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Living, dying and caring in advanced liver disease: the challenge of uncertainty

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Declaration

I hereby declare that

- a. This thesis has been composed by myself.
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Barbara Kimbell

Abstract

Background: The number of patients dying with advanced liver disease is rising dramatically. However, little is known about the experiences of these patients and their families in respect of their care and everyday life with the disease. Palliative care services are traditionally focused on cancer and more recently on other types of organ failure, but liver disease is relatively neglected.

Aim and objectives: This study aimed to broaden our understanding of the experience of living and dying with advanced liver disease. Specifically, it sought to explore the dynamic physical, psychosocial, existential and information needs of patients and their lay and professional carers, and to review their use of health, social and voluntary services. Additionally, this study examined the utility of a qualitative longitudinal, multi-perspective methodology in end-of-life research.

Methods: This study employed qualitative, multi-perspective serial in-depth interviews. Patients with different aetiologies of liver disease were recruited in hospital. They and their lay carers were interviewed up to three times over one year. Single interviews were undertaken with case-linked professionals. Interviews were recorded, transcribed and analysed using grounded theory techniques and NVivo 9.

Results: 15 patients, 11 lay carers and 11 professional carers were recruited, and 53 interviews conducted. Uncertainty was the key experience at all stages of the illness, across all domains, and for all participants: patients, lay carers and professionals. This uncertainty related to the nature of the illness, the unpredictability of disease pathway and prognosis, poor communication and information-sharing, and complexities of care. Coping strategies demonstrated a continuous quest to manage uncertainty. Current care arrangements were a poor fit with the high levels of physical and psychosocial need identified. The ubiquitous uncertainty meant that a care planning approach was difficult to introduce. Employing a qualitative longitudinal, multi-perspective approach emerged as a useful and effective way in which to conduct research with this patient group and contributed new learning with regard to its application in end-of-life research.

Conclusion: This study identified uncertainty as the central pervasive factor in the experiences of patients, lay and professional carers. The needs of this patient group are currently poorly met from diagnosis to bereavement. Uncertainty makes advance care planning important, but difficult to know when to start. More needs to be done to ensure that people living and dying with advanced liver disease and their families benefit from appropriate and timely supportive and palliative care.

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Glossary and abbreviations

Aetiology	Disease cause.
ALD	Alcohol-related liver disease.
Ascites	Accumulation of fluid in the abdominal cavity. The most common complication in advanced liver disease.
Biographical disruption	A key theoretical concept in chronic illness research developed by Bury (1982), which denotes the disruption of all aspects of the ill person's life world on account of their illness.
Cirrhosis	Extensive scarring of the liver caused by long-term continuous liver damage which inhibits normal functioning of the liver.
COPD	Chronic obstructive pulmonary disease.
Cryptogenic liver disease	A type of liver disease for which there is no easily identifiable cause.
Decompensation	The functional deterioration of the liver.
DEPCAT	Deprivation category. An indicator of socioeconomic status.
Diuretics	Medication which encourages the expulsion of excess water and salt from the body.
Endoscopy	A procedure where a thin, flexible telescope (endoscope) is passed through the throat or anus to examine the inside of the body.
HCC	Hepatocellular carcinoma, or primary liver cancer.
HCV	Hepatitis C. A type of liver disease caused by viral infection.
HE	Hepatic encephalopathy. A neuropsychiatric dysfunction in patients with advanced liver disease.

Hepatology	A branch of medicine with a specialist interest in the liver.
HRQoL	Health-related quality of life.
MELD	Model for end-stage liver disease. A scoring system used to determine the severity of liver disease and a predictor of mortality.
NAFLD	Non-alcoholic fatty liver disease. Caused by a build-up of fat in liver cells.
Non-malignant disease	A disease that is non-cancerous.
Paracentesis	Procedure to remove excess fluid that has accumulated in the abdominal cavity (ascites).
PBC	Primary biliary cirrhosis. An autoimmune type of liver disease.
PPI	Patient and public involvement.
PSC	Primary sclerosing cholangitis. An autoimmune type of liver disease.
QLL	Qualitative longitudinal.
SPICT	Supportive & Palliative Care Indicators Tool. A guide to identifying people at risk of deterioration and death.
(Illness) Trajectory	The course of an illness.

Overview of the thesis

Chapter one provides an introduction to the subject matter. It describes current developments in advanced liver disease in the UK, and issues related to the care of people living with the disease. It further sets out the aim and objectives of the present study and delineates its importance and scope.

Chapter two provides a review of the literature in respect of what is currently known about the patient experience in advanced liver disease and life with a chronic disease more generally. It goes on to define the intellectual problem posed by the current gaps in knowledge, which provides the basis of this study.

Chapter three describes the methodological and ethical considerations underpinning this research endeavour. It further sets out and justifies the study plan, i.e. the strategies chosen for participant recruitment and data generation.

Chapter four provides details of how the study was conducted in practice, including recruitment, participants, interviews and data analysis. It also offers reflections on the benefits and challenges of the chosen approaches, as well as on the researcher experience.

Chapters five to nine each describe a key aspect of the experience of living, dying and caring in advanced liver disease. Each chapter first presents the study findings relating to the topic in question, and concludes with a brief discussion of these findings in the context of the wider empirical and theoretical literature.

Chapter five sets the scene by reporting on the pathway to and experience of receiving a diagnosis as well as on the physical complications that commonly defined everyday life with the disease. It also highlights people's understanding of their condition and, relatedly, their information needs.

Chapter six describes the challenges inherent in everyday life with the disease and how people coped with them. It also highlights their holistic support needs and barriers to accessing support.

Chapter seven describes patients' use of services. It details their experiences in the care setting and considers the extent to which these services met their needs.

Chapter eight presents issues around prognostication and facing an uncertain future, including death. It also considers the experience of death and dying with advanced liver disease through retrospective lay carer accounts.

Chapter nine describes the experiences of those caring for people with advanced liver disease. It first considers the support needs and experiences of lay carers. It then sets out the challenges faced by those in the professional care setting.

Chapter ten synthesises the study findings of the previous chapters to respond to the specific research objectives set out in Chapter 1. It also acknowledges the limitations of this study and discusses the implications of its findings. Finally, it provides recommendations for future research and practice.

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Chapter 1: Introduction

This chapter outlines the rationale for undertaking this research. It describes the nature of the problem, both in relation to chronic liver disease and current care provision for people living and dying with non-malignant disease. It also sets out the purpose and importance of this study and details its aim and objectives. Finally, it defines the scope of the research and the key terms and language used in this thesis.

1.1 Background and statement of problem

1.1.1 The rise of chronic liver disease

Chronic liver disease constitutes a significant cause of morbidity and mortality worldwide (Bosetti et al., 2007, Lim and Kim, 2008). Liver disease currently ranks fifth among the leading causes of death in the UK, but is a growing problem (British Association for the Study of the Liver and British Society of Gastroenterology, 2009). Cirrhosis (extensive scarring of the liver) and primary liver cancer both signify the final stage in the chronic liver disease trajectory and thus reflect associated mortality. A review of the UK General Practice Research Database identified increases of 45% in the incidence and 68% in the prevalence of cirrhosis between 1992 and 2001 (Fleming et al., 2008).

An increase in deaths from chronic liver disease contrasts with falling mortality rates for many other major diseases. For example, between 1970 and 2010 UK-wide standard mortality rates for ischaemic heart disease and cerebrovascular diseases decreased by 71% and 72% respectively. Conversely, mortality rates for chronic liver disease and cirrhosis increased by almost 300% (World Health Organisation, 2012). Current UK-wide trends indicate that by 2030 more people will die from liver disease than heart disease (Moore and Sheron, 2009). Figure 1 overleaf illustrates the dramatic rise of chronic liver disease in the UK compared to other common causes of death over recent decades.

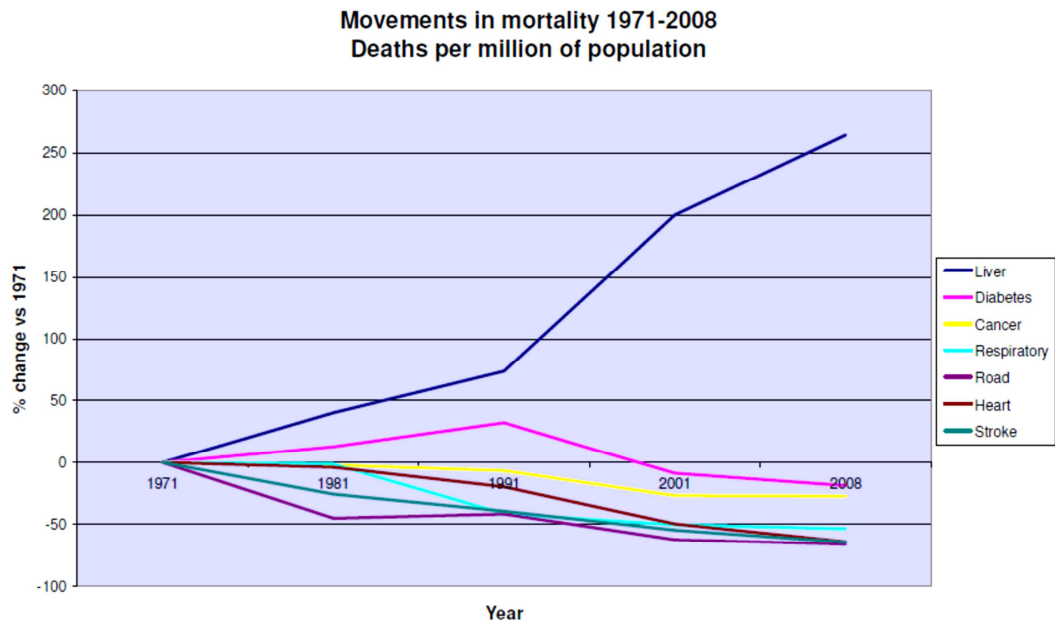


Figure 1: UK rate of liver-related deaths compared with other causes 1971-2008
(Source: British Liver Trust, 2013)

Across Europe, including Scotland, the leading causes of chronic liver disease are alcohol misuse, metabolic syndromes linked to rising levels of overweight and obesity, and viral hepatitis B and C (Blachier et al., 2013, Scottish Government, 2008a). The most common cause of chronic liver disease in the UK is alcohol-related liver disease (ALD) (Thomson et al., 2008). There is also a growing prevalence of non-alcoholic fatty liver disease (NAFLD) linked to increases in obesity (Fleming et al., 2008) and a large cohort of individuals with latent hepatitis C infection (McDonald et al., 2010). In the UK, hepatitis C is associated with intravenous drug use and infected blood transfusions prior to the introduction of blood screening in the early 1990s. In addition, some individuals develop autoimmune liver diseases.

1.1.2 The patient with chronic liver disease

Chronic liver disease affects people of a younger age than is typical in other chronic diseases such as heart or lung failure. The average age of death in liver disease is 59 (British Association for the Study of the Liver and British Society of Gastroenterology, 2009), and in England more than 1 in 10 of deaths of individuals in their 40s are now attributable to liver disease (National End of Life Care Intelligence Network, 2012). Deaths from liver disease are relatively more common

in men and deprived populations, and most frequently occur in hospital (National End of Life Care Intelligence Network, 2012).

While liver cirrhosis is irreversible, removing the causative factor can halt or delay further disease progression and reduce complications even once the disease has developed to this advanced stage. Hence, a termination of harmful behaviours such as alcohol or drug misuse as well as pharmaceutical treatment of hepatitis viruses can allow patients to return to good health. Given the insidious nature of chronic liver disease, however, many individuals remain unaware of its presence, resulting in a lack of timely treatment. Moreover, not all patients will succeed in overcoming the causative factors underlying their disease. This means that many individuals will progress to end-stage liver disease. The only viable life-prolonging treatment option at this stage is liver transplantation. This route, however, is only open to a small subset of patients who meet strict criteria, and subject to the availability of a suitable donor organ at a time of diminishing organ supplies (Sanchez and Talwalkar, 2006).

1.1.3 Patient care in advanced non-malignant disease

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation, 2010)

As can be seen from the above definition, palliative care has a vision of holistic care for all progressive life-limiting diseases. Although the ‘modern’ palliative care movement, instigated by Dame Cicely Saunders in the 1960s, sought to treat all people and all progressive diseases, palliative care has traditionally focused on the needs of cancer patients nearing the end of life, and is thus commonly understood by both public and many clinicians to hold this primary function. Yet most deaths in the population are in fact due to diseases other than cancer, and in particular those linked to major organ failure including the liver (Addington-Hall and Higginson, 2001). Access to specialist palliative care services is widening, but many people with organ failure remain poorly supported by existing services. This is despite evidence that patients with non-malignant disease such as heart or liver failure experience similar

levels of symptom burden and support needs as cancer patients (Murray et al., 2002, Roth et al., 2000).

Extending palliative care provision to better integrate non-malignant disease has been recognised as desirable but challenging (Addington-Hall, 1998, Addington-Hall and Higginson, 2001). One issue of particular consequence is the less predictable illness trajectory compared with that of cancer patients (Lunney et al., 2003, Murray et al., 2005). Figure 2 provides a comparison of the illness trajectories typically seen in cancer, organ failure and frailty/dementia.

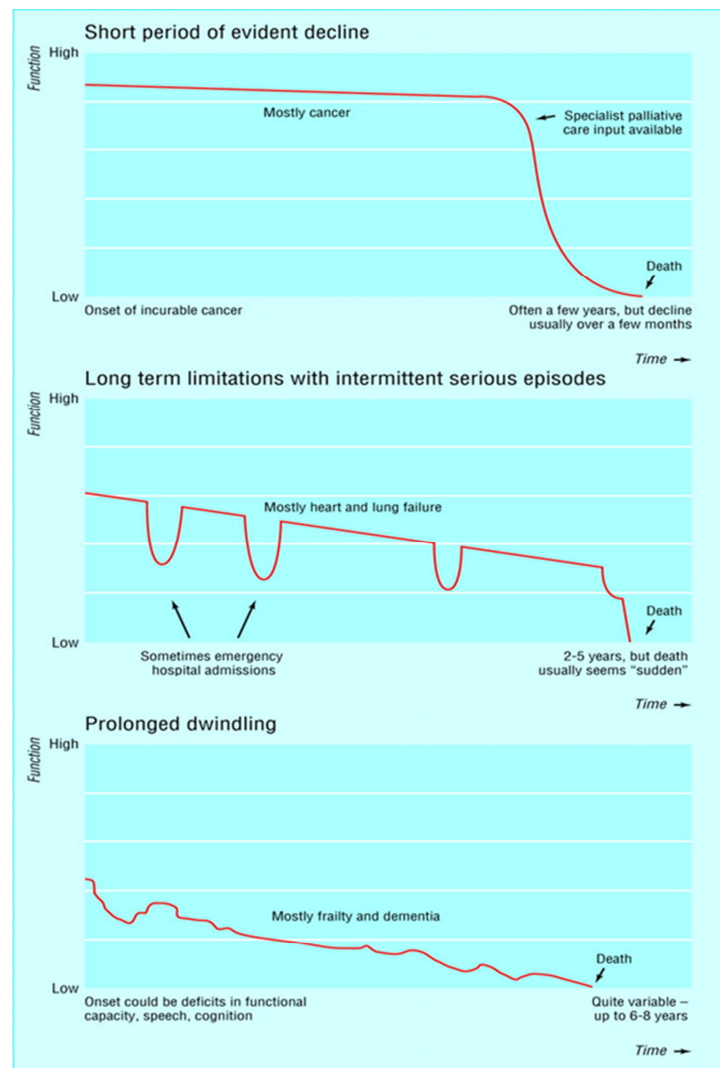


Figure 2: Typical illness trajectories in progressive chronic illness
(Source: Murray et al., 2005)

As the diagram shows, the typical disease progression in cancer is relatively fast, with a brief but dramatic decline towards death. In contrast, the pathway in organ failure is characterised by a slow but constant deterioration, punctuated by episodes of acute exacerbation which often require hospitalisation. A person with advanced liver disease may thus experience sudden death at any point throughout their illness trajectory, typically during an acute episode of, for example, gastrointestinal bleeding or severe infection.

This presents difficulties in terms of identifying the appropriate time for the introduction of supportive and palliative care for such patients. The traditional, and increasingly challenged, notion is that palliative care equates to the terminal phase of an illness. This perception results in support services being engaged only in the final days or weeks of a patient's life (Zheng et al., 2013). Given the lack of a clear terminal phase in the progression of chronic liver disease, and in the interest of optimising patients' quality of life and wellbeing in the last months (or even years) of life, supportive and palliative care should be initiated at the very earliest opportunity in the illness trajectory. This notion is supported by the World Health Organisation's vision of implementing palliative care approaches as early as possible in the course of a life-threatening illness (World Health Organisation, 2010). Early attention is also appropriate given the cognitive decline often associated with liver failure, which may challenge patients' ongoing decision-making abilities as their condition deteriorates and thus makes timely forward-planning desirable (Larson and Curtis, 2006).

The early introduction of a palliative care approach in chronic liver disease presents potential challenges for resourcing (Williams, 2005), and the effective management of a patient's holistic care across a number of relevant parties such as hospital-based clinicians, community-based primary care and palliative care staff, and social work services. Some evidence, however, suggests that closer integration of services can work effectively (Medici et al., 2008). Moreover, as most dying patients spend much of their last year in the community, primary care professionals are well placed to build on their existing relationships with patients (Murray et al., 2004). As such, their role in providing supportive and palliative care in the community should be further explored and professionals' capacity built accordingly (Barclay, 2001).

1.2 Research aim and objectives

To recap, current trends in some of the risk factors associated with chronic liver disease as well as diminishing donor organ resources point towards a dramatic increase in the number of patients living and dying with chronic liver disease in the coming years. At the same time, existing supportive and palliative care provision is often geared towards the needs of cancer patients and poorly configured and equipped to effectively support those with non-malignant disease.

The aim of this research is to broaden our understanding of the experience of living and dying with advanced liver disease, with a view to learning about individuals' needs and priorities in this context and to determine the suitability of current service provision.

The specific research objectives are as follows:

1. To explore the dynamic experiences, priorities and support needs of people with advanced liver disease, their lay carers and key health or social care professionals, and in particular their physical, psychosocial, existential and information needs in the last year of life.
2. To explore the use of health, social and voluntary sector services by this group and the extent to which existing services are perceived to meet their needs.
3. To contribute to the methodological knowledge base regarding the effectiveness of longitudinal, multi-perspective qualitative methods in end-of-life research.

1.3 Importance of this study

This research is considered important for a number of reasons:

- Given increasing morbidity rates vis-à-vis diminishing donor organ supplies, the number of patients living and dying with chronic liver disease is likely to rise dramatically in the coming years. An understanding of their needs and priorities is therefore needed to ensure appropriate and effective care and support for patients and their families.

- There is growing recognition that palliative care should be available on the basis of need and not simply diagnosis. Some headway is being made in this respect, as evidenced by the recent publication and growing use of the UK Gold Standards Framework for palliative care, giving prognostic guidance on a range of life-limiting illnesses (Royal College of Practitioners, 2006). Guidance relating to advanced liver disease, however, is not included.
- It is important to understand the progression of a disease in order that patients can be provided with the most appropriate care (Murray et al., 2005). While it is likely to resemble that of other major organ failures such as chronic obstructive pulmonary disease (COPD) or congestive heart failure, little is currently known about the illness trajectory in advanced liver disease, and in particular key dimensions such as psychological, social or existential wellbeing.

The above points were highlighted in a recent co-authored paper (see Appendix 1), which sought to stimulate further research to inform appropriate palliative care guidance for this patient group (Boyd et al., 2012). It was therefore hoped that the study data would serve to make a contribution to practice development in anticipation of the increasing number of people living and dying with advanced liver disease in the coming years.

1.4 Scope of this study

This research set out to explore the lived illness experience of people with advanced liver disease. It constituted broad, exploratory research to gain an overview of the range of issues that may affect individuals in everyday life and how these are understood and managed. Although this thesis attempts to provide a comprehensive account of this issue, it cannot be considered to describe the complete picture.

Most notably, the study findings relate only to an adult population and to a specific stage of the illness. Also, by targeting patients with a range of aetiologies, the data are unable to comment definitively on the collective experiences of any specific causal group. Finally, as this research was undertaken in fulfilment of a PhD award

and thus undertaken by an independent researcher, it was subject to resource limitations inherent in this arrangement.

This research aimed to contribute to the existing knowledge base in advanced liver disease. It did not specifically set out to formulate policy and practice development in supportive and palliative care. The recommendations offered in this thesis must therefore be understood in the context of the scale of this research and the limitations acknowledged both here and in Section 10.2.

1.5 Clarifying key terms and language

There is currently no clinical definition of what exactly constitutes advanced or end-stage liver disease. For the purposes of this study, advanced liver disease was considered the final phase of deterioration in the liver disease trajectory; that is, the stage of decompensated cirrhosis. A compensated liver is able to function normally despite progressive damage with cirrhosis. This phase can continue for many years and remain entirely asymptomatic. Decompensation relates to the point at which the liver's ability to adequately perform its range of functions ceases, resulting in serious symptoms and complications such as ascites (fluid accumulation in the abdomen), gastrointestinal bleeding, or hepatic encephalopathy (disordered mental and neuromuscular function) (Ginés et al., 1987). I therefore considered individuals experiencing the tangible symptoms and complications of decompensation as having advanced liver disease.

The term 'participant' will be used where this is meant to refer to those taking part in the research. In documenting the individual illness experiences, however, I considered it neither appropriate nor helpful to reduce study participants to a faceless status of 'patient' and 'lay carer'. All patient and carer participants were assigned a pseudonym, which I will use throughout the thesis except where clarification of their status is necessary to aid understanding (see Table 3, Section 4.3, for a list of pseudonyms used). Where the generic term 'patient(s)' is used this is done for ease, and in full recognition that no individual is wholly defined by their condition.

The term ‘lay carer’ used in this study refers to the person who provides the most help and support to the patient at home, irrespective of their relationship to the patient or the nature of the support provided. I considered this more inclusive than the term ‘family carer’ often seen in the literature (a sentiment which was borne out by the variety of lay carers who participated in this study; see Section 4.1.2 for details), and less stilted than ‘informal carer’, another commonly used term. As above, this term is used to aid description and discussion; again, I acknowledge that no ‘lay carer’ is solely defined by their caregiving role.

The ‘health and social care professionals’ referred to in this thesis relate to any individual providing some aspect of care for people with advanced liver disease in a professional capacity.

A glossary of key terms and abbreviations regularly used in this thesis can be found on page v.

A comment on language

This thesis is written from a first-person perspective. While there is some disagreement regarding the appropriateness of reporting research in this manner, using this approach here is informed by the following considerations. Firstly, using a first-person voice reflects the theoretical perspective underpinning the present study, which acknowledges the central role of the researcher in any research endeavour (see Section 3.1 for an elaboration on this matter). Secondly, it reflects my commitment to a reflexive stance throughout the research process, which constitutes good practice in qualitative research (see Section 3.7.2 for further detail in this respect). Lastly, I was keen to make this thesis accessible to as large an audience as possible and considered this best achieved by avoiding overly abstract and artificially detached language.

Chapter 2: Literature review

This chapter provides a review of relevant empirical and theoretical literature to contextualise the aims of this research. First, the review strategy is described. The second section gives an overview of what is currently known about the patient experience of advanced liver disease as well as an appraisal of this literature in terms of its contribution and current limitations. (A modified version of this section of the literature review was recently published (Kimbell and Murray, 2013), see Appendix 2.) The third section of this chapter outlines key theoretical literature relating to the experience of living with chronic illness. The final section summarises the intellectual challenges this review points towards, highlighting current gaps in knowledge and consequently the value of conducting this study.

2.1 Review strategy

Literature searches were conducted in MedLine, Web of Science, CINAHL and PsychINFO databases. The search was conducted in an iterative manner, with search terms and strategy evolving as familiarity with the literature increased and key papers were identified. Searches were also adapted to suit the different formats of the individual databases. Figure 3 shows the keywords and terms selected and searched for in abstracts.

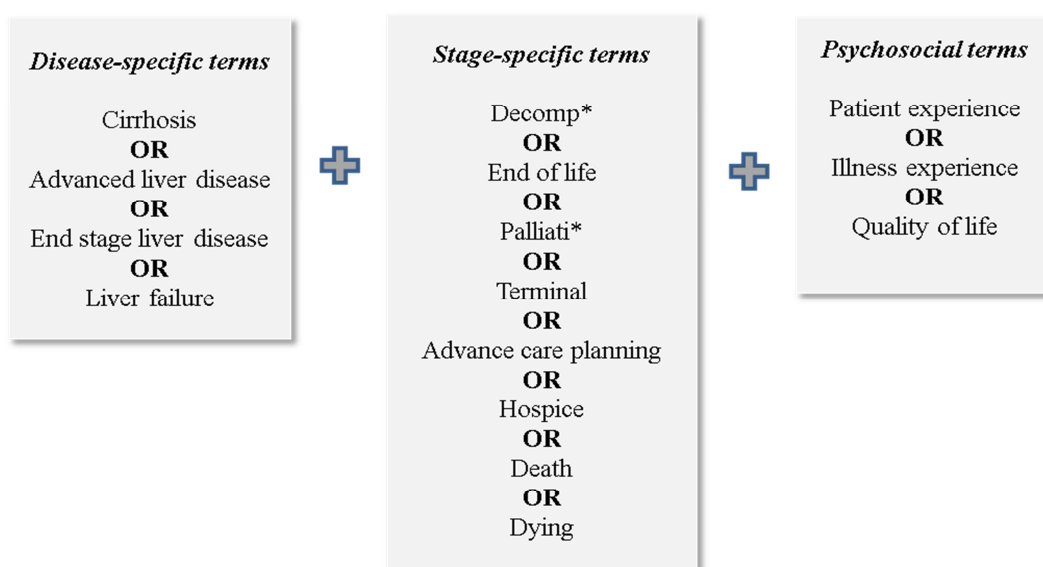


Figure 3: Literature review - Keywords and search terms

I supplemented this search with hand-searches of key journals such as Palliative Medicine and the British Medical Journal (BMJ), and set up email alerts for other relevant journals. I also consulted grey literature (e.g. conference proceedings, government reports), internet resources, bibliographies, reference lists, and the websites of key organisations such as the British Liver Trust, NHS Liver Care, Foundation for Liver Research, National Institute for Health and Care Excellence (NICE) and Healthtalk Online (DIPEX).

