

# Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers

Jenni Murray, John Young, Anne Forster and Robert Ashworth

## SUMMARY

**Background:** Over the last two decades, the need for a longer-term perspective to stroke management has become increasingly recognised. This paper reports a component of a larger project aimed at developing a systematic, primary care-based service for stroke aftercare.

**Aim:** To identify the types and prevalence of longer-term problems experienced by stroke patients and their carers in the United Kingdom (UK).

**Method:** Systematically identified quantitative surveys reporting the prevalence of long-term stroke-related problems were reviewed and the findings extracted and interpreted against a patient and carer defined classification system, identified during an earlier review of the qualitative stroke literature.

**Results:** Twenty-seven UK surveys, including approximately 6000 patients and 3000 carers, and two literature reviews were identified by the search methods. Most of the problem areas identified in the qualitative stroke literature review were reported in the quantitative surveys and an additional two problems were identified (falls and sexual problems). The prevalence of problems in each of the areas was as follows: 19% to 62% for emotional problems; 18% to 46% for social problems; 13% to 77% for service issues; 18% to 88% for poor communication; 33% to 100% for transfer of care; and 10% to 73% for other areas.

**Conclusion:** This review confirms the findings and recommendations from earlier work about the need for a longer-term holistic approach to the rehabilitation of stroke patients and support for carers. Having established the nature and frequency of the main problems experienced by stroke patients and their carers, the appropriate evidence-based interventions need to be identified and consolidated into a stroke service, facilitated by a robust patient-assessment process.

**Keywords:** stroke; long-term care; surveys; review; community services.

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## Introduction

THE notion of a comprehensive stroke service, which encompasses prevention and optimises outcomes after a disabling stroke, is now widely acknowledged.<sup>1</sup> Well-described service components include neurovascular (transient ischemic attack) clinics, stroke units and early discharge schemes. However, a truly comprehensive stroke service must also cater for the longer-term needs of patients and carers.

Despite acknowledgement of this over a decade ago,<sup>2</sup> longer-term support services remain poorly developed. The National Service Framework (NSF) for Older People<sup>3</sup> is testament to this with only general guidance offered rather than a specified service model. There is a strong argument (acknowledged in the NSF) that longer-term stroke support should be provided by Primary Healthcare Trusts.<sup>4</sup> However, the structure, content and process of a primary care-based strategy to address the longer-term needs of stroke patients and their carers is poorly defined and requires urgent clarification if progress is to be made. One potentially useful approach is to base the service response around the expressed longer-term needs of stroke patients and their carers.

To identify these needs, we recently conducted a review and synthesis of qualitative studies reporting on patients' and carers' experiences of living with stroke after returning home from hospital.<sup>5</sup> Five patient-centred problem areas were identified in the review, which could be further expanded into 14 sub-domains (Table 1). The qualitative design of the source studies meant that prevalence estimates for the user-focused problem areas were not reported. We could not, therefore, deduce from this literature whether some problem areas were more, or less, common and thus required a greater or lesser emphasis in a primary care-based service. To address this issue we have conducted a complementary review of the quantitative stroke studies, describing the frequency of stroke-related problems reported by patients and carers. By locating the quantitative survey results alongside their associated qualitative problem areas we aimed to inform the development of a targeted, user-based, primary care stroke service.

## Methods

We sought to identify all community-based United Kingdom (UK) stroke surveys reporting the prevalence of longer-term stroke-related problems. Published literature

**HOW THIS FITS IN**

*What do we know?*

Following stroke, patients and carers experience a range of long-term problems that extend beyond existing service model approaches. A recent review of the qualitative stroke literature revealed five main problem areas requiring attention.

*What does this paper add?*

The current review reports high prevalence estimates for the five problem areas. This implies that a longer-term review service for stroke patients needs to have a broad, multicomponent focus.

