Developing a Carer’s questionnaire for the National Audit of Dementia

A methodological case study

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Patient Experience Research Centre
Dementia

Diagnosis rate: 38% - 49%

UK population prevalence:

- 683,597 (2007)
- 1,735,087 by 2051
- Increase of 154% in 45 years

Hospital prevalence:

- 50% of admitted patients over age 70
- 2/3 hospital beds age 65+

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1. National Audit Office. Improving services and support for people with dementia. 2007
Policy context

Living well with dementia: A National Dementia Strategy
Commissioning for Quality and Innovation (CQUIN)

Prime Minister’s challenge on dementia 2020
Environments of care for people with dementia

Dementia Action Alliance
Dementia-Friendly Hospital Charter
CareQualityCommission
The National Audit of Dementia

Systematic review

Development of questions

Involvement of carers

Next steps
The National Audit of Dementia
Specification:

- Short (6-8 questions)
- Specific to hospital setting
- Broad definition of ‘carer’
- Focus on carer perspective
- Developed with the input of carers
# Systematic review

- # of records identified through database searching: 1,895
  - # of records after duplicates removed: 1,425
  - # of records screened following eligibility filters: 260
    - # of records removed through title and abstract screen: 237
    - # of full text articles excluded, with reasons: 11
    - # of full text articles assessed for eligibility: 23
      - # of records included in qualitative synthesis: 13
    - # of publications added from reference scanning: 1
Systematic review

Carer-centred themes
- Communication
- Involvement
- Relationships
- Recognition

Hospital-centred themes
- Staff knowledge
- Fundamental care
- Ward environment
- Discharge plans
### Initial question pool

12 source questionnaires

<table>
<thead>
<tr>
<th>Themes</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care coordination and planning</td>
<td>38</td>
</tr>
<tr>
<td>Information and Communication</td>
<td>33</td>
</tr>
<tr>
<td>Involvement</td>
<td>24</td>
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<tr>
<td>Person-centred care</td>
<td>18</td>
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<tr>
<td>Overall rating</td>
<td>12</td>
</tr>
<tr>
<td>Staff knowledge of dementia</td>
<td>10</td>
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<tr>
<td>Help from medical staff</td>
<td>8</td>
</tr>
<tr>
<td>Staff attitude towards carers</td>
<td>6</td>
</tr>
<tr>
<td>Basic care provision</td>
<td>4</td>
</tr>
<tr>
<td>Dementia-friendly environments</td>
<td>4</td>
</tr>
<tr>
<td>Having someone to contact</td>
<td>4</td>
</tr>
<tr>
<td>Access to services</td>
<td>3</td>
</tr>
<tr>
<td>Time with staff</td>
<td>2</td>
</tr>
<tr>
<td>Personal suggestions not covered above</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>168</strong></td>
</tr>
</tbody>
</table>
Shortlisting

- Duplicates
- Less relevant to setting
- Too specific
- Long / complicated

Refining the question pool

- Broad coverage
- Literature evidence

Agreeing items for testing

Long-form questionnaire for testing
- 15 questions
Carer involvement

2 local dementia carers support groups

Discussion topics:

• Experiences of hospital care

• The questionnaire (content, priorities, clarity, wording, design…)
Other user involvement

Face to face carer interviews

Patient and Public Involvement (PPI) Panel

Academic input
Carer feedback

Priorities:
• Communication
• Involvement
• Understanding & acknowledgement
• Staff knowledge and competence
• Personal care

Difficulties:
• Judging ward environment

Suggestions:
• Combining questions
Developing the pilot version

For each question please select your answer by putting a cross in the box  □  . If you make a mistake, please fill in the box  □  and put a cross in the correct box  □  .

Which of these best describes your relationship to the person you look after?  
1. Spouse or partner  2. Family member  3. Friend  4. Professional carer (health or social care)  5. Other

Are you one of the main carers for the person you look after? For example, family carer or key worker.  
1. Yes  2. No

PATIENT CARE

1. Do you feel that hospital staff were well informed and understood the needs of the person you look after?  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

2. Do you feel confident that hospital staff delivered high quality care that was appropriate to the needs of the person you look after?  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

3. Was the person you look after given enough help with personal care from hospital staff? For example, eating, drinking, washing and using the toilet.  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

4. Was the person you look after treated with respect by hospital staff?  
1. Yes, directly  2. Yes, to some extent  3. No  4. Don’t know

COMMUNICATION

5. Were you (or the patient, where appropriate) kept clearly informed about their care and progress during the hospital stay? For example, about plans for treatment and discharge.  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

6. Were you (or the patient, where appropriate) involved as much as you wanted to be in decisions about their care?  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

7. Did hospital staff ask you about the needs of the person you look after to help plan their care?  
1. Yes, definitely  2. Yes, to some extent  3. No  4. Don’t know

OVERALL

8. Overall, how would you rate the care received by the person you look after during their hospital stay?  

9. How likely would you be to recommend the service to friends and family if they needed similar care or treatment?  

10. Do you have any comments about the service provided by the hospital for the person you look after? For example, anything you were particularly happy or unhappy about?