I excluded papers whose main focus was paediatric liver disease, treatment development, acute liver failure, or outcomes relating to the patient experience post-liver transplantation. I did, however, retain qualitative studies exploring experiences post-liver transplantation where findings also made reference to the patient experience prior to the intervention.

2.1.1 Overview of the literature

Many studies focused on health-related quality of life (HRQoL) in general or in relation to liver transplantation. The studies employed a variety of quantitative assessment tools to measure physical and psychosocial aspects of liver disease (Martin, Sheridan and Younossi, 2002), ranging from generic instruments such as the Short Form SF-36 questionnaire to disease-specific tools like the Chronic Liver Disease Questionnaire (CLDQ), and psychological instruments such as the Becks Depression Scale.

In contrast, there were few qualitative studies. Of the 13 papers identified, six focussed on patients' experiences of liver transplantation. The remainder pertained to specific types of liver disease, in particular primary biliary cirrhosis (PBC). Only one study employed a longitudinal design. Table 1 overleaf provides an overview of the qualitative studies retrieved.

Table 1: Qualitative studies (or studies containing a qualitative element) retrieved

AUTHOR(S) (YEAR)	STUDY AIMS	METHODOLOGY	STUDY POPULATION	AETIOLOGIES REPRESENTED	KEY RESULTS
Bjørk and Nåden (2008)	To explore patients' experiences of being accepted and waiting for liver transplant.	<ul style="list-style-type: none"> • Interviews • Data analysis as per Kvale (1996) 	21 patients on transplant waiting list. 17 male, 4 female. Average age 46 yrs (27–62).	Mostly (?) post-hepatitis and primary sclerosing cholangitis (PSC) (not clear from description)	<ul style="list-style-type: none"> • Overwhelming lack of energy. Perceived linear relationship between lack of energy, physical limitations and mental distress. • Great uncertainty related to life and death. • Plethora of physical problems and discomfort, anxiety and lonely suffering expressed.
Blackburn et al. (2007)	To explore psychological parameters in fatigued and non-fatigued PBC patients.	<ul style="list-style-type: none"> • Semi-structured interviews (plus a range of validated psychological scores) 	24 patients. Gender split not stated. Average age 57.9 (+/- 8) yrs.	Primary biliary cirrhosis (PBC)	Results linking to specifically to qualitative portion of study not given. Overall key results: <ul style="list-style-type: none"> • High fatigue linked to higher levels of distress and perceived quality of life and lower self-efficacy for undertaking everyday activities.
Bornschlegel et al. (2011)	To describe the unmet needs of people with Hepatitis C.	<ul style="list-style-type: none"> • Telephone interviews • Data analysis method not stated 	180 patients. 98 male, 82 female. Overall age range or mean age not stated but 77% of sample between 42-61 yrs.	Hepatitis C	Unmet information needs relating to: <ul style="list-style-type: none"> • basic information about the virus • available support groups • counselling about preventing further liver damage and transmission prevention
Brown et al. (2006)	To explore what meaning people with liver failure ascribe to the experience of waiting for a transplant.	<ul style="list-style-type: none"> • Interviews • Phenomenological data analysis • 9 interviews with 6 participants (details of follow-up not stated) 	6 patients on transplant waiting list. 4 male, 2 female. Age range 46-63.	Hepatitis C, alcoholic liver disease, cryptogenic liver disease	<ul style="list-style-type: none"> • Illness experience transformative and disruptive • Lack of positive care felt to contribute to depression, hopelessness and worsening health • Pervasive experience of loss relating to perceived loss of personal control and freedom, important roles, and increasing disability • Feelings of frustration and boredom, sense of isolation and loneliness • Patients develop new perspectives on time

AUTHOR(S) (YEAR)	STUDY AIMS	METHODOLOGY	STUDY POPULATION	AETIOLOGIES REPRESENTED	KEY RESULTS
Fan and Eiser (2012)	To explore how patients perceived the impact of HCC on their lives and coped with its demands.	<ul style="list-style-type: none"> • Semi-structured interviews • Interpretative phenomenological analysis 	33 patients. 22 males, 11 females. Mean age 54.24 (31-76).	Hepatocellular carcinoma	<ul style="list-style-type: none"> • Many physical symptoms and psychological distress. • Disrupted social relationships • Adjustment to illness a dynamic process influenced by physical health, stage of disease, patients' illness perceptions and coping strategies. • Illness understanding added to patients' sense of control. • Observed transitions in patients' coping.
Forsberg et al. (2000)	To explore the subjective experiences of the meaning of having a liver transplantation.	<ul style="list-style-type: none"> • Interviews • Phenomenological analysis • Interviews covered experiences pre- and post-transplant 	12 patients 1 year post transplant. 3 males, 9 females. Mean age 51 years (24-63).	Primary sclerosing cholangitis, Laennec's cirrhosis, hepatitis, primary biliary cirrhosis, metabolic disease	Pre-transplant experience: <ul style="list-style-type: none"> • Feelings of grief and fear of the unknown • Existential thoughts common
Johnson and Hathaway (1996)	To explore the lived experience of end-stage liver failure and liver transplantation.	<ul style="list-style-type: none"> • Interview • Phenomenological analysis 	1 patient post-transplant. Female. Age 62.	Not stated	Pre-transplant experience: <ul style="list-style-type: none"> • Uncertainty • Feelings of loss of control related to increasing dependence, confusion/disorientation, anger/frustration and fear • Positive impact of spirituality, faith and social support
Jorgensen (2006)	To understand the lived experience of fatigue for people with PBC.	<ul style="list-style-type: none"> • Interviews • Interpretative phenomenological analysis 	8 patients. 1 male, 7 females. Age range 38-60.	Primary biliary chirrhosis	<ul style="list-style-type: none"> • Experience of fatigue all-encompassing and overwhelming, unrelenting, insidious and difficult to control • Patients plan lives around fatigue to preserve energy • Struggle to maintain normality • Feelings of dysphoria and general apathy

AUTHOR(S) (YEAR)	STUDY AIMS	METHODOLOGY	STUDY POPULATION	AETIOLOGIES REPRESENTED	KEY RESULTS
Lasker et al. (2005)	To explore family and friends' responses to chronic liver disease including gender differences.	<ul style="list-style-type: none"> • Survey, open-ended questions, posts to a Friends and Family listserv 	52 spouses, family members or friends	Primary biliary cirrhosis	<ul style="list-style-type: none"> • Males felt less affected than females by loved one's illness • Giving emotional support and being more accommodating most important support strategies • 54.5% overall access Internet-based support, but more females than males • Males' support action-oriented, females' socio-emotional
Lumby (1997)	To explore the experiences of surviving a liver transplant.	<ul style="list-style-type: none"> • Focus groups and storytelling • Analysis using NUDIST software • Longitudinal (2ys) 	8 patients post-transplant. 2 males, 6 females. No ages given.	No details given but a variety.	<p>Pre-transplant experience:</p> <ul style="list-style-type: none"> • Range of physiological states • Trust in medics even where poor care management • Effort to maintain independence throughout illness • Facing both life and death, but hope dominates
Montali et al. (2011)	To explore the illness experience of women with PBC from a gender perspective.	<ul style="list-style-type: none"> • Semi-structured interviews • Interpretative phenomenological analysis 	23 female patients. Mean age 59 (39-77).	Primary biliary cirrhosis	<ul style="list-style-type: none"> • Denial of patients' sick role by family and health professionals, trivialisation of fatigue, lack of consideration of patients' needs. • Fear of rejection and losing their social role • Need for biographical continuity
Robertson (1999)	To explore patients' perspectives on the effect of transplantation on quality of life.	<ul style="list-style-type: none"> • Semi-structured interviews • Cluster analysis 	5 patients post-transplant. No gender split or ages given.	No details given	<p>Pre-transplant experience:</p> <ul style="list-style-type: none"> • Physical symptoms impeded independence and limited activities and social life • Quality of life perceived as poor • Little acknowledgement of possible death
Wainwright (1997)	To explore patient experience of chronic liver disease.	<ul style="list-style-type: none"> • Interviews • Grounded theory 	10 patients post-transplant (reporting on pre-transplant experience) No gender split or ages given.	No details given	<ul style="list-style-type: none"> • Main debilitating complaint fatigue, many gastrointestinal symptoms, some mental impairment • Negative feelings due to physical limitations • Experience of stigma regardless of aetiology. • Desire to retain independence and self-manage illness

2.2 The patient experience in advanced liver disease

The following sections outline the key findings from the literature in relation to patients' experiences of living with advanced liver disease. They draw on both quantitative and qualitative studies identified through the review process in order to provide as comprehensive a picture as possible of the topic at hand. Findings are grouped into four broad areas: physical experience, psychological experience, socio-demographic variations, and supportive and palliative care.

2.2.1 The physical experience

Research with 575 people with end-stage liver disease and/or their surrogate decision-makers found that patients experienced substantial levels of pain, which compared with those reported by advanced cancer patients and exceeded those of patients with chronic obstructive pulmonary disease (COPD) and chronic heart failure (Roth et al., 2000). Pain was particularly marked in cirrhotic patients with additional hepatocellular carcinoma (Bianchi et al., 2003). However, as these were cross-sectional studies the nature and extent of the reported pain over time are unclear. The present study allowed me to explore this important experiential aspect.

Liver impairment also compromises the effective processing of nutrients. As such, malnutrition was found to be widespread among patients with advanced liver disease (Kalaitzakis et al., 2006). Panagaria and colleagues compared the nutritional status of participants with alcohol-related and non-alcoholic liver disease, alcohol addicts, and healthy controls (Panagaria et al., 2007). Features of malnutrition, such as nutrient and calorie deficiencies, were seen in all patients regardless of disease cause, but were particularly frequent and severe in those with alcohol-related liver disease (ALD). Malnutrition was also linked to gastrointestinal complications in cirrhotic patients, which may progressively impair their HRQoL (Kalaitzakis et al., 2006).

Patients with decompensated cirrhosis experience higher levels of fatigue than those with compensated cirrhosis and compared with healthy controls (Van der Plas et al., 2003, Van der Plas et al., 2007). Fatigue was particularly well investigated in the realm of primary biliary cirrhosis (PBC), where it constitutes a major debilitating symptom (Huet et al., 2000, Jorgensen, 2006). However, comparative research using

the Fatigue Impact Scale suggests that the negative effect of fatigue on patient wellbeing is in fact comparable across different types of liver disease (Jones, Gray and Newton, 2009). Similar to the overall aim of the present study, qualitative research by Wainwright (1997) sought to enlighten the holistic patient experience of living with advanced liver disease. He interviewed liver transplant survivors about their experience of living with the disease prior to the intervention. Respondents described several gastrointestinal complications and mental impairments, but felt particularly frustrated with the physical limitations caused by their high levels of fatigue. Overwhelming fatigue was also reported by patients awaiting liver transplantation (Bjørk and Nåden, 2008). The present study can add to current understanding of the experience of fatigue in advanced liver disease by virtue of its longitudinal design, which allows the consideration of the severity and persistence of fatigue over time.

Sleep problems are likely to contribute to the fatigue reported elsewhere. In their prospective survey study of cirrhotic patients, Cordoba and colleagues observed extensive sleep disturbance unrelated to any cognitive impairment (Cordoba et al., 1998). Problems such as short sleeping time, difficulties falling asleep, and fragmented nocturnal sleep were seen alongside poor daytime functioning marked by excessive sleepiness and frequent napping. The level of sleep problems seen in cirrhotic patients compared with that of gender- and age-matched controls with chronic renal failure, and was significantly higher than that of healthy controls (Cordoba et al., 1998, Mostacci et al., 2008). In other research, 69% of participants with cirrhosis suffered from some type of sleep disorder, with related negative impact on their psychological health (Bianchi et al., 2005).

Survey research with 544 cirrhotic patients reported that, compared with the general population, they perceived that most areas of their daily life had been affected by their illness, particularly the physical domain (Marchesini et al., 2001). Surprisingly, however, respondents felt significantly more affected by relatively minor symptoms such as muscle cramps and itching than some of the major, possibly life-threatening complications. This prompted the authors to suggest the inclusion of such symptoms in existing survey tools in order that they are considered in future research. The

findings also suggest that health professionals should give due attention to patients' symptom reporting, as effective treatment of these relatively minor ailments could facilitate significant improvements in their quality of life. The qualitative design of the present study had the potential to generate further insight in this area by encouraging participants to share freely the issues of greatest concern to them regarding living with advanced liver disease, including the physical complications they perceived as causing the most negative impact in everyday life.

2.2.2 The psychological experience

A common debilitating feature of advanced liver disease is increasing cognitive dysfunction. Hepatic encephalopathy (HE) is one of the main complications that may afflict patients in the latter stages of the disease and can manifest in a variety of neurological symptoms affecting attention, memory and psychomotor functions. HE often necessitates inpatient hospital treatment and precedes the death of many patients with advanced liver disease. While not all patients will develop this level of cognitive decline, studies have shown that a large number of patients will experience some cognitive impairment at a sub-clinical level (Pantiga et al., 2003), although reported prevalence rates for this vary widely (Collie, 2005). Nevertheless, research by Groeneweg et al. (1998) highlights the clinical relevance of sub-clinical hepatic encephalopathy (SHE). In their tests with 179 cirrhotic outpatients, those with confirmed SHE displayed significantly more impairment on both physical and psychosocial aspects of the Sickness Impact Profile scale than those without it. Given its evident impact on individuals' quality of life and daily functioning then, the authors suggest that routinely assessing and treating sub-clinical levels of cognitive dysfunction in this population may enhance the experience of living with the disease.

People with advanced liver disease reported more substantial levels of psychological distress than those with other types of organ failure such as COPD or congestive heart failure (Roth et al., 2000, Younossi et al., 2001), and age- and gender-matched controls (Bianchi et al., 2005). Impairment in patients' psychological wellbeing has been linked to both physical factors, e.g. fatigue (Blackburn et al., 2007), and social factors, e.g. stigma (Sogolow et al., 2010). A questionnaire study by Fritz and Hammer (2009) examined the impact of gastrointestinal symptoms on the quality of

life of 75 cirrhotic patients. 80% of the study sample experienced one or more symptoms which not only affected their quality of life, but also their psychological wellbeing. The authors concluded that treating psychological problems may effect an improvement in individuals' physical symptoms, and in turn in their overall quality of life. Indeed, it has been suggested that psychological distress is the best predictor of quality of life in people with liver cirrhosis (Kim, Oh and Lee, 2006).

Depression was particularly prevalent in this population, irrespective of disease cause (Gutteling et al., 2010). Assessing depression in 156 cirrhotic patients, Bianchi et al. (2005) found that over that half of their sample were depressed. Moreover, few had a known history of depression, thus suggesting that their liver disease was impacting on their mental health. In a prospective study by Singh et al. (1997), 64% of participants were positively assessed as suffering from depression. Compared with their non-depressed counterparts, depressed individuals reported significantly more adverse outcomes in several areas, such as adaptive coping, physical pain, and perceived quality of life. They also displayed a higher level of negative thinking about future prospects, and perceived themselves a greater burden to their carers. Most significantly, the researchers found that among patients waiting for a liver transplant, those with depression were more likely to die than non-depressed patients, regardless of the severity of their disease. The prevalence of depression in people with advanced liver disease is likely to be higher than currently estimated, in particular when one considers the large number of patients for whom transplantation is contraindicated (Heneghan and O'Grady, 2001). With such a dramatic effect on both illness experience and prognosis, depression in this patient group warrants dedicated attention in any therapeutic intervention.

Finally, a recent qualitative interview study explored the illness experience of 33 patients with hepatocellular cancer (Fan and Eiser, 2012). Patients' psychological adjustment to the illness was found to be a dynamic process influenced by their physical health, the stage of the disease, the patient's illness perceptions and their coping strategies. It appeared that understanding the nature of their illness, especially its causes, prognosis and treatment plans, was particularly important in promoting patients' sense of control. As this research focused on a specific type of liver disease

however, it is unclear how this experience compares to non-malignant aetiologies. The cross-sectional design of the study also limits insights into the dynamic nature of individuals' psychological experience as proposed by the authors. The design of the present study allowed me to contribute understanding in both these areas.

2.2.3 Socio-demographic variations

People with liver disease constitute a relatively younger patient population compared with other major diseases (British Association for the Study of the Liver and British Society of Gastroenterology, 2009, Roth et al., 2000). An assessment of cirrhotic patients of various aetiologies using the Short Form SF-36 questionnaire found age significantly correlated with worsening HRQoL (Afendy et al., 2009). Comparable survey research reported that the impact of cirrhosis was experienced more acutely by younger participants (Marchesini et al., 2001). The age differences observed in both studies may reflect a relatively more widespread impact of the disease on younger patients' lives in terms of their employment, family life and adjustment to a diagnosis of a life-limiting illness, compared with older individuals who are already beyond the most active phase of their lives.

Both studies also observed gender differences in the patient experience of advanced liver disease. Afendy et al. (2009) found that female patients showed more impairment in some areas of HRQoL than males. In the study by Marchesini et al. (2001), male participants cited paid employment and sexual function as their main worries in relation to their illness. In contrast, female respondents highlighted their home life and social life as primary concerns. As socio-demographic variations in the patient experience of advanced liver disease have so far received little attention, this research offered an opportunity to contribute insights in this area.

2.2.4 Supportive and palliative care

While there was some literature pertaining to the clinical management of symptoms and complications relating to the end stages of liver disease, there was a dearth of publications which considered the holistic aspects of supportive and palliative care for this patient group. It is important that professionals make it their business to

understand their patients' goals in this regard, as they constitute the difference in treatment for palliative care and disease-focused care (McGrew, 2001).

As discussed in Section 1.1.3, a typically erratic trajectory makes defining the right time at which to introduce palliative care in non-malignant disease difficult. McGrew (2001) posits that palliative care in liver disease should be introduced at the point at which symptoms of decompensated cirrhosis become evident. Alternatively, transplant assessment has been suggested as a good time at which to initiate conversations about palliative care (Adam, 2000, Hope and Morrison, 2011, Larson and Curtis, 2006). However, this approach does not accommodate the many people for whom transplantation is contraindicated. There is often a concern that patients may be unduly alarmed by a suggestion of a change in treatment towards palliative care. In a study of nearly 3000 patients with various advanced diseases including liver cirrhosis, however, a large minority (44%) expressed a preference for palliative care over life-prolonging treatment (Fox et al., 1999).

Effective holistic supportive and palliative support relies on the successful integration of disease-directed and palliative care goals. It has been suggested that palliative care is easily integrated into the standard management of advanced liver disease (Sanchez and Talwalkar, 2006). Medici and colleagues argue that concurrent access to hospice care for selected patients waiting for transplantation may improve their overall care experience (Medici et al., 2008). Their study found that hospice-based interdisciplinary staff and liver transplant teams were easily able to integrate their respective goals of care and develop effective partnership working.

2.3 Methodological critique of the empirical literature

HRQoL research employing survey-based methods has contributed greatly to our quantitative understanding of symptom burden and psychological distress in advanced liver disease, and provides the basis of many recommendations to more effectively target treatment and care. Moreover, assessing liver patients' HRQoL does not just serve as an assessment measure in its own right, but has also been found to be a useful predictor of mortality (Kanwal et al., 2009).

There are several limitations to this approach, however. Most HRQoL studies employ a variety of generic and/or disease-specific survey questionnaires. A literature review by Martin and colleagues cautions that these instruments tend to differ greatly from one another, and that researchers also use varied terminology to describe quality of life, thereby affecting its interpretation (Martin, Sheridan and Younossi, 2002). It is thus difficult to draw overall conclusions from the available research. The inherent failure of HRQoL measures to be truly patient-centred has also been noted (Carr and Higginson, 2001). This is in part due to the lack of an agreed definition of HRQoL, but is more importantly down to the individual nature of what constitutes quality of life, which is shaped by a person's culture, socio-demographics, and personal factors like experiences, expectations and beliefs. HRQoL studies are also subject to several methodological shortcomings, such as a lack of longitudinal comparisons and the arbitrary timing of QoL investigations (Cirrincione et al., 2002). Finally, the suitability of common HRQoL measures in the realm of palliative care has been questioned due to their lack of context-specific constructs such as symptom control, spirituality or family support (Kaasa and Loge, 2003). Importantly, patients themselves feel that pre-formulated questionnaires give no opportunity to make personal comment on their subjective illness experience (Benz, 2001, Lowe et al., 1990). Speaking from a patient perspective, Benz (2001, p203) argues that, "traditional questionnaires focus on how far function and pain affect the patient, but are only indicative of health status. Quality of life is determined by what a person says it is."

The literature focused on liver transplantation uses the same or similar quantitative assessment tools as HRQoL research to examine and compare patients' quality of life before and after transplantation. It is therefore subject to similar limitations as those outlined above. The qualitative liver transplantation literature identified relates to a very particular set of circumstances: awaiting transplantation. Many patients with advanced liver disease do not qualify for transplantation on account of co-morbidities, general frailty or continued drinking or drug-taking. While much can be learned from the insights of these patients awaiting transplantation, their experiences may not reflect those of the wider patient population with advanced liver disease.

Indeed, marked differences between transplant and non-transplant patients have been observed (Price et al., 1995).

Several studies recruited patients with different causes of liver disease. Their results indicate some variation in HRQoL and related factors, suggesting that there may be differences between aetiologies in the way advanced liver disease is experienced. At the same time, there is much aetiology-specific research into the patient experience with PBC and hepatitis C for example, but comparatively little in the realm of non-alcoholic fatty liver disease. This is also important given that PBC affects disproportionately more females; as described earlier, some studies suggest gender variations in the experience of living with advanced liver disease. This implies that it may be inappropriate to extrapolate from one type of liver disease to another, or to suggest that there exists a universal patient experience in advanced liver disease. This matter was given due attention during the data analysis phase of the present study.

So far this chapter has set out what is currently known about the patient experience of advanced liver disease, and offered an appraisal of the empirical literature. The following section provides additional context to this study by detailing some key theoretical literature with respect to living with chronic illness.

2.4 Theoretical perspectives in chronic illness

Over recent years, psychosocial theorising in the context of health and illness has increasingly challenged the dominance of the biomedical view, and generated growing interest in the patient perspective (Armstrong, 2000, Engel, 1977). This constitutes an important shift away from the concept of the ‘sick role’ which had previously dominated discourse in health and illness (Parsons, 1951). Parsons argued that being granted the sick role comes with certain rights and responsibilities for the ill person. Importantly, their key obligation is to actively strive towards recovering their health as soon as possible. However, this notion has been challenged in the context of chronic illness, where recovery of complete health is not an option (Nettleton, 1995). Indeed, there is increasing recognition of the need to gain a more subjective understanding of illness and its impact on daily life (Lawton, 2003).

2.4.1 Defining chronic illness

The key defining aspect of chronic illness is its temporal character. In chronic illness such as advanced liver disease, the person's condition is of an enduring nature. Unlike in acute illness, the chronically ill person's life is affected not solely in terms of temporary physical disability, but also the wider psychosocial context of their life world. Relationships, employment and expectations for the future all need to be adjusted to accommodate this permanent change to the person's life. As Charmaz (2000, p277) states, "Experiencing chronic illness means much more than feeling physical distress, acknowledging symptoms and needing care. It includes metaphor and meaning, moral judgements and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles."

The illness experience is defined by internal and external factors (Radley, 1994). Internal refers to the experience that is particular to the ill person, while external aspects concern the experience in relation to their social world. Radley gives the example of adjustment style as something that is commonly assumed to be closely related to a person's personality traits. However, the influence of others on an ill person's adjustment, such as their reactions to the illness and support provided, cannot be underestimated, and highlights the important social component in the individual illness experience (Charmaz, 1983, Radley, 1994, Radley and Green, 1987). Kleinman (1988, p180) similarly notes that, "Chronicity is not simply a direct result of pathology acting in an isolated person. It is the outcome of lives lived under constraining circumstances with particular relationships to other people."

Radley (1994) further argues that it is important to distinguish between the terms disease, illness and sickness, which are often used interchangeably in the context of chronic illness. In doing so, it becomes evident that medical knowledge alone, as applied by clinicians to the treatment of disease, cannot give a genuine insight into the reality of illness as experienced by the affected individual. Likewise, Kleinman (1988) urges for a distinction to be made between the patient and the sick person. He argues that the term 'patient' belongs firmly in the realm of biomedicine, as those living with chronic illness in fact spend more time in their everyday roles of ill family member or ill employee than in that of the patient. My agreement with this

assertion was highlighted in Section 1.5 and is reflected in my decision to refer to participants using pseudonyms so as to not reduce them to a status of ‘patient’ only.