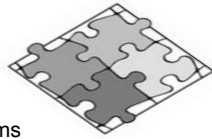


Table 1. Problem area domains identified in an earlier review of the qualitative stroke literature.<sup>5</sup>

Problem areas	
Domains	Sub-domains
Social and emotional changes	Social Emotional Attitude to recovery Relationships and self-perception
Services	Social Health Cross-cutting issues
Transfer of care	Process Preparation for living at home Abandonment
Communication	Written Verbal
Hospital experience	Therapy Critical events

was identified using a combination of methods including electronic database searching, cross-referencing and hand searching. An electronic search strategy was designed and run in MEDLINE (1982 onwards), AMED (1985 onwards), CINAHL (1982 onwards) and PsycInfo (1985 onwards). Search terms combined stroke with home, community, primary care, long-term, follow-up, emotional or social outcome. Hand searched journals included recent issues (2000 onwards) of *Clinical Rehabilitation and Stroke*. The Stroke Association was contacted for relevant publications not found by the approaches mentioned above. As the emphasis of the review was on the longer-term problems (i.e. post-acute or post-hospital discharge), studies were excluded if they were conducted in a hospital setting. Additionally, because healthcare systems have an important contextual role in determining recovery outcomes, only UK-based surveys were included. This is in line with the objectives of the overall project; to develop a model of care to be used within the UK.

Each paper was read by one reviewer (JM) and the findings extracted and mapped against domain and sub-domain headings previously identified as a classification of

user-focused, post-stroke problem areas.<sup>5</sup> Three reviewers (JY, AF, RA) independently verified the mapped findings for clarity and appropriate domain allocation. Where there was disagreement regarding domain allocation, consensus was reached by group discussion.

**Results**

*Study characteristics*

The search strategy identified 27 UK-based studies<sup>6-32</sup> (Geddes and Chamberlain, unpublished data, 2000.) and two reviews: one of mood disorders following stroke<sup>33</sup> and one addressing quality-of-life issues for carers of stroke patients<sup>34</sup> (Figure 1). The former provided a quantitative summary of the prevalence of depression, thus obviating the need to review individual studies. The latter, however, did not and it was therefore necessary to appraise the source studies. Over 6000 patients, ranging from 1 week to 5 years after stroke, and 3000 carers participated in the 27 individual studies.

Eight surveys were longitudinal.<sup>8,9,14,19,21,27,30,32</sup> Ten surveys included patients in institutional care<sup>6,7,12,22,24,25,27,28,31,32</sup> and, where possible, only data for those residing in their own or their main carer's home were extracted for this review.<sup>7,12</sup> Twenty-four studies were observational surveys; two were linked to randomised controlled trials<sup>19,26</sup> and one was part of an evaluation of community stroke rehabilitation teams from different areas in the UK. (Geddes and Chamberlain, unpublished data, 2000.) Twelve surveys were based on follow-up of hospital admissions.<sup>6,9,12,16,17,20,21,24,27,28,29,30</sup> The focus of 12 surveys was on use and perception of rehabilitation services.<sup>7,9,12,17,18,22-25,28,31</sup> (Geddes and Chamberlain, unpublished data, 2000.) The remaining studies related to knowledge, post-stroke complications, social and emotional consequences, and general issues.

*Prevalence of problem areas*

Prevalence estimates were identified for 10 of the original 14 problem sub-areas. The four sub-areas for which prevalence estimates were not located were: hospital experiences of therapy, hospital experiences of critical events, post-discharge abandonment, and verbal communication. The ranges of estimates for each of the identified sub-areas is summarised in Table 2.

*Emotional and social effects*

*Emotional effects.* The quantitative surveys suggested that the emotional consequences of stroke are highly prevalent, ranging from 18% to 62%, and long-lasting. Depression appears to represent a considerable problem in the early post-stroke period,<sup>30,33</sup> persisting in one-quarter of patients beyond 2 years following stroke.<sup>22</sup> Anxiety affected about one-third of patients in the first few weeks following stroke,<sup>30</sup> and after 5 years about one-fifth remained anxious.<sup>22</sup> Depression was less prominent in carers<sup>8,10,22</sup> and related to patient disability,<sup>8,10</sup> but anxiety and emotional distress were very prevalent, affecting about one-half of carers at 6 months after the stroke,<sup>8,26</sup> and about one-third at 3 to 5 years.<sup>12,22</sup> Between 2 and 3 years

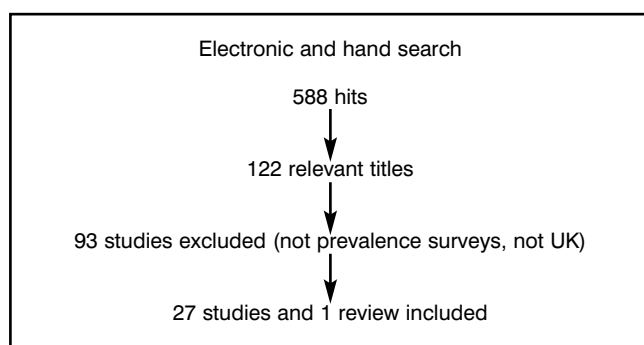


Figure 1. Search and selection process for UK stroke surveys.

