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How can primary care enhance end-of-life care for liver disease? A qualitative study of general practitioners' perceptions and experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017106
Article Type:	Research
Date Submitted by the Author:	31-Mar-2017
Complete List of Authors:	Standing, Holly; Newcastle University, Institute of Health & Society Jarvis, Helen; Newcastle University, Institute of Health & Society Orr, James; Newcastle University, Institute of Cellular Medicine Exley, Catherine; Northumbria University, Faculty of Health and Life Sciences Husdon, Mark; Freeman Hospital; Newcastle University, Institute of Cellular Medicine Kaner, Eileen; Newcastle University, Institute of Health and Society Hanratty, Barbara; Newcastle University, Institute of Health and Society / Newcastle University Institute for Ageing
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Gastroenterology and hepatology, Palliative care
Keywords:	PALLIATIVE CARE, liver diseases, terminal care, patient care

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3 **How can primary care enhance end-of-life care for liver disease? A qualitative**
4 **study of general practitioners' perceptions and experiences**
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7 **SUBMISSION TO: BMJ Open**
8

9 **AUTHORS**

10 Holly Standing, Helen Jarvis, James Orr,
11 Catherine Exley, Mark Hudson, Eileen Kaner, Barbara Hanratty
12

13 **Dr Holly C Standing**

14 Institute of Health and Society
15 Newcastle University,
16 Holly.standing@newcastle.ac.uk
17

18 **Dr Helen Jarvis**

19 Institute of Health and Society, Newcastle University, Biomedical Research Building,
20 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
21 Helen.jarvis2@newcastle.ac.uk
22
23

24 **Dr James Orr**

25 Institute of Cellular Medicine, Newcastle University
26 James.orr@newcastle.ac.uk
27
28

29 **Professor Catherine Exley**

30 Faculty of Health and Life Sciences,
31 Northumbria University,
32 Newcastle upon Tyne NE1 8ST
33 Catherine.exley@northumbria.ac.uk
34
35

36 **Dr Mark Hudson**

37 Freeman hospital, High Heaton, Newcastle upon Tyne, NE7 7DN
38 Institute of Cellular Medicine, Newcastle University
39 Mark.Hudson@nuth.nhs.uk
40
41

42 **Professor Eileen Kaner**

43 Institute of Health and Society, Newcastle University, The Baddiley-Clark Building
44 Richardson Road, Newcastle upon Tyne NE2 4AX
45 Eileen.kaner@newcastle.ac.uk
46

47 **Professor Barbara Hanratty***

48 Institute of Health and Society, Newcastle University, Biomedical Research Building,
49 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
50 Barbara.hanratty@newcastle.ac.uk
51

52 ***Author for correspondence: Barbara Hanratty**
53
54

55 **Word count** 3978 (including quotes)

56 **Key words (MeSH)** : terminal care, palliative care, liver diseases, patient care
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Abstract

Background: Liver disease is the third commonest cause of premature death in the UK. The symptoms of terminal liver disease are often difficult to treat, but very few patients see a palliative care specialist, and a high proportion die in hospital. Primary care has been identified as a setting where knowledge and awareness of liver disease is poor. Little is known about general practitioners' (GPs) perceptions of their role in managing end-stage liver disease.

Objective: To explore GPs' experiences and perceptions of how primary care can enhance end-of-life care for patients with liver disease.

Design: Qualitative interview study, thematic analysis

Participants: Purposive sample of 25 GPs from five regions of England

Results: GPs expressed a desire to be more closely involved in end-of-life care for patients with liver disease, but identified a number of factors that constrained their ability to contribute. These fell into three main areas; those relating directly to the condition, (symptom management and the need to combine a palliative care approach with ongoing medical interventions); issues arising from patients' social circumstances (stigma, social isolation and the social consequences of liver disease); and deficiencies in the organisation and delivery of services. Collaborative working with support from specialist hospital clinicians was regarded as essential, with GPs acknowledging their lack of experience and expertise in this area.

Conclusions: End-of-life care for patients with liver disease merits attention from both primary and secondary care services. Development of care pathways and equitable access to symptom relief should be a priority.

Abstract word count 249**Strength and limitations of this study:**

- To the best of our knowledge this is the first study to focus on the experiences' of primary care clinicians around managing end-of-life liver disease.
- GPs were recruited from a range of both rural and urban UK locations.
- Use of Semi-structured interviews allowed us to collect detailed descriptions of GPs' experiences of managing end-of-life liver disease.
- The study was conducted by a team of experienced researchers with a range of disciplinary backgrounds including clinical experience.
- The findings of our study are based on the reported knowledge and experiences' of self-selecting participants, their views may not be transferable to the wider GP population.

Introduction

End stage liver disease is an important challenge for providers of palliative and end-of-life care. Death rates have increased 400% since 1970, and it is now the third commonest cause of premature death in the UK.^{1, 2, 3} In 2012, around 11,000 deaths were attributed to liver disease in the UK. Patients have a complex and heavy symptom burden that is often poorly treated^{4, 5} and the psychosocial needs of patients and families may be considerable.⁶ The majority of patients present late to services, when liver disease is irreversible and around 70% die in hospital.⁷ The typical clinical course, of gradual decline punctuated by episodic decompensation, may mean that treatment is focused on prolonging life through means such as transplantation, and a palliative care approach is rarely considered.⁸ Liver

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2
3 transplantation is the only curative treatment in end stage liver disease but many
4 patients will be unsuitable due to co-morbidities, advancing age or ongoing alcohol
5 consumption. Some evidence suggests that patients who are considered and
6 rejected for organ transplantation, are unlikely to receive any palliative care.⁹
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14 There is a growing international consensus that end-of-life care for patients with liver
15 disease requires improvement.^{4 10-12} Primary care has been identified as a specific
16 area where care could be enhanced, particularly around the discussion of palliative
17 care needs with patients, the inclusion of patients on palliative care registers, and
18 improving communication between primary and secondary care.^{8 13} Primary care
19 professionals are well placed to provide holistic care that patients dying with liver
20 disease need, but are seldom involved. In addition, GP care for patients dying with
21 liver disease is not rated highly by bereaved relatives.¹⁴
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34 Little is known about how health professionals in primary care see their role in end-
35 stage liver disease, or what they view as the main barriers to providing high quality
36 care. This study intends to contribute to our understanding of this patient group and
37 to inform the development of appropriate services. The aim is to explore GP
38 experiences and perceptions of end-of-life care for patients with liver disease.
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45 **Methods**

46
47 This study employed qualitative methods, involving semi-structured interviews with
48 GPs from five geographical areas within England.
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Participants

Participants were recruited via National Institute for Health Research Clinical Research Networks and local networks of GP practices in the London, Thames Valley, Wessex, Yorkshire and the North East. Email invitations were sent to GP practices within these networks, and GPs who wished to participate then contacted the research team. Following the first phase of interviews, participants were purposively sampled in order to provide a wide range of clinical experience and degree of familiarity with liver disease, this involved targeting individuals in areas of high and low prevalence.

Data collection

A semi-structured interview guide was developed to cover issues identified through a review of the literature; including GPs' experiences of identifying and managing end-of-life liver disease. This was a 'living' document that evolved throughout data collection to allow exploration of emerging areas. Interviews were conducted face-to-face (n=2) or over the telephone (n=23). Interviews lasted between 15 and 50 minutes and were all conducted by the first author between March and August 2016. Field notes were taken to aid subsequent analysis. Informed consent was obtained from all participants. Data collection ceased when no themes were emerging from the interviews (see below for further detail).

Data analysis

Audio recordings of interviews were transcribed verbatim by an independent transcription company; transcripts were checked for accuracy by listening again to each recording. The NVivo 10 software package was used to manage the data.

A thematic analysis was conducted based on the approach of Glaser and Strauss¹⁵. The analysis was iterative, with data collection and analysis running concurrently throughout the study. Analysis of early transcripts informed the interview schedule for later interviews and each transcript was re-examined in light of subsequent interviews. The researchers began by familiarising themselves with the data through detailed reading of the transcripts followed by line-by-line coding.¹⁶ Field notes taken during data collection were used throughout analysis to enhance the reflective process.

Several quality control measures were employed to ensure trustworthiness of the data. A proportion of the transcripts (20%) were coded independently by three researchers, before coming together to compare their analysis. Data analysis and emerging themes were also discussed amongst the wider research team, which included individuals with clinical expertise in general practice and hepatology.

Findings

Twenty five GPs were interviewed. The majority had been qualified as GPs for five or more years, but few (4/25) had any specialist hepatology or gastroenterology training or experience. Participant characteristics are shown in table 1.

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4
5 Table 1 here
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10 Four themes were identified from the data analysis: the role of the GP,
11 acknowledging and accepting end-of-life, collaborative care pathways, and social
12 relationships and consequences. The quotations presented below are illustrative,
13 representing typical participant responses and demonstrating the varied viewpoints.
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20 21 **The role of the GP**

22
23 In this study, few of the interviewees had extensive first-hand experience of
24 managing patients with liver disease at the end-of-life. Those who did, reported that
25 they managed such cases infrequently, and some years may go by without them
26 seeing a case.
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35 *"[We manage] a lot of dying people, but not from the hepatology*
36 *point of view. I don't know if they tend to be managed in hospital*
37 *predominantly more than in primary care? That's a possibility, I*
38 *guess."* (GP 7)
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46 Some of the interviewees attributed their lack of expertise and experience of caring
47 for liver patients at the end-of-life to a reluctance amongst hospital clinicians to
48 relinquish control.
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55 *"There are some conditions, like liver disease, renal failure, they*
56 *[patients] all just end up dying in hospital for some reason. I don't*
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3 *know whether it's the hospital consultants that don't want to let them*
4
5 *go home... They need to let go and make sure there's a palliative*
6
7 *care plan in place...they don't do it." (GP 3)*
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11
12 The limited contact between GPs and patients dying with liver disease was attributed
13
14 to an unpredictable disease trajectory with periods of stability and decompensation,
15
16 and to patients remaining under the care of hospital services in their last weeks and
17
18 months. The GPs in this study shared a view that end-of-life care is a core
19
20 component of primary care, and interviewees questioned how appropriate it was for
21
22 specialist hospital clinicians to take a lead in palliative care. Patients with liver
23
24 disease were not regarded as distinct or different from patients dying with other
25
26 conditions, and a number of GPs expressed a desire for greater involvement in their
27
28 end-of-life care. Some participants implied that primary care involvement may
29
30 support more patients to die at home, rather than in hospital.
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36 *"I think primary care probably is best placed, in most cases, to look*
37
38 *after people- well not only for that [liver disease], for most end-of-life*
39
40 *care issues. So, yeah, I think the GP is probably the most important*
41
42 *person in the sense that they can bear in mind what the specialists*
43
44 *have advised, but at the end of the day, try and keep some of these*
45
46 *patients at home rather than having to have them admitted acutely."*
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48

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50 (GP 14)
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53 **Acknowledging and accepting end-of-life**

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55 Judging when a patient with liver disease is nearing the end-of-life was perceived to
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3 be a particular challenge. Communication about prognosis and the age of patients
4
5 were identified as important factors. Some of the GPs reflected on how
6
7 management decisions taken in hospital send out messages that influence care
8
9 provided in the community. Continuing to pursue active treatment may convey
10
11 optimism about the patient's life expectancy. Specifically, GPs referenced occasions
12
13 where patients had been placed on the waiting list for a liver transplant, which the
14
15 patient saw as offering them a second chance at life, even though they were critically
16
17 unwell and may die whilst waiting for an organ. Patients with a primary liver condition
18
19 are often younger than the typical palliative care patient. It is likely that clinicians are
20
21 more reluctant to give up on active treatment for younger patients, whilst patients
22
23 and families may also struggle to accept that the end-of-life is approaching.
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29
30 *“Those patients where it's a, kind of, grey area about whether they're*
31
32 *end-of-life or not. And I think that mainly stems from the fact that if*
33
34 *it's a young patient, it's more difficult for health care professionals,*
35
36 *the patients themselves, and families, to actually accept that the*
37
38 *person's dying” (GP1)*
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43 Mixed or uncertain messages may mean that care is compromised, if no one
44
45 engages the patient in discussions about the end-of-life, and a palliative approach is
46
47 never considered.
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52 *“I suppose, looking back it really was palliative care but they*
53
54 *[secondary care] put him on the transplant list because he's given up*
55
56 *alcohol and there was still this hope. So therefore we didn't really*
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3 *realise he was going to die as quickly as he did” (GP 11)*
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7 There was a shared feeling amongst interviewees, that specialists should provide
8 clear messages about patients’ prognoses, so that GPs can adopt an appropriate
9 management plan. At present, hospital specialists were perceived as failing to take
10 responsibility for identifying patients as end-of-life, and this had a detrimental impact
11 on primary care.
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21 *“I feel that it should be made compulsory for the secondary care,*
22 *tertiary care sectors, when they discharge, or when they’re seen in*
23 *the patient clinic, [to] prognosticate, ... then we can initiate also, the*
24 *discussion with the patient, in a much more positive way.” (GP 12)*
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32 **Collaborative care pathways**