2.4.2 Living with chronic illness

Illness as biographical disruption

A seminal concept in the study of long-term conditions is that of illness as biographical disruption (Bury, 1982). Bury suggests that the onset of chronic illness shakes up a person’s entire life world. It exposes them to the realities of pain, suffering and possible death, severely disrupts their relationships at home, work and their wider social network, and throws into disarray expectations and plans held for the future. It also represents a severe disturbance to an individual’s self-concept, requiring re-evaluation and adaptation. The experience of biographical disruption in the context of advanced liver disease was indicated in a small-scale interview study of six patients waiting for a liver transplant, who described their illness as both disruptive and transformative (Brown et al., 2006).

In recent years, however, the idea of illness as a biographical disruption has increasingly been questioned, and there have been calls to update and extend the concept in light of limitations to the original account (Lawton, 2003, Williams, 2000). Lawton (2003) puts forward several studies which challenge Bury’s notion of illness being necessarily experienced as biographically disruptive. She argues that the experience of living with existing morbidities or in difficult personal circumstances, such as poverty or drug misuse, may dampen the potential disruptive impact of a new diagnosis of illness. Consequently, such individuals may simply ‘slot’ this new experience into their already challenging lives. It was conceivable that this scenario might arise in the case of some individuals living with liver disease on account of long-term alcohol or drug misuse. The current study thus provided an opportunity to explore this notion within the context of advanced liver disease.

Loss of self

Charmaz builds on Bury’s notion of chronic illness as a critical disturbance to a person’s self-concept (Charmaz, 1983, 1987, 2002). She contends that long-term illness presents a serious challenge to the ill person’s sense of self, forcing them to

reconsider and continually adjust their notion of who they are and see themselves becoming as a result of their circumstances and illness experiences. In her seminal 1983 paper, Charmaz focuses on the diminishing self-concept and subsequent loss of self as a fundamental form of suffering. She identifies four challenges to one's self which may be experienced by the chronically ill and those close to them: living a restricted life; social isolation; discrediting definitions of self; and becoming a burden (Charmaz, 1983). Charmaz concludes that often the experience of suffering is conceptualised too narrowly, focusing solely on its physical expressions like pain or disability, while disregarding the many other ways in which individuals may experience suffering due to long-term illness. An interview study exploring the experiences of women living with PBC supports this notion (Montali et al., 2011). Their illness was found to impact greatly on the women's identities, particularly in relation to fears of losing their traditional social role and social rejection, and posed a challenge to biographical continuity.

Stigma

Experiencing stigma is a common feature of chronic disease (Stuenkel and Wong, 2013). Due to their condition, an ill person may be considered deviant from social norms and tarnished in character (Goffman, 1968). Stigma may be experienced in two ways: enacted and felt (Scambler and Hopkins, 1986). Enacted stigma relates to actual instances of stigmatisation experienced by a person on account of their illness rendering them different. Felt stigma relates to the ill person's perception or fear of being the victim of stigmatising behaviour by others, as well as feelings of shame and guilt they may hold about their circumstances.

The experience of stigma relates to a societal reaction towards an illness (Kleinman, 1988), and as such varies between conditions, settings and individuals. While some of the consequences of chronic ill health, such as disability or unemployment, may elicit stigmatising reactions in any disease context, some types of chronic disease are considered inherently more stigmatising than others (Charmaz, 2000). This is especially true where a disease may be blamed on the person engaging in high-risk behaviours, such as smoking as a cause of lung cancer (Chapple, Ziebland and McPherson, 2004). In the context of chronic liver disease in the UK, the dominance

of alcohol-related and viral causes of the disease alongside popular perceptions of the disease being generally self-inflicted render those living with liver disease likely victims of stigmatisation. Indeed, liver patients are often accused of having brought about their illness through excessive drinking or drug use, regardless of the true cause of their condition (Wainwright, 1997, Sogolow et al., 2010).

The ‘hard work’ of living with chronic illness

Chronic illness requires continuous effort by the ill person to remain actively involved in ‘normal’ life while managing the reality of being different on account of their illness. Three particular areas of ‘work’ for the ill person have been highlighted (Corbin and Strauss, 1985). They have to engage in ‘illness work’ involving ongoing symptom and routine disease management, ‘everyday life work’ relating to their daily tasks and responsibilities in the home or at work, and ‘biographical work’ in relation to the repeated biographical adjustments required along the illness trajectory.

This has been referred to as the ‘hard work’ of living with chronic illness (May, 2006). May (2006, p161) suggests that, “the physiological burden of illness is paralleled not only by a psychological burden, but also by a kind of social exhaustion.” He asks some pertinent questions about the efforts required by sick people to negotiate the practicalities of everyday living as well as the intricacies of interpersonal relationships, wider social organisation, and the healthcare system. Research confirms May’s notion of illness as ‘hard work’. In a participatory research study, people with various life-limiting conditions described a constant struggle to retain their independence in the face of the physical, social and emotional challenges associated with their illness as well as increasing dependence (Cotterell, 2008).

2.4.3 Professional care in chronic illness

The ill person actively seeking to establish control over their situation is commonly considered to have accepted their fate, and therefore to be adapting to their illness in a ‘healthy’ manner. In contrast, the ill person who expresses unrealistic optimism in relation to their situation, or fails to comply with medical instructions, may be perceived as living in denial about their circumstances. Heyink et al. (1989), for example, studied 18 patients who had been rejected for liver transplant. Many

expressed optimism about their future, which was clearly at odds with their actual medical prognosis.

Telford and colleagues argue that the concepts of acceptance and denial have, over time, developed negative connotations (Telford, Kralik and Koch, 2006). Nevertheless, health professionals use them widely and somewhat unquestionably in their assessment of patients' adjustment to chronic illness. Related to this is an implicit understanding that acceptance of one's fate regarding living with a chronic condition is a desirable and 'healthy' outcome, and that it reflects a person's coming to terms with their situation. Denial is seen at best as a necessary phase in the journey towards adjustment and acceptance, but one that must be swiftly overcome.

Relatedly, chronically ill people consider their growing dependence exacerbated by professionals' assumptions and paternalistic attitudes (Cotterell, 2008). Kleinman (1988) argues that current approaches to medical training are too narrowly focused on pathology, favouring those with treatable acute conditions. As a result, many healthcare professionals lack the skills and confidence to adequately recognise and support the complex holistic needs of the chronically ill person and their lay carer, who must struggle on by themselves in managing their increasingly challenging life circumstances. Kleinman (1988) likens this situation to an 'oppressive iron cage', often leading to a mutually frustrating relationship between the individual and the healthcare system. Indeed, patients waiting for liver transplantation felt that poor medical care was contributing to their low mood and declining health (Brown et al., 2006). This negative experience may in part be related to the current shortfalls in service provision and lack of specialist staffing observed in liver care services (Williams, 2004, Williams, 2009).

Having provided an overview of empirical and theoretical literature relevant to the patient experience of advanced liver disease, the following section summarises the intellectual problem highlighted by the literature review with a view to clarifying the rationale for the present study.

2.5 Defining the intellectual problem

The literature suggests that people living with advanced liver disease experience many physical and psychosocial challenges, and often of a greater severity than those reported in other chronic diseases. However, my review found the literature limited in the extent to which it was able to describe the lived patient experience of advanced liver disease. Some physical and psychological support needs can currently only be inferred from more clinically-focused research. While there has been some interest in the psychosocial experience of undergoing liver transplantation, I found only two studies that explicitly explored the everyday, holistic patient experience in advanced liver disease: one study of people with hepatocellular carcinoma (Fan and Eiser, 2012), and one exploring the experiences of females with PBC (Montali et al., 2011).

We currently lack understanding of liver patients' main concerns and priorities in relation to their illness. We also do not know how patients with advanced liver disease experience their medical treatment and care, and in particular their supportive and palliative care, and to what extent the support provided is perceived to meet their needs and goals (Boyd et al., 2012, Hope and Morrison, 2011). Similarly, there is currently little insight into liver patients' social, emotional, existential or information needs, and how these might change over time. All of these issues are likely to have a significant bearing on the perceived quality of life and overall illness experience of both the patient and their family, and may be especially pertinent as their illness progresses towards liver transplantation or death (Osborne et al., 2012). As discussed in Chapter 1, this is of particular interest given ongoing concerns regarding poorer availability of supportive and palliative care services for patients with non-malignant life-limiting diseases compared with cancer patients (Boyd and Murray, 2010).

The typical organ failure trajectory is marked by an erratic progression towards death (Murray et al., 2005) and liver patients' quality of life deteriorates with increasing disease severity (Younossi et al., 2001). This suggests that the patient experience may differ dynamically along the liver disease pathway. It is important to understand how people experience these fluctuations in their condition to allow changing needs to be recognised and responded to with acceptable and effective care. Current

research in liver disease is largely cross-sectional and quantitative. Qualitative longitudinal research which explores and captures the changing nature of patients' health in depth has the potential to provide useful insights here (Murray et al., 2009). This literature review found only one qualitative study using a longitudinal approach to explore patients' experiences of liver transplantation (Lumby, 1997).

In addition, there is currently only a very limited amount of qualitative research in this area. Of the 13 qualitative studies identified, many are situated in the liver transplantation literature and therefore not necessarily representative of the wider patient population with advanced liver disease. Moreover, they commonly employ a retrospective design, asking transplant survivors to recall their experiences prior to transplantation, and are therefore subject to the biases inherent in this approach.

Lawton's review of developments and changes in our conceptual understanding of lay experiences in health and illness stresses the importance of considering timing, setting and individual biographies to help illuminate the complex and diverse ways in which people experience illness (Lawton, 2003). By undertaking research that is qualitative, longitudinal, prospective and generic (i.e. not aetiology- or transplant-focused) I sought to respond to this notion, and to contribute new insights in the realm of advanced liver disease specifically.

2.6 Summary

There are many physical and psychosocial challenges for people living with advanced liver disease. However, no research was identified which describes the holistic, lived patient experience of advanced liver disease in depth. Given the erratic and unpredictable trajectory of the condition, it is imperative that a longitudinal, patient-centred approach is taken to illuminate the dynamic illness experience. I found no research which seeks the views of the individual who experiences and manages this condition through time. Insights have either been provided from a professional perspective or generated from predetermined standard questions. Only by letting affected individuals' illness experiences be told in their own words, and allowing them to speak freely and focus on the issues of greatest importance to them, will we be able to ascertain whether or not their needs are sufficiently supported

through current care structures and pathways. Given the rapidly increasing number of people predicted to be living with and dying from advanced liver disease in coming years, this deserves urgent attention. This study therefore sought to address this gap in our knowledge and understanding.

Chapter 3: Methodology

This chapter sets out the plan for this study, including justification for the choices that were made in the process. It first outlines the theoretical framework and methodology which informed the study design. It then provides details regarding study participation and the data sources used. Finally, it reflects on issues relating to research quality and ethics pertinent to the design and conduct of this study. (How this plan worked out in practice will be described and discussed in Chapter 4.)

3.1 Theoretical considerations

Research in the realm of health has traditionally centred on biomedical enquiry and has been dominated by a positivist, natural science paradigm which uses quantitative methods to verify or falsify a priori hypotheses about a phenomenon. This stance is based on the premise that there exists an objective reality or ‘truth’ independent of human perception, and that to gain an understanding of phenomena the researcher must extract that knowledge from the appropriate source by means of quantifiable methods, thus generating observable, testable and generalisable ‘hard’ data. This dominant approach has attracted increasing criticism over the years, however, and its ability to enlighten phenomena in the realm of human beliefs and behaviour has been questioned (Guba and Lincoln, 1994).

3.1.1 Qualitative research

As the illness experience is inherently a very personal, subjective and sensitive phenomenon, it seems appropriate for the purposes of this study to favour qualitative research methods over the use of more detached and standardised quantitative approaches. This notion is supported by previous end-of-life research showing that patients have a strong preference for a more personal interview approach over questionnaires when sharing such intimate and sensitive matters (Kendall et al., 2007, Sherman et al., 2005).

Despite being commonly presented as a unified approach there is no agreed definition for qualitative research. This is because qualitative research draws on a multitude of different philosophical theories, and a variety of methodologies and

methods are employed under this label. The key common feature of all qualitative research is its primary concern with meanings, perceptions and experiences. As such, it focuses on areas of interest less amenable to quantitative research methods and their focus on measurement and quantification.

Qualitative research employs an inductive approach to facilitate the exploration of poorly understood topics which lack existing theories to describe them. In doing so, it aims to capture the multi-faceted and value-rich contextual dimensions underlying and influencing the phenomenon in question by taking as its focus the perspective of the participant rather than that of the researcher.

3.1.2 Theoretical perspective

It is also important at the start of any research endeavour to acknowledge the theoretical perspective which will underpin and inform the design and conduct of the study (Carter and Little, 2007). This theoretical perspective reflects the fundamental beliefs that the researcher holds and is informed by ontological considerations (i.e. how they understand the nature of reality) as well as epistemological considerations (the theory of knowledge and how it can be demonstrated). The researcher's assumptions in both these areas directly influence the methodology and methods they will select for their study.

There is a wealth of literature describing different theoretical stances and methodologies common in contemporary research (e.g. Creswell, 2007, Crotty, 1998). It has been argued that there is no paradigm that is fundamentally correct or should be elevated above others, as all perspectives are based on human construction and therefore prone to error (Guba and Lincoln, 1994). Nevertheless, as mentioned earlier, the positivist paradigm with its focus on objectivity and quantification has proven particularly dominant in research enquiry. In health research, it is particularly suitable for describing population estimates of a disease problem or the functional relationships between patient characteristics and their health status.

In consulting the theoretical literature to identify my personal belief system underpinning my research, I was mindful of Creswell's argument that the adoption of

a particular stance did not oblige the researcher to always frame their research within that perspective (Creswell, 2007). Rather, different approaches may feel appropriate for different research endeavours. I found myself generally sympathetic to a pragmatist worldview which does not subscribe to a particular philosophical perspective, leaving the researcher to select those methods or procedures deemed most appropriate to answer their research questions within the parameters of the project in question. In respect of the subject matter and aim of the present study, however, I identified most closely with the constructivist paradigm as reflective of my own views and assumptions on the nature of reality in this context.

The constructivist paradigm

Constructivism takes as its focus the construction of meaning within the context of interaction with others (Berger and Luckmann, 1967). As such, it rejects the positivist notion of an objective truth and argues instead that there exist in fact multiple realities which are constructed by means of human interaction. This thinking constitutes an important shift away from ontological realism towards a more relativist stance. In the present study, this relativism is reflected in the notion that the illness experience is an inherently subjective experience as represented by individual, context-bound accounts.

Constructivism holds the epistemological premise that meaning and knowledge do not exist independently, simply awaiting excavation by the researcher, as suggested by conventional approaches. Conversely, it contends that both meaning and knowledge are actively constructed and understood through social interaction (as a result this approach is commonly referred to as 'social constructivism'). In the context of the research endeavour then, it is impossible to separate the researcher from their inquiry, as they play an active role in the construction of the reality they seek to investigate (Mantzoukas, 2004). Moreover, as each party brings their own values to knowledge construction, it is similarly impossible to remain free of the effects of those values and biases (Guba and Lincoln, 1989).

This is counter to the conventional tradition, which seeks to eliminate from its research any contextual variables that may confound the data. Rather than view the

influence of values as a contaminating factor in the research process, Guba and Lincoln (1989, p102) argue that, “values must be accorded a central place in human study because they come closer to the core of humanness than most other characteristics of people.” Consequently, it is necessary as a qualitative researcher to acknowledge the value-laden character of one’s study and to be reflexive and transparent about one’s own positioning in the research report (see Section 4.8 for my reflections on my role as researcher).

Given the above assumptions, a constructivist approach is unable to respond to positivist demands for the verification of scientific ‘truth’. Rather, its particular aim is discovery and the creation of a deeper understanding of a phenomenon (Schwandt, 1994). Consequently, understanding of the lived experience is sought through naturalistic methodologies and the viewpoint of those whose experiences are the object of investigation. A constructivist approach therefore responds well to the broad, exploratory intentions of this research, at the core of which lies the exploration of the dynamic needs and experiences of people with advanced liver disease and those of their carers.

3.2 Methodology

3.2.1 Selecting a research method

I assessed a number of methods for their suitability to help meet my research objectives. As outlined in the literature review, a number of studies in the realm of health-related quality of life in advanced liver disease sought to gather this type of information by way of questionnaire surveys. However, such an approach can only illuminate pre-determined topic areas, and can therefore only verify the researcher’s assumptions rather than generate a broad set of data reflective of the participant’s perspective. Moreover, a survey approach is limited in the extent to which it can tap into people’s thoughts, feelings and understandings of their situation. This subjective insight is crucial in enlightening the lived experience of advanced liver disease, however. Finally, patients are keen to share more personal experiences than a questionnaire allows (Kendall et al., 2007, Lowe et al., 1990, Sherman et al., 2005).

In considering my options within qualitative research then, I rejected the use of observational methods. I felt that such an approach would be unlikely to generate the same breadth of insight as could measures based on self-report, especially given the changeable and unpredictable nature of the advanced liver disease trajectory. I further anticipated challenges in relation to recruitment and ethics which could not easily be accommodated within the scope of this project.

I also rejected the use of text analytical methods like the diary method; that is, to collate participants' thoughts on their needs and experiences as written up in their own words. I deemed this approach inappropriate for this study on the grounds that people in the advanced stages of liver disease would likely be too unwell to be expected to sustain keeping a regular diary over the duration of a year. It would also require a much greater time investment on the part of the participants than other methods. Given their challenging and time-limited circumstances, I considered this too much of an imposition to place on these individuals.

I also ruled out the use of group interviews, or focus groups, on the basis of two considerations. Firstly, I felt that the topic in question was too personal and sensitive to be shared in a group setting. While some participants may appreciate the supportive environment a group discussion among peers can provide, there is the potential for causing distress in others, especially in relation to uncertainty or ignorance as regards prognosis and the contemplation of matters around death and dying in which some may not wish to engage. Secondly, I dismissed group interviews based on the supposition that different causes of chronic liver disease may bring about different needs and experiences for both patient and carer; I felt that this may be easier to establish using an individual approach.

Based on the above considerations, as well as a review of relevant literature, I concluded that the use of serial individual interviews would be best suited to the intended outcomes of this study.

3.2.2 Making the case for qualitative interviews

Bury (2001, p264) argues that, “Not only do language and narrative help sustain and create the fabric of everyday life, they feature prominently in the repair and restoring of meanings when they are threatened.” As such, narrative constitutes a key vehicle for exploring the lived experience of serious illness. Allowing individuals to speak freely about their life with illness sets this experience within the context of their life as a whole, and therefore enables an insight into how the illness interacts with the complexities of everyday life and how this is experienced and managed by the ill person. It also has the potential to go beyond the story itself to reveal how the illness affects the person’s sense of self and the strategies they employ to reconcile such challenges.

Open-ended or unstructured interviews are the most flexible approach by which to gather relevant data and are therefore well suited to the exploration of topics where little is currently known. Their loose format allows respondents to focus on the issues of greatest importance or relevance to them and thus to guide the direction of the conversation, thereby promoting the exploratory nature of the study. If conducted ethically and diligently, it is also an approach which is sensitive to participants’ needs, as it allows them maximum agency and control over what, when, how much and in what way to share information as part of the interview process. As Corbin and Morse (2003, p338) explain, “Unstructured interviews are shared experiences in which researchers and interviewees come together to create a context of conversational intimacy in which participants feel comfortable telling their story.” Interviews also reflect the essence of constructivism by virtue of their grounding in human interaction and construction (Mason, 2002). Interviews are, by their very nature, inescapably active and constructive (Holstein and Gubrium, 2004). Asking questions of a person is an unavoidably interactive process which engages the respondent in a process of making sense of their world, and consequently fosters the active creation of meaning and understanding.

Kvale (1994) explores a number of objections regularly levied against the contribution qualitative research interviews make to scientific inquiry, many of which originate from a positivist stance. However, some of these objections must be

challenged on the basis of being grounded in terminology which in itself is poorly defined and at times ambiguous. He also argues that there is too strong a focus on a perceived dichotomy between qualitative and quantitative concepts which, on closer inspection, is not borne out in reality. Indeed, some of the criticisms against qualitative interviews are equally applicable to quantitative methods. Kvale (1994, p169) concludes that, “in the long run the scientific merits of qualitative research will not be established by arguments of legitimation, but by contributions of significant new knowledge about a linguistically constituted social world.”

Multi-perspective interviewing

The present study employed a multi-perspective approach by seeking the views not only of patients, but also their main lay and professional carers. The intention was to gain as complete a picture as possible of the multi-dimensional experience of living with advanced illness by effectively creating in-depth, multi-perspective case studies, while also allowing for the consideration of the individual needs of those interviewed.

While a multi-perspective approach poses challenges in terms of time investment and complexities of data analysis, it provides a number of important benefits (Kendall et al., 2009). Multi-perspective research not only generates a deeper understanding of the lived illness experience, but also has real value in practice development by facilitating the formulation of recommendations for more supportive or effective practice as informed by the different perspectives and needs of those consulted.

Single versus joint interviewing

Giving participants the option of undertaking individual or joint interviews may improve research participation (Kirchhoff and Kehl, 2008). In similar research involving patients and lay caregivers around half preferred to be interviewed together (Kendall et al., 2009).

This was also true for studies conducted by Gysels and colleagues, which led to the researchers undertaking both individual and joint interviews as per participants' preferences (Gysels, Shipman and Higginson, 2008). They argue that conducting joint interviews generated interesting data on how the illness situation was

experienced and negotiated in a close relationship. At the same time, they found this arrangement to generate different data from when individuals were interviewed separately. These findings, however, contrast those of Morris (2001), who undertook joint interviews with cancer patients and their carers and found that they produced similar accounts to those conducted individually.

While joint interviewing may cause some participants to hold back on certain information they do not wish to disclose or discuss in front of the other person, individual interviews can equally lead to tension between patient and carer by creating a sense of secrecy and challenges relating to the disclosure or non-disclosure of what each party had shared in their respective interviews (Morris, 2001). Moreover, joint interviewing can lighten the burden on particularly vulnerable or poorly patients, as it allows that person to take rests during the interview as needed but still continue to participate (Morris, 2001).

3.2.3 Longitudinal approaches in qualitative research

Drawing on the findings from the literature review in Chapter 2, this study was formulated around a qualitative, longitudinal (QLL) research design. This allowed a consideration of the dynamic experience of living with advanced liver disease by studying key points and changes in participants' experiences and needs over time.

Longitudinal approaches are traditionally more common in quantitative research, but the value of applying a longitudinal approach in the qualitative realm is increasingly recognised, particularly in relation to informing and influencing policy and practice (Holland, Thomson and Henderson, 2006). There is currently no consensus on the timeline that is considered to constitute longitudinal research and a number of approaches are in use (Saldaña, 2003). In the realm of patient research, it has been posited that the timeframe for data generation must be sufficiently long to enlighten and understand the trajectory under investigation (Murray et al., 2009).

Based on considerations regarding the nature of advanced liver disease, previous end-of-life studies as well as the realistic scope of a PhD project, it was decided that data generation should be conducted over the course of 12 months, with the aim to

seek up to three interviews with each participating patient and lay carer. This reflects criteria set out by Young, Savola and Phelps (1991), who stipulate that in order to be considered truly longitudinal, QLL studies in the social sciences should aim for at least 2-3 data collection points over the course of at least a year.

Saldaña (2003) provides comprehensive guidance on the conduct of QLL research and identifies duration, time and change as the core principles underlying this approach. He also advises giving attention to the context in which change is observed and examined. It is these aspects which make QLL research particularly valuable, as their consideration makes it possible to illuminate characteristics of human experience not usually amenable to one-off research endeavours. Serial interviews can generate a variety of types of findings (Murray et al., 2009), thus demonstrating the potential of QLL methods as an effective ‘means of discovery’ (Holland, Thomson and Henderson, 2006). In the context of this study, it was anticipated that the longitudinal design would capture changes in the needs and experiences of patients and carers as the illness progressed, and highlight key points in the illness trajectory.

A QLL approach renders data analysis more complex and time-consuming than does ‘snapshot’ research and tends to generate large amounts of data, which may subsequently be difficult to manage (Holland, Thomson and Henderson, 2006). One characteristic of QLL research that requires particular attention is the way in which it increases the need for ethical considerations and conduct throughout the research process, such as seeking consent repeatedly at each data point and ensuring confidentiality in the face of large personal data sets being generated for each participant (Neale and Hanna, 2012).

It is particularly important to be mindful of the developing research relationship and its influence not only on the research process, but on researcher and researched alike (Thomson and Holland, 2003, White and Arzi, 2005). A QLL approach allows participants and researcher to develop their relationship over time, thereby supporting both parties to feel more at ease with the exploration of sensitive and personal issues in relation to the illness experience. It consequently facilitates the

sharing of more private accounts over primarily public illness discourse (Cornwell, 1984), and enables a more in-depth insight into their experiences than may be possible through a single interview (White and Arzi, 2005). A further benefit in QLL research is the flexibility it allows the researcher throughout the research process, especially in terms of being able to feed findings from earlier interviews back into the process to allow for further exploration or clarification.