Table 2. Summary of the prevalence of stroke related problem areas.

Problem areas	Prevalence estimates (%)
Emotional and psychological	11–62 <sup>8,22,31,24</sup>
Social and relationships	17–46 <sup>6,9,12,14,19,21</sup>
Services	13–77 <sup>7,9,17,21,24,25,28,29</sup>
Transfer of care	33–100 <sup>14,17,28</sup>
Communication	32–81 <sup>16,17,29</sup>
Other	10–73 <sup>6,19,21,27,32</sup>

after stroke, over one-third of patients<sup>6</sup> and almost half of all carers<sup>6,12</sup> described themselves as poorly adjusted.

**Social consequences.** Several studies investigated the social consequences of stroke, and the prevalence of problems in this area ranged from 19% to 46%. At 6 months after stroke, one-third of patients were unable to go to the shops.<sup>9</sup> By 18 months, one-third of patients reported feeling socially isolated,<sup>6</sup> less than 20% of drivers had returned to driving<sup>11</sup> and only 11% to 17% had returned to work.<sup>14</sup> The longer-term impact on social life for carers was greater, with two-thirds affected,<sup>6,31</sup> but social isolation was less frequent at under one-fifth.<sup>12</sup> One-third of co-resident carers indicated that they limited their outings because of fear that the patient might fall.<sup>19</sup>

After 18 months, about one-third of carers (including non-spousal) perceived the quality of the relationship with the patient to have declined since the stroke.<sup>14</sup> More specifically, 18% of patients reported a worse relationship with their spouse and 25% with their family as a whole.<sup>6</sup> A further consequence of stroke was sexual dysfunction, with over one-third of carers 2–3 years after stroke, reporting that their sex life had altered 'adversely'.<sup>6</sup> (For additional data, see Supplementary table 1.)

### Services

Service problem areas were common, affecting between 13% and 77% of patients. Many problems persisted at 2–3 years post-stroke. Patients and carers frequently perceived a need for further rehabilitation input after discharge from hospital,<sup>23</sup> (Geddes and Chamberlain, unpublished data, 2000.) but there was evidence that patients did not receive rehabilitation reviews<sup>25</sup> and that the majority of patients did not receive further therapy contact.<sup>9,28</sup>

Between a quarter and a half of patients reported problems with obtaining aids and adaptations.<sup>9,31</sup> Financial problems in the early period after stroke were a concern for 20% of patients,<sup>25</sup> but at 2–3 years only 8% had ongoing financial concerns.<sup>6,25</sup> Overall, two-thirds of patients were dissatisfied with the support that they had received from social services.<sup>14,17,31</sup> Rates of general practitioner (GP) contact at 6 weeks after discharge from hospital,<sup>24</sup> and at 6 months<sup>9,14</sup> and 1 year after the stroke,<sup>7</sup> were high, at half to over three-quarters of patients. Despite these high levels of contact, about one-third of patients were dissatisfied with the care provided by their GP.<sup>24</sup>

Several studies examined the relationship between community services provision and disability. Two found a significant relationship between level of dependency and services received,<sup>24,25</sup> whereas two did not.<sup>7,9</sup> A fifth study was a mixed situation with six out of nine services unrelated to disability.<sup>22</sup> With respect to GP care, two studies reported that the number of contacts was unrelated to disability,<sup>9,20</sup> whereas a third study reported that GPs were less likely to see those who were most disabled.<sup>12</sup> (For additional data, see Supplementary table 2.)

### Transfer of care

About one-third of patients reported dissatisfaction with the discharge preparation.<sup>14,17,24,28</sup> The proportion of carers who felt ill-prepared for their role increased over the first 9 months after discharge from 33% to 72%.<sup>17</sup>

### Communication

At 4 weeks following hospital discharge, only 12% of patients and 19% of carers reported that they had received written information from any source.<sup>16</sup> Other studies have found that the quality of information received was rated as poor by about one-third of patients and carers.<sup>17,31</sup> (Geddes and Chamberlain, unpublished data, 2000.)

