Research Briefing:
What happens to people with dementia identified in general hospital?

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Rethinking ‘dementia’: Multi-disciplinary approaches to understanding dementia in everyday life
Manchester, Friday 28th of May 2012
What happens to People with Dementia identified in general hospital?

Objectives of the research:

- To investigate the range of outcomes for people with dementia identified in general hospital
- To estimate family and societal costs of care for people with dementia identified in general hospital
- To identify the key predictors of better outcomes for people with dementia identified in general hospital
- For those people with dementia discharged from hospital to a care home, to explore their personal experience of the transition.
HLT referrals
N = 993
(includes 101 patients referred more than once)

Ineligible
N = 531

Eligible
N = 256

Eligibility unknown
(insufficient information)
N = 105

In study
N = 112

Not in study
N = 144

Carer did not want to participate
N = 56

Unable to contact carer
N = 5

Patient did not want to take part
N = 11

Patient deceased
N = 3

Patient moving out of area
N = 1

Patient discharged
N = 64

No applicable carer
N = 3

Transferred to another hospital
N = 1
Study One – measures

- The Alzheimer’s disease-related Quality of Life scale
- Geriatric Depression Scale -15 item version
- IADLS - Instrumental and Physical Activities of Daily Living Scales
- Physical illness – Burvill scale
- Clinical Dementia Rating scale
- Carer stress – the General Health Questionnaire GHQ-12
- Demographic data
From our research project, we show six hypothetical cases based on study findings, illustrating costs for different outcomes after general hospital in the UK. The cases show great variation in costs, in public and family contributions, and the potential costs if family (informal) care is fully costed.

- About the Project - What happens to people with dementia identified in general hospital?
Study Two: Exploring the transition from hospital to care home

Pre-move interviews = 23
Post-move interviews = 15
Dropped out = 1
Deceased = 7
<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>Women:13 Men: 2</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>Range:79-95 (mean 88)</td>
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<tr>
<td><strong>Dementia stage</strong></td>
<td>Mild 2: Moderate 7: Severe 6</td>
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<tr>
<td><strong>Admission reason</strong></td>
<td>Falls/fractures 8: Infections 4: Dehydration 2: Other 2</td>
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<tr>
<td><strong>Stay on ward</strong></td>
<td>Range: 22-74 days (mean 43.5)</td>
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<tr>
<td><strong>Previous home</strong></td>
<td>Owner 9: Renting 1: Sheltered 3: Extra Care 1: Care Home 1</td>
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<tr>
<td><strong>Formal care</strong></td>
<td>Yes 13: No 2</td>
</tr>
<tr>
<td><strong>Family carer</strong></td>
<td>Spouse 1: Grandchild 1: Child (including child’s partner) 13</td>
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Experiences before the hospital admission

• Information failures
• Varied experiences of social and health care services
• Uncertain futures
• Incremental increases in carer stress
• Carer feeling of ambiguity and guilt
• Mixed experiences of previous stays in care homes
Experiences of care in hospital

Carers generally:

- satisfied with medical care
- dissatisfied with personal care
- aware of time/resource limitations on wards
- dismayed at lack of expertise in working with patients with dementia
- attribute decline in competence to hospital stay
  - Mobility
  - Nutrition
  - Continence
She was in hospital 6 weeks. They were fine ...when she had her operation and looking after her arm, but dementia-wise, they got no idea. They’d bring her meals and take them away because they’d say she hadn’t ate them. They recon they got her out of bed to walk, but she couldn’t walk at all.

There was other people on the ward like her, and they just hadn’t got the time to make sure they had a drink ... she had three water infections when she was in there because she wasn’t drinking.

(#50)
Expectations of care homes

- Safety
- Decent treatment
- Expertise
- Stimulation (involvement and company)
- Some restoration of QoL
I know that she’s going to be safe, which is my main concern. I think that, hopefully, her quality of life will improve when she goes into a care home because they will make her get up and do things. And I think that er, I think actually she’ll improve from the fact that there’ll be less boredom. #35
Experience of care homes

• Selection based on ‘atmosphere’ and location
• Generally positive experiences of current care home
• Relationships with staff important
• Disappointment with ‘activities’
• Reduced carer stress
I’ve been well looked after and I can’t say that I regret...mind you I do regret not having a life of my own with my own children but they come to see me and in a way I’m happy.

I could go and live with my son but I don’t want to, I like it here, because my son’s got to work. He’s got a life and he’s got children. So I feel more at home here, in fact I do like it here.

I do like it, it’s the best one I’ve been to because they consider you, you know if there’s thing you need to talk about they come and have a little talk with you. #6
They’ve got a very good routine..’cos each time I’ve gone there they all look clean which I find very important and erm, I think they have breakfast and they go down...there’s a television lounge for the ones that are capable of sitting there...but, they just lie there, there’s heads nodding and that’s basically their day. But I mean I can honestly say that’s all they can do for them, make sure they’re warm, they’re dry, they’re fed, there’s nothing, I really believe there’s nothing physically you can do with them. #67
Costing dementia care after general hospital:
http://www2.warwick.ac.uk/fac/med/research/mhwellbeing/projects/dagh/

CABS Blog:
http://centreforagingandbiography.blogspot.co.uk/

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http://carolineholland.weebly.com/
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