3.3 Patient and public involvement

Despite a current lack of rigorous research into the benefits and efficacy of patient and public involvement (PPI) in palliative care, it is considered good research practice to consult and collaborate with individuals representative of the study population throughout the research process (Payne et al., 2005). Indeed, turning participants from passive objects of investigation into active participants in the shaping of palliative care research and practice is considered an ethical imperative (National Council for Palliative Care and NHS Centre for Involvement, 2009). Co-researching with a group of palliative care patients has been reported as an empowering experience for participants, creating ownership among those the research is targeting, and greatly enriching the study by harnessing their expertise and insight (Cotterell et al., 2007). Moreover, PPI helps to ensure that research priorities reflect those of the target population; this is vital for ensuring patient-centred, resource-efficient delivery, planning and evaluation of healthcare provision. PPI is regularly employed in the realm of cancer, but less commonly seen in non-malignant disease (Black, 2008).

PPI can take many forms. The chosen method should be informed by the nature and aims of the activity in question as well as available resources (National Council for Palliative Care and NHS Centre for Involvement, 2009). As a novice researcher in the realm of advanced liver disease, I was especially keen to work in partnership with lay ‘expert’ participants to guide my thinking and decision-making as the study evolved. Patient involvement in the context of this study was promoted as follows:

- Informal discussion with two individual liver disease patients who volunteered to share their experiences in the formative stages of the project. These conversations helped to develop my understanding of living with advanced liver disease, and informed the content of the interview guide and patient information sheet. They also provided an opportunity to reflect on the potential emotional impact of participants' illness stories on me as researcher.
- Regular meetings with a lay advisory group to scope, explore and discuss lay members' own experiences as liver patients as well as to seek their concerns, thoughts and advice in relation to the research process. Their involvement contributed to the data generation, analysis and dissemination aspects of the study. A description of the lay advisory group and reflections on its contribution to this research are provided in Section 4.5.

3.4 Participation

3.4.1 Sampling

In contrast to quantitative approaches which typically employ probability sampling, a qualitative approach commonly utilises purposive sampling methods. This reflects not only its primary aim of exploring social processes where achieving statistical representativeness is of less relevance, but also the commonly more time and cost consuming nature of qualitative research. In this study I employed a variation of purposive sampling referred to as selective or criterion sampling (Sandelowski, 1995). By selecting a sample that reflects a range of aetiologies typical in liver disease (e.g. alcohol-related, viral, autoimmune), the study gives due attention to what can be considered a key variable in the phenomenon under investigation and renders the sample representative of the varied liver disease patient population.

Qualitative research is frequently accused of using sample sizes that are considered too small or unrepresentative to generate reliable data. However, as described earlier in this chapter, its key aim is not to achieve generalisability, but to generate information-rich data through the in-depth investigation of a phenomenon. I agree with Sandelowski's notion that sample size should be determined on the basis of case appropriateness as opposed to pre-determined formulae (Sandelowski, 1995). She

contends that, “An adequate sample size in qualitative research is one that permits – by virtue of not being too large – the deep, case-oriented analysis that is the hallmark of all qualitative inquiry, and that results in – by virtue of not being too small – a new and richly textured understanding of experience.” (Sandelowski, 1995, p183). Kvale (1994) similarly feels that sample size depends on the purpose of one’s study, and that if the purpose is to generate a general understanding then it is better to focus on a smaller sample but to investigate it more intensely. In palliative care research specifically, the argument of qualitative methods being less effective due to a small yield has been shown not to hold up, with some quantitative studies in the field achieving recruitment rates of 17% or less (Hopkinson, Wright and Corner, 2005).

I aimed to recruit 16 to 20 patients with advanced liver disease of different aetiologies to the study, with an expectation that this would generate around 30 co-participants (15 lay carers and 15 professionals). This decision was guided by a number of key considerations, such as the scope of the study and the nature of the topic itself (Morse, 2000). It was also informed by previous studies in this field, which suggested this target number sufficient to achieve data saturation without generating an amount of data too unwieldy for in-depth analysis. The purposive selection of the sample to contain the most representative contributors, however, goes some way towards ensuring that the insight generated is as illustrative as possible of the wider liver patient population.

3.4.2 Identification of participants

Defining the patient with advanced liver disease

Unlike other organ failures, there is currently no agreed clinical definition of what constitutes advanced or end-stage liver disease. A review of the research literature in end-stage liver disease revealed a range of indicators used to define this population. The most commonly used tools for mortality assessment in advanced liver disease are the Child-Pugh and MELD (Model of End-Stage Liver Disease) scoring systems. However, these scores were not routinely calculated for patients at the recruiting centre and were therefore not a convenient selection criterion.

There is also no agreed method for defining the patient population in palliative care research (Borgsteede et al., 2006, Van Mechelen et al., 2012). For the purposes of their longitudinal study involving cancer, COPD and chronic heart failure patients, Steinhauser and colleagues defined 'end of life' broadly to include individuals with a 50% one-year mortality, a figure which was in line with the expected attrition rate for the present study (Steinhauser et al., 2006). The authors argued that a 50% one-year survival for an advanced disease means that most research participants should be able to take part in the study effectively and across multiple time points. At the same time, in the event of a patient's death during the study, it provides an opportunity to gain valuable insight into the final stages of the illness experience through retrospective follow-up with their carer. As this notion reflected the intentions of the present study it informed the adoption of the following recruitment criteria.

Inclusion criteria

In consultation with hepatology consultants it was decided to recruit patients with the presence of ascites (accumulation of fluid in the abdomen). Ascites constitutes the most common complication of advanced liver disease and an indicator of decompensation (i.e. the point at which the liver's ability to adequately perform its range of functions ceases) (Ginés et al., 1987). Ascites is also indicative of a poor prognosis; once developed, cirrhotic patients' expected mortality is approximately 50% at 2 years (Guevara et al., 2005). While this represents a wider window of time than that used by Steinhauser and colleagues, this approach was more likely to capture people with advanced disease more generally as opposed to those in the end stages, thereby responding more effectively to the broad, exploratory intentions of this project. Recruitment targeted both patients whose ascites were for the most part well controlled by diuretic medication, and those with diuretic-resistant ascites requiring regular draining of the excess fluid through a procedure called paracentesis.

Exclusion criteria

I excluded from the study those patients who were listed on the liver transplant register. This was due to the consideration that such patients were likely to have differing needs and experiences from those for whom this potentially life-saving intervention was contraindicated on the grounds of general frailty, co-morbidities or

continued drinking or drug-taking. Unlike their counterparts for example, liver transplant candidates receive dedicated care and support from a specialist hospital transplant team. They are also likely to be nurturing a strong sense of hope that their illness can be reversed through a transplant and that they will eventually be able to return to a normal, healthy life. Given the relatively small sample size of this study, I therefore felt that data gathered from these patients may dilute the overall findings. Moreover, there is already a substantial body of literature on the specific experiences of patients pre- and post-liver transplant, which is in contrast to a distinct dearth of literature on the experiences of patients who do not qualify for this intervention.

Patients were therefore excluded from the study if they:

- had another long-term condition or cancer as their most significant conditions,
- were judged by ward staff to have cognitive impairment, emotional distress or communication difficulties of a severity that would prevent them from participating in the study,
- were listed on the liver transplant register.

3.4.3 Recruitment

Consultation with the liver specialists also informed the decision to target adult patients attending the ward as inpatients due to a liver-related event. Patients were recruited from a 30-bed specialist gastroenterology and hepatology inpatient unit. This was deemed to be the most convenient location at which to access people in the advanced stages of the disease. The same liver unit had also recently hosted another research project in the realm of supportive and palliative care, and ward staff were therefore supportive and ideally ‘primed’ to assist with this study.

Patient recruitment procedure

I set out to recruit 16 to 20 socially diverse patients with a range of disease causes to the study. In consultation with clinical staff at the liver unit a recruitment strategy was formulated and agreed. Figure 4 overleaf provides a flowchart of the agreed recruitment strategy.

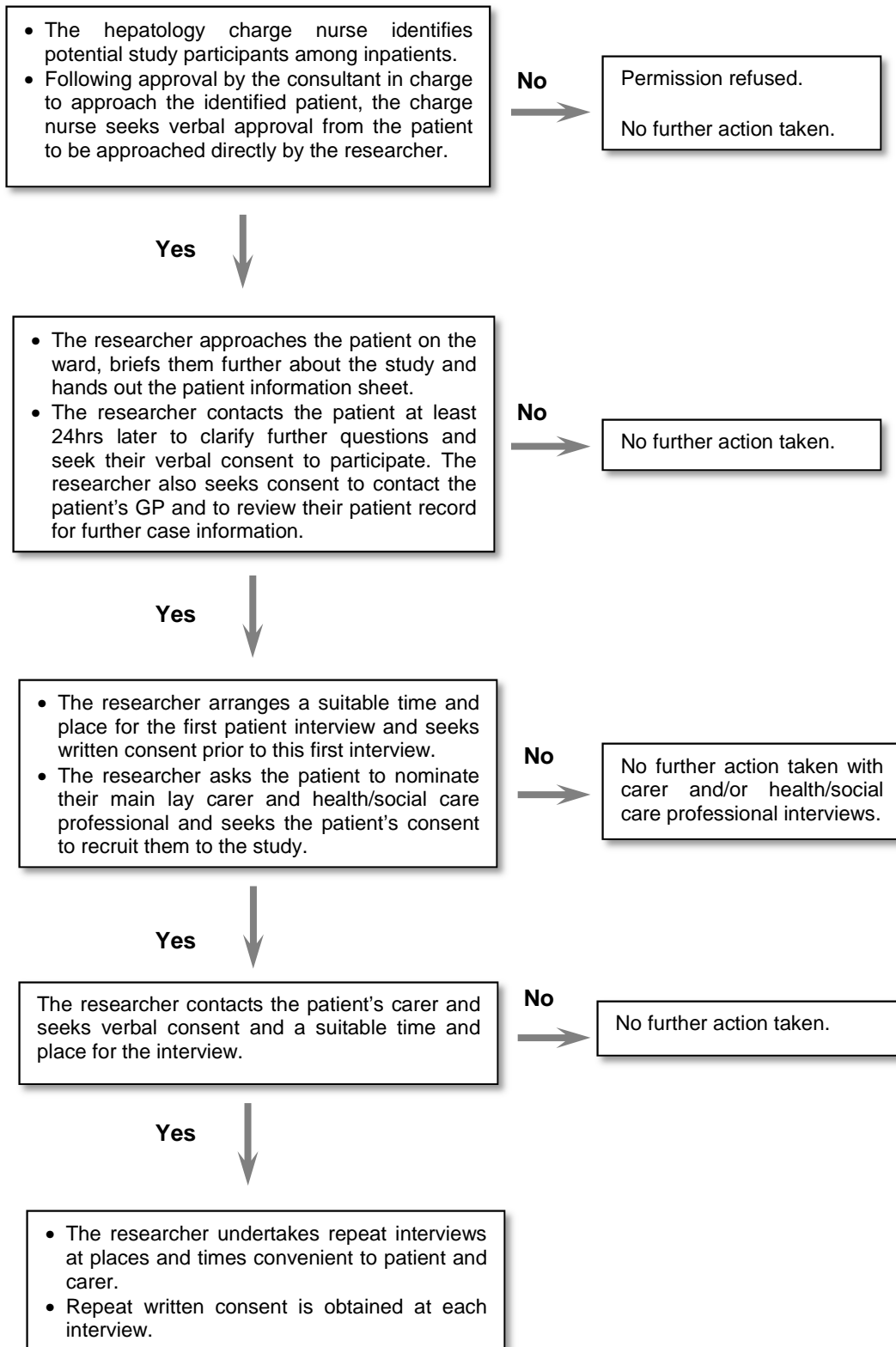


Figure 4: Flowchart of recruitment process

Recruitment of lay and professional carers

In keeping with a patient-centred approach, participants were asked to nominate the person they felt provided most of their support and care at home to be approached about contributing to the study. They were also asked to nominate the health or social care professional they felt was most involved in their clinical support and/or social care in respect of their liver disease.

Lay and professional carers were sent an information sheet explaining the purpose of the study and their involvement alongside a letter inviting them to participate in the research. This was followed up with a telephone call some days later to allow for questions to be clarified. If carers agreed to take part, arrangements were made for a convenient time and place to conduct the first interview.

3.4.4 Attrition

Given participants' advanced illness status, attrition was a key consideration in this research. The study design was informed by the experience of previous similar studies suggesting an average attrition rate of 50% at one year. Loss to death was an anticipated and intentional aspect of this study, serving to gain important insights into the needs and experiences of participants around this critical time through bereavement interviews with both lay and professional carers where appropriate.

3.5 Data sources

This study drew on three data sources: qualitative in-depth interviews, extensive field notes and patients' medical records.

3.5.1 Interviews

Interviews were guided by a loose topic guide based on the main areas of interest within the chronic illness experience such as receiving a diagnosis, managing the illness in everyday life, and care and support provision. Guides were used flexibly, however, to allow participants to be in control of the flow of the conversation and to speak as freely as possible about the issues of greatest concern to them. Copies of the interview topic guides can be found in Appendix 3.

Patient and lay carer interviews

Up to three in-depth interviews were conducted with each patient and lay carer over 12 months to facilitate the exploration of their needs and experiences over time. The interviews sought to elicit participants' accounts of their experiences leading up to the present circumstances, their current physical, psychosocial, existential and information needs and issues, and their thoughts about the future. Follow-up interviews sought to explore the evolving needs of patients and lay carers, and the adequacy of services and support provision.

Bereavement interviews

Where a patient died during the interview period a card of condolence was sent to their lay carer. Further contact was made about three months later to establish carers' interest in participating in a bereavement interview. Bereavement interviews sought to explore the patient's final episode of decline and the support and care offered to both patient and carer during that time.

Professional carer interviews

One-off interviews were conducted with the health or social care professionals. These interviews were undertaken at the end of the serial interview period for each patient and explored professionals' views of the illness trajectory and care of that patient as well as the wider patient population with advanced liver disease, and any perceived challenges in providing effective care. Given the difficulty of accessing busy professionals for research activity and the principal focus of this study being the person living with the disease, one-off rather than serial interviews with professionals were deemed sufficient to add important contextual information to the overall research endeavour.

3.5.2 Field notes

Extensive field notes were recorded in parallel to the recruitment and data generation phases to contextualise the interview data. The field notes document interactions with study participants during telephone conversations and interviews, events observed on the liver ward, and early analytical hunches. They also provide a record of reflections on practical and personal challenges and successes during the

recruitment and interview phases, ethical issues or dilemmas, and on my own skills, behaviour and prejudices as researcher.

3.5.3 Patient records

All patient participants consented to basic details being extracted from their medical records in order to provide supplementary clinical context to their experiences, and to allow for general comparisons to be made between participants and the wider patient population with advanced liver disease. Data recorded includes age, disease cause, co-morbidities, clinical parameters to calculate patients' MELD scores, frequency of hospital admissions relating to their liver disease, and death-related information where applicable. DEPCAT (deprivation category) scores, which give an indication of participants' socioeconomic status, were also calculated. An overview of some of these details is provided in Appendix 4.

3.6 Data analysis

The study data were analysed using analytical techniques drawn from grounded theory. Grounded theory has its origin in the work of Glaser and Strauss (1967), but has since been developed further by a number of its proponents (Charmaz, 2006, Strauss and Corbin, 1998). Grounded theory centres on an exploratory, iterative analytical process which seeks to move beyond description to generate new, or modify existing, theory about a phenomenon directly from the data as opposed to a priori hypotheses as is typical in scientific enquiry. Its particular focus is on the processes underlying people's experiences of a phenomenon. It is therefore a useful approach when looking to explore topics where little is currently known (Creswell, 2007), and is frequently employed in chronic illness research. Additionally, a central tenet of grounded theory is its consideration of individuals not as passive recipients, but as active agents in the research endeavor, a notion which is consistent with my theoretical position outlined earlier in Section 3.1.2. Charmaz' grounded theory approach in particular reflects a more subjective and reflexive, and as such more constructivist, stance than those purported by others (Charmaz, 1990). I consequently chose this approach to inform the data analysis of this study (Charmaz, 2006). Details of the analytical process itself are set out in Section 4.4.

Like other methodological approaches, grounded theory analysis is subject to limitations (e.g. Cutcliffe, 2000, Elliott and Jordan, 2010) and prone to misinterpretation (Suddaby, 2006). It has, for example, been criticised for some of its basic assumptions, its messy, non-linear approach to analysis, and what is perceived to be an over-fragmentation of data. I drew on practical strategies suggested by Elliott and Jordan (2010) to avoid some of the common pitfalls in grounded theory analysis.

3.7 Quality assurance

3.7.1 Rigour in qualitative research

Qualitative research is commonly accused of being less rigorous than quantitative approaches due to its perceived inability to adhere to scientific principles like validity, reliability and generalisability. At the same time, there are those who argue that it is in fact inappropriate to impose similar quality criteria to approaches that differ so widely in their underlying philosophies and the type of knowledge they seek. Mays and Pope (1995) argue in defence of qualitative research and claim that all research methods carry particular strengths and weaknesses, and that rigour in any type of research relies on a systematic, reflexive and transparent research process. Being explicit about one's approach and decisions should enable an independent researcher examining the data to arrive at corresponding conclusions. This consequently serves to confirm a study's rigour, thus making its findings acceptable and of value to the wider scientific community.

I question the applicability of this thinking to all qualitative research, however. As stated in Section 3.1.2, this study is underpinned by a constructivist philosophy. This stance sees knowledge as created through interaction, with the researcher playing an active role and shaping the process through their own perspective, values and experiences. I would argue that the same holds true for an independent researcher engaging with the data at a later stage. They too are likely to be influenced in their analysis by the personal background and perspective they bring to the activity, resulting in further manipulation and interpretation of the research product. Consequently, while it must be considered good research practice to operate in an

open and auditable manner, I disagree with Mays and Pope's notion that doing so provides a basis on which qualitative research studies should be assessed for their achievement of rigour (Mays and Pope, 1995).

Indeed, I share Rolfe's viewpoint in this matter (Rolfe, 2006). He criticises ongoing attempts to impose quality criteria from quantitative approaches to qualitative research, but also declares it a futile endeavour to try and develop a set of standards specific to the characteristics of qualitative research. This is because, as highlighted earlier in Section 3.1.1, qualitative research is not a unified, coherent paradigm as commonly presented in research text books, but incorporates a multitude of different beliefs and methods, with some in fact more closely aligned to a positivist stance than interpretive counterparts.

Rolfe also observes that the assessment of the quality of a piece of research in reality entails making subjective judgements on the way it is presented to the reader as opposed to the study per se - this applies to both qualitative and quantitative work. As such, he highlights the importance of providing a comprehensive audit trail which details considerations and decisions throughout the research process as well as reflexive notes from the researcher's perspective. These should then be considered in conjunction with the research report itself to allow for overall quality judgements to be made. In the present study, I have sought to respond to this idea by recording detailed information on my decisions throughout the research process as well as reflexive thoughts in relation to my role and experience as researcher; Chapter 4 presents details in this respect. This also reflects my theoretical 'home' within constructivism as it acknowledges that, as a result of my involvement, I am both explicitly and implicitly represented in the work that I present (Mantzoukas, 2004).

3.7.2 Reflexivity

It is considered important that researchers seek complete neutrality in order to avoid contaminating their research. However, both researcher and researched have been shown to influence the research process through a multitude of factors such as their positionality (Moser, 2008, Reinharz, 1997), personality (Moser, 2008), different 'selves' (Reinharz, 1997), unconscious processes (Bondi, 2003), and intersubjective

dynamics (Gadd, 2004). It is therefore vital that researchers acknowledge and reflect upon these issues in order to make their research more transparent and present data generation and analysis within the context in which they were created.

In line with recommendations by Finlay (2003), a reflexive stance was taken at all stages of the research process, employing both introspective and intersubjective reflection. Introspective reflection involves an in-depth consideration of my own role as researcher and the ways in which I may influence the process and outcomes of the study as described above. It also requires a conscious awareness and focus on both discursive and embodied self-reflexive processes as sources of insight and learning (Pagis, 2009). Intersubjective reflection refers to the close consideration of the researcher-participant relationship and their respective contributions to the research process. My learning in relation to these issues is reflected upon in Chapter 4.

3.8 Ethics of conducting research in palliative care

Four ethical principles underlie all professional conduct in the health sphere: autonomy (i.e. self-determination), beneficence (maximising good), non-maleficence (avoiding harm) and justice (i.e. fairness and equity) (Beauchamp and Childress, 1989). They constitute a “common moral commitment, common moral language, and common analytical framework for reflecting on problems in health care ethics” (Gillon, 1994, p184) and as such constitute key guidance for the conduct of research in the healthcare setting. Guillemin and Gillam (2004) distinguish between ‘procedural ethics’, which are generally subject to approval by an ethics committee, and ‘ethics in practice’, that is, the everyday ethical issues that may arise in the process of conducting a study. They argue that ethics in practice are of particular importance, as it is the researcher’s conduct throughout the research process which ultimately determines a study’s ethical appropriateness. It is therefore vital that the researcher remains alert to any potential ethical issues arising in the course of the study and continuously reflects on their conduct and decisions.

There has been much debate around involving patients nearing the end of life in consultations. A review of the main ethical debates in palliative care research concluded that no clear consensus exists on some issues, with some areas requiring

further exploration (e.g. the impact of such research on the researcher) (Duke and Bennett, 2010). However, there seems to be an increasing shift towards a general acceptance that it would be ethically and morally wrong to exclude these individuals from research involvement based on an assumption that it is too challenging, potentially harmful, or imposes on their limited time. Studies increasingly show that palliative care patients are in fact no more vulnerable than others (Addington-Hall, 2002, Casarett and Karlawish, 2000). Additionally, many ethical challenges levied against palliative care research are not unique to that realm (Casarett, Knebel and Helmers, 2003).

Most importantly, patients themselves wish to participate in research and particularly in qualitative research (Kendall et al., 2007, Sherman et al., 2005). It offers a purpose and role at a time when they may feel isolated and excluded from their social world due to advanced illness, and provides an opportunity to leave behind a legacy by being instrumental in helping others to experience improved care and support. Jubb (2002) contends that there is no justification for not undertaking research with palliative care populations to improve their standards of care, provided that the research is ethically sound. Keeley (2008) goes one step further, calling it a ‘moral obligation’.

3.8.1 Qualitative interviewing in palliative care research

The choice of qualitative interviewing in this study was in part informed by its previous successful application in several end-of-life studies (e.g. Cavers et al., 2012, Murray et al., 2002, Pinnock et al., 2011). Despite the important insights that this approach has generated, there remains some debate about whether it may in fact be harmful to participating patients and their carers.

Corbin and Morse (2003) examine some of the issues in relation to conducting interviews on sensitive topics. They suggest that the risks of breaking confidentiality or causing distress are actually greater when individuals confide in family or friends than when they participate in an ethically conducted, risk-controlled qualitative interview study. They conclude that while qualitative interviews may have the potential to cause some emotional upset, “there is no indication that this distress is

greater than in everyday life or that it requires follow-up counselling” (Corbin and Morse, 2003, p335). If anything, they contend, existing evidence suggests that there is more benefit than harm in taking part in potentially emotive research studies. This argument is supported by Gysels, Shipman and Higginson (2008), who assessed how palliative care patients and their carers taking part in two different qualitative studies had experienced being interviewed. Most of their respondents reported a positive experience and none of them considered being interviewed distressing. Furthermore, despite the authors observing their interviews with carers as very emotional events, carers themselves did not relate their distress to the interview process.

In light of the debates outlined above, participants’ welfare was of paramount importance in this study. I describe the steps undertaken to ensure both participant and researcher welfare in this study in Sections 4.7.1 and 4.7.2 respectively.

3.8.2 Ethical approval

This study was granted full ethical approval by South East Scotland Research Committee 1. Management approval was conferred by the NHS Research & Development Programme. Copies of the approval letters are provided in Appendix 5.

3.9 Summary

The research methodology and design for this study were informed by a constructivist theoretical perspective. Qualitative serial in-depth interviews were selected as the method most appropriate to help meet the research aim. Patient participants were sampled purposively and according to criteria agreed with liver specialists. They were recruited from an inpatient liver unit with the help of clinical staff. Patients nominated lay and professional carers involved in their support and care to approach to take part in the study. Data were analysed using methods based on the constructivist grounded theory approach advocated by Charmaz (2006). Patient and public involvement was sought to support the research process. Quality assurance and ethical study conduct were given utmost consideration.

Chapter 4: Conducting the study: process and reflections

The previous chapter outlined the plan for the study and the reasons behind it. This chapter describes how this plan worked out in practice. It documents the conduct of the study with regard to recruitment, participation, interviews and data analysis. It also details the involvement of the lay advisory group and its contribution to this study. I reflect upon the strengths and weaknesses of the chosen approaches and describe successes and challenges encountered during the research process. Finally, I consider my own place within this process as the researcher conducting this study.

4.1 Participants

4.1.1 Patients

Recruiting patients to this study proved challenging for several reasons (see Section 4.2.1 for some of the difficulties encountered in relation to patient recruitment). 38 patients were invited to participate in the study, of whom 25 agreed. Ten of these were lost to the study prior to their first interview, as they withdrew due to declining health, died, or could not be tracked down for interviewing. As a result, a total of 15 patients participated in this study. (My thoughts on the appropriateness of the sample size achieved are given at the end of this section.)

Fourteen patients remained in the study until they had completed three interviews or until their death, whichever came first. One patient was lost to follow-up as her condition deteriorated after the first interview and remained so poor that she had to be withdrawn from further participation. Nine participants died during the study.