Please turn over

ABOUT YOU

How do you define your gender?
1. Male  2. Female  3. Other

What is your age?
1. 18-24 years  2. 25-34 years  3. 35-44 years  4. 45-54 years  5. 55-64 years  6. 65-74 years  7. 75-84 years  8. 85 years and over

Please specify your ethnicity:

Thank you very much for your responses.

Please return the questionnaire in the FREEPOST envelope provided or to the address on the information sheet.
1. Did the ward provide a kind and caring atmosphere for the person you look after?

2. Do you feel that patients on the ward were checked on frequently enough, in case they needed help or assistance?

3. Was the ward adapted to provide a safe and comfortable environment for patients? For example, with aids for orientation and prevention of falls?
Examples - Revising and combining questions

Were you kept well enough informed about the care and progress of the person you look after while they were in hospital?

Was the care and treatment of the person you look after clearly explained to you in a way you could understand?

Were you (or the patient, where appropriate) kept clearly informed about their care and progress during the hospital stay? For example, about plans for treatment and discharge.
Next steps

Analyse results of pilot study:

Main pilot: 10 acute hospitals
Feasibility study: 5 community hospitals

Outcomes:

• Recruitment (different strategies)
• Response rates (data return)
• Qualitative feedback
• Data analysis (psychometric properties)
Psychometric analysis

- Missing data
- Endorsement frequencies
- Internal consistency (Cronbach’s \(\alpha\) and item-total correlations)
- Redundancy (inter-item correlations)
- Test-retest reliability

Subjective assessments:

- Content validity
- Acceptability
Feedback to Trusts from NAD

- Results fed back in reports to hospitals
- Key problems identified
- Action plans drawn up for quality improvement
Conclusions

• Recognises importance of carers
• Adds to the ways standards are assessed

But – not enough on it’s own:

• Questionnaires not rich source of feedback
• Complement through local involvement
Acknowledgements

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Thank you!

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Extra slides
Systematic review

Databases searched:
- Embase Classic + Embase (1947 to 2015 August 31)
- Ovid MEDLINE ® In-process and other non-indexed citations and Ovid MEDLINE ® 1946 to present
- HMIC Health Management Information Consortium 1979 to July 2015
- PsycINFO 1987 to September week 1 2015

Search terms:
- Dementia / cognitive impairment
- Carer / care-giver
- Experience / satisfaction
- Hospital care / inpatients
- Quality of care / good practice
- Questionnaire / survey
Systematic review

**Inclusion criteria:**

- Specific to dementia / cognitive impairment
- Results include information on carer perspective of hospital care.
- Publication types: primary research studies or reviews
- Language restrictions: English
- Date range: 1995 to present
- Full text available

**Exclusion criteria:**

- Non-UK setting
- Non-acute setting
- Diagnosis other than dementia
- Not reporting carer perspective
# Source questionnaires

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Inpatient/Community</th>
<th>National/Local</th>
<th>Patient/Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Previous National Audit of Dementia questionnaire</td>
<td>Inpatient</td>
<td>National</td>
<td>Patient and carer</td>
</tr>
<tr>
<td>2. Carer Wellbeing and Support questionnaire (mental health including dementia)</td>
<td>Both (general)</td>
<td>Either (academic)</td>
<td>Carer</td>
</tr>
<tr>
<td>3. NHS Inpatients questionnaire</td>
<td>Inpatient</td>
<td>National</td>
<td>Patient</td>
</tr>
<tr>
<td>5. National Survey of people with long term neurological conditions</td>
<td>Both (whole patient journey)</td>
<td>National (pilot stage)</td>
<td>Patient</td>
</tr>
<tr>
<td>6. NHS Community mental health questionnaire</td>
<td>Community</td>
<td>National</td>
<td>Patient</td>
</tr>
<tr>
<td>7. Personal Social Services Survey of Adult Carers</td>
<td>Community</td>
<td>National</td>
<td>Carer</td>
</tr>
<tr>
<td>8. VOICES survey (views of informal carers evaluation of services - national survey of bereaved people)</td>
<td>Both</td>
<td>National</td>
<td>Carer</td>
</tr>
<tr>
<td>9. The Carer's Checklist (dementia-specific)</td>
<td>General</td>
<td>Either</td>
<td>Carer</td>
</tr>
<tr>
<td>10. Mid Essex Hospital Trust Dementia Carer's Questionnaire</td>
<td>Inpatient</td>
<td>Local</td>
<td>Carer</td>
</tr>
<tr>
<td>11. Quality Mark (patients aged 65+)</td>
<td>Inpatient</td>
<td>National</td>
<td>Patient</td>
</tr>
<tr>
<td>12. Guys &amp; Thomas' dementia carers survey</td>
<td>Inpatient</td>
<td>Local</td>
<td>Carer</td>
</tr>
</tbody>
</table>
Combining questions

- Communication and being kept informed
- Being involved in care and working in partnership with staff
- Help with activities of daily living and personal care.
- Atmosphere of kindness, dignity and respect for patients.
Additional questions

- Safe admission and discharge processes.
- Support for the carer from hospital staff (helping with making arrangements, understanding their position)
- Need to intervene / advocate for the person to get good care.
- Ability to provide hands-on care if they want to.