33 Supporting patients with liver disease was seen as a collaborative effort, with GPs
34 acknowledging their need for specialist guidance, particularly when managing end-
35 of-life complications. Ascites was the most commonly mentioned and problematic
36 symptom experienced by patients with end-stage liver disease, requiring drainage in
37 hospital. Experiences of GPs in this study suggest that ease of access to this
38 procedure was highly variable. In some areas, pathways had been negotiated and
39 patients could be directly admitted to an appropriate ward. In others, GPs described
40 their concern at having to send patients to accident and emergency (A&E)
41 departments. Failure to arrange prompt access to treatment caused distress and
42 was a major source of adverse experiences during end-of-life care.
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3 *“We had a nightmare. He was building up litres of ascitic fluid on his*
4 *tummy every week or week to 10 days, and every time the hospital*
5 *had to send him acutely, new, to A&E and he had to sit in A&E for*
6 *hours. I was speaking to the liver specialist ... He needed regular*
7 *reviews and eventually they agreed to do it two weekly but even that*
8 *wasn't enough, it was building up and he was ending up going in as*
9 *an emergency every week.” (GP 11)*
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19 Where appropriate care pathways were not in place, interviewees suggested that
20 they were needed, to reassure the patient and GPs that support is available when
21 required.
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28 A number of participants suggested that a specialist nurse may hold the key to more
29 collaborative management of liver patients. They could act as an intermediary
30 between primary and secondary care, negotiating priorities and ensuring effective
31 and easy communication.
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39 *“It often helps when there is direct access to, say, a nurse specialist*
40 *in a field, or there is some other point of contact in secondary care*
41 *that say a family or the patient themselves can call directly for*
42 *advice.” (GP 14)*
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49 Although some GPs had encountered specialist nurses working in this type of role,
50 this was not a common experience. Unfavourable comparisons were made between
51 the services available for patients with liver disease, and other conditions, such as
52 cancer. Participants highlighted the potential benefit to patients and families, of
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3 having a specialist point of contact in the community, including prompt access to
4
5 advice and alleviation of fears and concerns.
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10 11 **Social relationships and consequences**

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13 GPs in this study argued that people with liver disease had many of the same
14
15 primary care needs as patients with other life-limiting conditions. However, the
16
17 severity of symptoms in end-of-life liver disease was felt to be different. Some of the
18
19 GPs acknowledged the potentially damaging impact on the patient's family, of seeing
20
21 their relative die at home.
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27 *"I think there is quite a strong push to keep people at home. Whether*
28
29 *that's right or wrong, I don't know really. If they've got ascites or*
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31 *portal hypertension, you know, they've got the risk of vomiting blood*
32
33 *and all the rest of it. Or they have been vomiting blood. I'm not*
34
35 *massively keen on keeping people at home because it's just a*
36
37 *rubbish picture in the mind of everybody, I think, you know, the family*
38
39 *left behind."* (GP 17)
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45 Families were perceived to be in need of support themselves, which was an
46
47 additional role for primary care. GPs described examples of relatives requiring
48
49 frequent contact and reassurance as the patient's condition deteriorated. The GPs in
50
51 this study differed in their attitudes towards these demands. Some took a holistic
52
53 view to the management of palliative patients, believing that these were part of the
54
55 standard practice of primary care.
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3 *"I think when we talk about palliative care it's not just a single person*
4 *who's the patient, it's about supporting and managing the family and*
5 *helping them through that bereavement stage because it starts right*
6 *at the diagnosis and they have to go through that journey. Death is a*
7 *part of life and giving them that support."* (GP 10)
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15 However, others felt that attending to the needs of patients' families was an extra
16
17 burden on their already overstretched resources.
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22 Limited social support and unfavourable social circumstances were often mentioned
23
24 as significant issues for patients with liver disease, particularly when alcohol or drug
25
26 misuse were factors. Several GPs referred to the 'chaotic' lifestyles of this patient
27
28 group, and resulting vulnerability to social isolation. Behaviours associated with
29
30 addiction were perceived to lead to the breakdown of the patients' social networks,
31
32 leaving few, if any people to provide support or care.
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38 *"the demographics of the alcohol dependent ones, who have often,*
39 *for various reasons and due to the nature of their disease, have*
40 *become quite isolated, they have not got many people around them*
41 *and so they don't have that support. They require much more*
42 *organisation and support in the background, so we make sure that*
43 *they do have that support."* (GP 10)
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52 Without alternative sources of support, socially isolated patients were believed to
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54 place extra demands on GPs and other health services. Even when social networks
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3 were maintained, there could be a dearth of responsible caregivers, as friends and
4
5 family often shared the problems of addiction and poor health.
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11 *“I can think of a couple of our households where maybe spouses and*
12 *partners may have liver cirrhosis themselves. I can think of two*
13 *couples – well, one person who died two years ago. His wife has*
14 *chronic liver disease as well.” (GP 4)*
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23
24 One of the most important consequences of social isolation, was that patients had
25
26 fewer choices over where they spent the end of their life. Without anyone to monitor
27
28 their condition, they were more likely to be admitted to hospital, and die there.
29
30

31
32 Liver disease is a potentially stigmatising condition, particularly when the underlying
33
34 cause is alcohol or substance misuse. Several of the GPs suggested that there is
35
36 often an assumption within the patient’s community that liver disease is self-induced
37
38 and they were culpable, even when substance misuse or alcohol are not factors.
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44 *“I think it’s a huge problem for people that have liver disease and*
45 *look like they have liver disease and people assume it’s related to*
46 *alcohol when, in fact, it might be due to auto-immune causes or other*
47 *forms of cancer or something like that or hepatitis as well.” (GP 23)*
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3 This assumed culpability has implications for the degree of support and sympathy
4 that the patient, and their families, receive. GPs also suggested that stigma could
5 hinder patients' acceptance of their prognosis, which in turn made the management
6 of their condition more challenging. As such, care of liver patients should include
7 psychological and social services.
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15 *"I think, inevitably and sadly, there is a stigma associated with liver*
16 *disease, and hence, that's why the psychological support is really*
17 *important"* (GP 25)
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22 However, some commented that stigmatisation occurred early in the patients'
23 illnesses, and to address this, changes would be needed well before end-of-life care
24 was being considered.
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29 **Discussion**

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31
32 This study provides insights into the challenge faced by general practitioners
33 providing end-of-life care for patients with chronic liver disease. Many GPs
34 expressed a desire to be more closely involved, but identified a number of factors
35 that constrained their ability to contribute. These fell into three main areas; those
36 relating directly to the condition, (symptom management and the need to combine a
37 palliative care approach with ongoing medical interventions); issues arising from
38 patients' social circumstances (stigma, social isolation and the social consequences
39 of liver disease); and deficiencies in the organisation and delivery of services.
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49 Collaborative working with support from specialist hospital clinicians was regarded
50 as essential, with GPs acknowledging their lack of experience and expertise in this
51 area.
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56 Strengths and limitations
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3 To our knowledge this is the first study to focus on the experiences of primary care
4 physicians in managing patients with end-stage liver disease. Our interviewees were
5 drawn from rural and urban areas in five different regions in England, and working
6 with a diverse range of communities. The relatively large number of GP participants
7 and varying levels of experience, expertise and interest in the subject, is a particular
8 strength of the study. With our qualitative design, we were not seeking
9 generalisability, but the diversity of the participants increases our confidence that we
10 have not overlooked important issues. The majority of interviews were conducted by
11 telephone, which may explain the ease and speed with which we recruited
12 participants, despite not offering any financial incentives. Use of the telephone is
13 thought to have promoted unguarded responses, but we acknowledge that it can be
14 more difficult to develop rapport in the absence of nonverbal cues and other facets of
15 face to face communication. However, we do not believe that this was a problem, as
16 GPs provided rich and insightful accounts of their experiences.

36 Comparison with other work

37
38 Our findings are consistent with recent research from Scotland that included
39 interviews with eight GPs along with other health care professionals. Communication
40 with secondary care, lack of expertise and limited confidence in prognostication were
41 all identified as concerns.¹³ Accurate assessment of prognosis in liver disease is
42 difficult given the unpredictable disease course. In some aspects this is similar to
43 other diseases characterised by episodes of decompensation, such as heart failure.
44 However, liver disease presents the additional challenge that recompensation and
45 improved liver function may be achieved in certain patients, such as those who
46 achieve abstinence from alcohol. A recent review of palliative care guidelines in
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3 heart failure and chronic obstructive pulmonary disease described wide variation in
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5 how patients are identified for palliative care, and attributed this, in part, to the
6
7 unpredictable disease course and the consequences for care planning.¹⁷ In common
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9 with liver disease, acknowledgement and development of end-of-life care has been
10
11 relatively recent for these conditions.¹⁷
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16 The GPs in our study agreed that, at the end-of-life, patients with liver disease ideally
17
18 need primary care and hospital specialists to work closely together. GPs are more
19
20 likely to have an established relationship with the patient and a greater
21
22 understanding of their social situation and needs, whereas specialists offer expert
23
24 knowledge on liver disease and treatment options. They highlighted the importance
25
26 that primary care physicians place on being able to provide a coordinating role, but
27
28 only when supported by members of the specialist teams. Managing complex and
29
30 unusual symptoms, or judging when to introduce a palliative care approach, for
31
32 example, all benefit from collaboration. The advantages of a multidisciplinary
33
34 approach have already been well documented in the palliative care literature.^{18 19}
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36 Several recent reviews on end-stage liver disease have also advocated this
37
38 approach.^{4 5 11}
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45 This study highlights the complexity of caring for patients with end-stage liver
46
47 disease. Expertise in acute medicine and palliative care are essential, but patients
48
49 and families also need sensitive and practical responses to their psycho-emotional
50
51 and social concerns, including stigma related to the perceived self-inflictedness of
52
53 the disease, social isolation and lack of income. Such generalist expertise and a
54
55 holistic, person-centred approach are the foundations of primary care. Community-
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3 based services already play an important role at the end-of-life for patients with
4
5 many different, complex conditions. However, this seldom includes people dying with
6
7 liver disease. Greater involvement of community services would be expected to
8
9 enhance the quality and appropriateness of palliative and terminal care for these
10
11 patients. As the number of deaths from chronic liver disease increases, it may be
12
13 increasingly necessary, in order to limit the burden on hospital teams.
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18 Some of the barriers to GP care for patients with end-stage liver disease may be
19
20 addressed by collaboration and communication between liver specialists and primary
21
22 care. Prompt and equitable access to treatment could be enhanced in a number of
23
24 ways. Specific innovations, such as the development of clear patient pathways,
25
26 specialist hepatology nurses in the community or district nurses trained to deal with
27
28 liver disease complications, all require resources. Specialist treatments such as
29
30 paracentesis could be delivered in locations such as community hospitals or
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32 hospices, where they are available, to reduce disruption to patients' lives.
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35 36 Conclusion

37
38 Our study suggests that end-of-life care for patients with liver disease requires
39
40 attention. Liver disease appears to pose management challenges in end-of-life care
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42 with a combination of complicated social situations and symptoms. Services tailored
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44 for these patients should build on the similarities with other conditions, but also
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46 reflect the differences. The adverse social consequences of illness for these patients
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48 and their families, may be particularly significant. Further research is needed to fully
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50 understand the burden on families and services. As health services seek greater
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52 integration with social care, improving care for patients with end-stage liver disease
53
54 should be a priority.
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Acknowledgements

We are grateful to the participants who generously gave their time to this study.

Ethics Approval

This study involved no patients and was assessed by the Health Research Authority and Newcastle University Research Ethics (Ref 188275).

Authors contribution

BH, EK, MH, JO, and CE designed the study. HS carried out the interviews. HS undertook the main analysis supported by BH and HJ. HS, HJ and BH drafted the manuscript, and all authors commented and approved the final version.

Funding statement

This work was supported by the NIHR School for Primary Care grant number 262.

Competing interests

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

Data sharing agreement

We do not have any additional unpublished data that can be shared.