Table 2 overleaf provides an overview of the 15 patients who participated in this study.

Number of patient participants	15
Male/Female	7/8
Mean age (range)	58.8 (35-84)
<i>Primary aetiology:</i>	
Alcohol-related liver disease	8
Non-alcoholic fatty liver disease	3
Hepatitis C	1
Hepatocellular carcinoma	1
Autoimmune hepatitis	1
Cryptogenic	1
Mean MELD ¹ score at time of recruitment (range)	16.3 (9-26)

Table 2: Overview of patient participants

4.1.2 Lay carers

11 of the nominated lay carers agreed to take part in the study. Two patients nominated two persons each and four did not nominate anyone. Two nominees declined participation. The nature and scope of the individual carer roles varied greatly and was defined by the type of relationship that patient and lay carer shared. Of the participating carers, seven were live-in spouses or partners and two were a patient's mother and sister. They provided the broad, holistic support typical of a close, familial relationship. One carer participant, however, was the patient's closest friend, who lived some distance away in another town and provided support mainly by telephone. Another carer participant was the patient's neighbour who looked in on him daily and assisted mainly with minor household chores.

Finally, one patient's carer participant changed in the course of the study. At the time of his first interview John² was living with his partner Jane, who supported him following his first acute hospital admission and subsequent diagnosis with advanced liver disease; she participated in a first interview. By the time of the second interview

¹ The MELD score is used as an indicator of the severity of liver disease and predictor of mortality. It is derived from three clinical parameters (serum bilirubin, prothrombin time international normalised ratio, serum creatinine). A score of 15 or more is considered an appropriate level at which to consider a patient for liver transplantation. (MERION, R. M. 2004. When is a patient too well and when is a patient too sick for a liver transplant? *Liver Transplantation*, 10, S69-73.)

² Not his real name. As stated in Section 1.5, all patients and lay carers were assigned pseudonyms.

John had returned to his wife Lisa; she participated in the remaining two interviews. This highlights a need to be mindful of the varied nature and scope of lay caregiving that can exist in patients' lives, which may also affect the extent to which individuals relate to the label of 'carer' in the role that is provided (Morris, 2001).

4.1.3 Professional carers

Ten patients nominated a health or social care professional involved in their ongoing clinical support and/or social care; one patient nominated two individuals. All agreed to be interviewed for this study. This group of 11 professional carers comprised of eight general practitioners (GPs), one consultant hepatologist, one hospital-based alcohol liaison nurse, and one community palliative care nurse.

A comment on sample size

The sample size of 15 patients and associated lay and professional carers was less than initially targeted, but proved sufficient for the exploratory aims of this study. A relative uniformity of views and experiences across patient, carer and professional accounts emerged early on in the interviews, suggesting that themes were approaching saturation. The sample was also large enough to accommodate the predicted attrition rate of 50%, and thus satisfied the intentions of this study with respect to being able to follow patient participants over what for many would be their last year of life, while also being able to learn from the experiences of those who died in the course of the study.

4.2 Recruitment

4.2.1 Recruiting patients

During the recruitment phase I regularly attended the liver unit's daily multi-disciplinary staff handover meeting in order to learn about any new patients admitted to the ward. This meeting was usually chaired by a charge nurse and attended by the physiotherapist, occupational therapist, pharmacist, junior doctors, and occasionally by an alcohol liaison nurse or a hepatology consultant. Each inpatient was discussed in turn, highlighting clinical developments, care and discharge plans, and associated challenges. Attending these meetings helped me to become a familiar face on the liver ward and build a good relationship with ward staff. My presence also helped to

keep the study at the forefront of staff's mind in what is a very busy, fast-paced working environment, and so aided the recruitment process.

Success with patient recruitment slowed considerably after the first weeks. This was mainly due to the same patients repeatedly returning to the ward for both routine and acute liver care, resulting in the pool of potential new recruits reducing steadily. To counter this, agreement was sought from clinicians and the local ethics committee to also recruit participants from outpatient clinics, whereby the attending consultant or registrar would advise eligible individuals of the study and pass on the information sheet. However, this did not prove a successful strategy due to clinicians' competing priorities in a hectic outpatient setting, and did not yield additional recruits.

Lessons learned from the recruitment process

Recruiting from an acute hospital ward was an interesting and educational, but very time-intensive process. I encountered several challenges during my time recruiting from the liver unit. The following outlines some of these challenges which serve as learning points for future research.

Unsurprisingly, liver patients are often very unwell during their hospital stay due to an acute exacerbation (including temporary cognitive impairment such as hepatic encephalopathy) and the unpredictable nature of the disease. Potential recruits to the study were usually identified to me by the charge nurse following the morning handover meeting. However, sometimes patients' poor condition meant that having staff approach a patient about the study at that time was not always possible. Additionally, patients were often asleep or away from their bed for medical procedures. Therefore, approaching patients about the study often meant having to monitor them over some days to catch them at an opportune moment where their condition and circumstances allowed them to have a considered conversation about research participation. This meant returning to the liver unit frequently at different times and days, taking up a lot of additional resources.

Relatedly, the unpredictable nature of the disease meant that sometimes inpatients would be on the road to recovery only to take a turn for the worse and deteriorate unexpectedly, in some cases leading to their death. The opposite could also be the

case, with patients making an unexpected recovery and being discharged sooner than anticipated. There were occasions where I would monitor a potential recruit for some days for a chance to speak to them about the study only to find that they had either suddenly died or been discharged. This proved especially challenging as I was not based near the hospital and so necessitated daily return visits to ensure that patients would not be missed.

Another challenge was the sometimes long turnover time for patients. John, for example, was an inpatient for four weeks before returning home. Where patients had agreed to participate in the research and were able and willing to, I interviewed them in a quiet room on the hospital ward. However, not everyone was comfortable with this, meaning that I sometimes had to wait several weeks before I was able to interview a participant in their own home, during which time they could be lost to the study as described above. For example, one patient who had agreed to participate in the study did not wish to be interviewed while in hospital. However, after three weeks on the liver ward he took a sudden turn for the worse and was transferred to the intensive care unit where he remained for a further two weeks. It was difficult for me to follow his progress during that time as I did not have access to this unit or its staff. The patient subsequently recovered and returned to the liver ward once more, but died a short while later. This case not only demonstrates the challenge of recruiting patients with advanced liver disease in an acute hospital setting, but also of retaining them in the study even at this very early stage.

There were positives to delayed discharge, however. My frequent presence in the liver unit helped to develop an early rapport with those who had agreed to participate in the study, sharing hellos and little chats during their days and weeks on the ward. By the time of their discharge and the subsequent first interview they were therefore already familiar and comfortable with me, which is likely to have aided retention and made the interview situation less threatening. Unexpectedly, my presence on the ward also attracted patients' interest more generally. Due to many patients returning regularly, I became a well-known face among inpatients also. This led to me being approached by patients curious as to my role on the ward and subsequently

proactively expressing their interest in participating in the study, although none of the participants were recruited in this manner.

Finally, recruiting from the acute hospital setting proved a challenge to achieving the desired spread of liver disease aetiologies among study participants. The majority of acute admissions to the liver ward were patients with alcohol-related liver disease (ALD). This is in part reflective of the distribution of aetiologies in the liver disease population (ALD being the most common cause of liver disease in the UK), but also of the more acute impact of these patients' lifestyle on disease progression. Few patients with autoimmune types of liver disease or primary liver cancer presented on the ward during the recruitment phase. Future research seeking a varied sample of liver disease patients may therefore find it easier to access different aetiologies from settings such as outpatient clinics or liver patient support groups.

4.2.2 Recruiting professionals

I was surprised about my success in recruiting professionals to this study, a group which can be difficult to engage in research due to their challenging workloads. All nominated professionals were prepared to participate, and many granted me an unexpectedly long time out of their busy schedule to accommodate the interview.

The success in this case may be due to requests being linked to a specific patient's study involvement as opposed to a generic request for research participation. Having been nominated by a patient as key to their care may have made professionals more willing to engage with this study, as it constituted support for both their patient and the research. However, many also demonstrated a real interest in the subject matter, particularly regarding the provision of palliative care to patients with non-malignant diseases, which may have contributed to their willingness to be involved.

4.3 Interviews

4.3.1 Patient and lay carer interviews

Overall, this study gathered 53 individual patient and carer perspectives through a combination of individual and joint interviews across a maximum of three time

points per patient/carer dyad. Up to three in-depth interviews were conducted with each patient and lay carer over 12 months.

Seven patients completed all three interviews. Interviews lasted between 30 minutes and 2.5 hours. 11 interviews were conducted jointly with patient and lay carer in accordance with their wishes. All except two of the carer interviews were conducted face-to-face. Three carers agreed to take part in bereavement interviews. The majority of interviews took place in the patient's or carer's home. A small number were conducted in a quiet room on the hospital ward or in a University office.

In order to best capture the nature of the liver disease trajectory and to promote participant retention, it seemed inappropriate to arrange the interviews according to a set timetable over the year of data collection. Rather, I maintained bi-monthly telephone contact with study participants after the initial interview in order to keep abreast of any changes in their condition or general circumstances. During the active recruitment phase I was also able to keep in touch with many of the existing participants during their frequent returns to the hospital ward for acute or routine admissions. This provided an additional unexpected means of keeping informed of important developments in participants' circumstances. Follow-up interviews were then scheduled accordingly to try and capture key changes in the trajectory whilst being sensitive to the needs of the participant at that time.

Regularly reconfirming participants' commitment to remaining in longitudinal end-of-life research is a matter of importance (Kendall et al., 2007). Upon being briefed about the study, participants initially consented verbally to taking part. They were then asked to confirm their consent in writing prior to their first interview taking place. This written consent was renewed before each subsequent patient or carer interview. Additionally, the bi-monthly telephone calls to check in with participants served as a means of process consent, allowing them a further opportunity to withdraw from the study if they so wished.

4.3.2 Professional carer interviews

One-off interviews were undertaken with the 11 healthcare professionals nominated by the patients as key to their support and care. Professional carer interviews lasted between 11 and 53 minutes. Six of the interviews were conducted face-to-face and five over the telephone in accordance with professionals' preferences.

Table 3 presented overleaf gives an overview of the patient and lay carer participants as well as of all interviews conducted at the different timepoints.

Table 3: Overview of patient and lay carer participants and interviews conducted

	Patient (pseudonym)	Lay carer (pseudonym)	Total no. of months in study	Completed patient interviews	Interviews per time point (P=patient; C=carer; P&C=joint)	Professional interviewed
1	John	Partner Jane; Wife Lisa	12	3	P&C1, P&C2, P&C3	---
2	Sarah	Friend Pamela	12	3	P1, P2, P3, C1, C2, C3	GP
3	Mary	<i>None nominated</i>	5	2	P1, P2	---
4	Fraser	Neighbour Betty	7	2	P1, P2, C1, Bereavement	Consultant
5	Fay	<i>None nominated</i>	11	3	P1, P2, P3	---
6	Donald	Wife Martha	1	1	P1, Bereavement	GP
7	Martin	Wife Cora	9	3	P1, P&C2, P&C3	GP, PC Nurse
8	Thomas	<i>Declined participation</i>	6	1	P1	GP
9	Ben	Partner Tamsin	12	3	P1, P2, P3, C1, C2	Alcohol liaison nurse
10	Aidan	<i>None nominated</i>	6	1	P1	---
11	Kate	Husband Michael	8	3	P&C1, P2, C2, P&C3	GP
12	Nadia	<i>None nominated</i>	6	1	P1	---
13	Carol	<i>Declined participation</i>	7	2	P1, P2	GP
14	Polly	Husband Jeff	5	1	P&C1, Bereavement	GP
15	Rebecca	Mother Julie; Sister Sue	9	3	P&C1, P&C2, P&C3	GP

4.3.3 Transcription of interviews

The manner in which interviews are transcribed can affect how the data is subsequently interpreted (Lapadat and Lindsay, 1999). With participants' agreement, all interviews were digitally recorded and transcribed verbatim in full. Colloquial speech was retained to remain close to the original dialogue, and emotions and non-verbal language noted to aid interpretation. All person-identifiable features were removed from the transcripts. Participants were also allocated a unique identification code unrelated to their name or personal details to be used for the duration of the study. Place names and other individuals' names mentioned in the interviews were removed. The identities of professionals were disguised where necessary in order to ensure that they could not be identified from their position or gender. Assistance with transcription was provided by two administrative helpers experienced in transcription in the realm of palliative care research. All transcripts were checked against their recordings to ensure accuracy of detail.

4.4 Analytic process

4.4.1 Use of qualitative data analysis software

There are advantages and disadvantages to using computer programmes for qualitative data analysis (Creswell, 2007). Importantly, they do not remove the researcher's task of coding, categorising and interpreting the data. I opted for QSR NVivo version 9 analytic software to help manage the large amount of data generated in the course of this study. NVivo software is not aligned to a particular analytical method, but presents a generic means by which to collate, sort and handle large volumes of qualitative data and undertake basic modelling and diagramming to support analysis (Bazeley and Jackson, 2013).

I imported into the programme all interview transcripts and related documentation pertaining to each patient case, as well as any notes generated in the course of analysis. My use of the software focused mainly on its coding facility and the recording of annotations and memos. I also kept an analytic journal in NVivo to record coding decisions as they happened for future reference. All analytical coding was conducted using this software.

4.4.2 Analytic approach

Based on the consideration of data analysis literature as well as previous similar studies I had initially identified narrative analysis as a suitable data analytic approach. Narrative research methods are usefully employed to explore the meanings embedded in individuals' narratives and thus generate a broad overview of subjective experiences (Bingley et al., 2008). This approach was therefore considered a good fit with the overall aim of this study, which sought to gain an understanding of liver patients' personal illness 'stories' from diagnosis to the present day.

However, early interview data indicated a lack of an 'advanced liver disease story' displaying the typical 'beginning, middle, end' narrative pattern to their experience. This was in part due to many participants only discovering their illness when it was already at a very advanced stage. Theirs was therefore often a rather short-lived experience of chronic illness marked by confusion, uncertainty and disjointed events. A more traditional 'story' was most often proffered by those with alcohol-related liver disease, whereby their alcohol dependency and associated struggles formed the core of their account due to its chronicity and tangible impact on all aspects of their life. While the apparent absence of an 'advanced liver disease story' must be regarded as an important observation in its own right, I felt that pursuing a narrative analytical approach would ultimately not serve to answer the research questions satisfactorily. Further consideration of analytical methods suited to the aims of the study as well as the lack of existing theory in this area of interest led me to draw on the analytical techniques of grounded theory, and specifically Charmaz' approach to data analysis (Charmaz, 2006). An outline of the philosophy underlying this approach was given in Section 3.6.

4.4.3 Applying grounded theory techniques

Charmaz' analytical approach provides a set of interpretive principles and practices, which may be applied and adapted flexibly (Charmaz, 2006). However, the key analytical techniques of coding, constant comparison and memo-writing, which are typical of a grounded theory approach, remain central here.

Coding

Grounded theory coding is an iterative process of separating, sorting and synthesising the data, leading the researcher from generic substantive coding to increasingly abstract and theoretical coding. Initial coding helps to ‘open up’ narratives to aid interpretation and gain a deeper sense of the overall data content.

I opted to conduct initial coding on a case-by-case basis, that is, to code all transcripts pertaining to one patient case (patient, lay carer, professional carer), before moving on to the next. To start this process I selected a case that I considered particularly rich in content and data variety to help create a good number of ‘base codes’ upon which to build the evolving coding structure. Coding was conducted line-by-line or by small text segment to highlight core meanings or actions expressed in participants’ accounts. In doing so I asked questions of the data (Glaser, 1978); this helped to identify and assign provisional labels to the coded text segments. I was mindful of Charmaz’ advice to conduct this phase speedily and spontaneously, remaining as open as possible so as to not prematurely close the mind to alternative interpretations and to promote “theoretical playfulness” (Charmaz, 2006, p71).

I stayed as close to the original text as possible, employing ‘in vivo’ codes wherever suitable. In vivo coding involves lifting codes directly from participants’ own words. This helps to retain actions and meaning, and places emergent codes more firmly in participants’ worlds. In vivo codes using participants’ own words were, for example, ‘Everybody’s dealt their hand’, ‘It was like I wasn’t there’ and ‘You’re always waiting for something’. Some of the early in vivo codes, however, were eventually changed to more inclusive labels as comparative events emerged across transcripts.

Initial coding of the first 9 of the 15 patient cases (equating to 27 transcripts) generated over 250 provisional codes. As the amount of codes started to become too unwieldy to manage, I decided to pause at this point and ‘tidy’ this extensive list of codes. This involved scrutinising each code in turn, clarifying its properties and boundaries, reviewing associated data for its fit, and reallocating data or renaming codes as necessary. Codes with comparable content were merged where appropriate. In addition, I applied a tentative sequential structure to the codes to aid locating them

within the expanding code list. I opted to follow what could be considered a ‘typical’ chronic illness pathway, grouping codes under the headers ‘Becoming ill’, ‘Living with liver disease’ and ‘Dying with liver disease’, which fitted well with the emergent codes. I retained lay and professional carers’ codes outwith this structure. I subsequently completed initial coding of the remaining transcripts. To illustrate the evolving coding structure, Appendix 6 contrasts sections of the structure after coding the first patient case with the structure at the end of the initial coding process.

Initial coding was followed by a phase of focused coding. Focused coding serves to move early codes from a purely descriptive level to more conceptual, generic categories, and as such lays the foundation for more abstract theorising. Using as a basis those codes emerging as most significant, larger segments of data are synthesised and assigned the label most representative of their meaning. Codes were thus refined, modified and reassembled as appropriate, and those which appeared of lesser frequency or importance eliminated. Great care was taken to note deviant cases in the data to test my assumptions and decisions taken in this process. Next, axial coding helped to define and organise the emerging higher level categories by exploring linkages and overlaps between categories and subcategories and determining their relationships using basic diagramming.

The final analytical step was that of theoretical coding. This is the process of examining the relationships between the categories and concepts identified through focused coding to inform a theory which “weaves the fractured story back together” (Glaser, 1978, p72). Doing so necessitated a return to the literature to identify existing models and theories which might help to make sense of and explain the data. Analytic discussions with the research team also helped to advance theoretical thinking at this point. Theories pertaining to the experience of biographical disruption (Bury, 1982) and loss of self in the context of chronic illness (Charmaz, 1983) were found to usefully explain several observations across the data. Ultimately, however, the theory of uncertainty in chronic illness was identified as providing the most extensive explanatory power to help bring together the overall ‘story’ of living, dying and caring in advanced liver disease (Mishel, 1990).

Constant comparative method

The constant comparative method was employed throughout all stages of coding to guide analytical decisions. Constant comparison demands direct interaction with the data by constantly comparing data, codes and categories looking for differences and similarities, and refining and modifying codes accordingly. This process is a useful test of any inferential leaps made during coding, leading those which are not viable to be rejected. Comparisons were also made sequentially by comparing data from earlier interviews with later ones for each patient case.

Memo-writing

Memo-writing is a key technique in grounded theory analysis and was undertaken throughout the analytical process. Memos are personal notes which encourage the researcher to take a step back from coding to explore, scrutinise, clarify and record their thoughts and assumptions about the data and emergent codes. Memos are not generally intended to be shared with an audience, but constitute a tool that helps the researcher to make sense of the coding process and provide a record of their intellectual analytical leaps from early substantive towards more formal theorising.

Evaluating the choice of analytic method

Employing grounded theory strategies for data analysis proved an effective means by which to meet the broad exploratory intentions of this research. The approach was responsive to the varied study sample and enabled the evaluation and collation of both descriptive and theoretical data to meet the research objectives, as will be demonstrated in subsequent chapters.

I still believe that narrative analysis would be a useful approach in this area of work. However, given my difficulties in detecting a 'liver disease story' in many of the individual accounts, this may be better suited to a smaller sample size and a more focused research question. Similarly, a case study approach exploring the subjective experiences of a smaller number of individuals would be able to make an interesting contribution to current understanding.

4.4.4 Conducting longitudinal analysis

There are no universally accepted guidelines for conducting qualitative longitudinal analysis. Typically, however, data are examined cross-sectionally, i.e. by time point, and longitudinally by case, and comparisons made within and across cases.

Following the end of each patient/carer/professional cluster's study involvement and having conducted initial coding of all transcripts relating to a group, I recorded the key issues and themes within each of these transcripts in a dedicated case summary. These case summaries thus provided an overview of issues for each cluster over time and formed the basis of my longitudinal analysis. They allowed me to take a step back from the detailed coding and scrutinising of the data content to gain a sense of the evolving picture. They also helped to consider which types of issues were raised by participants at which time points and how this compared between participants, which issues featured strongly throughout a participant's story and what this suggested about the nature and level of importance of the issues in question, and how the individual illness experience developed and changed dynamically over time.

Saldaña cautions that one must not simply ask time-orientated questions of the data such as 'when, how often, for how long', but also attend to the conditions underlying change by asking 'how, how much, in what ways, why' (Saldaña, 2003). He offers a menu of questions to stimulate the exploration of change observed over time within a dataset. These questions are summarised in Table 4 overleaf and were used to guide the longitudinal analysis.

As described in Section 4.3.1, this study did not use fixed time intervals between follow-up interviews, but set these flexibly in response to each participant's specific circumstances. As a result, participants' accounts were captured at very different stages of each person's illness pathway. Moreover, while all participants were deemed to be in the latter stages of advanced disease, there was great variation within this. At the time of their first interview for example, Kate had already lived with liver disease for a decade, while John and Martin had only recently been diagnosed. As such, I felt that comparative cross-sectional analysis across participants by data point, i.e. comparing all first, second and third interviews, was unlikely to yield useful

insights about the illness experience over time. Hence, temporal observations of the study data noted in the following chapters focus mainly on developments over time.

Framing questions	<ul style="list-style-type: none"> • What is different from one pod of data to the next? • When do changes occur through time? • What contextual or intervening conditions appear to influence and affect participant changes through time? • What are the dynamics of participant change? • What preliminary assertions about participant changes can be made as data analysis progresses?
Descriptive questions	<ul style="list-style-type: none"> • What increases or emerges through time? • What is cumulative through time? • What kinds of surges or epiphanies occur through time? • What decreases or ceases through time? • What remains constant or consistent through time? • What is idiosyncratic through time? • What is missing through time?
Analytic and interpretive questions	<ul style="list-style-type: none"> • Which changes interrelate through time? • Which changes oppose or harmonise with natural human development or constructed social processes? • What are the participant or conceptual rhythms? • What is the through line of the study?

Table 4: Questions to guide analysis of longitudinal qualitative data
(Source: Saldaña, 2003)

Challenges and benefits of using a longitudinal approach

Conducting the longitudinal analysis was made complex by the large volume of data available. I managed this by concentrating on the summaries I had written up for each patient/carer/professional cluster, using individual transcripts only for the verification of detail. Field notes of telephone conversations and encounters with participants in hospital between interviews provided further data of longitudinal relevance. This proved particularly useful in the case of those participants who had only been able to participate in one interview, as it still allowed an insight into their experiences over a period of time.

Using a longitudinal approach had a marked positive impact on the data generated in this study. Increasing familiarity and trust between researcher and researched promoted a gradual moving from public to more private accounts of the lived

experience of advanced liver disease. The former are designed to present the person and their circumstances in accordance with acceptable social norms, while the latter reflect their personal experiences, thoughts and feelings (Cornwell, 1984). The development of more intimate relationships with participants over time also allowed more sensitive topics to emerge in their accounts. Interviews became increasingly reflective through time, especially in the existential domain. Conversations during first interviews tended to be mostly medical and factual. Moreover, many interviewees were rather guarded at this stage. There are a number of possible explanations for these narrative changes over time:

- By necessity, a first interview needs to establish a certain amount of baseline and background information from participants such as illness origin, the period of diagnosis, or current care arrangements. There is thus not always scope for people to open up more intimately. Consequently, the conversation will be largely factual and clinical. Moreover, at this point participants will not know what to expect from the interview process and are therefore likely to share more factual information similar to what they are used to from a medical encounter.
- It is easier to relay feelings and expectations about current events as they are experienced in real time, when they are having their most tangible effect on people's lives. While the first interview seeks to establish a lot of background information then, there is less scope or prompt to reflect on current emotional matters for example.
- The evolving narratives suggest that a longitudinal approach helps to build rapport and relationships with participants, and that this allows the interviews to change qualitatively over time. As participants become used to the interview process and trust is established, people feel increasingly more comfortable to let down their guard, to show vulnerability, and to speak from the heart.
- Several participants professed to drawing therapeutic value from our interview encounters. As this value was recognised after the first interview, it may have set the stage for more private and open conversations on subsequent occasions.

Finally, there was some evidence of accounts being subject to reinterpretation through time as participants rethought or retold experiences or feelings. The longitudinal and multi-perspective aspects of the study also encouraged my own reinterpretation of some participants' stories. Getting to know participants more intimately through time helped me to better understand some of the accounts proffered in interviews as well as to re-evaluate some of their data, which in turn prompted me to look at some of their data in a different light.

4.4.5 Analytical challenges

Following participants over time generated a significant amount of data and provided rich material describing the interaction between individual and care domains. This not only made managing the data challenging, but also made data analysis complex and time-consuming.

