Developing a primary care-based stroke service: a review of the qualitative literature

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SUMMARY
The aim of this review was to identify the most frequently encountered longer-term problems experienced by stroke patients and their informal carers. Systematically identified qualitative studies describing self-reported experiences of stroke-related long-term problems were independently reviewed and the findings analysed using a clustering technique.

Twenty-three qualitative studies, which included approximately 500 patients and 180 carers, were identified by the search methods. Most of the studies were cross-sectional, United Kingdom-based, and employed semi-structured individual interviews. The review identified 203 problem areas, which were categorised into five domains: hospital experience; transfer of care; communication; services; and social and emotional consequences. The largest domain was the social and emotional consequences of stroke, representing 39% of all problem areas. These included problems relating to mood, social changes, attitudes to recovery, and changes in self-perception and relationships.

Service deficiencies, encompassing both health and social care, was the second largest domain, accounting for 29% of the problem areas.

The review provides a basis for a user-focused, longer-term stroke service. The need for responses that go beyond the traditional physical rehabilitation approach is evident, and research to identify broader treatment strategies is now required.

Keywords: stroke; systematic review; community health services; carers.

Introduction
In the past two decades, considerable progress has been made in describing the appropriate service provision for patients after they have had a stroke. An important development has been the conclusive demonstration by the Stroke Unit Trialists' Collaboration that organised multi-disciplinary care in hospital improves stroke mortality and morbidity.1 However, determining effective post-discharge care for stroke patients and their families has proved a more exacting challenge. Recently published guidelines and recommendations for stroke services demonstrate the relative deficiency in the knowledge base for longer-term stroke care. For example, the National Clinical Guidelines for Stroke devote only five of their 157 guidelines to longer-term social and rehabilitative patient management, and, of these, four were derived from expert opinion rather than research evidence.2 The five guidelines refer to the need to provide psychosocial support, improved information, driving advice, a six-month reassessment, and a named contact. The notion of a named contact has been further developed by the National Service Framework for Older People, which identifies a stroke co-ordinator.3 However, the role, responsibilities, and content of this post are poorly described. In addition, the structure for a comprehensive primary care-based stroke service needs to be defined.4 To address these issues, and to create a service that is relevant to patients and their carers, it is important that the longer-term stroke-related problems are fully identified. Thus, in the first stage of a larger developmental study, a comprehensive literature review was undertaken to identify the main problems experienced by stroke patients and their carers when at home. The findings from this stage will provide a platform for the development of a patient-centred, primary care-based stroke service.

Method
We sought to identify all published and unpublished qualitative literature relating to the experiences of stroke patients and carers after discharge home. Published literature was identified using a combination of methods, including electronic database searching, hand searching, and cross referencing. An electronic search strategy was designed primarily for MEDLINE (1987 onwards), and adapted to run in other databases and websites. These included AMED (1985 onwards), CINAHL (1982 onwards), Sociological Abstracts (1963 onwards), and PsycINFO (1984 onwards). The words 'stroke', 'patient', 'carer', 'experience', 'view', and 'qualitative' were used as search terms. Hand-searched key journals included Clinical Rehabilitation, Disability and Rehabilitation, and the Journal of Advanced Nursing. Grey literature was obtained by direct communication with researchers who were known to...
have carried out qualitative work.

The focus of the review was on longer-term experiences, but with a broad perspective. Therefore, after initial screening for relevance, the following types of study were excluded: those concerned mainly with hospital rather than community experience; those dealing specifically with a single discipline, such as physiotherapy; and those dealing with a single aspect of care, such as information provision.

Each qualitative paper was read independently by at least two reviewers, and the main findings recorded on a data extraction sheet. Following data extraction, the findings were then compared between reviewers to assess agreement. For items of disagreement, resolution was sought by group discussion leading to eventual consensus. In general, the policy was to be as inclusive as possible during data extraction.

