Self-Reported Long-Term Needs After Stroke

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Background and Purpose—Development of interventions to manage patients with stroke after discharge from the hospital requires estimates of need. This study estimates the prevalence of self-reported need in community-dwelling stroke survivors across the United Kingdom.

Methods—We conducted a survey of stroke survivors 1 to 5 years poststroke recruited through Medical Research Council General Practice Research Framework general practices and 2 population-based stroke registers. Levels and type of need were calculated with comparisons among sociodemographic groups, disability level, and cognitive status using the $\chi^2$ test or Fisher exact test, as appropriate.

Results—From 1251 participants, response rates were 60% (national sample) and 78% (population registers sample) with few differences in levels of reported need between the 2 samples. Over half (51%) reported no unmet needs; among the remainder, the median number of unmet needs was 3 (range, 1 to 13). Proportions reporting unmet clinical needs ranged from 15% to 59%; 54% reported an unmet need for stroke information; 52% reported reduction in or loss of work activities, significantly more from black ethnic groups ($P=0.006$); 18% reported a loss in income and 31% an increase in expenses with differences by age, ethnic group, and deprivation score. In multivariable analysis, ethnicity ($P=0.032$) and disability ($P=0.014$) were associated with total number of unmet needs.

Conclusions—Multiple long-term clinical and social needs remain unmet long after incident stroke. Higher levels of unmet need were reported by people with disabilities, from ethnic minority groups, and from those living in the most deprived areas. Development and testing of novel methods to meet unmet needs are required. (Stroke. 2011;42:1398-1403.)

Key Words: long-term needs ■ postacute care ■ stroke

Stroke is an acute event with long-term physical, psychological, and social consequences. Although much has been done to reverse the nihilism previously said to characterize acute stroke care, long-term stroke care is underdeveloped. The development of appropriate service provision is limited by the lack of robust estimates of long-term outcomes after stroke. Currently, data largely come from short-term cohort studies with limited follow-up (usually up to 1 year) and subject to selection bias because they are not population-based. In population-based studies, quality of life has been assessed between 2 and 21 years after stroke, activities of daily living up to 21 years in Auckland, up to 5 years in Perth, Australia, and 5 years in south London. Clinically defined outcomes may be of limited use in assessing long-term need after stroke and developing services to meet needs. There is evidence that commonly used functional outcome measures (for example, the Barthel Index) may underestimate dependence and that rehabilita-

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This study was approved by the Institute of Child Health/Great Ormond Street Hospital Research Ethics Committee, EC reference number: 09/H0713/17.

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stroke. To overcome potential selection bias in such studies, we included participants from the existing unbiased population stroke registers.

Methods

Study Population
The study population comprised a national sample of community-dwelling adults (>18 years of age) with first ever stroke 1 to 5 years earlier registered with a UK general practice participating in the Medical Research Council General Practice Research Framework and a second sample from the ongoing population-based South London Stroke Register (23) and the Oxford Vascular Study. (24) The Medical Research Council General Practice Research Framework is a network of 912 general practices engaged in clinical trials, epidemiological, and health services research with a trained practice-based research nurse responsible for managing projects at each practice. The General Practice Research Framework practices cover a range of geographic and socioeconomic locations across the United Kingdom, allowing access to a sample of practices representative of the general population.

Development of the Survey Instrument
A questionnaire was developed to assess patients' perceptions of needs after stroke that included questions from validated questionnaires. (25–27) Preliminary versions of the questionnaire were tested and reviewed by the King's College London Stroke Research Patients and Family Group (a service user research advisory group). The final questionnaire included 44 closed questions with response categories to identify level of change and need across the following domains: information about stroke; health after stroke; everyday living; work and leisure; friends, family, and use of support groups; finances; and demographic information. An open-ended question for additional comments was also included.

