Palliative care for cirrhosis: a UK survey of health professionals’ perceptions, current practice and future needs

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ABSTRACT

Objective To determine the knowledge and practice patterns of a UK cohort of relevant healthcare professionals (HCPs) about delivering palliative care in cirrhosis, and to inform priorities for future research.

Design An on-line questionnaire survey with closed and open responses.

Setting HCPs identified from the mailing list of special interest groups in hepatology and gastroenterology (liver), general practice and specialist palliative care (SPC) across the UK.

Results Of the 6181 potential contacts identified, 517 HCPs responded. Most believed a role exists for SPC in caring for people with cirrhosis, but many SPC HCPs felt ill prepared to provide good care to those facing death. Further training was needed in managing liver-related symptoms, symptom control and end of life issues. All HCP groups wished to increase community provision of palliative care support, but many general practitioners felt unable to manage advanced cirrhosis in the community. There were differences in the optimal trigger for SPC referral with liver HCPs less likely to refer at symptom deterioration. Prognostication, symptom management and service configuration were key areas identified for future research.

Conclusions All who responded acknowledged the role of SPC in caring for those dying with cirrhosis and need for further training to improve confidence and enable joint working between SPC, general practice and liver teams. Low response rates make it difficult to generalise these findings, which require further validation.

INTRODUCTION

Liver disease is the third largest cause of premature death in the UK1 and accounts for 2% of deaths in England.2 The increases in alcohol consumption, viral hepatitis and obesity in the UK suggest that liver disease is a growing public health problem.3 People with end stage liver disease (cirrhosis) have supportive and palliative care needs.4–7 The recent Lancet Commission report on improving liver care acknowledges the importance of primary care and hospital services in providing high quality care for people with cirrhosis.1 Nevertheless it skims over the care issues arising for those who are dying of liver disease. At present, this care is poor,8 most deaths from cirrhosis occur in hospital2 and more work is needed to understand how end of life (EoL) care for people with cirrhosis can be managed well.

The Royal Free Hospital London (tertiary centre) liver team and the Marie Curie Palliative Care Research Department, University College London held a national meeting of health professionals interested in these aspects of liver care in November 2013. The group recommended a national survey of primary, secondary and tertiary care providers to explore current attitudes and practices, and to identify training needs, ideas for service improvement and research priorities. Here we report the findings of this survey.

METHODS

We developed an online survey (see online supplementary appendix ii) to explore (A) referrals to specialist palliative care (SPC)—numbers, reasons, timing; (B) health professionals’ training needs;
The number of patients referred to specialist palliative care (SPC) from liver professionals by type of care and diagnosis

<table>
<thead>
<tr>
<th>Number referred by liver professionals to SPC</th>
<th>Number of referrals received by SPC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient care</td>
<td>Outpatient care</td>
</tr>
<tr>
<td>N</td>
<td>Per cent</td>
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<tr>
<td>-----</td>
<td>----------</td>
</tr>
<tr>
<td>None</td>
<td>7</td>
</tr>
<tr>
<td>1–5</td>
<td>45</td>
</tr>
<tr>
<td>6–10</td>
<td>49</td>
</tr>
<tr>
<td>11–20</td>
<td>38</td>
</tr>
<tr>
<td>21+</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>161</td>
</tr>
</tbody>
</table>

Reasons for referrals to SPC, from liver professionals and GPs were symptom control, terminal care and the need for hospice admission (table 2). Most liver and SPC professionals identified recognition of the EoL as the key trigger for SPC referral in cirrhosis. SPC professionals also considered onset of deterioration in symptoms and recurrent hospital admissions as appropriate triggers for referral to their service (table 2).
unpredictable trajectory of cirrhosis and the impact of impaired liver function on medication metabolism. SPC professionals recognised their training needs on liver specific issues such as the assessment and management of decompensated liver disease (86%; 198/231), pharmacology in cirrhosis (79%; 182/231), likely illness trajectory in cirrhosis (68%; 159/231), advances in the management of recurrent ascites (68%; 158/231) and information on prognostication (68%; 158/231).

Initiatives for improving EoL care in cirrhosis
Liver professionals suggested enhanced provision of palliative care whereas most SPC professionals prioritised improved liaison between secondary and primary care. GPs also favoured improved liaison (33/
39; 85%), more educational opportunities in specialist liver units (26/39; 67%) and improved provision of SPC (18/39; 46%).

