Care of Post-Stroke Patients: Identifying Circumstances In Which Specialist Referral May Be Beneficial

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Background and Aims

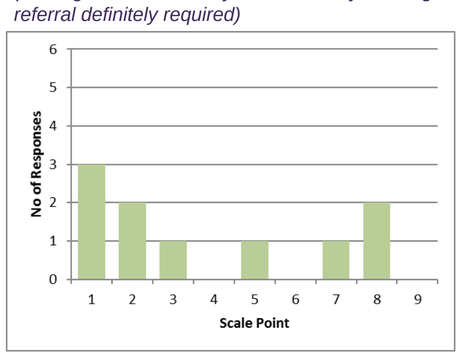
- Post-stroke 10 year survival rates are improving, which increase the need for long-term care of survivors. However, most interventions are targeted at the first year after stroke and there is a lack of evidence for interventions in the longer term and continuity of care in longer-term stroke care in the community.
- Patient needs continue long after discharge from acute stroke services, but are not always identified by health professionals. There is variation in GP referral rates at both GP and practice level, and the increasing financial burden on the NHS in the UK creates pressure to reduce referrals to specialist care. Guidelines for rehabilitation after stroke specify what long-term care stroke survivors should receive, but lack guidance about where this care should take place.
- **The aim of this study was to identify when a re-referral from primary care to specialist services may be beneficial in the long-term management of stroke survivors living in the community.**

Example (2 parts of 4 part scenario)

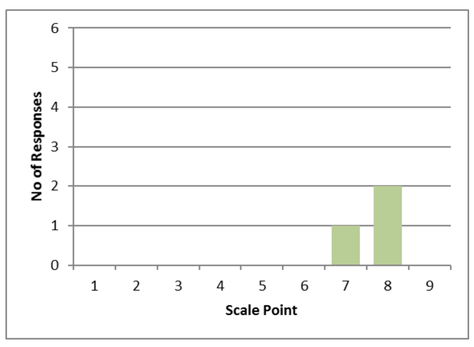
Mrs Farnham, a 71 year old, attends her local GP surgery with her husband 3 months after she experienced a left hemisphere stroke leaving her with significant right sided weakness. Since the stroke she has also struggled with receptive aphasia and emotional outbursts. She reports that she believes her "strength is improving" in her right upper limb with the help of weekly visits from a community physiotherapist and she is starting to help her husband with household tasks.

1) She tells you that she feels tired a lot. Her husband says this is especially noticeable after roughly half an hour of activity. She is currently having one hour of sleep after lunch. They feel this tiredness is hindering her recovery and would appreciate further advice.

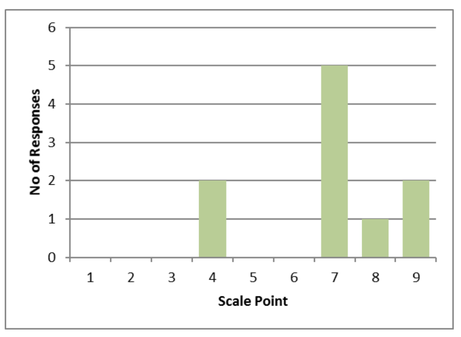
Assuming current provision in primary care, should this patient be referred to specialist services? (1 being referral definitely not necessary, 9 being referral definitely required)

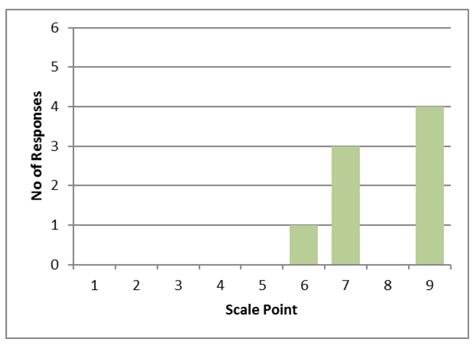


If you have indicated 7, 8 or 9 above, please indicate whether this referral should be made to a member of a stroke specialist team



2) Her husband reports that Mrs Farnham is becoming upset and distressed throughout the day following therapy input and social interaction with visitors. This is making it difficult for her physiotherapist to progress her treatment and fewer friends are visiting the home.





In this example, there was a spread of opinion and non consensus for the first part of the scenario, but consensus was gained in the second part as illustrated above; consensus was also gained for the two remaining parts of the scenario as post-stroke fatigue affecting day-to-day life would be an appropriate indication for referral to a stroke specialist team after an initial assessment by the GP has excluded other causes of tiredness. Referral may be required for a stroke survivor or carer for support (such as to social services or psychological services) if the carer is unable to cope as a result of the patient's fatigue.

Method

A modified RAND appropriateness method was used. Fictional scenarios were rated for need of referral by an expert 10-person panel. Topics were based on long-term post-stroke problem areas identified by the literature and qualitative focus groups and interviews done as part of the ongoing Improving Primary Care After Stroke (IPCAS) Programme.

Round 1: Online rating of scenarios as follows:

1) Is referral required for this patient?
2) Is specialist stroke referral required?
3) Is this scenario clear?

Round 2: A face-to-face panel meeting. Aggregate scores from the previous round were presented along with each panel member's own score. Each scenario was discussed and all re-scored as per 1 and 2 above.

Expert Panel

The 10 person panel* comprised a range of expertise in primary and specialist stroke care.

- 4 General Practitioners
- 1 Practice Nurse
- 3 Stroke Physicians
- 1 Physiotherapist
- 1 Occupational Therapist

** Representatives from the UK Stroke Association (UK charity) and a stroke psychologist were initially recruited but withdrew too late to be replaced.*

Results

Consensus for referral was defined as a median score of 7-9 on the 9-point scale without disagreement. "Disagreement" was defined as per the RAND Appropriateness Manual for a 10 person panel: "*At least three panellists rate the indication in the 1-3 region, and at least three panellists rate it in the 7-9 region.*"

69 scenarios were discussed in Round 2, each scored for need for referral and then if required, whether this should be to a stroke specialist. Consensus was achieved for 60 scenarios. 44 were deemed to require referral, of which only 12 achieved consensus for stroke-specialist referral. Topic areas in which one or more parts of the scenario did not reach consensus were: cardiovascular risk factors, mood, adjustment, pain, swallowing and employment. Consensus scores as well as panel comments were considered when drawing conclusions from the data.

Discussion

- The initial definition of "referral" was defined as a circumstance requiring a professional to make a referral outside of primary care. This was modified by the panel to only include services in which the patient required the service of a registered health professional (this included some services where self-referral is possible such as psychology and physiotherapy.
- The important role of non-medical organisations, including third-sector groups was highlighted in several scenarios during the discussion; these were not considered "referrals".
- The panel agreed that at the more severe end of each set of symptoms, if the primary care professional was not able to manage the symptoms adequately then a referral was likely to be useful.
- Where consensus was not reached, differences in opinion were not aligned to the different professional groups represented on the panel (i.e. the same conclusions were not reached by all GPs or all physicians for example).

Conclusions

- Although there is much agreement about when referrals back to specialist care are required, there are still problem areas for stroke survivors where this is not the case.
- Guidance about when referral is likely to be beneficial may help to ensure that stroke survivors receive good quality care, and that this care is consistent across the United Kingdom.

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