Administration of the Survey
In the national sample, a designated research nurse in participating practices identified eligible stroke survivors from the practice Qual- ity and Outcomes Framework stroke register using the following READ codes: G60 (subarachnoid hemorrhage); G61 (intracerebral hemorrhage); G64 (cerebral hemorrhage); and G66 (stroke and cerebrovascular accident unspecified). Those with a serious physical or mental illness, who were >5 years poststroke, or had declined to take part in research were excluded. Eligible patients were sent a questionnaire, an information booklet, consent form, cover letter, and a prepaid reply envelope. Participants returned their questionnaire, an information booklet, consent form, cover letter, and a prepaid reply envelope. Participants returned their questionnaire and signed consent form to the study coordinating center. Nonre- sponders were contacted by the practice research nurse after 3 weeks and then contacted by telephone if necessary after a further 2 weeks. Where participation was impeded by a disability, the nurse offered to complete the questionnaire with the participant over the phone or in a face-to-face interview.

Participants recruited to the population registers provided written informed consent and agreed to being contacted for future studies. Those whose follow-up fell between February 1, 2009, and June 30, 2009 (South London Stroke Register 1-, 3-, and 5-year follow-up; Oxford Vascular Study 1- and 5-year follow-up) were asked to complete the survey in addition to their regular register follow-up questionnaire. Approximately 3 weeks after the initial mail out, a trained researcher contacted nonresponders to remind them to complete and return the questionnaire or to arrange for the question- naire to be completed over the telephone or in a home interview by trained researchers. Participants without telephone contact details were sent a reminder letter. Exclusion criteria were the same as for the national sample.

Statistical Analysis
Frequencies and proportions were used to summarize levels and type of need. Differences in levels of unmet need between the national and population registers samples were also compared to investigate the impact of selection and response bias. Levels of unmet need were compared across age groups, by time since stroke, in those with and without self-reported communication problems, and across countries in the national sample. Data routinely collected in the population-based samples were used to make comparisons across ethnic groups, disability levels, and cognitive status. Comparisons were made using the χ² test or the Fisher exact test as appropriate. Because the population size of each of the 4 UK countries differs, to estimate levels of unmet need for the United Kingdom as a whole, responses from the 4 countries were weighted using population estimates from the 2001 census.

The total number of unmet needs reported by each respondent was calculated by summing the number of times a need was reported as unmet. Needs within the same domain were calculated as separate needs (for example, a patient reporting unmet need for emotional problems and continence problems in the health domain would be classified as having 2 unmet needs). The number of needs not fully met was also calculated by summing the number of times a need was reported as “unmet” or “only partially met.”

Postcode data from respondents living in England were used to identify respondents living in the 20% most and 20% least deprived areas of the country using the Index of Multiple Deprivation 2007. Although similar indices are available for Northern Ireland, Scot- land, and Wales, the most deprived areas within a country may not experience the same levels of deprivation as those in the most deprived areas of another country. Therefore, it is not possible to combine deprivation levels from each of the 4 countries. (27) Responses from England in the national and population-based registers were combined to conduct comparisons between the levels and types of need according to deprivation score. In the population register samples, socioeconomic status was measured using the Registrar General’s occupational codes.

The median and interquartile range of the total number of unmet needs was calculated across countries, sociodemographic groups, time since stroke, disability levels, and cognitive status. Compari- sons between groups were made using the Mann–Whitney U test (for 2 groups) or the Kruskal-Wallis test (where there were ≥2 groups). Stepwise linear regression models were then used to identify which factors were independently associated with the number of unmet needs in the population registers sample controlling for source population.

A sensitivity analysis was also carried out using the total number of needs not fully met as the outcome to assess the effect of defining a partially met need as unmet on the results of the multivariate analyses.

Results

Respondents
Response rates of 60% (571 of 958 questionnaires returned) and 78% (228 of 294) were achieved in the national and population registers samples, respectively. The latter had significantly higher proportions of respondents aged <65 years, from ethnic minority groups, and at 1 to 2 years since stroke (Table 1). Population register nonresponders did not significantly differ with respect to sex, age, and ethnicity (Table 2).