References

1. World Health Organisation. WHO European health for all database. 2012. <http://data.euro.who.int/> (accessed 22 January 2017).
2. Office National Statistics. Deaths registered in England and Wales: 2015. 2016; (accessed 9th September 2016). <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015> (accessed 22 January 2017).
3. University of Washington. The Liver Imaging Atlas: An Online Reference for Liver Imaging. 2017; 2017(22 January 2017). liveratlas.org (accessed 22 January 2017).
4. Boyd K, Kimbell B, Murray S, et al. Living and dying well with end-stage liver disease: Time for palliative care? *Hepatology* 2012;**55**(6):1650-51.
5. Roth K, Lynn J, Zhong Z, et al. Dying with end stage liver disease with cirrhosis: insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* 2000;**48**(5 Suppl):S122-30.

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- 2
- 3 6. Kimbell B, Murray SA. What is the patient experience in advanced liver disease? A scoping review
- 4 of the literature. *BMJ Supportive & Palliative Care* 2013;**bmjspcare-2012**.
- 5
- 6 7. National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of
- 7 life care in England. 2012. [http://www.endoflifecare-](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease)
- 8 [intelligence.org.uk/resources/publications/deaths_from_liver_disease](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease) (accessed 27
- 9 February 2017).
- 10 8. Kendrick E. Getting it Right Improving End of Life Care for People Living with Liver Disease.
- 11 London: National End of Life Care Programme, 2013.
- 12 9. Poonja Z, Brisebois A, van Zanten SV, et al. Patients with cirrhosis and denied liver transplants
- 13 rarely receive adequate palliative care or appropriate management. *Clin Gastroenterol*
- 14 *Hepatol* 2014;**12**(4):692-98.
- 15 10. Larson AM. Palliative Care for Patients with End-Stage Liver Disease. *Curr Gastroenterol Rep*
- 16 2015;**17**(5):18.
- 17 11. Walling AM, Wenger NS. Palliative care and end-stage liver disease. *Clin Gastroenterol Hepatol*
- 18 2014;**12**(4):699-700.
- 19 12. Potosek J, Curry M, Buss M, et al. Integration of Palliative Care in End-Stage Liver Disease and
- 20 Liver Transplantation. *Journal of Palliative Medicine* 2014;**17**(11):1271-77.
- 21 13. Kimbell B, Boyd K, Kendall M, et al. Managing uncertainty in advanced liver disease: a qualitative,
- 22 multiperspective, serial interview study. *BMJ open* 2015;**5**(11):e009241.
- 23 14. Office of National Statistics. National Survey of Bereaved People (VOICES). 2015. (accessed 27
- 24 February 2016).
- 25 15. Glaser BG, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*.
- 26 Chicago: Aldine Publishing Co, 1967.
- 27 16. Van Manen M. Practicing phenomenological writing. *Phenomenology and Pedagogy* 1984;**2**(1):1-
- 28 34.
- 29 17. Siouta N, Van Beek K, van der Eerden ME, et al. Integrated palliative care in Europe: a qualitative
- 30 systematic literature review of empirically-tested models in cancer and chronic disease. *BMC*
- 31 *Palliative Care* 2016;**15**:56.
- 32 18. Davidson PM, Paull G, Introna K, et al. Integrated, collaborative palliative care in heart failure:
- 33 the St. George Heart Failure Service experience 1999-2002. *J Cardiovasc Nurs* 2004;**19**(1):68-
- 34 75.
- 35 19. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease.
- 36 *Health Qual Life Outcomes* 2007;**5**:17.
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Table 1: Participant characteristics

Characteristic	Number of GPs
Sex	
Male	12
Female	13
Years of experience as GP	
<5 years	5
5-10 years	10
16-25 years	9
>25 years	1
Specialist hepatology/gastroenterology experience or training	
Yes	4
No	21
Size of practice	
<5,000	5
5-10,000	9
10,000-15,000	9
>15,000	2
Geographical area	
North West London	7
Wessex	8
North East and North Cumbria	5
Yorkshire and Humber	1
Thames Valley and South Midlands	4

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HS
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD, MSc, Bsc
3.	Occupation	What was their occupation at the time of the study?	Research Associate in the Institute of Health and Society, Newcastle University
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Conducting interviews and analysing data from patients, clinicians and

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No	Item	Guide questions/description
		family members
	Relationship with participants	
		In some areas authors knew the representatives from the clinical research networks who assisted with recruitment. In other areas there was no relationship. There were no prior relationships with GP participants.
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the	What did the participants know about the researcher? Reasons for

No	Item	Guide questions/description	
	interviewer	<i>e.g. personal goals, reasons for doing the research</i>	doing the research were provided in information sheets sent to participants before the interviews.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	HS is a medical Sociologist with a specialist interest in end of life issues
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis See page 6 of the article

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No	Item	Guide questions/description
Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?

No	Item	Guide questions/description	
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Over the telephone, workplace
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No one was present expect the participants and researchers
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Wide range of clinical experience from GP trainee to >30 years experience Participant characteristics are presented in Table 1
Data collection			

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No	Item	Guide questions/description	
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes, an interview schedule was developed. This was pilot tested with one interviewee See page 5 of the article
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were conducted
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording see page 6 of the article
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes see page 6 of the article

No	Item	Guide questions/description	
21.	Duration	What was the duration of the interviews or focus group?	15-50 minutes
			Yes, data collection was stopped when new themes were no longer emerging from the data. See page 5 of the article
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	3 See page 6 of the article

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No	Item	Guide questions/description	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No, documentation detailing development of themes is available upon request.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data See page 6 of the article
27.	Software	What software, if applicable, was used to manage the data?	NVivo10 See page 6 of the article
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes See pages 7-15 of the article

No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes there is consistency between the data presented and the findings. See pages 7-15 of the article
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, major themes are presented clearly in the article see pages 7-15.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, there are descriptions of diverse and minor themes in the article, see pages 7-15.

BMJ Open

How can primary care enhance end-of-life care for liver disease? A qualitative study of general practitioners' perceptions and experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017106.R1
Article Type:	Research
Date Submitted by the Author:	16-Jun-2017
Complete List of Authors:	Standing, Holly; Newcastle University, Institute of Health & Society Jarvis, Helen; Newcastle University, Institute of Health & Society Orr, James; Newcastle University, Institute of Cellular Medicine Exley, Catherine; Northumbria University, Faculty of Health and Life Sciences Husdon, Mark; Freeman Hospital; Newcastle University, Institute of Cellular Medicine Kaner, Eileen; Newcastle University, Institute of Health and Society Hanratty, Barbara; Newcastle University, Institute of Health and Society / Newcastle University Institute for Ageing
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Gastroenterology and hepatology, Palliative care
Keywords:	PALLIATIVE CARE, liver diseases, terminal care, patient care

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3 **How can primary care enhance end-of-life care for liver disease? A qualitative**
4 **study of general practitioners' perceptions and experiences**
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7 **SUBMISSION TO: BMJ Open**
8

9 **AUTHORS**

10 Holly Standing, Helen Jarvis, James Orr,
11 Catherine Exley, Mark Hudson, Eileen Kaner, Barbara Hanratty
12

13 **Dr Holly C Standing**

14 Institute of Health and Society
15 Newcastle University,
16 Holly.standing@newcastle.ac.uk
17

18 **Dr Helen Jarvis**

19 Institute of Health and Society, Newcastle University, Biomedical Research Building,
20 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
21 Helen.jarvis2@newcastle.ac.uk
22

23 **Dr James Orr**

24 Institute of Cellular Medicine, Newcastle University
25 James.orr@newcastle.ac.uk
26

27 **Professor Catherine Exley**

28 Faculty of Health and Life Sciences,
29 Northumbria University,
30 Newcastle upon Tyne NE1 8ST
31 Catherine.exley@northumbria.ac.uk
32

33 **Dr Mark Hudson**

34 Freeman hospital, High Heaton, Newcastle upon Tyne, NE7 7DN
35 Institute of Cellular Medicine, Newcastle University
36 Mark.Hudson@nuth.nhs.uk
37

38 **Professor Eileen Kaner**

39 Institute of Health and Society, Newcastle University, The Baddiley-Clark Building
40 Richardson Road, Newcastle upon Tyne NE2 4AX
41 Eileen.kaner@newcastle.ac.uk
42

43 **Professor Barbara Hanratty***

44 Institute of Health and Society, Newcastle University, Biomedical Research Building,
45 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
46 Barbara.hanratty@newcastle.ac.uk
47

48 ***Author for correspondence: Barbara Hanratty**
49

50 **Word count 3941** including quotes)
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52 **Key words (MeSH) :** terminal care, palliative care, liver diseases, patient care
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Abstract

Background: Liver disease is the third commonest cause of premature death in the UK. The symptoms of terminal liver disease are often difficult to treat, but very few patients see a palliative care specialist, and a high proportion die in hospital. Primary care has been identified as a setting where knowledge and awareness of liver disease is poor. Little is known about general practitioners' (GPs) perceptions of their role in managing end-stage liver disease.

Objective: To explore GPs' experiences and perceptions of how primary care can enhance end-of-life care for patients with liver disease.

Design: Qualitative interview study, thematic analysis

Participants: Purposive sample of 25 GPs from five regions of England

Results: GPs expressed a desire to be more closely involved in end-of-life care for patients with liver disease, but identified a number of factors that constrained their ability to contribute. These fell into three main areas; those relating directly to the condition, (symptom management and the need to combine a palliative care approach with ongoing medical interventions); issues arising from patients' social circumstances (stigma, social isolation and the social consequences of liver disease); and deficiencies in the organisation and delivery of services. Collaborative working with support from specialist hospital clinicians was regarded as essential, with GPs acknowledging their lack of experience and expertise in this area.

Conclusions: End-of-life care for patients with liver disease merits attention from both primary and secondary care services. Development of care pathways and equitable access to symptom relief should be a priority.

Abstract word count 249**Strength and limitations of this study:**

- To the best of our knowledge this is the first study to focus on the experiences' of primary care clinicians around managing end-of-life liver disease.
- GPs were recruited from a range of both rural and urban UK locations.
- Use of Semi-structured interviews allowed us to collect detailed descriptions of GPs' experiences of managing end-of-life liver disease.
- The study was conducted by a team of experienced researchers with a range of disciplinary backgrounds including clinical experience.
- The findings of our study are based on the reported knowledge and experiences' of self-selecting participants, their views may not be transferable to the wider GP population.

Introduction

End stage liver disease is an important challenge for providers of palliative and end-of-life care. Death rates have increased 400% since 1970, and it is now the third commonest cause of premature death in the UK.^{1, 2, 3} In 2012, around 11,000 deaths were attributed to liver disease in the UK. Patients have a complex and heavy symptom burden that is often poorly treated^{4, 5} and the psychosocial needs of patients and families may be considerable.⁶ The majority of patients present late to services, when liver disease is irreversible and around 70% die in hospital.⁷ The typical clinical course, of gradual decline punctuated by episodic decompensation, may mean that treatment is focused on prolonging life and a palliative care approach is rarely considered.⁸ Transplantation is an option only for selected patients,⁹ with

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3 some evidence suggesting that patients who are considered and rejected for organ
4 transplantation, are unlikely to receive any palliative care.¹⁰ Compared to cancer
5 patients, people with liver disease are less likely to discuss and plan their end of life
6 care.¹¹ Discussing care plans that acknowledge the proximity of death is difficult,
7 particularly when patients are receiving interventionist care. However, it is important,
8 as timely referral to palliative care can be compromised when the focus remains
9 inappropriately on treatment with curative intent.¹²
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21 There is a growing international consensus that end-of-life care for patients with liver
22 disease requires improvement.^{4 11 13 14} Primary care has been identified as a specific
23 area where care could be enhanced, particularly around the discussion of palliative
24 care needs with patients, the inclusion of patients on palliative care registers, and
25 improving communication between primary and secondary care.^{8 15} Primary care
26 professionals are well placed to provide holistic care that patients dying with liver
27 disease need, but are seldom involved. In addition, GP care for patients dying with
28 liver disease is not rated highly by bereaved relatives.^{8,16}
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41 Little is known about how health professionals in primary care see their role in end-
42 stage liver disease, or what they view as the main barriers to providing high quality
43 care. This study intends to contribute to our understanding of this patient group and
44 to inform the development of appropriate services. The aim is to explore GP
45 experiences and perceptions of end-of-life care for patients with liver disease.
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52 **Methods**

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54 This study employed qualitative methods, involving semi-structured interviews with
55 GPs from five geographical areas within England.
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Participants

Participants were recruited via National Institute for Health Research Clinical Research Networks and local networks of GP practices in the London, Thames Valley, Wessex, Yorkshire and the North East. Email invitations were sent to GP practices within these networks, and GPs who wished to participate then contacted the research team. Following the first phase of interviews, participants were purposively sampled in order to provide a wide range of clinical experience and degree of familiarity with liver disease. To do this, we expanded the study to include two additional geographical sites and worked with co-ordinators at the Clinical Research Networks to target practices in a variety of rural and urban locations, as well as areas of high and low prevalence of liver disease and substance misuse.