The list of patient and carer stroke-related problem areas was then grouped according to congruency, using a clustering method. Notes recording each of the individually extracted problem areas were randomly divided between four reviewers, who then grouped together the problem areas judged to have a similar construct, simultaneously, independently, and without consultation. Towards the end of the exercise, the emergent domains were interpreted and labelled, and subdomains identified. Detailed additional analysis of the contents of each domain was performed to ensure unambiguous interpretation of the problem areas and thus correct allocation.

Results

Study characteristics and main findings

Twenty-three relevant qualitative studies were identified (Figure 1) and reviewed.6–28 Their summaries are provided in Table 1. Approximately 500 patients, with an age range of between 17 and 91 years, up to six years after the onset of stroke, and 180 carers, had participated in these studies. Most studies were cross-sectional in design, and of the two that were longitudinal, only one presented the data such that the stroke ‘career’ could be followed.6,26 Insight into particular time points, most notably the transition from hospital to home, was provided by several studies. The review also includes one single discipline study that made extensive reference to general aspects of rehabilitation.28

In total, 203 problem areas were identified during the review process. These were subsequently organised into five domains (Table 2). The range of problems reported by patients and carers was diverse, encompassing service-based, psychological, and social issues. Not unexpectedly, several studies highlighted similar problems. For example, lack of written information was an issue reported in just over half of the 23 studies.

Hospital experience, transfer of care and communication

Although studies of the early post-stroke period were excluded, patients and carers still reflected on negative hospital and discharge experiences,8,15,16,18 leading to the domains of hospital experience and transfer of care.

Deficiencies in communication, mostly relevant written information, were commonly reported by patients and carers.6,18,21

Services

Service provision formed the second largest domain, representing 58/203 (29%) of all problems. Health service-related issues, comprising both primary care and therapy services, were raised in half the studies. With regard to primary care, patients and carers were unhappy about the quantity and quality of general practitioner (GP) contacts. Two studies reported on an expectation of home monitoring visits, which rarely occurred.13,18 Other studies found high rates of GP contact, but patients still felt that they lacked medical supervision.19,25,28 Further concerns related to a perceived lack of interest and stroke knowledge.9,16,19

Therapy-related problems included: lack of longer-term contact and social guidance; inappropriate goal setting; and limited access to, or unawareness of, services.9,11,18,20,24,25,28 Rehabilitation was considered to be too physically oriented, with deficiencies in social and psychological aspects of recovery.8,21

Social services were criticised for the inflexibility of home care, lack of contact with personnel, and lack of advice or guidance on claiming benefits, contributing to financial difficulties.9,13,19,23,28 Long delays and broken promises for aids and adaptations were recurring problems.6,14,17,20,25,28

Social and emotional effects of stroke

The largest domain was social and emotional effects, accounting for 80/203 (39%) of all problems found. Within this domain, mood changes were reported as a problem in

Figure 1. Literature search process.
Table 1. Characteristics of 23 qualitative studies of the longer-term experiences of stroke patients and their carers.