The nature of this study also created specific challenges for data analysis. About half the sample lived with alcohol-related liver disease. A number of these participants, when asked about their liver disease, tended to reply in relation to their alcohol problems, which to many was the more tangible, acute concern, as an inability to overcome these problems was key to their prognosis. Their liver disease was therefore often equated with alcohol dependency, and as a result many of these accounts were dominated by issues around alcohol rather than the resultant liver disease. Similarly, Sarah's friend Pamela commented on Sarah's fluctuating moods. However, it was unclear whether these were due to Sarah's ongoing depression (a long-standing diagnosis pre-dating her liver disease) or low moods relating to being seriously ill with liver disease, the challenge of remaining abstinent, or dealing with general life challenges such as her difficult family relations. Consequently, it was at times challenging to determine with any certainty which feelings and experiences related to which aspect of patients' illness. At the same time, these issues demonstrate the complex circumstances within which many people have to negotiate a life with advanced liver disease.

4.5 Working with a lay advisory group

As described in Section 3.3, I was keen for this research to benefit from the involvement and expert insights of lay individuals representative of my study population. Early on in the study I sought out a consultative relationship with a large and well-established regional liver support group. Initially, information on the proposed study was shared through the support group's newsletter (reaching a readership of around 2000 patients) and comments invited. I also presented the proposed study at one of the group's monthly meetings, providing an opportunity to hear the views of around 50 attending liver patients and their caregivers. A subgroup of support group users subsequently agreed to advise on and contribute to different aspects of the study for the duration of the project. This group met quarterly from June 2011 to January 2014. In addition, I continued to provide study updates to the main liver support group newsletter throughout the duration of the research so as to give opportunity to others to comment and contribute.

I had hoped to achieve a representative spread of aetiologies, gender and ages in the advisory group similar to my study sample. I was also keen to involve lay carers where possible. As this was a self-selected group, however, I was unable to exert much control over its membership. I also accepted that volunteers would be unlikely to include people at the advanced stages of disease as they would generally be too unwell to participate. Three volunteers dropped out along the way. The single lay carer volunteer also withdrew due to conflicting priorities. Finally, the core advisory group members comprised of five females and one male ranging in age from 30 to 69 years. Three members had PBC, one had PSC, and one had experienced acute liver failure. Three had received a liver transplant. One volunteer was a liver disease patient, but had also previously supported a parent with liver disease and so was able to provide views from both patient and carer perspectives.

4.5.1 Benefits of working with a lay advisory group

While this group was not an ideal match to the study sample, it still made an invaluable contribution to this study in the following ways:

1. Most group members lived with an autoimmune type of liver disease - an under-represented group in the study sample. While I was unable to use group members' stories and comments as study data, they served to confirm that their experiences were in fact comparable to those of study participants, despite the differing aetiologies. This observation thus adds weight to some of the study findings.
2. Only two people with ALD had volunteered to participate in the advisory group. One person died suddenly before the first meeting, the other found speaking about their illness too challenging and did not return after attending one meeting. Group members confirmed that it was difficult to attract patients with ALD and NAFLD to their support group, as many struggled with guilt and perceptions of stigma. This was valuable information for future patient recruitment and relates to a point made in Section 4.2.1. I recruited my study participants from a hospital liver ward where the predominant disease cause represented was ALD, making it difficult to achieve a spread of aetiologies across the sample. It appeared to be the opposite when approaching the support group. This suggests that a multi-site recruitment strategy may be best if a sample of different liver disease aetiologies is the aim.
3. The group discussions gave an opportunity to explore issues raised in the interviews in more detail. The typical interview situation is fast-paced and time-limited, with many issues raised only briefly or in passing, making it difficult to pick up on all in detail during the interview itself. There is also not always an opportunity to follow these up with the participant at a later stage due to attrition. The advisory group thus provided an invaluable opportunity to consider some issues in depth, helping to evaluate their relative importance and whether they warranted being explored with other participants in subsequent interviews. Hence, discussions with the lay advisory group ensured that potentially interesting or important issues raised by study participants were less likely to go unnoticed and unexplored.
4. None of the advisory group members were at the advanced, decompensated stage of liver disease. Those who had undergone liver transplantation tended to speak from the perspective of their post-transplant life with its ongoing challenges and care, unless specifically asked about their experiences prior to transplantation. However, I

was struck how, regardless of the stage of liver disease a person was at, many of the psychological, social and care-related experiences mirrored those expressed by the study participants living with very advanced disease. Indeed, the main difference along the liver disease trajectory seemed to relate to the physical complications experienced, although fatigue was universally cited as the main debilitating issue.

5. Consulting with the advisory group provided an opportunity to get an ‘insider’ opinion on the emerging coding framework and its fit with the everyday experience of living with liver disease. This feedback gave me confidence in the framework’s suitability and validity to support ongoing data analysis.

Overall I feel that I, the researcher, and the study itself benefitted immensely from the involvement of the lay advisory group. Especially as a PhD researcher working predominantly in an independent and isolated manner it was reassuring to link with a group of ‘expert’ co-researchers throughout the research process, and to have my thoughts and perceptions confirmed and challenged in equal measure. I was also pleased to note that group members themselves enjoyed and benefitted from their involvement. One member in particular commented how participating in the group had helped them to feel less isolated about living with their illness, and to realise the value of sharing experiences with others.

4.6 Evidencing the quality of study conduct

As described in Section 3.7.1, I followed Rolfe’s approach to facilitating quality judgements to be made regarding the conduct of this study by recording a detailed audit trail (Rolfe, 2006). Procedural decisions taken during the recruitment and data generation phases of the research were recorded in extensive field notes, which also document contextual information about interactions, observations and personal reflections. Using qualitative data analysis software has been noted as a useful means by which to leave a comprehensive audit trail (Seale, 2001). My analytical decision trail is documented in NVivo through a detailed data analysis journal, copies of the coding structure at different time points, and time-stamped memos showing my evolving analytical ideas about cases, codes and categories. Minutes of meetings

with the study's lay advisory group detail discussions around challenging or emergent issues during all phases of the study.

4.7 Ethical and safety considerations

As stated in Section 3.2.3, longitudinal research has the potential to magnify some of the ethical issues inherent in qualitative research (Neale and Hanna, 2012). The developing relationship between researcher and researched over time is particularly critical in this respect (Watson, Irwin and Michalske, 1991). Appendix 7 presents an ethical dilemma which arose in the course of this study. Participant and researcher welfare were safeguarded throughout this study in the following ways.

4.7.1 Protecting the participant

Interviews were conducted in accordance with previous recommendations regarding safe research practices (Pratt, 2002). These note the importance of understanding the characteristics of one's particular participant group so that interviews may be planned and conducted in the safest and most appropriate way. I achieved this by consulting with the lay advisory group in advance of the first interviews to develop my understanding of potentially challenging or distressing issues in this context.

Further protection was sought by conducting interviews, where possible, in the patient's own home, a comfortable and familiar setting. Consent was renewed before each interview and participants reminded that they could pause or terminate the interview at any time. Offering joint or separate interviews gave patient and lay carer a choice about how to engage with the researcher. In the case of separate interviews, great care was taken not to divulge information from another interviewee in that patient/carer/professional cluster. I also tried to be sensitive to participants' wellbeing during the interview encounter and followed guidance for dealing with distress by employing active listening, offering breaks, giving the opportunity to talk through the distress, and allowing interviewees to change the subject to a less threatening or emotive topic (Pratt, 2002).

Finally, all participants were anonymised at the time of recruitment by the use of a unique identification code separate to their personal details, thereby ensuring

anonymity and confidentiality throughout the research process. For the purposes of this thesis, however, patient and lay carer participants were subsequently assigned a pseudonym to return the human voice to the data presented and help the reader connect and empathise with participants' experiences.

Interviewing vulnerable people

Commenting on the impact of research participation on palliative patients, Gysels and colleagues acknowledge that they were unable to assess whether their participants experienced any distress following the researcher's departure (Gysels, Shipman and Higginson, 2008). They suggest that this could be given attention by using a longitudinal research format. While some participants in the present study became distressed during their interviews, none wished to pause or break off the interview at that point. More importantly, all were happy to remain in the study for further interviewing. This finding lends support to observations on interviewing patients and caregivers respectively (Lowe and Gill, 2006, Funk and Stajduhar, 2009). Where participants experienced distress during interviews, this was seen as them expressing and dealing with the upsetting nature of their situation. Research interviews may consequently constitute a means of coping for some interviewees.

The willingness of the participants of the present study to continue their involvement despite at times struggling emotionally during the interviews, as well as many of them commenting on how helpful they found taking part in the research, suggests that the interviews were indeed contributing to their coping. Participants can exercise their power over the interview situation, and thus protect themselves, by choosing what, how and in what detail to answer (Kvale, 2006). This strategy was employed by several participants in this study, who circumvented any questions that prompted them to contemplate a possible decline in the future.

4.7.2 Protecting the researcher

Building a relationship with and hearing the experiences of those nearing the end of their life and their lay caregivers during the research process has the potential to cause distress for the researcher. I benefitted from being part of a large research team which is extensively experienced in end-of-life research and able to provide peer

support and supervision. Access to independent counselling sessions was also available, and encouraged to be used, through the University.

Particular consideration was given to the potentially volatile nature of some patients' home environment, particularly in the case of those with alcohol or drug-related liver disease. These individuals may live in chaotic home environments that are unsafe for a lone researcher to visit. Background information on each patient where this may be the case was ascertained from ward staff. Lone worker precautions such as reporting in and out of interviews, maintaining mobile phone contact, and carrying a personal alarm were also taken when visiting participants at home.

4.8 The reflexive researcher

As described in Section 3.7.2, the practice of reflexivity centres on the notion that both researcher and researched are actively engaged in the co-construction of knowledge and directly impact on research in a number of ways. As a researcher, it is important to be mindful of one's influential role in shaping the research process and to consider the implications arising from this. Reflexivity thus closely relates to ethical practice, as it is the sensitising tool which enables the researcher to recognise and address ethical dilemmas as they arise (Guillemin and Gillam, 2004).

In reflecting upon my role as researcher, two factors stand out as having impacted on the research process. Firstly, I was conscious of the way in which my status as doctoral researcher was understood. I had recruited patients from an acute hospital ward, so it was conceivable that I would be perceived as a type of healthcare professional, despite explaining my background and role to participants at the time of recruitment. I had also learned from my informal discussions with a patient during the planning stages of the study that 'doctoral research' was prone to being misinterpreted as a clinical endeavour. Indeed, over the course of the study several participants asked me for medical advice despite my repeatedly reminding them that I was not a clinician. An enduring perception of me as a healthcare professional may have influenced some participants' accounts. Indeed, when I asked Rebecca after our first interview how she had felt about speaking about her experiences she likened it

to a medical encounter, stating that she hadn't minded it because, "I do it with the doctor practically every time I'm there anyway."

I was further aware of my age as an influential factor in the research process. Five of the participants were in their mid-30s to early 40s, and therefore of a similar age to me. This fostered the development of a much deeper relationship than was the case with older participants; some participants referred to me as a friend. I also found it easier to relate to these individuals' lives and the impact the disease was having on them, and as a result I was considerably more emotionally affected by their stories.

In general, despite my professional role as researcher, I could not help but be touched by participants' struggles and worries, especially as I got to know them better over time. During the recruitment phase I was also occasionally faced with witnessing first-hand the last days and hours of a participant's life as they lay dying in the very hospital ward from which I was recruiting. Furthermore, having grown close to participants over their months of study involvement, the sudden death of a patient was often upsetting, as was saying goodbye to those still alive at the end of the study. Emotional involvement is unavoidable in relational research (Bondi, 2005, Watson, Irwin and Michalske, 1991). Longitudinal research in particular can leave researchers emotionally vulnerable (Dickson-Swift et al., 2009); indeed, considerable effort was required to manage my emotions throughout the research process. This experience highlighted to me the importance of self-care throughout the research process as well as access to appropriate counselling support for the researcher. I was grateful to have access to excellent support, both from members of the research team and at home.

4.9 Summary

15 patients, 11 lay carers and 11 case-linked professionals were recruited to the study. 53 interviews were conducted in total. Using analytical strategies of grounded theory proved an effective approach to meeting the overall research aim. The involvement of a lay advisory group aided both the research conduct and the researcher experience. A safe and ethical study conduct was sought throughout. The successes and challenges encountered in respect of the study design and the research process provide valuable learning for future research.

The next five chapters outline the main study results and discuss these in relation to the wider empirical and theoretical literature. Chapter 5 describes participants' accounts of becoming ill, their physical experience of advanced liver disease, and their understanding of the condition. Chapter 6 shows how everyday life was negotiated in light of the illness. Chapter 7 focuses on patient participants' experiences in the care setting. Chapter 8 outlines their considerations and experiences in relation to deterioration and death. Finally, Chapter 9 presents the perspectives of lay and professional carers about providing support for people with advanced liver disease.

Chapter 5: Onset, manifestation and understanding of the disease

This chapter first presents findings in relation to the lead up to and experience of receiving a diagnosis of advanced liver disease. It then details patient participants' accounts of the physical complications they faced as a consequence of their illness, and how these impacted on their everyday lives. It also illustrates the extent to which they understood their illness and its implications. Finally, these findings are discussed in relation to other research and relevant theoretical literature.

5.1 First symptoms

As shown in Section 4.1.1, a range of aetiologies were represented in this sample. Most participants found their first symptoms vague and difficult to interpret.

I didn't feel particularly well, but I couldn't tell you why I didn't feel well. I just had put it down to the fact I was a bit stressed out. (*Kate, 41, cryptogenic LD, first interview*)

I was extremely anaemic, I was tired all the time, I had no energy. I was just, I was feeling sick, I was nauseous, I was, you know, generally I just felt crap, you know? I don't know any other way to put it, I just felt so bad. (*Sarah, 38, ALD (HCV), first interview*)

The uncertainty surrounding early symptoms meant that for many the first indication of their illness came with the emergence of physical complications already associated with advanced disease; that is, decompensated cirrhosis (the point at which the patient's liver is irreversibly damaged and on a likely pathway towards liver failure). Among this sample, the first tangible complication was commonly an appearance of ascites (fluid accumulation in the abdominal cavity causing abdominal distention).

We were in Turkey for, on holiday. The second day I was there I started going up like a balloon. And that is not an exaggeration, it was like a balloon. (*Thomas, 75, NAFLD, first interview*)

It was only with this stomach here that I found out about the liver and the kidneys. I hadn't a clue. I never had any pain or didn't hold me back any, nothing at all. (*Martin, 77, ALD (NAFLD), first interview*)

Other early symptoms preceding diagnosis were difficulties with limb coordination, poor balance, lack of appetite, sickness, stomach pains and mild jaundice.

5.2 Receiving a diagnosis

At the time of recruitment, patient participants had been aware of their diagnoses of chronic liver disease from around 10 years in Kate's case to only a month in John's. In most cases, participants had been alerted to problems with their liver two to five years earlier. Due to non-specific symptoms, however, many only received an actual diagnosis of liver disease when the condition was already advanced.

Participants with alcohol-related liver disease (ALD) in particular had often received warnings by their GPs in the past regarding raised liver function tests, but had not heeded them. Many admitted that they had had a hunch about their health slowly declining due to continued drinking. Some had even understood the meaning of symptoms, but had remained in denial.

Ben: I could see I was getting a bit yellow and, like, I knew that was the danger signs.

BK: But you still needed to get to quite a bad state before you accepted for yourself you needed to go and see someone?

B: Aye. I did know, but as I say I was scared to go in because I knew it was going to be really bad.

(Ben, 35, ALD, first interview)

There was also evidence of collusion from their lay carers in this regard.

It was quite a few years ago we first heard that he had slight damage to his liver. And obviously it was really worrying, but I think like Ben I kind of sort of blocked it out, just, that it's not going to be that bad. And you never think it's going to get really serious.

(Tamsin, partner of Ben, 35, ALD, first interview)

The signs *were* there, but I'm just as bad. You hope it's just going to go away again, yet you know it's not. *(Jane, partner of John, 68, ALD, first interview)*

Despite recognition of the warning signs many did not appreciate the seriousness of their situation at the time. Receiving a diagnosis of advanced disease consequently still came as a shock.

I think I knew it was my liver, well I did know. I didn't know how bad it was, so it came as a bit of a, I don't know if it was a shock when I was told how bad it was, but it certainly knocks you back a bit. *(Aidan, 58, ALD, first interview)*

Professionals' use of the word 'cirrhosis' in this context was particularly confusing for those with disease causes other than alcohol misuse, as people tended to associate the term with such problem behaviour.

BK: What did you make of that, being told that you've got cirrhosis?

Fay: Well I just thought it was a drunken condition. (...) I've never heard of anybody else having it other than heavy drinkers.

(Fay, 84, NAFLD, first interview)

Donald: They just told me that I had liver...they called it another name, it sort of fooled me for a wee while. (...)

BK: Cirrhosis? (...)

D: That was it. And it wasn't until I seen it printed in a letter they sent me, when I got the letter that's when I realised it was [primary liver] cancer.

(Donald, 74, HCC (NAFLD), first interview)

Patients' experience of the onset of their illness was therefore one marked by uncertainty. This uncertainty related to the insidious nature of their early symptoms, resulting for many in a late diagnosis of their condition. Receiving a diagnosis was a similarly ambiguous event, magnified by unclear professional vocabulary used to communicate the diagnosis.

5.3 Physical complications

Several participants experienced recurring varices (dilated blood vessels prone to rupturing), which required ongoing surveillance and regular treatment. Only two participants occasionally experienced jaundice, a symptom commonly associated with liver damage. Memory problems, anaemia and weight loss were all mentioned. The following section presents the physical complications most commonly described by the participants.

5.3.1 Fatigue

The most debilitating issue across all patient participants was fatigue, which was marked by extreme tiredness and physical weakness.

I fall asleep quite a lot during the day just for no apparent reason. (*Kate, 41, cryptogenic LD, second interview*)

I never moved out of my bed at all yesterday. I was so lethargic I felt I'd no strength at all. (...) I was lucky if I could hold my head up, never mind anything else. (*Mary, 66, autoimmune hepatitis, second interview*)

The onset of fatigue was unpredictable and often sudden, adding uncertainty to daily life.

Sometimes I can become ill within a couple of hours. Like I could be completely well, go shopping, come home, have a wee rest 'cause I've been shopping and then just be totally exhausted within a couple of hours and just have absolutely no energy at all, like, be totally wasted. (*Sarah, 38, ALD (HCV), first interview*)

Persistent fatigue curbed participants' ability to engage in valued activities.

I've always liked housework and I've never been the person that would sit and look at something. But nowadays I think, "I'll do that tomorrow." It's not really like me (...) but I've just not got the energy. (*Fay, 84, NAFLD, second interview*)

In many cases the experience of fatigue was related to insomnia. Nocturnal sleep problems caused enduring tiredness, which in turn made people sleep during the day.

I'm up quite early, well I was up at 7 o'clock this morning and watched, put the TV on. Probably by about 1.30pm I sleep. Sometimes I fall asleep at tea time and then when it comes to night time it's like, well I've already slept so I can't sleep. So that makes me agitated. I can't get comfy. (*Rebecca, 37, ALD, first interview*)

The physical exhaustion also interfered with sleep by causing anxiety.

Sometimes I'll not sleep because (...) sometimes I'm really exhausted, almost passing out with exhaustion, I'm scared to sleep so I'll sit up, because I'm scared if I do go to sleep then I won't wake up. (*Sarah, 38, ALD (HCV), first interview*)

Insomnia was also a disruptive problem in its own right, with some simply unable to fall asleep.

I want to sleep, I try to sleep, but I just can't seem to fall over if you know what I mean. (*Aidan, 58, ALD, first interview*)

5.3.2 Ascites

Ascites, marked by a gradual swelling of the abdomen due to fluid accumulation, was the other major physical complication disrupting participants' lives. The first onset of ascites was again marked by uncertainty.

I got the doctor out one morning because my tummy was really, really big and it wasn't going anywhere. And I'd put up with it for about 3 weeks because I thought (...) I was maybe constipated. (...) I phoned up to get the doctor in and I says, "Look I've got an awfully sore tummy." (*Nadia, 56, ALD (HCV), first interview*)

This huge swelling appeared and we were all laughing and carrying on, you know, saying it looks like, because it did look like I was pregnant. (...) I had a pregnancy test done because everybody else round about me's saying, "Are you sure you're not pregnant?" (*Kate, 41, cryptogenic LD, first interview*)

Six of the 15 patients experienced refractory ascites requiring regular paracentesis (an inpatient treatment to drain off the reaccumulating fluid). The frequency of this event was a source of great frustration for them.

I says, "How long does this last or what?" [The doctor] says, "It could last forever, it just depends. But they'll control it a bit." I thought when he said they would control it it would be every, maybe 3 to 6 months or something, not every fortnight. (*Martin, 77, ALD (NAFLD), third interview*)

However, for those whose ascites could generally be controlled with diuretic medication infrequent problems with ascites were equally as disruptive. The sporadic experience of fluid accumulation also left people uncertain as to how to best manage these incidents.

My stomach just got huge. My ankles were huge. And I'm like well, do I actually do more exercise, do I do more walking? But I just didn't have the energy. So I didn't actually know what was best. So did I have to lay and rest and have my legs elevated, or to actually try and walk it off? (*Rebecca, 37, ALD, first interview*)

Ascites were often accompanied by a shortness of breath due to the accumulating fluid pressing against internal organs.

Mary: I went up [to the hospital] (...) and I had to sit on the benches outside for about 10 minutes before I could catch my breath. And I had to get a taxi home. (...)

BK: Was that because you had so much fluid?

M: It was, yes.

(*Mary, 66, autoimmune hepatitis, second interview*)

Ascites was not only a burden by causing discomfort, but by impacting on participants' ability to engage in even the most basic of tasks such as personal hygiene and getting dressed.

[Friend] will be coming in in a wee while because she's going to give me my shower. I mean I can't even take a shower, that's how bad it is. I can't get my arms round, you know, to my back. (*Mary, 66, autoimmune hepatitis, second interview*)

I can't really put my socks and shoes on now, because I can't bend. (*Fay, 84, NAFLD, third interview*)

Finally, the following excerpt from my field notes reflecting on an encounter with Thomas on the hospital ward summarises well the pervasive disruptive impact of ascites on the lives of patients and lay carers alike.

He'd just had 15 litres drained off him yesterday and seemed understandably relieved to shed this weight once again. He said his life really was just unbearable now, with the recurring ascites rendering him immobile again within days, and the immobility in turn making him physically inflexible and all-round uncomfortable. He said his wife was really feeling the strain of the situation too, commenting that he effectively became a baby in those days where she had to do everything for him.

5.3.3 Motor coordination and mobility problems

Several participants described occasional problems with motor coordination.

There's a funny thing going on, it's like I'm thinking to myself I want to go to such and such a place, but when I stand up my legs don't seem to want to take me there. It's like they're not getting the message, you know, and they start to go all wobbly and all this kind of carry on. (*Kate, 41, cryptogenic LD, first interview*)

A wee while ago I kept falling. I would miss a step going up over the curb or something and just, bang. And I was going to the job centre the other day and I just got to the top stair, top step, I did, I went down with a thump. I can't get back up when I'm down. I've got to get a hand to get up (...) my legs will no work. (*Aidan, 58, ALD, first interview*)

Poor mobility also proved a challenge for many. This was often linked to carrying fluid, general physical weakness and fatigue.

Fraser: Just moving about, getting up from [the settee], I can't do it. Well I can, but it takes a while. Getting out my bed it takes a while, ken, so it's either I go to my bed or stay up here. It was five o'clock this morning before I went to my bed.

BK: Oh, why was that?

F: I just couldn't get up [from the settee], I was stuck.

(*Fraser, 60, ALD, second interview*)

Several participants recounted incidents of falling. These falls triggered a loss of confidence in their abilities and a restriction of their activities to avoid further falls.

I'm terrified to go out in case I fall. (*Fraser, 60, ALD, second interview*)

Uncertainty then was also evident in participants' problems with mobility and motor coordination. This related both to their lack of understanding of the source of these problems and their unpredictable occurrence, which affected their levels of activity and ability to engage socially.

5.3.4 Pain

Only Fraser mentioned regularly experiencing pain to debilitating levels, though he did not elaborate on the nature of this pain. As pain is a common feature in advanced chronic disease, I was struck by the lack of mention of it in participants' accounts. I consequently enquired directly about the incidence of pain relating to their liver disease in later interviews. Several participants denied experiencing any pain related to their illness.

You don't feel as if you've got a problem with your liver, ken, it's not a pain. So your liver can be damaged and you don't know. That's the strange thing about the liver, there's no pain. (*Ben, 35, ALD, first interview*)

The pain comes from treatment at the hospital rather than...you know, trying to stick needles in you (...) but I can't really say that it's been painful, no. (*Kate, 41, cryptogenic LD, third interview*)

For those who confirmed instances of pain, these were typically related to their recurrent ascites, with the accumulating fluid eventually starting to press on internal organs causing discomfort.

I'm never really in any pain. The only pain I get into is if this [ascites] gets really bad then I tend to get a bit of a pain across the back, but they tell me this is just pressing on the lungs, you know? (*Thomas, 75, NAFLD, first interview*)

Having the fluid drained off in hospital then removed this pain.

I was saying to the doctor that I'm getting an awful pain down here, like a stabbing pain. She says that'll be the pressure of the fluid pressing on whatever, she says. She says it'll go away when this is taken away, and it did. (*Aidan, 58, ALD, first interview*)

Some were rather grateful for the absence of pain, as it helped them not to worry unduly about their illness.