Data collection

A semi-structured interview guide was developed to cover issues identified through a review of the literature; including GPs' experiences of identifying and managing end-of-life liver disease. This was a 'living' document that evolved throughout data collection to allow exploration of emerging areas. Interviews were conducted face-to-face (n=2) or over the telephone (n=23). Interviews lasted between 15 and 50 minutes and were all conducted by the first author between March and August 2016. Field notes were taken to aid subsequent analysis. Informed consent was obtained from all participants. Data collection ceased when no themes were emerging from the interviews (see below for further detail).

Data analysis

Audio recordings of interviews were transcribed verbatim by an independent transcription company; transcripts were checked for accuracy by listening again to each recording. The NVivo 10 software package was used to manage the data.

Data collection and analysis ran concurrently throughout the study. Analysis of early transcripts informed the interview schedule for later interviews and each transcript was re-examined in light of subsequent interviews. A thematic analysis was conducted.¹⁷ The first stage involved researchers familiarising themselves with the data through detailed reading of the transcripts followed by line-by-line coding.¹⁸ Field notes taken during data collection were used throughout analysis to enhance the reflective process. Several quality control measures were employed to ensure trustworthiness of the data. A proportion of the transcripts (20%) were coded independently by three researchers, before coming together to compare their analysis. Data analysis and emerging themes were also discussed amongst the wider research team, which included individuals with clinical expertise in general practice and hepatology.

Findings

Twenty five GPs were interviewed. The majority had been qualified as GPs for five or more years, but few (4/25) had any specialist hepatology or gastroenterology training or experience. Participant characteristics are shown in table 1.

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7 Four themes were identified from the data analysis: the role of the GP,
8 acknowledging and accepting end-of-life, collaborative care pathways, and social
9 relationships and consequences. The quotations presented below are illustrative,
10 representing typical participant responses and demonstrating the varied viewpoints.
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19 **The role of the GP**

20 In this study, few of the interviewees had extensive first-hand experience of
21 managing patients with liver disease at the end-of-life. Those who did, reported that
22 they managed such cases infrequently, and some years may go by without them
23 seeing a case.
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32 *“[We manage] a lot of dying people, but not from the hepatology*
33 *point of view. I don’t know if they tend to be managed in hospital*
34 *predominantly more than in primary care? That’s a possibility, I*
35 *guess.” (GP 7)*
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44 Some of the interviewees attributed their lack of expertise and experience of caring
45 for liver patients at the end-of-life to a reluctance amongst hospital clinicians to
46 relinquish control.
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52 *“There are some conditions, like liver disease, renal failure, they*
53 *[patients] all just end up dying in hospital for some reason. I don’t*
54 *know whether it’s the hospital consultants that don’t want to let them*
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3 *go home... They need to let go and make sure there's a palliative*
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5 *care plan in place...they don't do it." (GP 3)*
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10 The limited contact between GPs and patients dying with liver disease was attributed
11 to an unpredictable disease trajectory with periods of stability and decompensation,
12 and to patients remaining under the care of hospital services in their last weeks and
13 months. The GPs in this study shared a view that end-of-life care is a core
14 component of primary care, and interviewees questioned how appropriate it was for
15 specialist hospital clinicians to take a lead in palliative care. Patients with liver
16 disease were not regarded as distinct or different from patients dying with other
17 conditions, and a number of GPs expressed a desire for greater involvement in their
18 end-of-life care. Some participants implied that primary care involvement may
19 support more patients to die at home, rather than in hospital.
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34 *"I think primary care probably is best placed, in most cases, to look*
35 *after people- well not only for that [liver disease], for most end-of-life*
36 *care issues. So, yeah, I think the GP is probably the most important*
37 *person in the sense that they can bear in mind what the specialists*
38 *have advised, but at the end of the day, try and keep some of these*
39 *patients at home rather than having to have them admitted acutely."*
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51 **Acknowledging and accepting end-of-life**

52 Judging when a patient with liver disease is nearing the end-of-life was perceived to
53 be a particular challenge. Communication about prognosis and the age of patients
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3 were identified as important factors. Some of the GPs reflected on how
4 management decisions taken in hospital send out messages that influence care
5 provided in the community. Continuing to pursue active treatment may convey
6 optimism about the patient's life expectancy. Specifically, GPs referenced occasions
7 where patients had been placed on the waiting list for a liver transplant, which the
8 patient saw as offering them a second chance at life, even though they were critically
9 unwell and may die whilst waiting for an organ. Patients with end stage liver disease
10 are often younger than the typical palliative care patient.¹⁹ It may be that clinicians
11 are more reluctant to give up on active treatment for younger patients,²⁰ whilst
12 patients and families may also struggle to accept that the end-of-life is approaching.
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“Those patients where it's a, kind of, grey area about whether they're end-of-life or not. And I think that mainly stems from the fact that if it's a young patient, it's more difficult for health care professionals, the patients themselves, and families, to actually accept that the person's dying” (GP1)

Mixed or uncertain messages may mean that care is compromised, if no one engages the patient in discussions about the end-of-life, and a palliative approach is never considered.

“I suppose, looking back it really was palliative care but they [secondary care] put him on the transplant list because he's given up alcohol and there was still this hope. So therefore we didn't really

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3 *realise he was going to die as quickly as he did” (GP 11)*
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7 There was a shared feeling amongst interviewees, that specialists should provide
8 clear messages about patients’ prognoses, so that GPs can adopt an appropriate
9 management plan. At present, hospital specialists were perceived as failing to take
10 responsibility for identifying patients as end-of-life, and this had a detrimental impact
11 on primary care.
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21 *“I feel that it should be made compulsory for the secondary care,*
22 *tertiary care sectors, when they discharge, or when they’re seen in*
23 *the patient clinic, [to] prognosticate, ... then we can initiate also, the*
24 *discussion with the patient, in a much more positive way.” (GP 12)*
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32 **Collaborative care pathways**

33 Supporting patients with liver disease was seen as a collaborative effort, with GPs
34 acknowledging their need for specialist guidance, particularly when managing end-
35 of-life complications. A small number of respondents mentioned hepatic
36 encephalopathy as a challenge in the management of end-of-life liver patients, and a
37 potential source of distress for relatives. The interviewees suggested that they
38 would benefit from further training to deal with this complication. Ascites was the
39 most commonly mentioned symptom experienced by patients with end-stage liver
40 disease, requiring drainage in hospital. Experiences of GPs in this study suggest that
41 ease of access to this procedure was highly variable. In some areas, pathways had
42 been negotiated and patients could be directly admitted to an appropriate ward. In
43 others, GPs described their concern at having to send patients to accident and
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3 emergency (A&E) departments. Failure to arrange prompt access to treatment
4
5 caused distress and was a major source of adverse experiences during end-of-life
6
7 care.
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10
11 *“We had a nightmare. He was building up litres of ascitic fluid on his*
12 *tummy every week or week to 10 days, and every time the hospital*
13 *had to send him acutely, new, to A&E and he had to sit in A&E for*
14 *hours. I was speaking to the liver specialist ... He needed regular*
15 *reviews and eventually they agreed to do it two weekly but even that*
16 *wasn't enough, it was building up and he was ending up going in as*
17 *an emergency every week.” (GP 11)*
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28 Where appropriate care pathways were not in place, interviewees suggested that
29 they were needed, to reassure the patient and GPs that support is available when
30 required.
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33
34 A number of participants suggested that a specialist nurse may hold the key to more
35 collaborative management of liver patients. They could act as an intermediary
36 between primary and secondary care, negotiating priorities and ensuring effective
37 and easy communication.
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46 *“It often helps when there is direct access to, say, a nurse specialist*
47 *in a field, or there is some other point of contact in secondary care*
48 *that say a family or the patient themselves can call directly for*
49 *advice.” (GP 14)*
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55 Although some GPs had encountered specialist nurses working in this type of role,
56 this was not a common experience. Unfavourable comparisons were made between
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3 the services available for patients with liver disease, and other conditions, such as
4
5 cancer. Participants highlighted the potential benefit to patients and families, of
6
7 having a specialist point of contact in the community, including prompt access to
8
9 advice and alleviation of fears and concerns.
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11 12 13 14 15 16 **Social relationships and consequences**

17
18 GPs in this study argued that people with liver disease had many of the same
19
20 primary care needs as patients with other life-limiting conditions. However, the
21
22 severity of symptoms in end-of-life liver disease was felt to be different. Some of the
23
24 GPs acknowledged the potentially damaging impact on the patient's family, of seeing
25
26 their relative die at home.
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31 *"I think there is quite a strong push to keep people at home. Whether*
32
33 *that's right or wrong, I don't know really. If they've got ascites or*
34
35 *portal hypertension, you know, they've got the risk of vomiting blood*
36
37 *and all the rest of it. Or they have been vomiting blood. I'm not*
38
39 *massively keen on keeping people at home because it's just a*
40
41 *rubbish picture in the mind of everybody, I think, you know, the family*
42
43 *left behind."* (GP 17)
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49 Families were perceived to be in need of support themselves, which was an
50
51 additional role for primary care. GPs described examples of relatives requiring
52
53 frequent contact and reassurance as the patient's condition deteriorated. The GPs in
54
55 this study differed in their attitudes towards these demands. Some took a holistic
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3 view to the management of palliative patients, believing that these were part of the
4
5 standard practice of primary care.
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10 *“I think when we talk about palliative care it’s not just a single person*
11 *who’s the patient, it’s about supporting and managing the family and*
12 *helping them through that bereavement stage because it starts right*
13 *at the diagnosis and they have to go through that journey. Death is a*
14 *part of life and giving them that support.”* (GP 10)
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21 However, others felt that attending to the needs of patients’ families was an extra
22
23 burden on their already overstretched resources.
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29 Limited social support and unfavourable social circumstances were often mentioned
30
31 as significant issues for patients with liver disease, particularly when alcohol or drug
32
33 misuse were factors. Several GPs referred to the ‘chaotic’ lifestyles of this patient
34
35 group, and resulting vulnerability to social isolation. Behaviours associated with
36
37 addiction were perceived to lead to the breakdown of the patients’ social networks,
38
39 leaving few, if any people to provide support or care.
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44 *“the demographics of the alcohol dependent ones, who have often,*
45 *for various reasons and due to the nature of their disease, have*
46 *become quite isolated, they have not got many people around them*
47 *and so they don’t have that support. They require much more*
48 *organisation and support in the background, so we make sure that*
49 *they do have that support.”* (GP 10)
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3 Without alternative sources of support, socially isolated patients were believed to
4 place extra demands on GPs and other health services. Even when social networks
5 were maintained, there could be a dearth of responsible caregivers, as friends and
6 family often shared the problems of addiction and poor health.
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16 *“I can think of a couple of our households where maybe spouses and*
17 *partners may have liver cirrhosis themselves. I can think of two*
18 *couples – well, one person who died two years ago. His wife has*
19 *chronic liver disease as well.” (GP 4)*
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28 One of the most important consequences of social isolation, was that patients had
29 fewer choices over where they spent the end of their life. Without anyone to monitor
30 their condition, they were more likely to be admitted to hospital, and die there.
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35 Liver disease is a potentially stigmatising condition, particularly when the underlying
36 cause is alcohol or substance misuse. Several of the GPs suggested that there is
37 often an assumption within the patient’s community that liver disease is self-induced
38 and they were culpable, even when substance misuse or alcohol are not factors.
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48 *“I think it’s a huge problem for people that have liver disease and*
49 *look like they have liver disease and people assume it’s related to*
50 *alcohol when, in fact, it might be due to auto-immune causes or other*
51 *forms of cancer or something like that or hepatitis as well.” (GP 23)*
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6 This assumed culpability has implications for the degree of support and sympathy
7
8 that the patient, and their families, receive. GPs also suggested that stigma could
9
10 hinder patients' acceptance of their prognosis, which in turn made the management
11
12 of their condition more challenging. As such, care of liver patients should include
13
14 psychological and social services.
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17
18 *"I think, inevitably and sadly, there is a stigma associated with liver*
19
20 *disease, and hence, that's why the psychological support is really*
21
22 *important"* (GP 25)
23