Because there were few significant differences between the national and population register samples, we report results from the national sample with frequencies using weighted data. Where significant differences between the national and population register samples were found, we report both estimates.

Overall 51% reported having no unmet needs; among the remainder, the median number of unmet needs was 3 (range, 1 to 13) across a range of different domains. Unmet needs are
presented in relation to physical and other stroke-related problems, information, and impact on social participation.

### Physical and Other Stroke-Related Problems

Of those who had experienced problems related to mobility, falls, pain, and incontinence, unmet needs were reported by 62 (25%), 48 (21%), 34 (15%), and 43 (21%) respondents, respectively. Of those with stroke-related emotional problems, 80 (39%) reported unmet need. Higher proportions of unmet needs were reported in relation to fatigue, memory, and concentration (Table 3).

### Information Needs

Two hundred eighty-four respondents (54%) reported wanting more information about their stroke (cause, prevention of recurrence). There were no differences in reporting unmet needs for information by age, gender, ethnicity, disability level, or time since stroke. However, need for more information about stroke was significantly different among the 4 devolved nations ($P=0.009$). In Northern Ireland, 91 (66%) reported wanting more information about their stroke followed by 42 (65%) in Wales, 76 (54%) in England, and 75 (49%) in Scotland.

### Impact on Social Participation

One hundred thirty-three (52%) of respondents reported a change in work activities since their stroke. In univariate analyses of population registers sample data, a higher proportion of people from black (N=19 [73%]) or other (N=31 [75%]) ethnic groups compared with white (N=30 [40%]) reported a change in work-related activities ($P=0.006$). Three hundred five (67%) reported a change for the worse in the number or type of leisure activities or interests because of their stroke. In the population registers, a higher proportion of people from black (N=32 [80%]) and other (N=9 [82%]) compared with white (N=76 [57%]) ethnic groups reported this change ($P=0.012$).

One hundred five (18%) respondents reported experiencing a loss in income and 177 (31%) reported experiencing an increase in expenses. However, only 19 (2%) respondents reported needing any advice on money management or 25 (3%) required information on employment after stroke.

### Factors Associated With Unmet Need

Significantly more respondents from England living in the most deprived quartile reported a loss in income since stroke (N=32 [29%]) compared with those in the least deprived quartile (N=9 [10%]; $P=0.007$). Significantly more respondents living in the most deprived quartile in England reported needing benefits advice (N=37 [35%]) compared with those in the least deprived quartile (N=10 [13%]; $P<0.001$).
We compared unmet need between respondents with self-reported communication problems and those without (Table 4). Those with a communication problem were significantly more likely to report negative changes in work activities ($P<0.001$); leisure activities ($P<0.001$); relationships with partner/spouse, family, and friends ($P<0.001$); loss of income ($P=0.001$); and increased expenses ($P=0.009$). Significantly higher needs for information were reported in relation to driving ($P<0.001$) and employment ($P=0.034$).

Multivariable analysis sought to identify independent predictors of total number of unmet needs using data from the population registers sample only. Ethnicity ($P=0.032$) and disability, measured by the Barthel Index ($P=0.014$), were significantly associated with the total number of unmet needs. The number of unmet needs increased with worsening disability. Respondents in the black ethnic group had more unmet needs than those in white ethnic group. We found no associations between unmet need and age, gender, cognitive status, or time since stroke.

### Discussion

This study provides robust estimates of self-reported unmet need in a population with high levels of disability at high risk of further vascular events and for whom services are acknowledged as underdeveloped.4,28 Unmet needs were reported across a range of clinical domains, including mobility, falls, incontinence, fatigue, and emotional well-being. Unmet needs were also reported for information and aspects of social participation.