<table>
<thead>
<tr>
<th>Area</th>
<th>Focus</th>
<th>Method</th>
<th>Patients (n)</th>
<th>Carers (n)</th>
<th>Sampling method and source of participants</th>
<th>Age (years) (^a)</th>
<th>Time of interview(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leicester, UK(^6)</td>
<td>Problems of coping and effect of hospital information programme</td>
<td>Semi-qualitative study, CS, ISS</td>
<td>13</td>
<td>13</td>
<td>NR, hospital admissions</td>
<td>61 (mean)</td>
<td>6 months PD</td>
</tr>
<tr>
<td>Washington, USA(^7)</td>
<td>Perception of losses</td>
<td>CS, ISS, and structured</td>
<td>60</td>
<td>NR</td>
<td>Purposive, NR</td>
<td>54 to 81</td>
<td>3 months to 6 years PS</td>
</tr>
<tr>
<td>Newcastle upon Tyne, UK(^8)</td>
<td>Recommendations for improving services</td>
<td>CS, I-structured, and SS</td>
<td>62</td>
<td>49</td>
<td>Consecutive, hospital records</td>
<td>43 to 95</td>
<td>3 years PS</td>
</tr>
<tr>
<td>Birmingham, UK(^9)</td>
<td>Perceived need</td>
<td>CS, ISS</td>
<td>20</td>
<td>15(^b)</td>
<td>NR, hospital discharges</td>
<td>75 (mean)</td>
<td>PD (NOS)</td>
</tr>
<tr>
<td>California, USA(^10)</td>
<td>Patients' experiences of recovery following lacunar stroke</td>
<td>Longitudinal, IU and structured</td>
<td>13</td>
<td>NA</td>
<td>Sampled by stroke type, NR</td>
<td>50 to 88</td>
<td>72 hours to 6 months PS</td>
</tr>
<tr>
<td>Utah, USA(^11)</td>
<td>Needs following termination of home health services</td>
<td>CS, ISS</td>
<td>20</td>
<td>NR</td>
<td>Convenience, home health services</td>
<td>78 (67 to 89)</td>
<td>2 to 10 months PS (or 3 to 8 weeks PD)</td>
</tr>
<tr>
<td>Umea, Sweden(^12)</td>
<td>Experience of living with stroke sequelae and future expectations</td>
<td>CS, participant observation of photographs with ISS</td>
<td>29</td>
<td>NA</td>
<td>NR, hospital stroke unit</td>
<td>60 to 91</td>
<td>18 to 22 months PS</td>
</tr>
<tr>
<td>North Yorkshire, UK(^13)</td>
<td>Need among service users</td>
<td>CS, ISS</td>
<td>39</td>
<td>NR</td>
<td>Purposive, responders in a postal questionnaire</td>
<td>73 (mean)</td>
<td>Two-thirds within 3 years PS</td>
</tr>
<tr>
<td>Alabama, USA(^14)</td>
<td>Major problems after returning home</td>
<td>CS, I (NOS)</td>
<td>10</td>
<td>10</td>
<td>NR, hospital, outpatient clinic or rehabilitation setting</td>
<td>45 to 82</td>
<td>4 months or less PS</td>
</tr>
<tr>
<td>Bradford, UK(I)(^15)</td>
<td>Qualitative comparison of participants in a specialist nurse RCT(^c)</td>
<td>CS, ISS</td>
<td>30</td>
<td>15</td>
<td>Purposive, intervention study</td>
<td>NR</td>
<td>12 to 18 months PS</td>
</tr>
<tr>
<td>Bradford, UK(II)(^16)</td>
<td>Patients' expectations of their GPs</td>
<td>CS, ISS</td>
<td>30</td>
<td>15</td>
<td>Purposive, intervention study</td>
<td>NR</td>
<td>12 to 18 months PS</td>
</tr>
<tr>
<td>London, UK(^17)</td>
<td>Psychosocial and social consequences of stroke</td>
<td>CS, ISS</td>
<td>40</td>
<td>NR</td>
<td>Consecutive, NETSOS register</td>
<td>71 (mean)</td>
<td>10 months PS</td>
</tr>
<tr>
<td>Southampton, UK(^18)</td>
<td>Information needs</td>
<td>CS, ISS</td>
<td>21</td>
<td>10</td>
<td>Purposive, hospital admissions and discharges</td>
<td>50 to 85</td>
<td>During hospital stay, 1 month PD, 2 to 12 months PD</td>
</tr>
<tr>
<td>Nottingham, UK,(^19)</td>
<td>Experience of community stroke service</td>
<td>CS, ISS</td>
<td>57</td>
<td>NR</td>
<td>Stratified, systematic: stroke register</td>
<td>Mostly 65 to 85</td>
<td>Three-quarters within 2 years PS</td>
</tr>
<tr>
<td>Kidderminster, Worcester, London, Birmingham(^20)</td>
<td>Experience over range of issues. CS, I and FG with informal discussion</td>
<td>Convenience: support groups</td>
<td>34(^c)</td>
<td>23(^c)</td>
<td>FGs; NR I: 7-55</td>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>Leicester, UK(^21)</td>
<td>Compare experiences of services between Asian and white survivors</td>
<td>CS, ISS</td>
<td>28</td>
<td>18</td>
<td>Stratified purposive, 3 hospitals</td>
<td>75 (median)</td>
<td>3 months PS</td>
</tr>
</tbody>
</table>