24
25 However, some commented that stigmatisation occurred early in the patients'
26
27 illnesses, and to address this, changes would be needed well before end-of-life care
28
29 was being considered.
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32 **Discussion**

33
34 This study provides insights into the challenge faced by general practitioners
35
36 providing end-of-life care for patients with chronic liver disease. Many GPs
37
38 expressed a desire to be more closely involved, but identified a number of factors
39
40 that constrained their ability to contribute. These fell into three main areas; those
41
42 relating directly to the condition, (symptom management and the need to combine a
43
44 palliative care approach with ongoing medical interventions); issues arising from
45
46 patients' social circumstances (stigma, social isolation and the social consequences
47
48 of liver disease); and deficiencies in the organisation and delivery of services.
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52 Collaborative working with support from specialist hospital clinicians was regarded
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54 as essential, with GPs acknowledging their lack of experience and expertise in this
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56 area.
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5 A majority of interviewees had little direct experience of patients dying of liver
6
7 disease and as a consequence, they may not have been familiar with all the
8
9 management challenges of end stage liver disease. For example, hepatic
10
11 encephalopathy is a common concern in the care of end stage liver patients, yet few
12
13 of the interviewees discussed it. This is not surprising, as primary care clinicians
14
15 would seldom have responsibility for managing hepatic encephalopathy, if they are
16
17 not dealing day to day with end-of-life care for liver disease patients.
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21 22 23 Strengths and limitations

24
25 To our knowledge this is the first study to focus on the experiences of primary care
26
27 physicians in managing patients with end-stage liver disease. Our interviewees were
28
29 drawn from rural and urban areas in five different regions in England, and working
30
31 with a diverse range of communities. The relatively large number of GP participants
32
33 and varying levels of experience, expertise and interest in the subject, is a particular
34
35 strength of the study. With our qualitative design, we were not seeking
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37 generalisability, but the diversity of the participants increases our confidence that we
38
39 have not overlooked important issues.
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46 The majority of interviews were conducted by telephone, which may explain the ease
47
48 and speed with which we recruited participants, despite not offering any financial
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50 incentives. Use of the telephone is thought to have promoted unguarded responses,
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52 but we acknowledge that it can be more difficult to develop rapport in the absence of
53
54 nonverbal cues and other facets of face to face communication. However, we do not
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2
3 believe that this was a problem, as GPs provided rich and insightful accounts of their
4
5 experiences.
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8 9 Comparison with other work

10 Our findings are consistent with recent research from Scotland that included
11
12 interviews with eight GPs along with other health care professionals. Communication
13
14 with secondary care, lack of expertise and limited confidence in prognostication were
15
16 all identified as concerns.¹⁵ Accurate assessment of prognosis in liver disease is
17
18 difficult given the unpredictable disease course. In some aspects this is similar to
19
20 other diseases characterised by episodes of decompensation, such as heart failure.
21
22 However, liver disease presents the additional challenge that recompensation and
23
24 improved liver function may be achieved in certain patients, such as those who
25
26 achieve abstinence from alcohol. A recent review of palliative care guidelines in
27
28 heart failure and chronic obstructive pulmonary disease described wide variation in
29
30 how patients are identified for palliative care, and attributed this, in part, to the
31
32 unpredictable disease course and the consequences for care planning.²² In common
33
34 with liver disease, acknowledgement and development of end-of-life care has been
35
36 relatively recent for these conditions.²²
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45 The GPs in our study agreed that, at the end-of-life, patients with liver disease ideally
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47 need primary care and hospital specialists to work closely together. GPs are more
48
49 likely to have an established relationship with the patient and a greater
50
51 understanding of their social situation and needs, whereas specialists offer expert
52
53 knowledge on liver disease and treatment options. They highlighted the importance
54
55 that primary care physicians place on being able to provide a coordinating role, but
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3 only when supported by members of the specialist teams. Managing complex and
4
5 unusual symptoms, or judging when to introduce a palliative care approach, for
6
7 example, all benefit from collaboration. The advantages of a multidisciplinary
8
9 approach have already been well documented in the palliative care literature.^{23 24}
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11 Several recent reviews on end-stage liver disease have also advocated this
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13 approach.^{4 5 14}
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19 This study highlights the complexity of caring for patients with end-stage liver
20
21 disease. Expertise in acute medicine and palliative care are essential, but patients
22
23 and families also need sensitive and practical responses to their psycho-emotional
24
25 and social concerns, including stigma related to the perceived self-inflictedness of
26
27 the disease, social isolation and lack of income. Such generalist expertise and a
28
29 holistic, person-centred approach are the foundations of primary care. Community-
30
31 based services already play an important role at the end-of-life for patients with
32
33 many different, complex conditions. However, this seldom includes people dying with
34
35 liver disease. Greater involvement of community services would be expected to
36
37 enhance the quality and appropriateness of palliative and terminal care for these
38
39 patients. As the number of deaths from chronic liver disease increases, it may be
40
41 increasingly necessary, in order to limit the burden on hospital teams. Innovations,
42
43 such as the development of clear patient pathways, specialist hepatology nurses in
44
45 the community or district nurses trained to deal with liver disease complications, all
46
47 require resources. Specialist treatments such as paracentesis could be delivered in
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49 locations such as community hospitals or hospices, where they are available, to
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51 reduce disruption to patients' lives.
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56 (Box 1 here)
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5 In recent years, UK health policy has increasingly promoted patient choice; an ability
6
7 to deliver end of life care in the patient's preferred location and facilitate choice in
8
9 place of death are used as markers of care quality, with death at home often an
10
11 implicit goal of palliative care.^{25 26} GPs in this study expressed some scepticism that
12
13 home death is always the best option for patients with liver disease, or their families.
14
15 Concerns centred around the nature of the symptoms and clinical input needed to
16
17 manage them, which were potentially distressing for families to observe. Balancing
18
19 the wishes of patients, families and clinical carers is a fundamental part of end of life
20
21 care. More in depth enquiry to elicit patient, family and professional views and
22
23 experiences of place of death in liver disease would help to clarify the resources
24
25 required to ensure death at home is acceptable and achievable.
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31 Conclusion

32
33 Our study suggests that end-of-life care for patients with liver disease requires
34
35 attention. Liver disease appears to pose management challenges in end-of-life care
36
37 with a combination of complicated social situations and symptoms. Services tailored
38
39 for these patients should build on the similarities with other conditions, but also
40
41 reflect the differences. The adverse social consequences of illness for these patients
42
43 and their families, may be particularly significant. Further research is needed to fully
44
45 understand the burden on families and services. As health services seek greater
46
47 integration with social care, improving care for patients with end-stage liver disease
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49 should be a priority.
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Acknowledgements

We are grateful to the participants who generously gave their time to this study.

Ethics Approval

This study involved no patients and was assessed by the Health Research Authority and Newcastle University Research Ethics (Ref 188275).

Authors contribution

BH, EK, MH, JO, and CE designed the study. HS carried out the interviews. HS undertook the main analysis supported by BH and HJ. HS, HJ and BH drafted the manuscript, and all authors commented and approved the final version.

Funding statement

This work was supported by the NIHR School for Primary Care grant number 262.

Competing interests

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

Data sharing agreement

We do not have any additional unpublished data that can be shared.

References

1. World Health Organisation. WHO European health for all database. 2012. <http://data.euro.who.int/> (accessed 22 January 2017).
2. Office for National Statistics. Deaths registered in England and Wales: 2015. 2016; (9th September 2016). <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015> (accessed 22 January 2017).
3. University of Washington. The Liver Imaging Atlas: An Online Reference for Liver Imaging. 2017; 2017(22 January 2017). liveratlas.org (accessed 22 January 2017).
4. Boyd K, Kimbell B, Murray S, et al. Living and dying well with end-stage liver disease: Time for palliative care? *Hepatology* 2012;55(6):1650-51. doi: 10.1002/hep.25621
5. Roth K, Lynn J, Zhong Z, et al. Dying with end stage liver disease with cirrhosis: insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Journal of the American Geriatrics Society* 2000;48(5 Suppl):S122-30.
6. Kimbell B, Murray SA. What is the patient experience in advanced liver disease? A scoping review of the literature. *BMJ Supportive & Palliative Care* 2013;bmjpspcare-2012 doi: 10.1136/bmjpspcare-2012-000435

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3 7. National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of
4 life care in England. 2012. [http://www.endoflifecare-](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease)
5 [intelligence.org.uk/resources/publications/deaths_from_liver_disease](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease) (accessed 27
6 February 2017).
- 7
8 8. Kendrick E. Getting it Right Improving End of Life Care for People Living with Liver Disease.
9 London: National End of Life Care Programme, 2013.
- 10 9. European Association for the Study of the Liver. EASL clinical practice guidelines: liver
11 transplantation. *Journal of Hepatology* 2016;64(2):433-85.
- 12 10. Poonja Z, Brisebois A, van Zanten SV, et al. Patients with cirrhosis and denied liver transplants
13 rarely receive adequate palliative care or appropriate management. *Clinical*
14 *Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American*
15 *Gastroenterological Association* 2014;12(4):692-98. doi: 10.1016/j.cgh.2013.08.027
- 16 11. Potosek J, Curry M, Buss M, et al. Integration of Palliative Care in End-Stage Liver Disease and
17 Liver Transplantation. *Journal of Palliative Medicine* 2014;17(11):1271-77.
- 18 12. Gott M IC, Gardiner C, Richards N, Cobb M, Ryan A, Noble B, Bennett M, Seymour J, Ward S,
19 Parker C. Transitions to palliative care for older people in acute hospitals: a mixed-methods
20 study. *Health Services and Delivery Research* 2013;1(11)
- 21 13. Larson AM. Palliative Care for Patients with End-Stage Liver Disease. *Current Gastroenterology*
22 *Reports* 2015;17(5):18. doi: 10.1007/s11894-015-0440-6
- 23 14. Walling AM, Wenger NS. Palliative care and end-stage liver disease. *Clinical Gastroenterology*
24 *and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological*
25 *Association* 2014;12(4):699-700. doi: 10.1016/j.cgh.2013.11.010
- 26 15. Kimbell B, Boyd K, Kendall M, et al. Managing uncertainty in advanced liver disease: a qualitative,
27 multiperspective, serial interview study. *BMJ open* 2015;5(11):e009241. doi:
28 10.1136/bmjopen-2015-009241
- 29 16. Office for National Statistics. National Survey of Bereaved People (VOICES). 2015. (accessed 27
30 February 2016).
- 31 17. Braun V, Clarke, V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
32 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
- 33 18. Ritche J, Lewis J. Qualitative Research Practise: A Guide for Social Science Students and
34 Researchers. London: SAGE Publications 2003.
- 35 19. Office for National Statistics. Deaths registered in England and Wales (Series DR): 2015. 2016.
36 (accessed 31 May 2017).
- 37 20. Department of Health. The impact of patient age on clinical decision-making in oncology. 2012.
- 38 21. Thompson GN, Chochinov, H.M., Wilson, K. G., McPherson, C. J., Chary, S., O'Shea, F. M., Kuhl, D.
39 R., Fainsinger, R. L., Gagnon, P.R., Macmillan, K. A. Prognostic Acceptance and the Well-Being
40 of Patients Receiving Palliative Care for Cancer. *Journal of Clinical Oncology*
41 2009;27(34):5757-62.
- 42 22. Siouta N, Van Beek K, van der Eerden ME, et al. Integrated palliative care in Europe: a qualitative
43 systematic literature review of empirically-tested models in cancer and chronic disease. *BMC*
44 *Palliative Care* 2016;15:56. doi: 10.1186/s12904-016-0130-7
- 45 23. Davidson PM, Paull G, Introna K, et al. Integrated, collaborative palliative care in heart failure:
46 the St. George Heart Failure Service experience 1999-2002. *The Journal of Cardiovascular*
47 *Nursing* 2004;19(1):68-75.
- 48 24. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease.
49 *Health and Quality of Life Outcomes* 2007;5:17. doi: 10.1186/1477-7525-5-17
- 50 25. Department of Health. End of Life Care Strategy. 2008.
51 [https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-](https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life)
52 [high-quality-care-for-adults-at-the-end-of-their-life](https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life) (accessed 13th June 2017).
- 53 26. National Institute for Health and Care Excellence. NICE Quality Standards on End of Life Care.
54 2011. <https://www.nice.org.uk/guidance/qs13> (accessed 13th June 2017).
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Table 1: Participant characteristics

Characteristic	Number of GPs
Sex	
Male	12
Female	13
Years of experience as GP	
<5 years	5
5-10 years	10
16-25 years	9
>25 years	1
Specialist hepatology/gastroenterology experience or training	
Yes	4
No	21
Size of practice	
<5,000	5
5-10,000	9
10,000-15,000	9
>15,000	2
Geographical area	
North West London	7
Wessex	8
North East and North Cumbria	5
Yorkshire and Humber	1
Thames Valley and South Midlands	4

Box 1**Next steps in primary end of life care for liver disease: GP perceptions of areas for development**

- Education and training in symptom management for end stage liver disease
- Collaborative care pathways between primary care and hepatologists
- Service delivery that takes into account patient and family social circumstances and stigma
- Provision of support for family caregivers
- Consideration / research into the role of home death

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For peer review only

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HS
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD, MSc, Bsc
3.	Occupation	What was their occupation at the time of the study?	Research Associate in the Institute of Health and Society, Newcastle University
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Conducting interviews and analysing data from patients, clinicians and

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No	Item	Guide questions/description
		family members
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? In some areas authors knew the representatives from the clinical research networks who assisted with recruitment. In other areas there was no relationship. There were no prior relationships with GP participants.
7.	Participant knowledge of the	What did the participants know about the researcher? Reasons for

No	Item	Guide questions/description	
	interviewer	<i>e.g. personal goals, reasons for doing the research</i>	doing the research were provided in information sheets sent to participants before the interviews.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	HS is a medical Sociologist with a specialist interest in end of life issues
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis See page 6 of the article

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No	Item	Guide questions/description
Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?