Analysis of open responses from 137/195 liver professionals (88 doctors and 49 nurses), identified specific and more detailed improvements which could be made to the delivery of EoL care, in reconfiguring services and improving clinicians’ skill base:

i. Earlier SPC involvement: Significant time points in the patient journey, such as assessment for liver transplantation, repeated hospital admissions or onset of need for regular paracentesis could prompt SPC referral. Understanding of appropriate triggers and markers of deterioration may support health professionals to recognise when symptomatic patients would benefit from SPC which can be delivered in parallel with more aggressive treatments.

ii. Better community provision of liver services: Better liaison between liver teams, primary care and SPC could enable patients to receive community nursing and paracentesis, enhanced by hospice outpatient services to provide support and symptom control as required, which may reduce emergency admissions to hospital.

iii. Development of clearer care pathways: Understanding of care pathways would guide liver professionals to identify which patients with cirrhosis had reached the EoL phase and what to do next. An EoL pathway would provide a framework to consider withdrawal of medication and opportunities for patients and those close to them to access counselling and support.

iv. Ways of improving communication skills: Liver professionals recognised that patients and family members had little understanding about their disease or its severity. At the same time, they themselves lacked confidence in having honest discussions about these topics. Sharing of information about the disease, its likely trajectory and symptoms might allow more open discussions about future care, and choices about place of care, interventions and services available.

Table 4 Research themes identified by discipline

<table>
<thead>
<tr>
<th>Disease-specific information</th>
<th>SPC (n=114)</th>
<th>Liver professionals (n=93)</th>
<th>General practice (n=14)</th>
<th>Total (n=221)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom management</td>
<td>59</td>
<td>35</td>
<td>6</td>
<td>100</td>
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<tr>
<td>Prognosis</td>
<td>23</td>
<td>18</td>
<td>1</td>
<td>42</td>
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<tr>
<td>Needs assessment</td>
<td>11</td>
<td>15</td>
<td></td>
<td>26</td>
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<td>Epidemiology</td>
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<td></td>
<td></td>
<td>6</td>
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<tr>
<td>Psychosocial impact</td>
<td>4</td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Stakeholder understanding of liver disease</td>
<td>2</td>
<td>1</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>New treatments</td>
<td>3</td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Service model approaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimal service structure</td>
<td>14</td>
<td>5</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>Evaluating added value of palliative care</td>
<td>8</td>
<td>5</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Barriers/improving access to SPC</td>
<td>8</td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to improve management of liver patients</td>
<td>3</td>
<td>3</td>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

SPC, specialist palliative care.

Key priorities for future research

Open responses on research priorities were received from 221 participants. Table 4 highlights the key findings. (1) Disease specific information—all groups highlighted the need to understand: symptom control (in particular how best to manage recurrent ascites, pruritus and encephalopathy, and opioid pharmacology when liver function is compromised), and prognostication (in particular identifying the earliest point when deterioration is irreversible); (2) Service models—SPC and liver professionals prioritised exploring whether palliative care adds value (economical or quality of life), the best way of managing patients in the community to avoid hospital admissions, and the evaluation of an early palliative care intervention versus usual care; understanding would be enhanced by exploring the experience of patient and their family members in (A) their understanding of prognosis and their own wishes about future preference of care (B) what specific needs they have as a result of the illness.

DISCUSSION

This is the first UK-based national survey on the perspectives of health professionals responsible for delivering care to people with cirrhosis who are facing death.

Referrals from liver teams to SPC are relatively uncommon and usually made late in the illness when death is very close. Understanding of the role of SPC was poor. All health professionals, irrespective of specialty, recognised that they required further training to improve their skills in caring for people with advanced cirrhosis. For SPC, this training centred on increasing awareness of specific issues involved in managing patients with liver disease, such as the implications of impaired liver function on symptom control and medication use. For liver professionals, future training should support them to identify...
patients for whom cure is no longer likely and to shift the emphasis of care from burdensome interventions to a more supportive care role. All groups recognise the need for collaborative working earlier in the illness so that discussions about the future can be raised at key points such as transplant assessments or exacerbations of symptoms. We identify symptom management, prognostication, and overall service structure as key areas for future research.

Our findings support key recommendations from a recent review of palliative care in end stage liver disease including better collaboration between liver health professionals and SPC and the identification of potential triggers for palliative care consultations. Our work also supports recommendations from the Lancet Commission report on the role of primary care in liver disease and the need for community hepatology posts for GPs to work more closely with liver professionals.