\(^a\)Refers to age of participants (mean, median, range). Carers' ages are only given if the study was exclusively carer-focused. \(^b\)Thirty-five interviews were conducted from an original set of 40. In the absence of sufficient information, it was assumed that the five outstanding were carers. \(^c\)These studies utilised the same set of patients and carers from one RCT. CS = cross-sectional; RCT = randomised controlled trial; SS = semi-structured; U = unstructured; I = individual; FG = focus group; PS = post stroke; PD = post discharge; NOS = not otherwise specified; NA = not applicable; NR = not reported; NETSOS = North East Thames Stroke Outcome Study (continued over page).
Table 1 (continued). Characteristics of 23 qualitative studies of the longer-term experiences of stroke patients and their carers.

<table>
<thead>
<tr>
<th>Area</th>
<th>Focus</th>
<th>Method</th>
<th>Patients/Caregivers</th>
<th>Sampling method and source of participants</th>
<th>Age (years)</th>
<th>Time of interview (w)</th>
<th>Characteristics of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bradford, UK (II)</td>
<td>Professional and patient/carer</td>
<td>CS, ISS</td>
<td>30</td>
<td>Purposive, intervention study</td>
<td>NR</td>
<td>12 to 18 months</td>
<td></td>
</tr>
<tr>
<td>Sheffield, UK</td>
<td>Experience of caring</td>
<td>CS, ISS</td>
<td>NA</td>
<td>Convenience, stroke and carers club</td>
<td>7</td>
<td>1 to 2 years</td>
<td></td>
</tr>
<tr>
<td>New York, USA</td>
<td>Personal experiences of stroke rehabilitation</td>
<td>CS, ISS, longitudinal, I</td>
<td>6</td>
<td>Convenience, stroke support group</td>
<td>6</td>
<td>4 to 6 months</td>
<td></td>
</tr>
<tr>
<td>London, UK (III)</td>
<td>Main problems faced in community</td>
<td>CS, ISS</td>
<td>16</td>
<td>Purposive, hospital discharge records</td>
<td>76 (mean)</td>
<td>Up to 10 months</td>
<td></td>
</tr>
<tr>
<td>Preston, UK (IV)</td>
<td>Lived experience of recovery</td>
<td>CS, ISS, FG, and I</td>
<td>6</td>
<td>Purposive, intervention study</td>
<td>67 (mean)</td>
<td>Monthly from admission to 12 months</td>
<td></td>
</tr>
<tr>
<td>Bradford and Keighley, UK</td>
<td>Problems with occupational therapy</td>
<td>CS, ISS</td>
<td>30</td>
<td>Purposive intervention study</td>
<td>NR</td>
<td>12 to 18 months</td>
<td></td>
</tr>
<tr>
<td>Preston, UK (IV)</td>
<td>Experience of recovery</td>
<td>CS, ISS, FG, and I</td>
<td>7</td>
<td>Purposive interview study</td>
<td>NR</td>
<td>2 years</td>
<td></td>
</tr>
</tbody>
</table>

References: 12, 14, 17, 27

Discussion

This review describes the problems and difficulties experienced by patients who have been living at home for some years after a disabling stroke, and their carers. It is the first time this qualitative literature has been systematically identified and synthesised. It is particularly timely, as the National Service Framework for Older People requires local stroke co-ordinators to provide longer-term support to stroke patients and their families — a role that requires an understanding of the types of problems commonly encountered.