No	Item	Guide questions/description	
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Over the telephone, workplace
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No one was present expect the participants and researchers
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Wide range of clinical experience from GP trainee to >30 years experience Participant characteristics are presented in Table 1
Data collection			

No	Item	Guide questions/description	
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes, an interview schedule was developed. This was pilot tested with one interviewee See page 5 of the article
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were conducted
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording see page 6 of the article
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes see page 6 of the article

No	Item	Guide questions/description	
21.	Duration	What was the duration of the interviews or focus group?	15-50 minutes
			Yes, data collection was stopped when new themes were no longer emerging from the data. See page 5 of the article
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	3 See page 6 of the article

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No	Item	Guide questions/description	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No, documentation detailing development of themes is available upon request.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data See page 6 of the article
27.	Software	What software, if applicable, was used to manage the data?	NVivo10 See page 6 of the article
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes See pages 7-15 of the article

No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes there is consistency between the data presented and the findings. See pages 7-15 of the article
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, major themes are presented clearly in the article see pages 7-15.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, there are descriptions of diverse and minor themes in the article, see pages 7-15.

BMJ Open

How can primary care enhance end-of-life care for liver disease? A qualitative study of general practitioners' perceptions and experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017106.R2
Article Type:	Research
Date Submitted by the Author:	13-Jul-2017
Complete List of Authors:	Standing, Holly; Newcastle University, Institute of Health & Society Jarvis, Helen; Newcastle University, Institute of Health & Society Orr, James; Newcastle University, Institute of Cellular Medicine Exley, Catherine; Northumbria University, Faculty of Health and Life Sciences Husdon, Mark; Freeman Hospital; Newcastle University, Institute of Cellular Medicine Kaner, Eileen; Newcastle University, Institute of Health and Society Hanratty, Barbara; Newcastle University, Institute of Health and Society / Newcastle University Institute for Ageing
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Gastroenterology and hepatology, Palliative care
Keywords:	PALLIATIVE CARE, liver diseases, terminal care, patient care

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4 **study of general practitioners' perceptions and experiences**
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7 **SUBMISSION TO: BMJ Open**
8

9 **AUTHORS**

10 Holly Standing, Helen Jarvis, James Orr,
11 Catherine Exley, Mark Hudson, Eileen Kaner, Barbara Hanratty
12

13 **Dr Holly C Standing**

14 Institute of Health and Society
15 Newcastle University,
16 Holly.standing@newcastle.ac.uk
17

18 **Dr Helen Jarvis**

19 Institute of Health and Society, Newcastle University, Biomedical Research Building,
20 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
21 Helen.jarvis2@newcastle.ac.uk
22
23

24 **Dr James Orr**

25 Institute of Cellular Medicine, Newcastle University
26 James.orr@newcastle.ac.uk
27
28

29 **Professor Catherine Exley**

30 Faculty of Health and Life Sciences,
31 Northumbria University,
32 Newcastle upon Tyne NE1 8ST
33 Catherine.exley@northumbria.ac.uk
34
35

36 **Dr Mark Hudson**

37 Freeman hospital, High Heaton, Newcastle upon Tyne, NE7 7DN
38 Institute of Cellular Medicine, Newcastle University
39 Mark.Hudson@nuth.nhs.uk
40
41

42 **Professor Eileen Kaner**

43 Institute of Health and Society, Newcastle University, The Baddiley-Clark Building
44 Richardson Road, Newcastle upon Tyne NE2 4AX
45 Eileen.kaner@newcastle.ac.uk
46

47 **Professor Barbara Hanratty***

48 Institute of Health and Society, Newcastle University, Biomedical Research Building,
49 Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL
50 Barbara.hanratty@newcastle.ac.uk
51

52 ***Author for correspondence: Barbara Hanratty**
53
54

55 **Word count 4091** including quotes)

56 **Key words (MeSH) :** terminal care, palliative care, liver diseases, patient care
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Abstract

Background: Liver disease is the third commonest cause of premature death in the UK. The symptoms of terminal liver disease are often difficult to treat, but very few patients see a palliative care specialist, and a high proportion die in hospital. Primary care has been identified as a setting where knowledge and awareness of liver disease is poor. Little is known about general practitioners' (GPs) perceptions of their role in managing end-stage liver disease.

Objective: To explore GPs' experiences and perceptions of how primary care can enhance end-of-life care for patients with liver disease.

Design: Qualitative interview study, thematic analysis

Participants: Purposive sample of 25 GPs from five regions of England

Results: GPs expressed a desire to be more closely involved in end-of-life care for patients with liver disease, but identified a number of factors that constrained their ability to contribute. These fell into three main areas; those relating directly to the condition, (symptom management and the need to combine a palliative care approach with ongoing medical interventions); issues arising from patients' social circumstances (stigma, social isolation and the social consequences of liver disease); and deficiencies in the organisation and delivery of services. Collaborative working with support from specialist hospital clinicians was regarded as essential, with GPs acknowledging their lack of experience and expertise in this area.

Conclusions: End-of-life care for patients with liver disease merits attention from both primary and secondary care services. Development of care pathways and equitable access to symptom relief should be a priority.

Abstract word count 249**Strength and limitations of this study:**

- To the best of our knowledge this is the first study to focus on the experiences' of primary care clinicians around managing end-of-life liver disease.
- GPs were recruited from a range of both rural and urban UK locations.
- Use of Semi-structured interviews allowed us to collect detailed descriptions of GPs' experiences of managing end-of-life liver disease.
- The study was conducted by a team of experienced researchers with a range of disciplinary backgrounds including clinical experience.
- The findings of our study are based on the reported knowledge and experiences' of self-selecting participants, their views may not be transferable to the wider GP population.

Introduction

End stage liver disease is an important challenge for providers of palliative and end-of-life care. Death rates have increased 400% since 1970, and it is now the third commonest cause of premature death in the UK.^{1, 2, 3} In 2012, around 11,000 deaths were attributed to liver disease in the UK. Patients have a complex and heavy symptom burden that is often poorly treated^{4, 5} and the psychosocial needs of patients and families may be considerable.⁶ The majority of patients present late to services, when liver disease is irreversible and around 70% die in hospital.⁷ The typical clinical course, of gradual decline punctuated by episodic decompensation, may mean that treatment is focused on prolonging life and a palliative care approach is rarely considered.⁸ Transplantation is an option only for selected patients,⁹ with

1
2
3 some evidence suggesting that patients who are considered and rejected for organ
4 transplantation, are unlikely to receive any palliative care.¹⁰ Research suggests that
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6
7 people with liver disease are less likely to be involved in end of life discussions and
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9
10 planning than cancer patients, though data are limited .¹¹ Discussing care plans that
11
12 acknowledge the proximity of death is difficult, particularly when patients are
13
14 receiving interventionist care. However, it is important, as timely referral to palliative
15
16 care can be compromised when the focus remains inappropriately on treatment with
17
18 curative intent.¹²
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22
23 There is a growing international consensus that end-of-life care for patients with liver
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25 disease requires improvement.^{4 11 13 14} Primary care has been identified as a specific
26
27 area where care could be enhanced, particularly around the discussion of palliative
28
29 care needs with patients, the inclusion of patients on palliative care registers, and
30
31 improving communication between primary and secondary care.^{8 15} Primary care
32
33 professionals are well placed to provide holistic care that patients dying with liver
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35 disease need, but are seldom involved. In addition, GP care for patients dying with
36
37 liver disease is not rated highly by bereaved relatives.^{8,16}
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43 Little is known about how health professionals in primary care see their role in end-
44
45 stage liver disease, or what they view as the main barriers to providing high quality
46
47 care. This study intends to contribute to our understanding of this patient group and
48
49 to inform the development of appropriate services. The aim is to explore GP
50
51 experiences and perceptions of end-of-life care for patients with liver disease.
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Methods

This study employed qualitative methods, involving semi-structured interviews with GPs from five geographical areas within England.

Participants

A heterogeneous purposive sampling approach was employed to ensure that a variety of perspectives and experiences of management of liver disease were sampled e.g. previous management of an end of life liver patient, views on whether management should be primary care or secondary care led, as well as a range of practice sizes and localities. Participants were recruited via National Institute for Health Research Clinical Research Networks (CRN) and local networks of GP practices in London, Thames Valley, Wessex, Yorkshire and the North East of England. Sampling began with one CRN and was expanded during the course of the study to include four additional areas. Co-ordinators at the CRNs were utilised to target practices in a variety of rural and urban locations, as well as areas of high and low prevalence of liver disease and substance misuse. Email invitations were sent to GP practices within these networks, and GPs who wished to participate then contacted the research team..

Data collection

A semi-structured interview guide was developed to cover issues identified through a review of the literature; including GPs' experiences of identifying and managing end-of-life liver disease. This was a 'living' document that evolved throughout data collection to allow exploration of emerging areas. Interviews were conducted face-to-face (n=2) or over the telephone (n=23). Interviews lasted between 15 and 50

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2
3 minutes and were all conducted by the first author between March and August 2016.
4
5 Field notes were taken to aid subsequent analysis. Informed consent was obtained
6
7 from all participants. Data collection ceased when no themes were emerging from
8
9 the interviews (see below for further detail).
10

11 12 13 14 *Data analysis*

15
16 Audio recordings of interviews were transcribed verbatim by an independent
17
18 transcription company; transcripts were checked for accuracy by listening again to
19
20 each recording. The NVivo 10 software package was used to manage the data.
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24
25 Data collection and analysis ran concurrently throughout the study. Analysis of early
26
27 transcripts informed the interview schedule for later interviews and each transcript
28
29 was re-examined in light of subsequent interviews. A thematic analysis was
30
31 conducted.¹⁷ The first stage involved researchers familiarising themselves with the
32
33 data through detailed reading of the transcripts followed by line-by-line coding.¹⁸
34
35 Field notes taken during data collection were used throughout analysis to enhance
36
37 the reflective process. Several quality control measures were employed to ensure
38
39 trustworthiness of the data. A proportion of the transcripts (20%) were coded
40
41 independently by three researchers, before coming together to compare their
42
43 analysis. Data analysis and emerging themes were also discussed amongst the
44
45 wider research team, which included individuals with clinical expertise in general
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47 practice and hepatology.
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55 **Findings**

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3 Twenty five GPs were interviewed. The majority had been qualified as GPs for five or
4
5 more years, but few (4/25) had any specialist hepatology or gastroenterology training
6
7 or experience. Participant characteristics are shown in table 1.
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9

10
11 Table 1 here
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14
15
16 Four themes were identified from the data analysis: the role of the GP,
17
18 acknowledging and accepting end-of-life, collaborative care pathways, and social
19
20 relationships and consequences. The quotations presented below are illustrative,
21
22 representing typical participant responses and demonstrating the varied viewpoints.
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28 **The role of the GP**

29
30 In this study, few of the interviewees had extensive first-hand experience of
31
32 managing patients with liver disease at the end-of-life. Those who did, reported that
33
34 they managed such cases infrequently, and some years may go by without them
35
36 seeing a case.
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41