Lessons can be learned from research on the management of people with other advanced non-malignant diseases. In the UK, in advanced heart failure and advanced kidney disease, shared care approaches have been developed involving multiprofessional collaboration between primary care and specialist services, and SPC input when required. The key elements are sensitive communication with patients and their families especially earlier in the illness, holistic assessment and care involving multiprofessional working across boundaries. While planning at a national level is not easy, on a local level, it would be important to improve education and coordination of service provision between liver specialists, GPs and SPC professionals.

We note the very low response rate to our survey, which currently limits the generalisability of our findings which require further validation. This low response rate may be due to limitations in our methods. Data protection issues prevented us from accessing mailing lists directly, which was the responsibility of the special interest groups, so the delivery of the mail-out was inconsistent. Email circulations may have been incomplete, and overlap in the membership of our targets groups (eg, BASL and the BSG liver section) may underestimate the response rate. However, our highest response rate of 24% achieved from SPC is still lower than the 33% considered standard for on-line surveys. It is possible, but we cannot be certain that there is currently a reluctance to consider issues of EoL care among those working with people with cirrhosis. However, it is likely that the potential benefits of a palliative approach to care, either early and in parallel to more aggressive treatments, or in managing the terminal phase are not yet recognised.

Our response rates might have been higher had the research team been able to access directly the mailing list from each of the different organisations. This would have enabled the research team to check for duplicate participants and personalise the invitation letter before sending out to each health professional. We might also have been able to ensure that each non-responding professional received up to two follow-up emails to encourage their participation in the survey. Furthermore, if finances were available, we would have given participants on receipt of their response a non-monetary incentive such as Amazon gift cards to be used for educational purposes. Some of these initiatives have been identified in a Cochrane review as increasing response rates in electronic surveys.

CONCLUSION

While there are plans to address the high mortality from liver disease, these initiatives will be slow to demonstrate any impact on mortality figures and many will continue to die with high symptom burden and little care planning at the EoL. The financial challenges faced by the NHS over the next years as outlined by the NHS England Chief Executive confirm that we cannot expect significant financial support to address the problem. We recommend research that takes account of economic costs and benefits, and improves our understanding of the needs of patients with cirrhosis and their families, enhances communication with those at risk of death, enables smoother links across care boundaries, and informs training for all professionals involved in treatments and care.

Key messages

What is already known about this subject?

- There is increasing number of deaths from liver disease in the UK.
- Most deaths from liver disease occur at a relatively young age and in patients with a higher degree of social deprivation.
- Access to palliative care for people with end stage liver disease (cirrhosis) has been limited and most deaths from cirrhosis occur in hospital.

What this paper adds?

- This study is the first UK national survey to specifically explore current attitudes and practices of different health professionals caring for patients with cirrhosis near the end of life, using on-line survey methodology.
- We identify symptom management, prognostication, and overall service structure as key areas for future research.

How might it impact on future clinical practice?

- Increase collaborative working between liver professionals and specialist palliative care to meet the needs of patients with end stage liver disease.
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Contributors JL, VV and SD were responsible for the conception and design of this work, acquisition, analysis and interpretation of data, drafting the work and giving final approval. JB was responsible for the design of the work, data analysis and interpretation, drafting the work and giving final approval. LG, KH, AM, DT and LJ were responsible for the design of this work, revising it critically for important content, and giving final approval.

Competing interests None declared.

Ethics approval UCL Ethics committee (3552/002).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Extra data is available by emailing Dr Joe Low at joseph.low@ucl.ac.uk.

REFERENCES
9 StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP.

Thank you for taking the time to answer our survey. Please answer the questions as accurately and thoroughly as you can.

**Demographics**

1. **What is your professional background?**
   
   Doctor [ ]
   Nurse [ ]
   Allied Health Professional [ ]
   Other [ ] Please specify: ____________________

2. **In which geographical (NHS) Regions do you work?**
   England [ ]
   North of England [ ]
   Midlands and East of Anglia [ ]
   South of England [ ]
   London [ ]
   Wales [ ]
   Scotland [ ]
   Northern Ireland [ ]

   What Trust do you work for? Name of Trust: ________________________________

**What is the name of the Trust that you work in**

3. **Do you work in**
   Primary Care [ ] [if clicked, will take user directly to GP section]
   Hepatology [ ] [if clicked, will take user directly to liver specific section]
   Gastroenterology [ ] [if clicked, will take user directly to liver specific questions]
   Specialist palliative care [ ] [if clicked, will take user to 3(a)].

