The review process post-stroke: policy and practice

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Background to the six-month review (6MR)

Key drivers
- National Stroke Strategy (Dept Health 2007)
- NICE (CG162) Stroke rehabilitation guideline (2013)

Rationale: unmet need
- *Self-reported long-term needs after stroke* (McKevitt et al. 2011)
- *Struggling to Recover* (Stroke Association 2012)
- *Supporting Life After Stroke* (CQC 2011)

Evidence
- Forster et al. (1996): No significant difference in perceived health, social activities, or stress among carers between groups at any point.
- Forster et al. (2009): no clinical benefits at 12 months; intervention group expressed greater satisfaction with information provision.
Availability of the six-month review
(Royal College of Physicians 2015a, p38)
Research question

Purpose

Implementation

Outcomes

Mechanisms
Methodology

**Approach**
- Critical realism (Bhaskar 1978)

**Methodology**
- Qualitative

**Method**
- Multiple case study (Yin, 2014)

**Tools**
- Documentary analysis
- Interviews
- Observation
Data collection: 46 patients, 30 carers, 28 professionals

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
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<tbody>
<tr>
<td><strong>Patients (Carers):</strong></td>
<td>26 (14)</td>
<td>15 (11)</td>
<td>5 (5)</td>
</tr>
<tr>
<td><strong>Providers:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Stroke nurse specialist</td>
<td>3</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>- Stroke Association co-ordinator</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td><strong>Others: CCGs, GPs, therapists et al.</strong></td>
<td>7</td>
<td>6</td>
<td>2</td>
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**Across sites:** Royal Collage Physicians Stroke Working Party, South East Coast Strategic Clinical Network, Stroke Association regional directors, stroke specialist orthoptist = 6

<table>
<thead>
<tr>
<th>Observations</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
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<tbody>
<tr>
<td>Of reviews</td>
<td>17</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Other observations</td>
<td>11</td>
<td>5</td>
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Social versus medical model review

Commissioners and providers viewed the 6MR as a mechanism to identify unmet need. However, this was informed by their professional identity and organisational policy:

**Stroke Nurse Specialists**
- **Medical model**
  - Clinical expertise directs interaction
  - Liaise with consultants & GPs
  - Tailored observations
  - Advice on medications
  - 45-60mins

**Stroke Association co-ordinator**
- **Social model**
  - Focus on daily life
  - Listening
  - Signposting to community services
  - Perfunctory blood pressure monitoring
  - 60+mins
### Social structures versus individual agency

<table>
<thead>
<tr>
<th>Stroke nurse specialists</th>
<th>Stroke Association</th>
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<tr>
<td>I have become more medical model orientated these day which I assume is because of the limited other resources we can offer these days to make the patient’s life easier...</td>
<td>It is a holistic review and I think it is vital that it is not just a medical review, it needs to be all encompassing</td>
</tr>
<tr>
<td>That's a hugely important role... looking at weight, diet, blood pressure, medication, all of that... is... an integral part of the review</td>
<td>I’m very much looking at the whole person and how to support them ... that [6MR] is very medically based isn’t it? So that is an NHS agenda</td>
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<td>I think they [SA] are only able to deliver a very tick box superficial review</td>
<td>We’re just told to do it [take blood pressure]! I don’t know...</td>
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<tr>
<td>She [SA] does not read blood test reports or... look into like other related investigations, such as cardiac</td>
<td>I would like to reduce other information we have to collect at the same time because... it makes it impersonal</td>
</tr>
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Implications for patients and carers

Social context & long-term conditions

Stroke: effects on structure & function

Loss of valued roles; reduced participation; reliance on others

Emotional sequelae

Education, information, support and advice

Delays or gaps in service provision

Inpatient experience → Transition home → Follow-up services → 6MR
A typology of response to the 6MR

1. **Proactive** & self-managing
   - Resilient, determined, active pre-stroke
   - Positive relationships
   - Mild-moderate stroke, good recovery

2. **Independent** but not engaged
   - Activated but have their own approach
   - Lack of trust/‘non-compliant’
   - Other priorities &/or beliefs about rehab

3. **Passive** orientation
   - Perceived as ‘non-compliant’
   - Mostly lacked trust
   - Multiple long-term conditions &/or complex social circumstances
Dissonance of expectations

- I feel that I had so much wasted time. I used to sit in my room five, six hours a day, and Saturdays and Sunday (M, 79yrs)
- There’s such a gap between what goes on in hospital and what goes on in the community... I couldn’t cope (F, 56yrs)
- The needs for people who are my age are... a lot different (M, 28yrs)
- I felt they had a timeframe and then they had to leave you on your own to get on with it... when you need them the most they are not there (F, 37yrs)
- We didn’t know where we were going, what was going to be next... (C36)
- I suddenly thought, Christ, I’m here on my own. What am I going to do? I can’t even get out to the toilet (F, 63yrs)
Outcomes: policy aspirations versus reality

**Policy aspirations** (e.g. improved quality of life) were not evident and were based on assumptions that

- Identifying unmet need would lead to its amelioration
- Provision of information will lead to behavioural change
- Little questioning except for one manager:

  *Do I honestly believe that as a nation we should be spending however many millions of pounds implementing this service and is that the most important thing to stroke patients? My honest answer would be, "No."*

**Tangible outcomes:**

- Follow-up, investigations, medication adjustments (SNS only)
- Referrals within NHS (SNS only)
- Signposting to community services (SA>SNS)
- Information including secondary prevention (generic vs. tailored)
A policy based on individual responsibility

- Policy discourse emphasised personal responsibility for secondary prevention and self-management:

  ‘Effective lifestyle interventions require changes in behaviour such as smoking, exercise, diet and alcohol consumption. Although it is the responsibility of the individual to change his or her own behaviour, healthcare practitioners have a responsibility to give accurate information, advice and support to help people to make and maintain lifestyle changes’ (RCP, 2016, p108).

- This does not take account of contextual factors, treatment burden, illness beliefs or the one-off nature of the 6MR.
Conclusion

There were many tensions inherent in the 6MR which impacted on purpose, implementation and outcomes:

- Medical vs. social model
- Systemic requirements vs. reviewer’s agency
- Patient expectations vs. reviewer’s agenda including
  - Different illness understandings and belief systems
  - Arbitrary timeframe vs. when needed (‘hotspots’)
  - Experiences along the care pathway, especially therapy
  - Burden of illness for patient and carer
- Policy emphasis on individual responsibility vs. wider social context
- Consider targeting the 6MR, as McKeivt (2011) suggested

Thank you
References

• Care Quality Commission (2011). *Supporting Life After Stroke*. 