42 *"[We manage] a lot of dying people, but not from the hepatology*
43
44 *point of view. I don't know if they tend to be managed in hospital*
45
46 *predominantly more than in primary care? That's a possibility, I*
47
48 *guess."* (GP 7)
49
50

51
52
53 Some of the interviewees attributed their lack of expertise and experience of caring
54
55 for liver patients at the end-of-life to a reluctance amongst hospital clinicians to
56
57 relinquish control.
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5 *“There are some conditions, like liver disease, renal failure, they*
6
7 *[patients] all just end up dying in hospital for some reason. I don’t*
8
9 *know whether it’s the hospital consultants that don’t want to let them*
10
11 *go home... They need to let go and make sure there’s a palliative*
12
13 *care plan in place...they don’t do it.” (GP 3)*
14
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16
17
18 The limited contact between GPs and patients dying with liver disease was attributed
19
20 to an unpredictable disease trajectory with periods of stability and decompensation,
21
22 and to patients remaining under the care of hospital services in their last weeks and
23
24 months. The GPs in this study shared a view that end-of-life care is a core
25
26 component of primary care, and interviewees questioned how appropriate it was for
27
28 specialist hospital clinicians to take a lead in palliative care. Patients with liver
29
30 disease were not regarded as distinct or different from patients dying with other
31
32 conditions, and a number of GPs expressed a desire for greater involvement in their
33
34 end-of-life care. Some participants implied that primary care involvement may
35
36 support more patients to die at home, rather than in hospital.
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42
43 *“I think primary care probably is best placed, in most cases, to look*
44
45 *after people- well not only for that [liver disease], for most end-of-life*
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47 *care issues. So, yeah, I think the GP is probably the most important*
48
49 *person in the sense that they can bear in mind what the specialists*
50
51 *have advised, but at the end of the day, try and keep some of these*
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53 *patients at home rather than having to have them admitted acutely.”*
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55 (GP 14)
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Acknowledging and accepting end-of-life

Judging when a patient with liver disease is nearing the end-of-life was perceived to be a particular challenge. Communication about prognosis and the age of patients were identified as important factors. Some of the GPs reflected on how management decisions taken in hospital send out messages that influence care provided in the community. Continuing to pursue active treatment may convey optimism about the patient's life expectancy. Specifically, GPs referenced occasions where patients had been placed on the waiting list for a liver transplant, which the patient saw as offering them a second chance at life, even though they were critically unwell and may die whilst waiting for an organ. Patients with end stage liver disease are often younger than the typical palliative care patient.¹⁹ It may be that clinicians are more reluctant to give up on active treatment for younger patients,²⁰ whilst patients and families may also struggle to accept that the end-of-life is approaching.

21

“Those patients where it's a, kind of, grey area about whether they're end-of-life or not. And I think that mainly stems from the fact that if it's a young patient, it's more difficult for health care professionals, the patients themselves, and families, to actually accept that the person's dying” (GP1)

Mixed or uncertain messages may mean that care is compromised, if no one engages the patient in discussions about the end-of-life, and a palliative approach is never considered.

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5 *"I suppose, looking back it really was palliative care but they*
6 *[secondary care] put him on the transplant list because he's given up*
7 *alcohol and there was still this hope. So therefore we didn't really*
8 *realise he was going to die as quickly as he did"* (GP 11)
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16 There was a shared feeling amongst interviewees, that specialists should provide
17 clear messages about patients' prognoses, so that GPs can adopt an appropriate
18 management plan. At present, hospital specialists were perceived as failing to take
19 responsibility for identifying patients as end-of-life, and this had a detrimental impact
20 on primary care.
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29 *"I feel that it should be made compulsory for the secondary care,*
30 *tertiary care sectors, when they discharge, or when they're seen in*
31 *the patient clinic, [to] prognosticate, ... then we can initiate also, the*
32 *discussion with the patient, in a much more positive way."* (GP 12)
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41 **Collaborative care pathways**

42 Supporting patients with liver disease was seen as a collaborative effort, with GPs
43 acknowledging their need for specialist guidance, particularly when managing end-
44 of-life complications. A small number of respondents mentioned hepatic
45 encephalopathy as a challenge in the management of end-of-life liver patients, and a
46 potential source of distress for relatives. The interviewees suggested that they
47 would benefit from further training to deal with this complication. Ascites was the
48 most commonly mentioned symptom experienced by patients with end-stage liver
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3 disease, requiring drainage in hospital. Experiences of GPs in this study suggest that
4
5 ease of access to this procedure was highly variable. In some areas, pathways had
6
7 been negotiated and patients could be directly admitted to an appropriate ward. In
8
9 others, GPs described their concern at having to send patients to accident and
10
11 emergency (A&E) departments. Failure to arrange prompt access to treatment
12
13 caused distress and was a major source of adverse experiences during end-of-life
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15 care.
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21 *“We had a nightmare. He was building up litres of ascitic fluid on his*
22
23 *tummy every week or week to 10 days, and every time the hospital*
24
25 *had to send him acutely, new, to A&E and he had to sit in A&E for*
26
27 *hours. I was speaking to the liver specialist ... He needed regular*
28
29 *reviews and eventually they agreed to do it two weekly but even that*
30
31 *wasn't enough, it was building up and he was ending up going in as*
32
33 *an emergency every week.” (GP 11)*
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37 Where appropriate care pathways were not in place, interviewees suggested that
38
39 they were needed, to reassure the patient and GPs that support is available when
40
41 required.
42

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44 A number of participants suggested that a specialist nurse may hold the key to more
45
46 collaborative management of liver patients. They could act as an intermediary
47
48 between primary and secondary care, negotiating priorities and ensuring effective
49
50 and easy communication.
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55 *“It often helps when there is direct access to, say, a nurse specialist*
56
57 *in a field, or there is some other point of contact in secondary care*
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3 *that say a family or the patient themselves can call directly for*
4
5 *advice.” (GP 14)*
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8 Although some GPs had encountered specialist nurses working in this type of role,
9 this was not a common experience. Unfavourable comparisons were made between
10 the services available for patients with liver disease, and other conditions, such as
11 cancer. Participants highlighted the potential benefit to patients and families, of
12 having a specialist point of contact in the community, including prompt access to
13 advice and alleviation of fears and concerns.
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25 **Social relationships and consequences**

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27 GPs in this study argued that people with liver disease had many of the same
28 primary care needs as patients with other life-limiting conditions. However, the
29 severity of symptoms in end-of-life liver disease was felt to be different. Some of the
30 GPs acknowledged the potentially damaging impact on the patient’s family, of seeing
31 their relative die at home.
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41 *“I think there is quite a strong push to keep people at home. Whether*
42 *that’s right or wrong, I don’t know really. If they’ve got ascites or*
43 *portal hypertension, you know, they’ve got the risk of vomiting blood*
44 *and all the rest of it. Or they have been vomiting blood. I’m not*
45 *massively keen on keeping people at home because it’s just a*
46 *rubbish picture in the mind of everybody, I think, you know, the family*
47 *left behind.” (GP 17)*
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3 Families were perceived to be in need of support themselves, which was an
4
5 additional role for primary care. GPs described examples of relatives requiring
6
7 frequent contact and reassurance as the patient's condition deteriorated. The GPs in
8
9 this study differed in their attitudes towards these demands. Some took a holistic
10
11 view to the management of palliative patients, believing that these were part of the
12
13 standard practice of primary care.
14

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18 *"I think when we talk about palliative care it's not just a single person*
19
20 *who's the patient, it's about supporting and managing the family and*
21
22 *helping them through that bereavement stage because it starts right*
23
24 *at the diagnosis and they have to go through that journey. Death is a*
25
26 *part of life and giving them that support."* (GP 10)
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30 However, others felt that attending to the needs of patients' families was an extra
31
32 burden on their already overstretched resources.
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38 Limited social support and unfavourable social circumstances were often mentioned
39
40 as significant issues for patients with liver disease, particularly when alcohol or drug
41
42 misuse were factors. Several GPs referred to the 'chaotic' lifestyles of this patient
43
44 group, and resulting vulnerability to social isolation. Behaviours associated with
45
46 addiction were perceived to lead to the breakdown of the patients' social networks,
47
48 leaving few, if any people to provide support or care.
49
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52
53 *"the demographics of the alcohol dependent ones, who have often,*
54
55 *for various reasons and due to the nature of their disease, have*
56
57 *become quite isolated, they have not got many people around them*
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3 *and so they don't have that support. They require much more*
4
5 *organisation and support in the background, so we make sure that*
6
7 *they do have that support.” (GP 10)*
8
9

10 Without alternative sources of support, socially isolated patients were believed to
11 place extra demands on GPs and other health services. Even when social networks
12 were maintained, there could be a dearth of responsible caregivers, as friends and
13 family often shared the problems of addiction and poor health.
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23 *“I can think of a couple of our households where maybe spouses and*
24 *partners may have liver cirrhosis themselves. I can think of two*
25 *couples – well, one person who died two years ago. His wife has*
26 *chronic liver disease as well.” (GP 4)*
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36 One of the most important consequences of social isolation, was that patients had
37 fewer choices over where they spent the end of their life. Without anyone to monitor
38 their condition, they were more likely to be admitted to hospital, and die there.
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43 Liver disease is a potentially stigmatising condition, particularly when the underlying
44 cause is alcohol or substance misuse. Several of the GPs suggested that there is
45 often an assumption within the patient's community that liver disease is self-induced
46 and they were culpable, even when substance misuse or alcohol are not factors.
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3 *"I think it's a huge problem for people that have liver disease and*
4 *look like they have liver disease and people assume it's related to*
5 *alcohol when, in fact, it might be due to auto-immune causes or other*
6 *forms of cancer or something like that or hepatitis as well."* (GP 23)
7
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16 This assumed culpability has implications for the degree of support and sympathy
17 that the patient, and their families, receive. GPs also suggested that stigma could
18 hinder patients' acceptance of their prognosis, which in turn made the management
19 of their condition more challenging. As such, care of liver patients should include
20 psychological and social services.
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26
27
28 *"I think, inevitably and sadly, there is a stigma associated with liver*
29 *disease, and hence, that's why the psychological support is really*
30 *important"* (GP 25)
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35 However, some commented that stigmatisation occurred early in the patients'
36 illnesses, and to address this, changes would be needed well before end-of-life care
37 was being considered.
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41

42 **Discussion**

43
44 This study provides insights into the challenge faced by general practitioners
45 providing end-of-life care for patients with chronic liver disease. Many GPs
46 expressed a desire to be more closely involved, but identified a number of factors
47 that constrained their ability to contribute. These fell into three main areas; those
48 relating directly to the condition, (symptom management and the need to combine a
49 palliative care approach with ongoing medical interventions); issues arising from
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3 patients' social circumstances (stigma, social isolation and the social consequences
4 of liver disease); and deficiencies in the organisation and delivery of services.
5

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7 Collaborative working with support from specialist hospital clinicians was regarded
8 as essential, with GPs acknowledging their lack of experience and expertise in this
9 area.
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16 A majority of interviewees had little direct experience of patients dying of liver
17 disease and as a consequence, they may not have been familiar with all the
18 management challenges of end stage liver disease. For example, hepatic
19 encephalopathy is a common concern in the care of end stage liver patients, yet few
20 of the interviewees discussed it. This is not surprising, as primary care clinicians
21 would seldom have responsibility for managing hepatic encephalopathy, if they are
22 not dealing day to day with end-of-life care for liver disease patients.
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34 Strengths and limitations

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36 To our knowledge this is the first study to focus on the experiences of primary care
37 physicians in managing patients with end-stage liver disease. Our interviewees were
38 drawn from rural and urban areas in five different regions in England, and working
39 with a diverse range of communities. The relatively large number of GP participants
40 and varying levels of experience, expertise and interest in the subject, is a particular
41 strength of the study. With our qualitative design, we were not seeking
42 generalisability, but the diversity of the participants increases our confidence that we
43 have not overlooked important issues.
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3 The majority of interviews were conducted by telephone, which may explain the ease
4 and speed with which we recruited participants, despite not offering any financial
5 incentives. Use of the telephone is thought to have promoted unguarded responses,
6
7 but we acknowledge that it can be more difficult to develop rapport in the absence of
8 nonverbal cues and other facets of face to face communication. However, we do not
9 believe that this was a problem, as GPs provided rich and insightful accounts of their
10 experiences.
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20 Comparison with other work