3a. Do you work in:
   Hospital [ ]
   Hospice [ ]
   Community [ ]

   [After options in 3a answered, then take user to SPC section]
SPC – Specific Questionnaire

4a. In principal, do you accept referrals for patients with cirrhosis near the end of life from liver teams?

Yes / No

b) How many patients did you see with a diagnosis of end stage liver disease in the last year?
(Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21 +

If this box ticked, go to 5


c) What percentage of your patient load has a principal diagnosis of cirrhosis/liver disease?
(Please just give a rough estimate) _____ %


d) Did any of these referral originate from GPs?
Yes [if ticked, go to 5e]/ No [if ticked, go to 5f]

e) How many? (Please just give a rough estimate) _______

Of all referrals in the last year:

f) How many were for hospital Specialist Palliative Care? (Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21 +


g) How many were for specialist palliative care at home? (Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21 +


h) How many were for hospice admission? (Please just give a rough estimate)

None
5. What were the reasons for patients with cirrhosis (near the end of life) being referred to Specialist palliative care by liver teams/General Practitioners?

Tick all reasons that apply:
Symptom Control
End of life issues
Hospice/Palliative Care
Communicating difficult news
Ethical decision making
Social/family
Bereavement support
Other If other ticked, List main reason [Open text]: __________

6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?
Yes/No/Don’t know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

Tick all reasons that apply:
Initial diagnosis
Deterioration in symptoms
Consideration of advanced liver management
Recurrent hospital admissions
End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)
lack of resources
lack of beds (including respite bed facilities)
implications for staff training
organisational decision
lack of expertise
none/few referred (by liver team or GP)
Cardiac professionals can do this
Unable to provide specialised liver therapy
Other

If other ticked, List main reason [Open text]:

9. Do you feel you have the appropriate skills and knowledge to look after this group of patients?
Yes/No

10. Please list what training (if any) you would need to improve your skills and knowledge in caring for this group of patients with cirrhosis.

Tick all reasons that apply:
Education on assessment and management of decompensated liver disease
Up to date information about advances in managing recurrent ascites
Education on pharmacology in cirrhosis
Information on prognostication
 Likely illness trajectory in cirrhosis
Other

If other ticked, List main reason [Open text]:

11. What do you think are the barriers to providing care to this patient group?

Tick all reasons that apply:
High frequency of complex and difficult social circumstances
Lack of education of SPC providers on managing cirrhosis patients
Lack of education of liver teams in end of life care
Lack of possibilities for joint working between SPC/GP/liver teams
Other

If other ticked, List main reason [Open text]:

12. Which of the following do you think would improve end of life care for patients with cirrhosis?

Tick your main answer:
Improved liaison between secondary and primary care
Improved provision of specialist palliative care
More education opportunities in specialist liver units
Other

Please specify what:

10a. Have you received any referrals for patients with hepatocellular carcinoma? Yes/No
b) How many referrals for patients with hepatocellular carcinoma did you receive in the last year? (Please just give a rough estimate)

None □
1-5 □
6-10 □
11-20 □
21+ □

11. What are your key priorities for research in end stage liver disease?

OPEN TEXT

Thank you for completing this questionnaire
4a) Do you refer any of your patients to Specialist Palliative care? Yes/No

Yes [if ticked, go to 4b]/ No [if ticked, go to 4d]

b) How many patients from in-patient care did you refer to specialist palliative care in the last year? (Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21+

If responses to 4[b] and 4[c] were BOTH ticked as None, go to 5 [ii]
Otherwise, go to 5 [i]

5 i. What are the reasons for referral to SPC?

Tick all reasons that apply:
- Symptom Control
- End of life issues
- Hospice/Palliative Care
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement support
- Other

If other ticked, list main reason [Open text]: __________

5 ii) Patients were not referred to specialist palliative care for the following reasons;
Tick all reasons that apply:

Patients were not identified as at the EOL
The liver team were able to manage the patients’ needs
Palliative care do not accept referrals for liver patients
No palliative care service to refer to
Other Please specify: _____________

6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?
   Yes/No/Don’t know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

   Tick all reasons that apply:
   Initial diagnosis
   Deterioration in symptoms
   Consideration of advanced liver management
   Recurrent hospital admissions
   End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)

   lack of resources
   lack of beds (including respite bed facilities)
   implications for staff training
   organisational decision
   lack of expertise
   none/few referred (by liver team or GP)
   Cardiac professionals can do this
   Unable to provide specialised liver therapy
   Other If other ticked, List main reason [Open text]: __________

9. How could care for patients with cirrhosis at the end of life be improved?

   Open TEXT
10. Please list what training (if any) you would need to improve your skills in caring for this group of patients with cirrhosis near the end of life.

