Therapeutic Transitions in Dementia Care

Older Adult Mental Health Services
Presentation Overview
Nick Stevens, Head of Older Adult Services

• Service context
• Scope of work across Older Adult services
• Focus on dementia
  – National drivers
  – Local drivers
• Innovations and outcomes
• Early intervention, neuropsychological assessment and pre- and post assessment and diagnostic counselling and support
• Learning to understand and develop interventions for people with behaviours that challenge families, carers and staff
Neuropsychological Assessment and Dementia:

Its relationship with the transition to ‘living well’ through the pre and post assessment counselling, diagnosis and support process

Dr Caroline Formby
Clinical Psychologist
Overview

- Background
- Film clips of staff experience
- Pre- and post-assessment counselling and support
- Film clips from carer and client experience and outcome
- Summary
Background

- Living well with dementia – What does this mean? For who?
- Early diagnosis is crucial – transition to ‘living well’
- When neuropsychological assessment is indicated
  - Diagnosis of MCI is considered
  - Inconsistency between client and carer report
  - Unusual presentation
  - Clarification of different dementia presentations
- Pre-assessment and post-diagnostic counselling and support
  - Evidence base for psychological and psychosocial support
  - Clients and carers cope better longer term
  - Financial consequence for systems in the longer term
  - Neuropsychological assessment - targeted cognitive, psychological and psychosocial support
Staff Experience

- Staff members from Dudley Memory service and the Trust were asked to give their views based on their experience of the value of neuropsychological assessment, subsequent diagnosis and support for clients and for carers as well as for their practice.
- **Staff Experience Film**
- Some of the themes that emerged

<table>
<thead>
<tr>
<th>Benefits outweigh costs of testing</th>
<th>Value of cognitive rehabilitation</th>
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<tr>
<td>Identification of cognitive problems</td>
<td>Increased empowerment and sense of personal control</td>
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<td>Reframing the diagnosis away from catastrophe</td>
<td>Increased confidence and perceived ability to cope</td>
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<td>Time required to assimilate diagnosis</td>
<td>Helping clients and carers move from denial to adjustment</td>
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<td>Positive ways of ‘breaking bad news’</td>
<td>Elucidation of cognitive deficits / strengths and carer coping</td>
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<td>Promotion of understanding leading to acceptance</td>
<td>Active involvement of client and carer in whole process</td>
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<td>The importance on knowing</td>
<td>MDT working and staff support</td>
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Pre-assessment Counselling

• Openness, honesty – using the ‘D’ word
  – Clarity over use of term ‘dementia’ (Bamford, 2004; Karneili-Miller et al, 2007; Phillips et al., 2012
  – Evidence that people “want to know” (Manthorpe et al, 2011; Pratt & Wilkinson, 2001)

• Expectations, fears and coping strategies
  – People often hold negative attitudes & false beliefs
  – Reduce sense of ‘shock’ at diagnosis and potential for denial

• Facilitating informed consent

• Involvement of family members
  – Shared understanding of perceived problems
  – Shared journey to adjustment and acceptance – ‘living well’
Post-Diagnostic Counselling

• Process of providing support with coming to terms with the diagnosis of dementia for clients and carers – 1 to 3 sessions
• Diagnosis sharing - good practice
  – Delivered with sensitivity and appropriately communicated
  – Accounting for emotional impact, pacing & time, validating person
• Link objective cognitive measures with reported difficulties
  – Helps client and carer to feel validated
  – Understand impact of dementia, promoting acceptance and reducing denial
• Link to issues covered in pre-assessment counselling
  – Address fears, expectations, address emotional impact, emphasise resilience
• Instil sense of hope, empowerment and living well despite the diagnosis
• Further information sharing
## Carer Experience

Carer experience of attending neuropsychological assessment interview and post assessment feedback and counselling with her father.

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<td>Expectation of uncovering extent of problems</td>
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<td>Short screening measures not sensitive enough</td>
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<td>Carer anxiety due to difficulty feeling ‘heard’</td>
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<tr>
<td>Client denial affecting assessment process</td>
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<td>Carer frustration</td>
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<td>Inclusion of carer in assessment valued</td>
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<td>Consideration of premorbid abilities</td>
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<td>Emotional containment valued</td>
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<td>Respect and empathy</td>
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<td>Relief</td>
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<td>Empowerment of client during assessment</td>
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<td>Non-judgmental</td>
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<td>Frank / honest yet emotionally supportive</td>
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<td>Ecological validity of testing</td>
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<td>Validation of carer perspective</td>
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<td>Delivering ‘bad news’ positively</td>
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<tr>
<td>Relief about objective evidence</td>
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<tr>
<td>‘Knowing’ and link with interventions</td>
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<tr>
<td>Reduction in carer anxiety and frustration</td>
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<td>Cognitive strategies and client empowerment</td>
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Client Experience

Client experience of 12 month diagnosis of MCI, followed by neuropsychological assessment, feedback and post-assessment support.

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<td>Assumptions based on experience of dementia</td>
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<td><strong>Waiting increased anxiety</strong></td>
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<td>Feeling well-being, coping differently</td>
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<td><strong>Knowing empowers to cope</strong></td>
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<td>KNOWING</td>
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Summary

- Dementia increasingly biggest transition of older age
- Psychologists in Early Stage Dementia Pathway (BPS, 2014a)
  - Diagnosis (differential and delivery)
  - Pre and post assessment counselling
  - Training, supervision, service development
  - Post diagnostic psychosocial interventions (BPS, 2014b)

- Positive outcome evidenced by client and carer experience
Thank you

• Client - Lorna
• Carer – Jan
• Staff
  – Jackie Stevens, Senior Clinical Lead, Older Adult Inpatient Services, DWMH
  – Edwina Gould, Specialist Nurse in Dementia, Dudley Memory Service, DPCT
  – Brian Levy for his help with the video editing
References

References


• National Institute of Health and Care Excellence (NICE) 1.4.6.1 Addressing needs that arise from the diagnosis of dementia.