It just makes it easier to not worry, because with the state my liver's still in, if I had the pain to go with that I'd be just sitting completely worried all day going, "Oh my liver, oh God, oh no," you know what I mean? (*Ben, 35, ALD, first interview*)

There was some indication that pain may have become more of a feature in the final stages of the illness, however. In my last interview with Martin and his wife Cora, conducted two months before his death, Cora suggested that pain was starting to become a regular occurrence.

Cora: When you were getting up out of your bed, that's when he used to feel the pain and then it would go away. But this last, after the last drain, not that drain but the drain before, it seems to be a regular occurrence and it's lasting longer, the pain.

Martin: Yes, well, that was this morning when I got up and I sat here, and it was quite painful there.

(Martin, 77, ALD (NAFLD), and Cora, wife of Martin, third interview)

Donald's GP also indicated that Donald had experienced pain towards the end.

Pain control didn't really become an issue until later on. *(GP of Donald, 74, HCC (NAFLD))*

5.3.5 Medication

To manage these and other physical complications arising from their liver disease, participants were subject to an extensive and complex medication regime. This ranged from laxatives to diuretics and fortifying supplements, alongside medication for any co-morbid conditions. Given this complexity, many felt rather overwhelmed by the number of tablets they were required to take and relied on support from friends and family to manage their medication.

Honestly, if it was me I'd just say, "Oh, pfff, drop kick." I wouldn't bother taking them. (...) It would be ok if it was one or two that's fine, but that's 17, 19, I mean 19 tablets, eh? And eye drops. And puffers. Oh pffff. *(Martin, 77, ALD (NAFLD), first interview)*

One day I got confused, I'm not kidding you, I was so confused I didn't know what I was doing. So I phoned [friend]. I said, "[Friend], you'll have to come down. I'm so confused with the tablets." *(Mary, 66, autoimmune hepatitis, second interview)*

Indeed, without access to similar support, some had given up trying to get to grips with their medication regime.

The amount of pills I take it's unbelievable and you get sick of taking some of them, they go in the bucket. I put them in the bucket, they ken I put them in the bucket. I can't be bothered taking them. *(Fraser, 60, ALD, first interview)*

Fluctuations in participants' condition and unexpected side effects meant that their medication was frequently reviewed and amended, which added to their confusion.

I don't know what they're all for. [To Martin] You don't know what they're all for either. They'll say they've changed that, that, that, and I'll say, "What?" How am I supposed to know? I just know I've to give him them. *(Cora, wife of Martin, 77, ALD (NAFLD), second interview)*

Taking diuretics for the management of ascites was particularly disruptive to daily life.

If you want to go for a walk or something, you know, you can't really, you know? You got to either take them really early on and then go after they stop working, or, you know, take the tablets later on and then during the night you're maybe needing the toilet. (*Sarah, 38, ALD (HCV), second interview*)

When I'm on these tablets I can't be outside because I get, like even from here to that toilet, you know, it just, it hits me like that. (*Rebecca, 37, ALD, second interview*)

Dealing with a complex and ever-changing medication regimen was thus a further source of uncertainty for patients and caregivers alike. This uncertainty related to the nature of the tablets they were expected to take and their safe management. Diuretic medication added further uncertainty with respect to its timely administration to allow patients to engage in planned activities.

5.3.6 Changes in physical status over time

Most participants experienced a general progressive physical decline. This was particularly tangible where it manifested in an increase in hospital admissions for repeat paracentesis. While some could sense the steady deterioration in their condition, they were not always able to articulate this.

Mary: I feel as though I'm getting weaker and weaker.

BK: So you actually feel like physically, you're physically deteriorating?

M: Yes. But how can you explain that to a doctor? This is what I don't know.

(*Mary, 66, autoimmune hepatitis, second interview*)

In many cases, however, participants' wellbeing fluctuated over days and weeks, offering brief windows of respite or improvement.

He was fine for a wee while. He was looking well and my granddaughter come up and cut his hair and all that. He really looked healthy and then all of a sudden he went down again. (*Betty, neighbour of Fraser, 60, ALD, bereavement interview*)

Successful management of their ascites led to a brief increase in motivation for some participants to become more active.

Maybe about three weeks you feel better, you feel a wee bit more energetic, yes, you want to walk that wee bit further, and then it just starts going down again so...I suppose it's all to do with this [ascites], everything. (*Aidan, 58, ALD, first interview*)

Fatigue was unpredictable and could vary from day to day.

Sometimes I'll get up and, like, do the ironing or whatever or go for a walk along the road and I'll come back and be absolutely exhausted, and other days I can do it no problem. So it's just all about kind of up one day, down the next kind of thing, so it's very unpredictable. (*Kate, 41, cryptogenic LD, second interview*)

Participants spoke of having good days and bad days, relating both to their physical and psychological wellbeing on any given day.

It's day by day. I don't know how I'm going to feel. (*Rebecca, 37, ALD, third interview*)

Sometimes you meet [Sarah] and she's on great form and she's like a full person, and other times you meet her and she's like just a less than half a person and just can't seem to cope. (*Pamela, friend of Sarah, 38, ALD (HCV), first interview*)

Uncertainty was therefore also a feature of participants' physical experience over time. Complications were unpredictable in both onset and nature. This allowed people to experience occasional instances of 'good days', while never allowing them to fully recover to their previous levels of health.

Although most participants experienced a slow but steady decline in their physical condition, a key difference must be noted between people with ALD and those with liver disease from other causes. Unlike their non-ALD counterparts, ALD patients have the opportunity to take control of their illness due to its self-inflicted nature by alcohol misuse. Success with sobriety varied across ALD participants, but a small number of cases demonstrated positive change through time. John and Sarah, who succeeded in overcoming their alcohol dependency in the course of the study, both experienced increasingly improved health.

I am getting better every day. I mean, I've got my tired days but I am getting stronger every day. (*Sarah, 38, ALD (HCV), second interview*)

BK: So have you got any physical symptoms at all leftover from...?

John: Not really. (...) I feel a lot better I think than I ever did.

(*John, 68, ALD, third interview*)

5.4 Understanding liver disease

The following sets out participants' understanding of their condition and its implications for the future. Regardless of aetiology, most had had little knowledge of

liver disease prior to their diagnosis, reflecting a general lack of public discourse in this respect.

Until I had an alcohol problem I didn't have a clue what your liver was actually for. (*Ben, 35, ALD, first interview*)

I know there is drinking, cirrhosis of the liver. That's the only one that I know of. (*Mary, 66, autoimmune hepatitis, first interview*)

As a result, Nadia was rather alarmed when she was first diagnosed with hepatitis C.

At first I thought it was AIDS, I was convinced it was AIDS I had. (...) That's how naïve I was, I thought it was the same as AIDS. (*Nadia, 58, ALD (HCV), first interview*)

Those with liver disease caused by alcohol misuse were clear about the origin of their illness. Similarly, most participants with NAFLD accepted that their condition was likely to be linked to their having diabetes. However, some participants struggled to understand why they were ill.

I've not got a clue how or why I've got the liver complaint. I've not got a clue. I don't even know how you catch a liver complaint. (*Mary, 66, autoimmune hepatitis, first interview*)

I don't know what's the cause because, I mean, I never ever done anything for it to be like this, you know? (*Polly, 68, NAFLD, first interview*)

As this uncertainty about the origin of their illness was frequently reiterated within and across interviews, it clearly constituted a matter of great concern to these participants. There was also widespread uncertainty about which physical symptoms to ascribe to their liver disease.

This lack of energy thing, I mean, is that quite normal for somebody who's got liver disease (...) or am I just milking it a bit? Should I be ok or what? I don't know what all this is about. (*Kate, 41, cryptogenic LD, first interview*)

I've had a sore back for the last few years, and it's like when I'm bending, cutting in the kitchen, like chopping, it gets worse. Does the liver, does your bending, can that give you a sore back? (*Ben, 35, ALD, first interview*)

Patients' uncertainty about what constituted typical symptoms of liver disease also manifested itself during the recruitment phase. Some inpatients I approached about the study were reluctant to participate as they felt unable to comment on their experience of living with advanced liver disease due to a lack of definite symptoms.

Despite both their accounts highlighting several physical complications typical of liver disease, Fay and Polly also echoed this sentiment.

Fay: I can't say I've got anything wrong with my liver because I don't feel any different.
BK: So you don't know if the symptoms that you have are in any way linked to the liver or not?
F: That's right.
(*Fay, 84, NAFLD, first interview*)

Polly: Well, you've got the same symptoms all the time (...)
BK: OK. So what sort of symptoms are they then?
P: Well to be honest I don't know, because I mean the only thing I can tell you is I get anaemic, that's the only thing I can tell you.
(*Polly, 68, NAFLD, first interview*)

This ambiguity in relation to the origins and characteristic features of their condition thus made it difficult for participants to make sense of their physical illness experience.

5.4.1 Wishing to understand liver disease

Despite the uncertainty their lack of understanding was causing them, some preferred to remain ignorant of the nature of their condition.

I'm scared to ask because the more complicated it gets, the more it seems real and scary.
(*Ben, 35, ALD, first interview*)

I was going to go down to the library and get out a doctor book about the liver and I went, "No Mary, you don't want to ken." (*Mary, 66, autoimmune hepatitis, first interview*)

Although some participants felt well informed about some aspects of their condition, the consensus was that information-sharing by professionals was generally poor.

It's not so much misinformation, it's no information. (*Kate, 41, cryptogenic LD, first interview*)

Participants were generally prepared to proactively ask questions of professionals. However, their poor understanding of their condition left them unsure about the questions they should be asking.

I don't know what it is I want from them. I think that's half of the problem, because I don't know what the right questions are to ask or what it is I should be asking. (*Kate, 41, cryptogenic LD, second interview*)

BK: So do you feel that you're kind of confident enough or happy enough to ask the doctors questions? (...)

Nadia: Not really no, because I don't really know what I'm asking.
(*Nadia, 58, ALD (HCV), first interview*)

Even where answers were offered by healthcare professionals, they were often considered unsatisfactory.

I don't mind asking the doctors questions, it's the answers that I get back! It's a "I don't know," or "I'm not quite sure," or "What do *you* think?" I'm not the one to think or make sure or whatever, it's up to the doctor to tell *me* what's what! And if you don't get an answer from the doctor that does worry you, which can make the complaint, the complaint that you've got worse than what it is. (*Mary, 66, autoimmune hepatitis, first interview*)

Clarity about one's situation was also hampered by conflicting information received from different sources.

You're seeing lots and lots of different doctors all the time and you know, one of them is telling you one thing and another one's telling me something else and you're thinking, "Well, what's all that about then? Who am I supposed to be listening to here?" (*Kate, 41, cryptogenic LD, first interview*)

Both the seeking and receiving of information about their condition was thus yet another aspect of participants' illness experience that was beset with uncertainty.

5.4.2 Knowing what to expect

Participants were particularly poorly informed about what to expect from their illness, and where it was likely to lead in the future. This left them uncertain and worried as to how to behave to appropriately support their health.

Somebody should be able to sort of say, "Well this will happen sometime or that will happen sometime," and you know, warn you that it's going to do and what you've got to do when it happens. (*Thomas, 75, NAFLD, first interview*)

However, not everyone was keen to know what the future held in store for them.

I don't know how excruciating this is going to be. Not got a clue, don't want to know. I'll just take it as it comes. (*Rebecca, 37, ALD, third interview*)

From Michael's perspective as a caregiver, dealing with the uncertainty in this respect was not so much about professionals imparting more factual information.

Rather, he felt that they should alert patients and their families to the realities of managing an illness as unpredictable and uncertain as advanced liver disease.

People get frustrated about not knowing what's going on (...), but if you say right at the onset this is what's going to happen, it's going to be a big rollercoaster, it is going to be full of ups and downs, there's going to be lots of times of nothing happening, people will come and change opinions by the second and that's what is literally going to happen, be ready for it, it's fair to challenge it and ask questions but don't be surprised if that again changes, you know, that information that comes through. So if you can get that information across to the patient (...) that in itself for me is understanding what's going on. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

5.4.3 Knowing how to self-manage

One type of information that nearly all participants hankered for was clear advice on how to self-manage the illness in everyday life. The only guidance typically given was to abstain from alcohol and reduce the intake of salt. Overall, this was considered insufficient information.

It's all very well saying don't touch alcohol. I mean I know that, so there's no point telling me again and again and again. (...) Is there anything else you can do to at least give what's left of my liver a chance to function? (*John, 68, ALD, third interview*)

The lack of guidance on how to help promote their own health left participants feeling frustrated and annoyed.

You know how they say maybe, like for cancer patients, eat this or eat that or eat the next thing. I'm not getting told, "Well you could eat this, you could eat that or the next thing," or "This'll help you," or "It'll help you with your immune system," blah blah. I don't know! And it's unanswered questions. It does my head in, it really does. (*Mary, 66, autoimmune hepatitis, first interview*)

I'm uptight at the way they're treating me because, you know, I feel as though I'm getting it in bits and pieces and all that. (...) There should be a list or something handed to me or somebody should sit down with you and go over all these points and say, "Thou shalt not and thou cannot and thou can." (*Thomas, 75, NAFLD, first interview*)

Seeking self-management advice may be considered one way in which participants sought to regain some control in the context of a largely uncertain and alien illness experience. The absence of such guidance therefore constituted a major source of frustration in their lives. How participants coped in light of this lack of self-care opportunity will be described in Chapter 6.

5.5 Discussion of findings

The above findings reveal uncertainty as the defining feature of the onset of advanced liver disease. This uncertainty caused participants much anxiety and frustration in relation to many aspects of their condition: its origins, nature, management and implications. In light of uncertainty emerging as such a salient and influential characteristic, a closer look at current understandings of uncertainty in chronic illness is first needed in order that the present findings can be located and understood in this context.

5.5.1 The theory of uncertainty in chronic illness

The dynamic and unpredictable nature and timing of physical, cognitive and lifestyle changes in the course of a chronic illness make uncertainty a key characteristic of that experience (Mast, 1995). Uncertainty is described as a person's inability to form a cognitive schema, or internal representation, of a situation on account of a paucity of cues (Mishel, 1988). It occurs, "when details of situations are ambiguous, complex, unpredictable or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general" (Brashers, 2001, p478). The person is consequently unable to confidently appraise their circumstances, make sense of events and experiences, anticipate likely outcomes, and determine their resources to cope with them, which may increase the stressfulness of the situation (Lazarus, 1993).

Mishel (1981) was the first to apply the concept of uncertainty in the context of health and illness. Drawing on several theories of cognitive appraisal, her Uncertainty in Illness theory was originally conceptualised around the experience of acute illness events, but later reformulated in recognition of the specific characteristics of the chronic illness experience (Mishel, 1990). She proposed that uncertainty in illness can take four forms: ambiguity regarding the state of the illness, the complexity of treatment and system of care, lack of information about diagnosis and illness severity, and the unpredictability of the disease trajectory and prognosis (Mishel, 1988). More recently it has been suggested that, in addition to these medical sources of uncertainty, personal and social sources also exist (Brashers et al., 2003).

In the illness context then, uncertainty constitutes a potential stressor and an important factor in a person's ability to adapt and cope, although this conceptualisation has been recognised as being subject to a Western cultural preference for predictability and control (Mishel, 1990). Figure 5 below illustrates the main components and pathways of Mishel's theory of uncertainty.

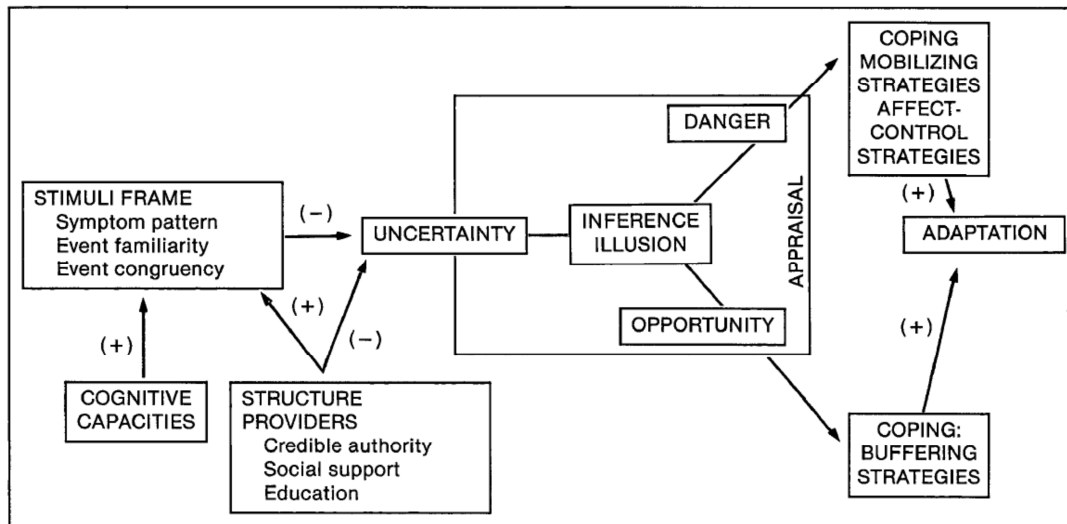


Figure 5: Model of perceived uncertainty in illness
(Source: Mishel, 1988)

According to the model, three antecedents are thought to influence uncertainty:

1. The individual's stimuli frame: this relates to the consistency of symptoms, the person's familiarity with events, and the predictability of events.
2. The person's cognitive capacity to process information, which may be affected by factors such as stress or medication.
3. The presence of structure providers: these are resources which assist the person with the interpretation of illness-related events or information.

Much of applied research links uncertainty in illness to adverse experiential outcomes such as anxiety and depression. However, Mishel (1990) asserts that the experience of uncertainty is not inherently negative, but is in fact a neutral cognitive state. Its impact on a person's illness experience is dependent upon the value that is

put upon it, i.e. whether it is appraised as a danger or an opportunity. For example, remaining ignorant of their prognosis may be anxiety-inducing for some individuals, but the preferred cognitive state for others. As shown in Figure 5, the appraisal of a situation involves two processes: inference, which is informed by the person's traits, experience and knowledge as well as contextual clues, and illusion, which relates to beliefs that are constructed out of uncertainty and typically result in its appraisal as an opportunity.

The appraisal of a situation as a danger or opportunity affects the coping strategies people will adopt. Danger appraisal encourages strategies to reduce uncertainty through mobilising actions (such as direct action or information-seeking) and emotion management (e.g. through faith or disengagement). Conversely, appraisal as an opportunity results in attempts to uphold uncertainty by actively blocking new, and potentially negative, stimuli (e.g. through avoidance or re-prioritisation). Over time, individuals may also revise their evaluation of uncertainty from one status to the other (Mishel, 1990). However, both approaches to coping, where effective, will facilitate adaptation and thus a more positive illness experience.

Uncertainty theory has been widely employed to assess the experiences of patients and their families in a range of acute and chronic health problems (Hummel, 2013, Neville, 2003). In liver disease, studies have shown that uncertainty plays a major role in the patient experience both pre- and post-transplantation (e.g. Bjørk and Nåden, 2008, Brown et al., 2006, Lasker et al., 2010), but there is scant application of the theory to the experience of living with chronic liver disease more generally (e.g. Bailey et al., 2009). In the following, I consider the findings presented in this chapter within the specific context of current understandings of uncertainty in chronic illness as described above, while also making reference to the wider disease-specific literature.

5.5.2 Receiving a diagnosis

For many participants, receiving a diagnosis of liver disease came late in the disease trajectory. Their first symptoms of liver damage had commonly been non-specific, causing uncertainty about their nature. Eventually the first tangible symptoms,

already typical of advanced liver disease, prompted a firm diagnosis. The often late identification of liver disease due to its clinically silent nature has been noted previously (Heneghan and O'Grady, 2001, Wainwright, 1997), and was borne out in this sample.

It is conceivable that this characteristic of early liver disease contributed to the finding that those misusing alcohol had not heeded their GPs' warnings following raised liver function test results. To a lay person, blood test results are likely to be a rather abstract and elusive indicator of ill health; an absence of actual symptoms causing tangible discomfort might therefore mean that they do not grasp that their health is in fact damaged and requires restorative action (Charmaz, 2000). Alternatively, early warnings may have been dismissed due to a lack of treatment offered by health professionals, an action which may facilitate patients' appreciation of the seriousness of the situation (Blaxter and Cyster, 1984).

However, the anticipation of a loss of valued roles, responsibilities or self may also cause individuals to suspend seeking help (Charmaz, 2000). This notion may serve to explain the finding that even where ALD participants had recognised early symptoms as an indication of possible liver damage, they had opted to deny these for as long as possible. In this context then, the cognitive process of illusion looks to have been at play. Uncertainty about their health status was employed as an opportunity and consciously maintained to help preserve their identity in the face of a likely threat.

Receiving an explicit diagnosis of advanced liver disease was an unexpected and alarming event for many. This experience was heightened by healthcare professionals' use of ambiguous terminology when communicating the diagnosis. Several participants were left uncertain about their status when given a diagnosis of 'cirrhosis', a term they were only familiar with in relation to people misusing alcohol. Use of similarly unhelpful professional language has been reported in the context of receiving a diagnosis of lung cancer (Yardley, Davis and Sheldon, 2001). The authors cautioned that professionals need to be mindful of the language they use and, given the impact of receiving a diagnosis of serious illness, individualise their approach in the context of a patient's specific background and circumstances.

Doctor-patient communication as a key area of interest in this study will be elaborated on in Chapter 7 in the context of participants' accounts of their care.

5.5.3 The physical experience of advanced liver disease

Patients had often received their diagnosis at a point where for many their liver damage was irreversible, treatment options limited and prognosis poor. From that point forward their illness was erratic, unpredictable and disruptive to everyday life, alongside slow but steady deterioration. The physical complications experienced were manifold and pervasive. They could also be seen to interrelate, such as the link between fatigue, sleep problems and mental wellbeing, and ascites contributing to mobility problems. As the physical features of advanced liver disease have been extensively described in the literature, I will only briefly discuss some key observations made in relation to this aspect of participants' illness experience.

Fatigue

Fatigue constituted the most debilitating issue across all patient participants, reinforcing findings in similar, cross-sectional qualitative studies in advanced liver disease (Bjørk and Nåden, 2008, Wainwright, 1997). This finding also contributes to results reported elsewhere that fatigue is pervasive in various malignant and non-malignant chronic diseases including organ failure (Janssen et al., 2008, Solano, Gomes and Higginson, 2006). Moreover, the longitudinal format of this study gives insight into the severity and unpredictable yet enduring nature of the everyday experience of fatigue in advanced liver disease. The data also highlight patients' uncertainty regarding the legitimacy of fatigue as a typical feature of their condition.

The data also support the notion that fatigue is a multi-dimensional experience with physical, emotional and mental features (Rodrigue et al., 2010). In the present study, fatigue could be seen to relate to participants' sleep, anxiety and understandings of self. In heart failure, it has been argued that any attempt to relieve patients' fatigue should not simply focus on symptom management to minimise severity and distress, but should also support patients to draw on their personal resources and abilities to manage the fatigue experience (Falk et al., 2007). In light of the psychological impact of fatigue witnessed in the present sample, I agree with this stance.

Finally, given the range of aetiologies represented in this sample, the data also reinforces work by Jones et al. (2009) that the experience of fatigue is comparable between different groups of liver patient. Moreover, as their study did not include patients with ALD, the present study adds to their findings by showing that fatigue was just as crippling an experience for people with this particular disease cause.

Motor coordination and mobility issues

Problems related to motor coordination and mobility emerged as more troublesome than previously indicated in the liver disease literature. It has been suggested elsewhere that many of the more 'minor' complications experienced by cirrhotic patients, such as problems with motor function, memory or sleep, may be indicative of subclinical levels of hepatic encephalopathy (HE), a condition affecting the central nervous system and common in people with liver cirrhosis (Groeneweg et al., 1998). The study findings imply support for this notion; however, it is also conceivable that these problems were linked to patients' fatigue as discussed above.

The present findings intimate that motor and mobility problems are possibly more widespread and unsettling for patients than previously acknowledged. Indeed, these problems were also confirmed by members of the study's lay advisory group. The relatively poor consideration of these difficulties may be due to them falling victim to the time pressures of a typical medical consultation, where more acute and critical clinical issues are prioritised by healthcare professionals in that time. Alternatively, it may be that patients ascribe them comparatively less importance and so omit them from conversation during a medical encounter. In light of the participants of this study feeling uncertain about the typical features of advanced liver disease, another explanation is that patients simply do not connect these problems to their condition. Possibly as a consequence of some of the above points, issues related to motor coordination and mobility are not always available for selection on the quality-of-life questionnaires commonly used to assess liver patients' physical experience, thus leading to a relative underreporting of their prevalence and impact in the current literature.

This study has found psychomotor and mobility difficulties to impact negatively on patients' quality of life. The uncertainty associated with these problems additionally challenges their sense of identity by curbing their ability to engage in valued roles and activities, and fosters social isolation. Irrespective of the underlying cause then, patients should be more routinely assessed for such problems and corrective treatment provided where possible. Some of the uncertainty expressed in relation to these complications could be alleviated by forewarning and reassuring patients that difficulties with motor coordination and mobility constitute a characteristic part of their condition.

Pain

Pain was noteworthy by its absence in participants' accounts. Among this sample, pain was not experienced as the pervasive and disruptive problem typically seen in advanced disease. These findings challenge those of previous studies reporting substantial pain among people with advanced liver disease (Bianchi et al., 2003, Roth et al., 2000). Also, as these were cross-sectional questionnaire studies, they were unable to offer insight into the nature and extent of the pain experienced over time. In the present study, pain was generally associated with intermittent episodes of discomfort only, until it emerged as a more permanent feature in the final stages of the illness.