Tick all reasons that apply:
Symptom Control [ ]
End of life issues [ ]
Communicating difficult news [ ]
Ethical decision making [ ]
Social/family [ ]
Bereavement counselling [ ]
Other [ ] Please specify what: ____________

11. Which of the following do you think would improve end of life care for patients cirrhosis?

Improved liaison between secondary and primary care [ ]
Improved provision of specialist palliative care [ ]
More education opportunities in specialist liver units [ ]
Other [ ] Please specify what: ____________

12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

Thank you for completing this questionnaire
Primary Care

4) a) Do you receive referrals from liver centres for palliative care/end of life care? Yes/No
   b) Do you routinely provide end of life care for your patients? Yes/No
   c) Do you take part in a GSF? Yes/No

5) Do you feel you have the skills to manage patients with cirrhosis near the end of life in the community? Yes/No

6) Have you referred ANY patients with cirrhosis to specialist palliative care? Yes/No
   If Yes, go to 7; If No, go to 9

7) For those who have referrals to Specialist PC, reasons for your referral?
   Tick all reasons that apply:
   Symptom Control □
   End of life issues □
   Hospice/Palliative Care □
   Communicating difficult news □
   Ethical decision making □
   Social/family □
   Bereavement support □
   Other □ If other tick, List main reason(s): ____________

8) How many patients with cirrhosis have you referred in the last year? (Please just give a rough estimate)
   None □
   1-5 □
   6-10 □
   11-20 □
   21 □

9) a) Do you think that patients with cirrhosis can be adequately managed in the community? Yes/No/Don’t Know
   b) Please give a reason for your responses?
      Open TEXT
10) Please list what training (if any) you would need to improve your skills in caring for patients with cirrhosis near the end of life.

**Tick all reasons that apply:**
- Symptom Control
- End of life issues
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement counselling
- Other

Please specify what: ____________

-----------------------------------------------------------------------------------------------------------------------------

11. Which of the following do you think would improve end of life care for patients with cirrhosis?

- Improved liaison between secondary and primary care
- Improved provision of specialist palliative care
- More education opportunities in specialist liver units
- Other

Please specify what: ____________

12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

-----------------------------------------------------------------------------------------------------------------------------

**Thank you for completing this questionnaire**
Appendix ii: Number of potential respondents identified from each organisation by professional group.

Respondents $n = 6181$

Gastroenterology / Heptology

- BSG $n = 500$
- RCN gastro $n = 3000$
- BASL $n = 804$
- BLNF $n = 100$
- London liver group $n = 149$

Specialist palliative care

- APM $n = 840$
- Help the hospice $n = 313$
- National Nurse consultant group (Palliative Care) $n = 27$

Primary care

- PCSG $n = 448$

Key:

PCSG - Primary Care Society for Gastroenterology

BASL - British Association Study Liver

BSG - British Society of Gastroenterology – Liver section

BLTNF - British Liver Trust Nurses Forum

RCN - Royal College of Nursing gastro-enterology section

APM - Association for Palliative Medicine
Appendix iii: Respondents professional background by speciality

<table>
<thead>
<tr>
<th>Respondents professional background</th>
<th>Respondents Speciality</th>
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<tr>
<td></td>
<td>Gastro-entrology</td>
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<td>AHP</td>
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</tr>
<tr>
<td>Doctor</td>
<td>55</td>
</tr>
<tr>
<td>Nurse</td>
<td>42</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>97</td>
</tr>
</tbody>
</table>
Appendix iv: Respondents’ speciality by site of NHS Region

<table>
<thead>
<tr>
<th>In which geographical (NHS) Region do you work?</th>
<th>Number (percentage) of respondents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gastro-entrology</td>
<td>Hepatology</td>
</tr>
<tr>
<td>London</td>
<td>15 (15)</td>
<td>31 (32)</td>
</tr>
<tr>
<td>Midlands and East of England</td>
<td>17 (18)</td>
<td>21 (21)</td>
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<tr>
<td>North of England</td>
<td>33 (34)</td>
<td>15 (15)</td>
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<tr>
<td>Northern Ireland</td>
<td>1 (1)</td>
<td>2 (2)</td>
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<tr>
<td>Scotland</td>
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<tr>
<td>South of England</td>
<td>20 (21)</td>
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<td>Wales</td>
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<td>5 (5)</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>97 (100)</strong></td>
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