Self-report of need may be considered both a weakness and a strength of the study depending on views of the limitations of objective and subjective assessments of outcome and need. Although participants were asked to report unmet needs since stroke, it is possible that not all those reported were directly caused by stroke but related to other conditions or circumstances. Nevertheless, this does not of itself negate levels of unmet need reported. Further studies would be needed to compare levels of need reported here and those in an age-matched population. Although these estimates are representative of the needs of long-term stroke survivors, they may underrepresent the needs of the total stroke population given the increased rates of mortality in those with the most severe strokes. It has been argued that both assessed and perceived

### Table 3. Proportion of Respondents Reporting Stroke-Related Health Problems and the Extent to Which Need Met

<table>
<thead>
<tr>
<th>No. Reporting a Problem (Weighted %)</th>
<th>Proportion Reporting Need Unmet (Weighted %)</th>
<th>Proportion Reporting Need Met to Some Extent (Weighted %)</th>
<th>Proportion Reporting Need Met (Weighted %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility problems 321 (58.4)</td>
<td>25</td>
<td>43</td>
<td>32</td>
</tr>
<tr>
<td>Falls 265 (43.9)</td>
<td>21</td>
<td>47</td>
<td>32</td>
</tr>
<tr>
<td>Incontinence problems 217 (37.2)</td>
<td>21</td>
<td>40</td>
<td>39</td>
</tr>
<tr>
<td>Pain 249 (39.5)</td>
<td>15</td>
<td>34</td>
<td>51</td>
</tr>
<tr>
<td>Fatigue problems 301 (51.7)</td>
<td>43</td>
<td>36</td>
<td>21</td>
</tr>
<tr>
<td>Emotional problems 244 (38.4)</td>
<td>39</td>
<td>34</td>
<td>27</td>
</tr>
<tr>
<td>Concentration problems 260 (44.7)</td>
<td>43</td>
<td>41</td>
<td>16</td>
</tr>
<tr>
<td>Memory problems 260 (42.8)</td>
<td>59</td>
<td>25</td>
<td>16</td>
</tr>
<tr>
<td>Speaking difficulties 194 (34.3)</td>
<td>28</td>
<td>39</td>
<td>33</td>
</tr>
<tr>
<td>Reading difficulties 148 (23.2)</td>
<td>34</td>
<td>43</td>
<td>23</td>
</tr>
<tr>
<td>Sight problems 212 (37.2)</td>
<td>26</td>
<td>35</td>
<td>39</td>
</tr>
</tbody>
</table>

### Table 4. Associations Between Self-Reported Communication Problem and Need

<table>
<thead>
<tr>
<th>No. (% UK Weighted)</th>
<th>With Communication Problem</th>
<th>No Communication Problem</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for help/information relating to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke 172 (53.1)</td>
<td>110 (55.3)</td>
<td>0.753</td>
<td></td>
</tr>
<tr>
<td>Diet 143 (36.9)</td>
<td>76 (37.5)</td>
<td>0.936</td>
<td></td>
</tr>
<tr>
<td>Home aids 72 (17.4)</td>
<td>26 (11.3)</td>
<td>0.214</td>
<td></td>
</tr>
<tr>
<td>Home adaptations 45 (11.1)</td>
<td>19 (7.0)</td>
<td>0.289</td>
<td></td>
</tr>
<tr>
<td>Moving home 25 (4.9)</td>
<td>10 (2.1)</td>
<td>0.251</td>
<td></td>
</tr>
<tr>
<td>Driving advice 49 (16.2)</td>
<td>14 (6.4)</td>
<td>0.031</td>
<td></td>
</tr>
<tr>
<td>Public transport advice 36 (7.9)</td>
<td>10 (7.2)</td>
<td>0.860</td>
<td></td>
</tr>
<tr>
<td>Holiday information 86 (25.2)</td>
<td>25 (13.6)</td>
<td>0.041</td>
<td></td>
</tr>
<tr>
<td>Sexual relations 30 (7.7)</td>
<td>7 (4.2)</td>
<td>0.569</td>
<td></td>
</tr>
<tr>
<td>Benefit advice 69 (22.2)</td>
<td>21 (6.2)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Money management advice 16 (2.8)</td>
<td>3 (1.8)</td>
<td>0.627</td>
<td></td>
</tr>
<tr>
<td>Employment advice 23 (4.9)</td>
<td>2 (0.2)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Change since stroke reported in</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport and travel 173 (60.7)</td>
<td>65 (35.1)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Work activities 105 (65.5)</td>
<td>27 (26.3)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Leisure activities 211 (79.4)</td>
<td>92 (48.5)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Partner/spousal relations 109 (51.4)</td>
<td>33 (28.3)</td>
<td>0.005</td>
<td></td>
</tr>
<tr>
<td>Family relations 111 (38.7)</td>
<td>23 (8.9)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Other relations 167 (51.0)</td>
<td>40 (17.0)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Loss of income 83 (24.7)</td>
<td>22 (9.5)</td>
<td>0.004</td>
<td></td>
</tr>
<tr>
<td>Increased expenses 131 (40.4)</td>
<td>44 (18.0)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
</tbody>
</table>
needs should be evaluated to inform service development and delivery.29 There were high rates of unmet clinical need but higher rates of unmet need in areas not typically addressed by current services. Unmet perceived needs may reflect expectations and knowledge1 but may also indicate where service provision should be developed.