### Other problems reported

Health-related complications as a consequence of stroke reported in the surveys included incontinence, shoulder pain and falls. Prevalence estimates suggest that urinary incontinence<sup>32</sup> and shoulder pain<sup>27</sup> are problems for a minority of patients (10% and 12% respectively) 2–3 years after stroke. Two quantitative studies reported high fall rates, ranging from 36% to 73%, within the first 6 months after discharge from hospital.<sup>19,27</sup> Up to 48% of carers reported various health complaints resulting from their caring role. (For additional data, see Supplementary table 3.)

## Discussion

### Main findings

The main purpose of this review was to identify prevalence estimates for the key problem areas reported by patients and carers as they recover and adjust to the effects of the stroke over the ensuing years. This task was not curiosity driven but a highly practical one: to help prioritise services toward those problem areas with high prevalence, therefore creating the greatest impact for the greatest number of patients and carers. A key strength of the review is its

methodological approach, in which quantitative findings were extracted and interpreted against a patient and carer defined classification system, identified following an earlier review of qualitative stroke literature.<sup>5</sup> Thus the two literature reviews are complementary and should provide a framework for the efficient targeting of resources for client-centred problems within the context of a primary care-based stroke service.

The majority of the patient and carer defined problem areas previously described<sup>5</sup> were highly prevalent. This suggests that an effective primary care-based stroke-aftercare service must have a broad focus. Improving the transfer of care; better written information; more equitable and needs-based social, therapy and healthcare services; improved social and emotional support — all require attention and incorporation to develop an effective primary care stroke-service model.

### Strengths and weaknesses of the current review

Most of the problem areas identified in our earlier systematic review of qualitative stroke-related literature<sup>5</sup> have been investigated in quantitative surveys. The subjective experience of abandonment — a strong theme in the qualitative studies — was not addressed in the quantitative reports, presumably because no appropriate measure was available. However, issues relating to abandonment might be inferred from the high prevalence of service deficits. Two types of problem, not identified in the earlier qualitative review, related to the high prevalence rates of falls and sexual problems. Considering the frequency with which they occur, their absence in the qualitative studies is surprising, but demonstrates the complementary methods of the two literature reviews.

Most of the problem areas are well represented in the UK stroke literature. However, for other areas, such as relationships and sexual problems, only a weak body of evidence exists. More extensive coverage can be found in the European literature. These studies could have been included in our review, but differences in cultural attitudes and service provision would cast doubt over their applicability to the UK and therefore conflict with our overall objective to develop a model of care for use in the UK.

There are important limitations to the source studies. Most were relatively small-scale and based on local populations and, as such, the findings may not be nationally representative. Only three of the UK surveys were geographically unrestricted.<sup>15,18,31</sup> The source of participants may have also introduced bias. About half of the studies included hospital admissions only, thus introducing a potential bias towards a more disabled group. However, given that the large majority of patients are admitted to hospital following stroke in the UK, the representativeness of these studies is likely to be reasonable for the purposes of this review. Finally, only one of the surveys that reported on the prevalence of depression made any comparisons with 'healthy' age-matched controls.<sup>11</sup> However, the stroke group was highly selected and therefore not representative of the wider stroke population. We cannot, therefore, comment on how the prevalence of depression among stroke patients compares with other population types (healthy or otherwise). Between-study compar-

isons are not feasible owing to the use of different screening and diagnostic instruments, varying cut-off points for case-ness, and diversity in the social characteristics between populations studied.<sup>33</sup>

### Implications for future model development

The next step in the development of a primary care-based model for stroke aftercare, is to determine the evidence-based interventions appropriate to the areas of need identified by the qualitative<sup>5</sup> and quantitative reviews. For some areas, such as the management of depression, the evidence base is already very strong and its inclusion in the model will be more of a prompt for good practice. However, for other areas the identification and promotion of effective interventions incorporated into the model may serve to change the clinical behaviour of primary care professionals. Undoubtedly there will also be areas where the evidence base is weak. Highlighting these gaps will be an important part of the model development. In addition, an assessment system to reliably identify problem areas particular to individual patients and carers requires development. It may be possible to adapt the currently available standardised-assessment instruments (<http://www.doh.gov.uk/scg/sap/toolsandscales/>)<sup>35</sup> but they will need to be reviewed in the first instance to determine the face validity of the assessment questions in relation to the identified prevalent longer-term post-stroke problem areas.

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### Supplementary information

Additional information accompanies this paper at <http://www.rcgp.org.uk/>

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