
Median hospital stay	14d (IQR 7-32)	15d (IQR 6-39)
Mortality	37%	27%
Readmission	42%	42%
MMSE improved ≥3	43%	27%
ADL improved ≥3	25%	36%
Care home placement	32%	20%

Rehabilitation

The process of trying to help people who have suffered some impairment to maximise psychological well being, functional ability and social integration

Rehabilitation

- Re-enablement
- Re-settlement
- Re-adjustment

Maximising function, maximising choice

Why rehab might not work

- Memory loss, apraxia, understanding, agnosia, executive function loss
- Progression of disease
- Frailty
- Complications
- Upset, distress, fear, non-cooperation

Why rehab might not work

- Low expectations, nihilism
- Provoked and untreated distress
- Untreated symptoms
- Disengagement or conflict with families
- Performance targets
- Poor follow on services

Why rehab might work

- Recovery of acute illness
- Recovery of delirium
- Reversal of deconditioning
- Avoidance of complications
- Access implicit or procedural memory
- Use retained abilities
- Minimise threat and create productive relationships

How rehab might work

- Dementia awareness and expertise
- Slow down
- Follow the sprit of ethical and legal decision making
- Adaptation vs restoration
- Mental health specialist intermediate care
- Community mental health teams
- Rehab approach in care homes

Medical model

- Diagnose
- Treat
- Discharge

Comprehensive Geriatric Assessment

- Diagnosis
- Function
- Mental Health
- Social
- Environmental

Principals of palliative care

- Meticulous management of symptoms or problems
- Open communication
- Psychological, emotional and spiritual support of the patient and those close to them

Social model (disability movement)

Disability is an oppression by the majority in Society on those with different abilities

Oliver 1990

The experience of dementia

- Neurological impairment
- Personality
- Biography
- Mental and physical health
- Social environment and relationships

Malignant social psychology

Psychological need	Detractors	Enhancers
Attachment	 Accusations Treachery Invalidation Acknowledgement Genuineness Validation 	
Inclusion	StigmatisingIgnoringBanishmentMockery	Encouraging participationBelongingFun
Identity	InfantilizingLabellingDisparagement	RespectAcceptanceRecognition
Occupation	Disempowerment Disruption Imposition Objectification	EmpoweringEnablingFacilitatingCollaborating
Comfort	 Withholding attention Exclusion either physical or psychological Outpacing – rushing 	WarmthProviding security and safetyRelaxed pace

Person-centred care

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

Process differences, from casenotes

	MMHU (n=110)	Standard care (N=95)
Cognitive assessment (MMSE)**	52%	26%
Collateral cognitive history**	64%	33%
Collateral function**	81%	42%
OT**	83%	37%
SLT**	18%	2%
PT	88%	82%
Clear medical diagnosis*	92%	77%
Progress discussed with family*	86%	75%
Intermediate care used	13%	5%
CMHT referral*	20%	9%

^{*}p<0.05, **p<0.001

NIHR TEAM Trial: outcomes at 90 days

	MMHU (n=309)	Standard care (N=290)	P (adjusted)
Median days at home	51d	45d	0.3
Not returned home	26%	30%	0.5
Died	22%	25%	0.9
Median initial LOS	11d	11d	0.2
Readmission	32%	35%	0.8
Total LOS in 90d	16d	16d	0.8
Move to care home	20%	28%	0.3

NIHR TEAM Trial: health status at 90d

	MMHU (n=241)	Standard care (N=219)	P (adjusted)
Median MMSE/30	16	16	0.6
Median total NPI/44	19	17	0.5
Median Barthel/20	12	13	0.8
Median London Handicap/100	33	42	0.9
Median DEMQOL	84	84	0.7
Median proxy DEMQOL	93	93	0.8

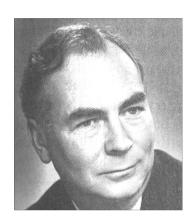
NPI: Neuropsychiatric Inventory, behavioural and psychological symptoms

MMSE: mini-mental state examination

DEMQOL: Dementia Quality of Life scale

Objectives of health care

- Prevention (of disease or complications)
- Cure (of disease or complications)
- Defer death
- Relieve symptoms
- Improve physical and social function
- Give information
- Support families and other carers



THE ROCK CARLING FELLOWSHIP

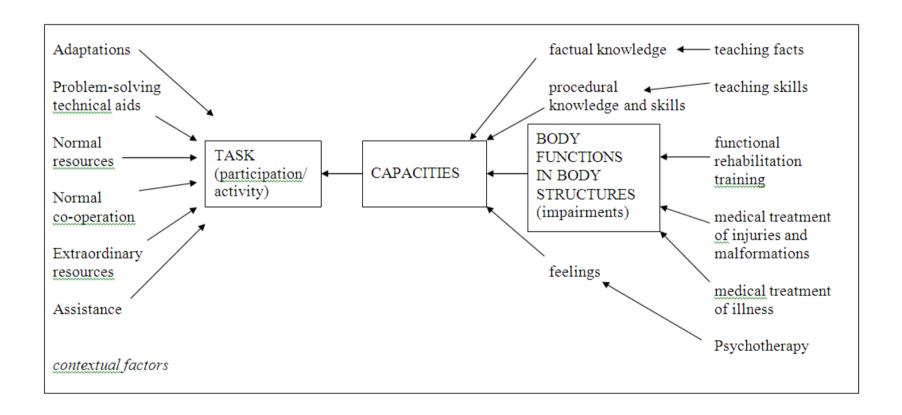
The role of medicine

DREAM, MIRAGE,

OR NEMESIS?

ICF model

Figure 8.1: Schematic representation of the WHOs framework for rehabilitation – the *International Classification of Functioning, Disability and Health* (ICF). The aim is to maximise activity and participation. Arrows represent necessary conditions. Devised by Dr <u>Tormod Jaksholt</u>



Rehabilitation in dementia

- Eclectic
- Be realistic about goals
- Live with uncertainty, don't jump to conclusions
- Take time
- 'Functional approach'
- Work with families and other carers
- Work in teams, value specialists.
- Process is as important as product

Mr M: end of the story

- Long discussions with wife and son: impass
- Rehab efforts continues
- Behaviour settled
- Mobility improved, able to walk 30m with frame
- Went home with social care and CMHT follow up

Mr M: end of the story

Dear All

I've just taken a rather long and strange phone call from a Mrs M - her husband was on B47 for 6 weeks, she said you would remember him?!

I don't think she wanted to complain as much as she wanted to say the ward team (MDT) told her she wouldn't cope and he needed to go into a home. She wants you to know she is coping and he's sat in the garden enjoying the sunshine!!

It was a really strange conversation - I'm sure there is more to this than meets the eye!!!

Regards John

Matron

Rehabilitation in dementia

More to this than meets the eye