We are reasonably confident in the estimates presented because the overall response rate was high for an older and more disabled population. There were few statistically significant differences in levels of unmet need between the 2 samples, suggesting that potential selection and response bias in the general practice-based sample were limited. Inclusion of the population registers also allowed comparison between minority ethnic groups, something not usually possible with a national sample.

The wide range and number of unmet needs found in this survey of all-age adult stroke survivors was surprisingly similar to results reported from surveys of young (18 to 65 years) adult stroke survivors.19,20 We did not find differences in the range or type of unmet need reported by age category, suggesting that age per se may not be associated with perception of unmet need. Over one third of respondents reported experiencing emotional problems (including depression, crying) after the stroke. This is a similar prevalence to the pooled estimate (33%) of clinically assessed poststroke depression reported in a systematic review of observational studies.30 Of those reporting emotional problems, just under one third reported receiving all the support needed. This reinforces the requirement to implement strategies to help stroke survivors address the range of emotional problems they may experience.4

The consequences of stroke for caregivers have been extensively investigated with a focus on emotional wellbeing; it has also been argued that studies in this area suffer from heterogeneity and methodological limitations and are largely atheoretical.31 Nevertheless, estimates of caregiver burden range from 25% to 54%32 and stroke disability appears to be associated with caregiver outcomes.33 In this study, just over one fourth of national sample and one fifth of the population registers sample reported experiencing negative changes in their family relationships. One fifth (21%) of respondents reported negative changes in family relationships; 42% of respondents in the national sample and 36% in the population registers sample reported a negative change in their relationship with their spouse/partner. A recent review of the social consequences of stroke reported that estimates of negative impact on family relationships ranged from 5% to 54%.33 Just over half of respondents in the population samples register and the national sample reported unmet need for information about stroke. This need did not appear to be associated with respondent characteristics or time since stroke. Studies have consistently reported stroke survivor dissatisfaction with the provision of information and there is as yet little clear guidance from studies of interventions about how best to meet this need.34

Implications for Clinical Practice
Highlighting the lack of research attention paid to management of patients with stroke after discharge from the hospital, Williams and Rudd have called for the development and evaluation of different models of intervention.35 This requires robust evidence of the nature, extent, and prevalence of such needs that goes beyond clinically defined outcomes. Almost half of stroke survivors report unmet clinical and social needs up to 5 years after the incident stroke, suggesting a requirement to develop primary care-based strategies to assess and meet need. Specific subgroups—those with ongoing disability, including communication problems, from ethnic minority groups, and those living in deprived areas—may be at greater risk of unmet need in the long-term. However, approximately half of stroke survivors report no areas of unmet need suggesting that a targeted approach to long-term support may be warranted.

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