While the search strategy for the review was rigorous, allowing for the identification of studies from a diverse literature base, it remains possible that some studies were overlooked. However, there was considerable congruency between the separate studies, with more than 50% contributing to at least three out of the five domains. Methods of synthesising qualitative literature have not yet been adequately developed, but this approach, using several reviewers, data extraction forms, and discussion to resolve disagreements, is pragmatic. The source studies were mainly based on thematic analysis of semi-structured interviews with patients and carers. While there is at present no standardised approach for assessing the quality of qualitative research, the flexibility of study design, sampling methods, and analytical validity, are known quality issues. Based on these, variation in the methodological rigour of the 23 studies was apparent, but was difficult to comment on objectively.

The interview techniques employed in the studies suggest that the findings will closely resemble the patients’ and carers’ versions of the later stages of their stroke recovery, rather than a professional viewpoint. Most studies used a semi-structured interview method, and a potential bias would have arisen if the patients and carers had been guided towards particular areas that coincided with the problem domains identified. However, the semi-structured approach is designed to be discursive and broad, and the interview format within these studies would have varied considerably. Although most of the studies were small, when synthesised in this review they form a larger and more influential body of evidence, with greater potential for generalisability. However,
the contribution from younger stroke patients was relatively under-represented. Only one study exclusively addressed the problems faced by younger stroke patients.20

Most of the studies identified patients and carers from hospital sources, and, therefore, the pooled sample included in this review may over-emphasise the problems of more severely affected patients. However, the core objective of sampling in qualitative research is to select information-rich cases for in-depth study, and the purposive sampling strategies used in some of the studies did attempt to capture a range of experiences. While the domains of problem areas have been numerically weighted according to the frequency with which they were reported in the source studies, this does not represent a hierarchy of importance. Indeed, constructing such a hierarchy would be problematic, given the individuality of experience that was portrayed so strongly by the qualitative studies. Additionally, it was not possible to comment on the prevalence of the separate issues. A complementary review of the quantitative literature reporting longer-term stroke sequelae will provide a more complete picture. However, the standardised measures used in quantitative surveys limit the understanding of the stroke experience. Thus, for example, the prevalence of post-stroke mood disorders is known about, but there is less information about specific qualitative constructs, such as feelings of abandonment and isolation.

An unexpected finding was the emergence of a hospital domain in which patients and carers had vivid recollection of critical events during their hospital stay. The prominence of these issues, even years after the stroke, suggests that for some patients cognitive resolution can be difficult to achieve.

The complementary needs of carers was an important finding in the review. Lack of attention and priority to the needs of carers has been well documented.31,32 For these reasons, a separate carer domain was considered. However, the range of experiences and problems were similar between patients and carers, and therefore they have been presented in combined form in the results. However, the appropriate service response will require separate assessments of patients’ and carers’ needs, in line with existing policy and practice.3

The main finding of the review was the diversity and range of problem areas experienced by patients and carers that extended beyond existing service model approaches and which focus predominantly on secondary prevention and physical functioning. The largest domain to emerge related to the social and emotional consequences of stroke, suggesting that patients and carers view their health care holistically. An inevitable consequence of performing such a review is the loss of richness provided within the individual studies. The social and emotional domain retains some of this richness, and provides a sense of the real experience of stroke aftermath. If these areas represent the benchmarks by which patients ultimately judge their stroke recovery, there is undoubtedly a considerable challenge for the develop-
opment of primary care-based stroke services. The longer-term needs of stroke patients and their families have been neglected and require attention from primary health care teams. This review should inform a user-focused approach. However, more work is required to determine the appropriate responses to these identified longer-term needs, and the optimal organisational structure, to promote effective service delivery.

References

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