• NICE and SCIE (2006). Dementia: Supporting people with dementia and their carers in health and social care. NICE Clinical Guideline 42. Available at www.nice.org.uk/CG42 [NICE guideline]


Transitions in Dementia

Older Adult Psychology

Managing behaviours that challenge services:
Clinical Implementation Group

Dr Julia Cook
Clinical Psychologist
“A disease is never a mere loss or excess – there is always a reaction, on the part of the affected individual, to restore, replace, to compensate for and to preserve its identity, however strange the means may be”

Oliver Sacks
Overview

• Background
• Film clips of staff experience
• Context for non-pharmacological approaches and brief overview
• Behavioural work in the Trust via leadership and creativity
Behaviours that challenge

• “…actions that detract from the well-being of individuals due to the physical or psychological distress they cause within the settings they are performed” (James, 2011)

• Cognitive decline; struggle to communicate unmet needs (Cohen-Mansfield, 2001)

• Actions are an attempt to maintain well-being or ease distress
Cost of dementia and behaviours that challenge

Financial
- £27,647 per year (HERC, 2010) on average per client with dementia → more for people with behaviours that challenge

Personal
- Too many to list, but including:
  - Major source of distress for carers/family/individual
  - Reason why many require hospitalisation or 24 hour care
National Picture

- Time for Action (Banerjee, 2009)
- 25% of people with dementia in the UK prescribed anti-psychotics:
  - significant side-effects
  - effective in only one in five presentations (James, 2011)
- Non-pharmacological approaches should be first line treatment (NICE/SCIE, 2006; Banerjee, 2009; National Dementia Strategy, 2009).
Why not medicate? I

• Long history of excessive and inappropriate use of major tranquilisers i.e. antipsychotics (Ballard et al., 2009; Sink et al., 2005; National Dementia Strategy, 2009; Banerjee, 2009).

• Concerns re: growing use of benzodiazepines

• Medication plays important role, especially when used to treat underlying causes (e.g. pain, metabolic, psychosis)

• However, poor evidence base for using in people with dementia to tackle behaviour that challenges.

• Interactions e.g. statins are known to increase agitation

• Side-effects – sedation, cardiac problems, increasing cognitive impairment, falls risks….. (Banerjee, 2009)
Why not medicate? II

For every 1000 CB cases treated over a 12 week period 91–200 patients will improve. But there’ll be an additional: 10 deaths, 18 vascular events (50% severe) and 60–94 patients with gait disturbance (Banerjee 2009)

Figure 3.1 Anti-psychotic side-effects
What is the rationale for an alternative, non-pharmacological approach?

“Implementing behavioural interventions instead of antipsychotic medication could lead to savings of 54.9 million across the UK, resulting in a reduction in side effects such as the occurrence of strokes and falls (NHS Institute of Innovation and Improvement, 2011), which would result in an increase in the quality of life of people living with dementia.” (BPS, 2013)
Psychological approaches: I

- Creation of guidelines to address unmet needs (i.e. lead to behaviours that challenge) on dementia wards (e.g. Newcastle Model – James, 2011)

- Thorough assessment; a number of potentially causal areas:
  - cognitive/perceptual
  - physical/metabolic
  - psychological e.g. pre-morbid personality, mental health
  - social
  - environmental and care practices

- Targets causal factors

- Provides proactive and reactive strategies

Assessment: Information collected by behaviour charts (include events, reaction, consequences), discussions with family/staff, observation, functional analysis
Psychological approaches: II

Figure 1.1 BC iceberg analogy
Psychological approaches: III

- Behaviours are expressions of needs that we all have, which are poorly communicated due to the cognitive difficulties associated with dementia.
What are we doing in the Trust? I

- **Clinical Implementation Group** – Local innovative leadership, including senior nursing staff, psychiatry, pharmacy and psychology (chair)
  - maximise use of multi-disciplinary approach with available resources
  - creative thinking about individuals in our care

- Core aim: enhance personhood (Kitwood, 1997) and well-being of individuals who demonstrate behaviour that challenges
What are we doing in the Trust? III

Aims and Tasks:

- **Behavioural Guidelines**
  - Implement behavioural guidelines and facilitate use
- **Medication**
  - Examine use of antipsychotics, MAPA restraint
  - Enhance psychiatry’s ability to minimise use of antipsychotics
  - Medication audits
  - Review of antipsychotic prescribing policy and care pathways
- **Ward environment**
  - Environmental changes
- **Approaches**
  - Formulation
  - Tool-box approach
  - Embed approach as part of assessment; admission – care – discharge
  - Inclusion via MDT approach to behaviour – unified approach

Staff

- Examination of staffing
- Staff training
- Regular discussion groups – support staff, develop framework for individual client

Combined approach which makes the best use of various available options
Future

• Ambition is to expand to community – prevention

• Link with future home-treatment initiatives, care in the community etc.

• Reduce carer difficulties and adverse impact of behaviours that challenge
Summary

• Transitions into inpatient care and upon discharge into community (whether home, care home, etc.)

• Role of psychology in working with behaviours that challenge
  o Supporting staff/carers – psycho-education and facilitating use of skills
  o Conducting neuropsychological/psychological assessments
References


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