21
22 Our findings are consistent with recent research from Scotland that included
23 interviews with eight GPs along with other health care professionals. Communication
24 with secondary care, lack of expertise and limited confidence in prognostication were
25 all identified as concerns.¹⁵ Accurate assessment of prognosis in liver disease is
26 difficult given the unpredictable disease course. In some aspects this is similar to
27 other diseases characterised by episodes of decompensation, such as heart failure.
28
29 However, liver disease presents the additional challenge that recompensation and
30 improved liver function may be achieved in certain patients, such as those who
31 achieve abstinence from alcohol. A recent review of palliative care guidelines in
32 heart failure and chronic obstructive pulmonary disease described wide variation in
33 how patients are identified for palliative care, and attributed this, in part, to the
34 unpredictable disease course and the consequences for care planning.²² In common
35 with liver disease, acknowledgement and development of end-of-life care has been
36 relatively recent for these conditions.²²
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3 The GPs in our study agreed that, at the end-of-life, patients with liver disease ideally
4 need primary care and hospital specialists to work closely together. GPs are more
5 likely to have an established relationship with the patient and a greater
6 understanding of their social situation and needs, whereas specialists offer expert
7 knowledge on liver disease and treatment options. They highlighted the importance
8 that primary care physicians place on being able to provide a coordinating role, but
9 only when supported by members of the specialist teams. Managing complex and
10 unusual symptoms, or judging when to introduce a palliative care approach, for
11 example, all benefit from collaboration. The advantages of a multidisciplinary
12 approach have already been well documented in the palliative care literature.^{23 24}
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14 Several recent reviews on end-stage liver disease have also advocated this
15 approach.^{4 5 14}
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32 This study highlights the complexity of caring for patients with end-stage liver
33 disease. Expertise in acute medicine and palliative care are essential, but patients
34 and families also need sensitive and practical responses to their psycho-emotional
35 and social concerns, including stigma related to the perceived self-inflictedness of
36 the disease, social isolation and lack of income. Such generalist expertise and a
37 holistic, person-centred approach are the foundations of primary care. Community-
38 based services already play an important role at the end-of-life for patients with
39 many different, complex conditions. However, this seldom includes people dying with
40 liver disease. Greater involvement of community services would be expected to
41 enhance the quality and appropriateness of palliative and terminal care for these
42 patients. As the number of deaths from chronic liver disease increases, it may be
43 increasingly necessary, in order to limit the burden on hospital teams. Innovations,
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3 such as the development of clear patient pathways, specialist hepatology nurses in
4 the community or district nurses trained to deal with liver disease complications, all
5 require resources. Specialist treatments such as paracentesis could be delivered in
6 locations such as community hospitals or hospices, where they are available, to
7 reduce disruption to patients' lives.
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18 In recent years, UK health policy has increasingly promoted patient choice; an ability
19 to deliver end of life care in the patient's preferred location and facilitate choice in
20 place of death are used as markers of care quality, with death at home often an
21 implicit goal of palliative care.^{25 26} GPs in this study expressed some scepticism that
22 home death is always the best option for patients with liver disease, or their families.
23 Concerns centred around the nature of the symptoms and clinical input needed to
24 manage them, which were potentially distressing for families to observe. Balancing
25 the wishes of patients, families and clinical carers is a fundamental part of end of life
26 care. More in depth enquiry to elicit patient, family and professional views and
27 experiences of place of death in liver disease would help to clarify the resources
28 required to ensure death at home is acceptable and achievable.
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45 Conclusion

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47 Our study suggests that end-of-life care for patients with liver disease requires
48 attention. Liver disease appears to pose management challenges in end-of-life care
49 with a combination of complicated social situations and symptoms. Services tailored
50 for these patients should build on the similarities with other conditions, but also
51 reflect the differences. The adverse social consequences of illness for these patients
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3 and their families, may be particularly significant. Further research is needed to fully
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5 understand the burden on families and services. As health services seek greater
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7 integration with social care, improving care for patients with end-stage liver disease
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9 should be a priority.
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11 12 13 14 15 16 **Acknowledgements**

17 We are grateful to the participants who generously gave their time to this study.
18

19 20 21 **Ethics Approval**

22 This study involved no patients and was assessed by the Health Research Authority
23
24 and Newcastle University Research Ethics (Ref 188275).
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27 28 **Authors contribution**

29 BH, EK, MH, JO, and CE designed the study. HS carried out the interviews. HS
30
31 undertook the main analysis supported by BH and HJ. HS, HJ and BH drafted the
32
33 manuscript, and all authors commented and approved the final version.
34

35 36 **Funding statement**

37 This work was supported by the NIHR School for Primary Care grant number 262.
38

39 40 **Competing interests**

41 We have read and understood BMJ policy on declaration of interests and declare
42
43 that we have no competing interests.
44

45 46 **Data sharing agreement**

47 We do not have any additional unpublished data that can be shared.
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50 51 52 **References**

- 53 1. World Health Organisation. WHO European health for all database. 2012.
54 <http://data.euro.who.int/> (accessed 22 January 2017).
55
- 56 2. Office for National Statistics. Deaths registered in England and Wales: 2015. 2016; (9th September
57 2016).
58

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2
3 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015> (accessed 22 January 2017).
- 4
5 3. University of Washington. The Liver Imaging Atlas: An Online Reference for Liver Imaging. 2017;
6 2017(22 January 2017). liveratlas.org (accessed 22 January 2017).
- 7
8 4. Boyd K, Kimbell B, Murray S, et al. Living and dying well with end-stage liver disease: Time for
9 palliative care? *Hepatology* 2012;55(6):1650-51. doi: 10.1002/hep.25621
- 10
11 5. Roth K, Lynn J, Zhong Z, et al. Dying with end stage liver disease with cirrhosis: insights from
12 SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of
13 Treatment. *Journal of the American Geriatrics Society* 2000;48(5 Suppl):S122-30.
- 14
15 6. Kimbell B, Murray SA. What is the patient experience in advanced liver disease? A scoping review
16 of the literature. *BMJ Supportive & Palliative Care* 2013;bmjpspcare-2012 doi:
17 10.1136/bmjpspcare-2012-000435
- 18
19 7. National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of
20 life care in England. 2012. [http://www.endoflifecare-](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease)
21 [intelligence.org.uk/resources/publications/deaths_from_liver_disease](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease) (accessed 27
22 February 2017).
- 23
24 8. Kendrick E. Getting it Right Improving End of Life Care for People Living with Liver Disease.
25 London: National End of Life Care Programme, 2013.
- 26
27 9. European Association for the Study of the Liver. EASL clinical practice guidelines: liver
28 transplantation. *Journal of Hepatology* 2016;64(2):433-85.
- 29
30 10. Poonja Z, Brisebois A, van Zanten SV, et al. Patients with cirrhosis and denied liver transplants
31 rarely receive adequate palliative care or appropriate management. *Clinical*
32 *Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American*
33 *Gastroenterological Association* 2014;12(4):692-98. doi: 10.1016/j.cgh.2013.08.027
- 34
35 11. Potosek J, Curry M, Buss M, et al. Integration of Palliative Care in End-Stage Liver Disease and
36 Liver Transplantation. *Journal of Palliative Medicine* 2014;17(11):1271-77.
- 37
38 12. Gott M IC, Gardiner C, Richards N, Cobb M, Ryan A, Noble B, Bennett M, Seymour J, Ward S,
39 Parker C. Transitions to palliative care for older people in acute hospitals: a mixed-methods
40 study. *Health Services and Delivery Research* 2013;1(11)
- 41
42 13. Larson AM. Palliative Care for Patients with End-Stage Liver Disease. *Current Gastroenterology*
43 *Reports* 2015;17(5):18. doi: 10.1007/s11894-015-0440-6
- 44
45 14. Walling AM, Wenger NS. Palliative care and end-stage liver disease. *Clinical Gastroenterology*
46 *and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological*
47 *Association* 2014;12(4):699-700. doi: 10.1016/j.cgh.2013.11.010
- 48
49 15. Kimbell B, Boyd K, Kendall M, et al. Managing uncertainty in advanced liver disease: a qualitative,
50 multiperspective, serial interview study. *BMJ open* 2015;5(11):e009241. doi:
51 10.1136/bmjopen-2015-009241
- 52
53 16. Office for National Statistics. National Survey of Bereaved People (VOICES). 2015. (accessed 27
54 February 2016).
- 55
56 17. Braun V, Clarke, V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
57 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
- 58
59 18. Ritche J, Lewis J. Qualitative Research Practie: A Guide for Social Science Students and
60 Researchers. London: SAGE Publications 2003.
19. Office for National Statistics. Deaths registered in England and Wales (Series DR): 2015. 2016.
(accessed 31 May 2017).
20. Department of Health. The impact of patient age on clinical decision-making in oncology. 2012.
21. Thompson GN, Chochinov, H.M., Wilson, K. G., McPherson, C. J., Chary, S., O'Shea, F. M., Kuhl, D.
R., Fainsinger, R. L., Gagnon, P.R., Macmillan, K. A. Prognostic Acceptance and the Well-Being
of Patients Receiving Palliative Care for Cancer. *Journal of Clinical Oncology*
2009;27(34):5757-62.

22. Siouta N, Van Beek K, van der Eerden ME, et al. Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC Palliative Care* 2016;15:56. doi: 10.1186/s12904-016-0130-7
23. Davidson PM, Paull G, Introna K, et al. Integrated, collaborative palliative care in heart failure: the St. George Heart Failure Service experience 1999-2002. *The Journal of Cardiovascular Nursing* 2004;19(1):68-75.
24. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease. *Health and Quality of Life Outcomes* 2007;5:17. doi: 10.1186/1477-7525-5-17
25. Department of Health. End of Life Care Strategy. 2008. <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life> (accessed 13th June 2017).
26. National Institute for Health and Care Excellence. NICE Quality Standards on End of Life Care. 2011. <https://www.nice.org.uk/guidance/qs13> (accessed 13th June 2017).

Table 1: Participant characteristics

Characteristic	Number of GPs
Sex	
Male	12
Female	13
Years of experience as GP	
<5 years	5
5-10 years	10
16-25 years	9
>25 years	1
Specialist hepatology/gastroenterology experience or training	
Yes	4
No	21
Size of practice	
<5,000	5
5-10,000	9
10,000-15,000	9
>15,000	2
Geographical area	
North West London	7
Wessex	8
North East and North Cumbria	5
Yorkshire and Humber	1
Thames Valley and South Midlands	4

Box 1

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4 **Next steps in primary end of life care for liver disease: GP perceptions of**
5 **areas for development**
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- Education and training in symptom management for end stage liver disease
 - Collaborative care pathways between primary care and hepatologists
 - Service delivery that takes into account patient and family social circumstances and stigma
 - Provision of support for family caregivers
 - Consideration / research into the role of home death

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HS
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD, MSc, Bsc
3.	Occupation	What was their occupation at the time of the study?	Research Associate in the Institute of Health and Society, Newcastle University
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Conducting interviews and analysing data from patients, clinicians and

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No	Item	Guide questions/description
		family members
	Relationship with participants	
		In some areas authors knew the representatives from the clinical research networks who assisted with recruitment. In other areas there was no relationship. There were no prior relationships with GP participants.
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the	What did the participants know about the researcher? Reasons for

No	Item	Guide questions/description	
	interviewer	<i>e.g. personal goals, reasons for doing the research</i>	doing the research were provided in information sheets sent to participants before the interviews.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	HS is a medical Sociologist with a specialist interest in end of life issues
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis See page 6 of the article

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No	Item	Guide questions/description
Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?

No	Item	Guide questions/description	
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Over the telephone, workplace
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No one was present expect the participants and researchers
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Wide range of clinical experience from GP trainee to >30 years experience Participant characteristics are presented in Table 1
Data collection			

No	Item	Guide questions/description	
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes, an interview schedule was developed. This was pilot tested with one interviewee See page 5 of the article
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were conducted
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording see page 6 of the article
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes see page 6 of the article

No	Item	Guide questions/description	
21.	Duration	What was the duration of the interviews or focus group?	15-50 minutes
			Yes, data collection was stopped when new themes were no longer emerging from the data. See page 5 of the article
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	3 See page 6 of the article

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No	Item	Guide questions/description	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No, documentation detailing development of themes is available upon request.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data See page 6 of the article
27.	Software	What software, if applicable, was used to manage the data?	NVivo10 See page 6 of the article
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes See pages 7-15 of the article

No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes there is consistency between the data presented and the findings. See pages 7-15 of the article
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, major themes are presented clearly in the article see pages 7-15.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, there are descriptions of diverse and minor themes in the article, see pages 7-15.