This study demonstrates the value of qualitative research for extending our understanding of patients' illness experiences. It is possible that quantitative survey tools do not exclusively identify the persistent levels of pain typical in advanced disease and comparable to that reported in other conditions. Indeed, some have questioned the absence of longitudinal comparisons and the arbitrary timing of quality-of-life research (Cirrincione et al., 2002). Depending on the timing of their completion by the patient, questionnaire responses may thus reflect short-lived episodes of pain related to, for example, ascites, inactivity or medical treatments, thereby giving a distorted picture of liver patients' pain experience. Moreover, the participants in the study by Roth et al. (2000) were hospitalised patients. It is conceivable that their pain perception was affected by these circumstances, especially if the reason for their hospitalisation rendered them in pain at that time.

Relatedly, given my study data suggesting the emergence of more permanent and problematic pain towards participants' final days and weeks alongside an erratic but steady downwards trajectory in general, it may be that previous studies captured pain experiences relating to these later, final stages of the illness. Lastly, in light of participants in this study admitting to great confusion with regard to their medication regimen, it is possible that they were unaware that basic levels of pain were in fact medicated for. Regardless, it must be concluded that pain does not dominate the illness experience among people with advanced liver disease.

5.5.4 The psychological experience of advanced liver disease

Low mood

The nature of this study does not allow a firm statement to be made about the incidence of depression and anxiety among this sample. Some participants declared an existing diagnosis of depression, but its relationship with their liver condition was unclear. However, low mood was frequently expressed by all participants and was evident in their demeanour during interviews. The vulnerability of one's body and resultant dependency can impact greatly on individuals' psychological wellbeing (Charmaz, 1997). Moreover, there is extensive evidence that uncertainty, where this has been appraised as a danger, fosters a pessimistic outlook as well as anxiety and depression. The ubiquitous uncertainty found in relation to both patients' physical experience and their understanding of advanced liver disease consequently provides a plausible explanation for the widespread low mood identified here.

This finding is also consistent with previous assertions that psychological status, levels of coping, and quality of life of cirrhotic patients are extremely poor (Bianchi et al., 2005, Singh et al., 1997). Psychological distress and depression have also been linked with disordered sleep (Bianchi et al., 2005). Insomnia was also a common problem among my study participants, reflecting the existing literature in advanced liver disease (Bianchi et al., 2003, Mostacci et al., 2008). Combined with participants' expressions of low mood then, this finding may in fact be indicative of affective disorder.

As low mood affects patients' clinical experience, psychological wellbeing should be regarded a priority to improve the patient experience in advanced liver disease. This may include pharmacological and therapeutic interventions; however, I would argue that exploring and subsequently addressing some of the uncertainties experienced by patients may go a long way towards alleviating their low feelings. It has been suggested that nurses could play a key role in promoting positive coping by addressing and pre-empting some of the uncertainties experienced by patients and their families (Hilton, 1992, Madar and Bar-Tal, 2009).

Impact on patients' sense of self

The constant fluctuation and unpredictable onset of the above and other physical challenges made everyday life uncertain and frustrating. They interfered with basic tasks like personal hygiene and restricted previously valued activities. They also affected social relationships by rendering patients reliant on others for support, while at the same time reducing their ability to engage with wider social networks. Similar experiences have been witnessed in heart failure (Murray et al., 2002). As a result, participants struggled to align the self they knew and aspired to with the uncertain and challenging reality of their lives (Charmaz, 1997).

The results of this study lend support to the notion that four particular challenges affect the sense of self of those living with chronic illness: living a restricted life, social isolation, discrediting definitions of self, and becoming a burden (Charmaz, 1983). All four issues were clearly represented in the data. Managing this assault on one's identity was thus an additional, and possibly competing, challenge for patients alongside the need to manage the many uncertainties presented by the disease itself.

The uneven trajectories that define many chronic illnesses commonly allow patients periods of respite from acute ill health and a temporary return to previous or redefined levels of normality and self (e.g. Pinnock et al., 2011). In the context of advanced liver disease, however, its relentless pervasive impact across physical, psychological and social domains made any sustained distancing from the condition impossible. Constant fluctuations and disruptive events defied adaptation to its pace. Conversely, the nature of the condition increasingly necessitated patients' immersion

in their illness, whereby the requirements of the condition dominated and defined patients' actions (Charmaz, 1997).

5.5.5 Understanding liver disease

The absence of open, public discourse about liver disease through government policy, health systems or the media (over recent decades seen most prominently in the realm of cancer) contributes to the lack of both public and private understanding about the condition and its typical features identified in this study. The influence public discourse carries was evidenced by participants' alarm at being diagnosed with 'cirrhosis', a term they associated with alcohol dependency in line with past celebrity media coverage to that effect. A similar lack of public understanding has been noted in COPD (Momen et al., 2012).

This lack of even a basic awareness of the nature of liver disease formed the basis of participants' uncertainty regarding the origins of their illness and related complications. Patients were faced with circumstances and symptoms of which they had no experience or knowledge, and no general reference point. This uncertainty was further increased by an apparent lack of education as part of their ongoing medical care. These findings resonate with previous research in ALD, where patients showed similarly poor understanding of the nature of their condition and its clinical features (Blaxter and Cyster, 1984).

Understanding a disease and its implications, from the causal factors to treatments to a likely prognosis, can give patients a sense of control over the situation (Fan and Eiser, 2012) and may serve to reduce their loss of self (Charmaz, 1983). Moreover, a medical understanding of the disease may promote its conceptualisation as an entity separate from the ill person's self, thus helping individuals distance themselves from the disease (Bury, 1982). However, as I have argued earlier, the data suggest that in advanced liver disease it is not easily possible to create such distance due to the condition's persistent and all-encompassing nature. In spite of this, access to unambiguous information is desirable as an important means by which to inhibit the stressful experience of uncertainty (Brashers, 2001, Mishel, 1988).

Poor understanding of their condition, its symptoms and management has also been reported in cardiorespiratory patients (Exley et al., 2005) and people with heart failure (Boyd et al., 2004, Murray et al., 2002). Understanding symptoms and treatment have been shown to help reduce uncertainty in heart failure (Winters, 1999). In the present study, the absence of factual understanding left participants struggling to make sense of and legitimise some of the physical difficulties they were experiencing, thus adding to their psychological illness burden.

5.5.6 Information needs

Uncertainty, alongside patients' poor understanding, also impacted on their ability to proactively seek a better understanding of their illness and its implications. Some were confused and uncertain about what they would want to know more about. At the same time, there was evidence that living with uncertainty about one's condition was a preferred state for some, a finding also reported in COPD (Pinnock et al., 2011). In these instances, uncertainty could again be seen to be employed as an opportunity. Faced with potentially threatening information, these individuals chose to actively maintain their uncertainty (Mishel, 1990). Remaining ignorant was utilised as a preferred positive option for safeguarding one's self and wider psychological wellbeing - not knowing was considered better than knowing (Neville, 2003). Uncertainty was thus managed based on the person's assessment of whether having certainty about their condition would empower or undermine them (Cohen, 1993). This finding confirms that reducing uncertainty is not necessarily a person's desired goal (Brashers et al., 2000).

Most patient participants felt frustrated about what they perceived to be a paucity and poor quality of information provided by care professionals. At the same time, they displayed differing levels of need regarding the nature of the desired information. Some participants displayed a real tension between wishing to gain more information and not wanting to know, which added to their anxieties. Evidently then, information has the potential to increase or decrease uncertainty. Even where new information fails to reduce the ambiguity of the person's situation, it may serve to prompt a re-evaluation of uncertainty (Brashers et al., 2000). The findings of this study also

remind us of the importance of tailoring information to individual need and imparting this in the right manner, context and setting. It is essential that professionals ascertain patients' level of understanding and encourage them to ask questions in order to establish how much information they wish for and their readiness to receive it (Parker et al., 2007, Sell et al., 1993).

Contemplating the perceived lack of information about their condition among this group, I considered that a number of scenarios were likely to be at play here:

- The deliberate omission of information in an area, perhaps in an attempt by professionals to uphold patients' hopes and not unduly alarm them. However, professionals may be acting overcautiously in this regard. An interview study of lung cancer patients about their experience of receiving a diagnosis revealed that none felt they had been given too much information; in fact, they would have appreciated more (Sell et al., 1993).
- Clinical or professional uncertainty about particular features of the disease rendering healthcare providers unable to provide certain information. In such instances, professionals should alert patients and their families to these uncertainties, and support them in accepting that uncertainty is a reality of their life with chronic illness (Mishel, 1999).
- Information that was in fact provided, but was too medicalised, complex or piece-meal to be taken on board by the participants. The quality of information given by professionals can impact upon the patient's appraisal of an uncertain situation and is dependent on the quality of its features: clarity, accuracy, completeness, volume, ambiguity, consistency, applicability and patients' confidence in the source of the information (Babrow, Kasch and Ford, 1998).
- Information provided by professionals and received by participants, but conflicting that given by other professionals involved in their care, leaving patients confused. This scenario will be examined in more detail in Chapter 7 in the context of patient participants' care experiences.

- Information provided, but forgotten about or not taken on board due to a lack of cognitive ability by patients to comprehend, assimilate and apply the information. This could be due to information overload, its content being too upsetting to be absorbed, or fatigue or minimal HE interfering with information retention or processing.
- Information that was provided, but deliberately ‘buried’ by patients as it was too emotional to contemplate and threatened the person’s sense of self.
- Information that was simply overlooked and so not passed on by professionals, or not necessarily considered relevant or important to patients to be offered up front, but that would have been readily available if patients had asked for it. However, the data showed that people were often unsure about what questions to ask or lacked the confidence to ask them.

Finally, it is worth considering to what extent participants were actually alert to a lack of information before they started to talk about their experiences as part of the interviews. My prompting questions may have served to highlight to them certain issues they had not been told about or had been uncertain of, and as a result now perceived these as important and lacking. At the same time, the interviews may have constituted the first time that these patients had got to contemplate and articulate what they would want more of, or were lacking at the moment, as regards information. It is therefore conceivable that the interviews contributed to the creation of ‘dissatisfied customers’.

5.5.7 The special case of alcohol-related liver disease

The results point towards some specific characteristics of the patient experience in ALD that are worth noting. The findings suggest that the physical challenges and experiences are comparable between aetiologies. The main observable difference was that ALD participants were generally better able to take on board and come to terms with their illness as they fully understood its cause and, to some extent, had ‘seen it coming’. This finding diverges from previous research where ALD patients

displayed considerable ignorance and confusion regarding their diagnosis (Blaxter and Cyster, 1984).

Moreover, these participants had the ability to interrupt and influence their illness trajectory by ceasing their harmful alcohol consumption. This change in their behaviour was able to halt further progression of the disease and stabilise their condition. Both John and Sarah were examples of this scenario. In both cases, traumatic acute hospital admissions on account of their liver damage served as the turning point in their illness experiences. An experience may be considered a turning point where it can be seen to have a transformational effect on a person's life (Denzin, 1989). Faced with uncertainty relating to both present and future, both participants recognised sobriety as the single factor in the context of their illness that they would be able to exert control over. As such, pursuing sobriety constituted both a means of managing uncertainty and an opportunity for change. This finding lends support to the notion that uncertainty is an evolving process, in that individuals may gradually revise their evaluation of uncertainty from danger to opportunity (Mishel, 1990). Embracing uncertainty may subsequently facilitate a new orientation to life.

The ability to have relative control over the progression of their illness resulted in these particular participants having markedly different experiences in some aspects of their illness. Further related observations in this respect will be highlighted and discussed throughout the following chapters where appropriate.

5.6 Concluding remarks

Participants' accounts of the beginnings and everyday physical and psychological experience of advanced liver disease were marked by pervasive and enduring uncertainty. Consequently, I found that uncertainty theory as applied to chronic illness provided explanatory power for many of the study's findings (Mishel, 1990). Uncertainty is beset with ambiguity, vagueness, unpredictability and a lack of information (Mishel, 1981). All of these aspects were clearly represented in the data described in this chapter. To my knowledge, this is the first time uncertainty theory has been used to illuminate the lived experience of advanced liver disease.

Uncertainty was an important mediating factor in respect of people's poor understanding of liver disease and information-seeking behaviour. The information shared by professionals was perceived as limited and of poor quality. Being explicit about the uncertain nature of the condition may in itself serve to reduce patients' anxieties in this respect.

The results in this chapter contribute some new insights to the literature in advanced liver disease. They show the ubiquity and complexity of some of the complications experienced, such as fatigue and ascites, and give an indication of their relative impact on participants' everyday lives. Issues relating to patients' motor co-ordination and mobility emerged as more widespread and troublesome than previously intimated. Conversely, pain was notable by its relative absence. The ability of ALD patients to delay disease progression by way of sustained sobriety, and to consequently embark on a divergent illness pathway to that of their counterparts, was highlighted.

Chapter 6: Negotiating everyday life

The previous chapter indicated that the experience of advanced liver disease was from its very beginning defined by widespread and enduring uncertainty, which related to the unpredictable nature of the disease as well as patients' poor understanding of their condition.

This chapter considers the experience of negotiating everyday life with the disease. First, it highlights some life-related stressors affecting participants' lives. It then shows how patients coped, and the strategies they employed to manage their challenging circumstances. It further describes the impact the illness had on their social relationships. Lastly, it sets out patients' holistic support needs and some of the barriers to accessing appropriate support. A discussion of these findings in the context of previous research and the theoretical literature concludes this chapter.

6.1 Life-related stressors

In addition to the physical challenges and a poor general understanding of their disease as described in the previous chapter, participants' illness experience was also affected by factors which related to general life circumstances beyond their illness.

6.1.1 Inability to work

Many patient participants of working age had been forced to take long-term sickness leave from work; in some cases their employment had since been terminated. The inability to work was felt acutely in this group, particularly by the younger participants, and contributed to their low mood.

The more that you're not working the more depressed you get, sitting in here. (*Ben, 35, ALD, first interview*)

Uncertainty about the likelihood of being able to work again in the future added to their sorrow.

I still get a bit down when I think about what's going to happen with work and if I'm ever going to be able to work again. (*Carol, 45, ALD, second interview*)

Participants actively missed not being able to go work as it had made them feel 'normal'. Over time, they started to struggle with the lack of purpose to their days, as it made days feel long and frustrating to endure.

Stuck in this house day after day, it's just like I exist. It's not like a life. (*Ben, 35, ALD, third interview*)

6.1.2 Financial pressures

The inability to work put these individuals under great financial pressure, which added to the burden of their illness.

It's the financial side of things that's bothering me more than anything else, just because I know there's going to be no money coming in at the end of the month. (*Kate, 41, cryptogenic LD, first interview*)

As time passed, younger participants found themselves increasingly financially dependent on their families to make ends meet. Given the uncertain circumstances, however, their caregivers felt similar pressure.

We're not quite sure where we are going to go now, because Kate contributes financially and she can't do that anymore and won't be able to for some time. Do we sell the house? Do we move? Do we do it now when Kate's quite well? Do we wait, keep our fingers crossed that things are going to be ok? (*Michael, husband of Kate, 41, cryptogenic LD, first interview*)

6.1.3 Accommodation issues

Some participants were also dealing with worries regarding their accommodation. In some cases this was related to the suitability of their current abode, especially with regard to having to negotiate stairs in their often weakened and unstable condition. For those with a lack of social support, regular rehousing by social work services added to the challenges of their illness experience.

I think there were problems in some of the tenancies that he was in. So sometimes he would come in[to hospital] and he would become homeless while he was in with us and we would have to try and sort out further accommodation for him. (*Consultant of Fraser, 60, ALD*)

Aidan lived in temporary social care accommodation, which demanded that residents were absent for no more than three days at a time or risked being removed from the abode. Aidan's regular inpatient attendance for paracentesis therefore meant that

every admission put his home at risk, with the regular delays in having the procedure carried out causing additional stress and uncertainty in this respect.

I phoned up [the temporary accommodation] last night and they said, (...) “I thought you would have got it done today,” and I says, “Aye so did I,” I says. “But they’re coming to do it tonight,” which they didn’t. So we’ll wait and see what happens today but I says to him, “If I get it done today I’ve still got to get out tomorrow.” (*Aidan, 60, ALD, first interview*)

6.1.4 Alcohol dependency

The illness accounts of participants who identified as alcohol dependent were dominated by their struggles to overcome this harmful behaviour. They recognised the urgent necessity to conquer their alcohol problems in order to gain control over their advancing liver disease, while at the same time struggling with uncertainty about their ability to achieve this.

Ben: There’s going to be problems in life and I don’t know what I’m going to turn to, because I can’t turn to alcohol now. I’m going to have to deal with stuff like adults instead of panicking and going into the fridge.

BK: How does that prospect make you feel?

B: Scared. Because it’s going to get a lot worse before it gets better in the future.

(*Ben, 35, ALD, first interview*)

For these participants, the quest to achieve abstinence occupied their minds over and above any concerns about their liver disease, which added considerably to their psychological burden.

The above illustrates how the illness related to participants’ wider life circumstances, with a knock-on effect on their psychological wellbeing, sense of self, and close relationships. All of these factors constituted further sources of uncertainty in the overall illness experience.

6.1.5 Stigma

Participants were acutely aware of the stigmatising reputation of liver disease, and especially its popular association with alcohol misuse. Some participants related incidents of stigma in relation to this common assumption in the healthcare setting.

People automatically assume that you've got an alcohol problem. It's an automatic, even doctors in the hospital (...) they'll say to me, "So how's the drinking going?" And I'll say, "I don't know, because I don't drink." (*Kate, 41, cryptogenic LD, first interview*)

While most denied any actual experience of stigmatising behaviour by professionals, several participants with ALD perceived stigma due to the nature of their illness.

Rebecca: I might just be paranoid but I feel like they treat me different to other patients.

BK: OK. In what way?

R: Because they get more attention than me. (...) They're always really nice to them. Sometimes I feel like they just walk past me.

(*Rebecca, 37, ALD, third interview*)

Participants also perceived illness-related stigma in everyday life. The largely invisible nature of their illness was one factor in this respect.

I see people looking at me on the bus too because I got a bus pass as well, and you see people, even the drivers, two of the drivers said to me, "How did you manage to get a bus pass then?" (*Kate, 41, cryptogenic LD, third interview*)

There was concern about people's assumptions tarnishing one's reputation.

I went down to the Co-op the other day on Tuesday, and [neighbour] next door, his mum was standing outside the Co-op and she went, "Oh Mary," she says, "what a weight you've put on." I said, "It's not weight, (...) it's fluid." Another woman accused me of drinking. I says, "You spread that about [the village]," I said, "I'll take you to the cleaners. Defamation of character." (*Mary, 66, autoimmune hepatitis, second interview*)

The anticipation of stigma was thus a further source of uncertainty in participants' lives and led many to adopt strategies for avoiding potentially stigmatising situations, such as pre-empting false assumptions or avoiding disclosure altogether.

I go to (...) great lengths to make sure they know it was not drinking, because that's the first thing I say to them, I say, "It's not drink-related, because I didn't drink a lot." (*Thomas, 75, NAFLD, first interview*)

BK: Is there a reason why you don't give people any details [about wife's illness]?

Jeff: No. The way I look at it is that's our business, you know? You're better keeping it because somebody maybe says something, somebody adds something else onto it, you know? You know what people are like.

(*Jeff, husband of Polly, 68, NAFLD, first interview*)

6.2 Coping

6.2.1 Characteristics of patients' coping

Increasing physical complications over time negatively affected participants' psychological state, often due to a realisation that continued physical decline was likely as well as feelings of uncertainty and fear about future developments.

Participants' coping with their illness varied between individuals and over time. Some expressed acceptance of their situation. Despite the added ambiguity of having liver damage through unidentified causes, Kate was philosophical about her lot.

It's just one of them, you know? You live with what you've got and everybody's got something, that's how I think of it. (*Kate, 41, cryptogenic LD, third interview*)

Those with liver disease from self-inflicted causes such as alcohol were equally accepting of their plight.

There's not point feeling sorry for yourself. What's done is done. And I've done it myself, so. (*Rebecca, 37, ALD, second interview*)

Older participants found it easier to accept their fate on account of their age.

I can't do nothing else. (...) It's no as if I'm a young man or anything. I'm 75, so I've had a good life ken, and I've had a good time. (*Donald, 74, HCC (NAFLD), first interview*)

Learning to cope with their situation was a process which evolved over time.

Julie: I think if you worried about it that much you would really, wouldn't go out the house, you wouldn't do anything.

Rebecca: I did for a wee while.

(*Rebecca, 37, ALD, and Julie, mother of Rebecca, second interview*)

I don't feel the need to be in people's company all the time, you know? I was really lonely before, but I don't feel lonely, even when I'm alone I'm not lonely now. (*Sarah, 38, ALD (HCV), second interview*)

For those enjoying an overall more stable physical condition, feeling physically well promoted a more positive mindset and thus better coping.

If I wasn't feeling terribly well it would certainly be worrying me, I wouldn't be happy at all. But I feel fine so that's that, that's an advantage. (*John, 68, ALD, third interview*)

One notable exception to the above was Ben, who experienced an inverse relationship between his physical and psychological condition. Feeling progressively better with debilitating symptoms subsiding owing to successful abstinence, Ben was eager to return to work and his previous levels of activity in general. However, his overall condition remained too poorly to allow him to do so. Being forced to recuperate at home without a focus to his days and little to distract him from the enduring uncertainties of his situation therefore affected his coping negatively.

As you've said before, what's the worst that can happen? In the past I used to agree with you, but now... Well, I could go to hospital again. I could end up dead. I could end up losing [partner and son] again. I might never get back to work or full fitness again. See, I was positive last time I spoke to you, but now it's all negative thoughts. (*Ben, 35, ALD, second interview*)

Indeed, despite expressions of acceptance and an indication of a positive outlook from some participants, low mood was widespread across the sample.

Before I was happy-go-lucky, laughing and joking with everybody and anybody, but now it's, I don't know, I just want to curl up now. (*Mary, 66, autoimmune hepatitis, second interview*)

Uncertainty and a fear of the unknown contributed to participants' poor coping.

I'm scared to get out my bed now every day, because as I say the fear, you know, of what I've done to myself, the damage that I might've caused myself, I can't get out of my mind. (*Ben, 35, ALD, second interview*)

6.2.2 Impact on self-image

Several participants were also preoccupied with the physical stigmata of their liver disease, which affected how they felt about themselves and their experience.

We were going to go down to [town] tomorrow, [friend] and I, but the way I look I feel that I'm an embarrassment. (...) I'm an embarrassment with the bulge. (*Mary, 66, autoimmune hepatitis, second interview*)

My arms are like sticks. I've no muscle in them and like, it disgusts me, like, looking at my body in the mirror because of how skinny I've got, and that dents your confidence. (*Ben, 35, ALD, third interview*)

All patient participants engaged in comparisons between their present and their past selves. Several described themselves as strong and determined characters. The changes brought about by their illness therefore unsettled their existing self-image, making them feel increasingly anxious and low.

I don't want to have to rely on other people. That's the frightening part, because I've never had to do it. Other people always rely on me and I don't like that feeling at all, having to rely on other people. (*Kate, 41, cryptogenic LD, first interview*)

The loss of previous abilities was particularly acutely felt.

Sometimes I lie in the room and cry and just think about things, you know, things that you could remember that you could do and now you can't. (*Fraser, 60, ALD, first interview*)

Importantly, being able to engage in treasured activities such as travel, work or physical activity was what had made participants feel 'normal', a status they were yearning to reclaim. For those with underlying alcohol problems, having to remain abstinent constituted an additional barrier to feeling 'normal'.

I'd like to be normal and have a social drink, not get drunk, but have a social drink. But I can't do that. (*Sarah, 38, ALD (HCV), second interview*)

Participants also felt that the illness had changed them as a person. This was an idea many found difficult to come to terms with.

It feels like I'm...this isn't my life like, I've stepped into somebody else's shoes. Like a few years ago that was me, that was Ben, that was my life, and now I don't know who I am. (*Ben, 35, ALD, third interview*)

John and Sarah were notable exceptions in this respect. Unlike some of their ALD counterparts, both succeeded in remaining abstinent throughout the course of the study and as a result were able to enjoy improved overall health and quality of life. They too felt that their illness experience had changed them as a person. However, they perceived this as a positive event, as they were able to reclaim their original selves prior to alcohol dependency.

In a sense I am more normal than I was when I was normal, because alcohol's been taken out of the equation. (*John, 68, ALD, third interview*)

6.2.3 Coping strategies

Participants displayed a range of coping strategies to manage their challenging circumstances. The following were the most prominent approaches employed across the sample.

Getting on with it

Many participants had resigned themselves to their fate and felt that all they could do was to 'just get on with it'.

There's no way out of it, no even a short cut. You've just got to grin and bear it. (*Fraser, 60, ALD, first interview*)

This stance of 'getting on with it' was evident in some people's quests to continue to lead a 'normal' life. However, success in this regard proved elusive for most.

I do try. I make an effort, like, appearance-wise and cleaning-wise and cooking-wise and stuff, but after it I'm knackered. (*Rebecca, 37, ALD, third interview*)

Taking one day at a time

One strategy which helped participants control these challenges was to narrow their focus to one day at a time.

You can't turn around and plan for the future or nothing, you know? You just take everything as it comes, day by day. (*Jeff, husband of Polly, 68, NAFLD, first interview*)

Because of the liver I don't know how long I've got left (...) so I live for today. (*Sarah, 38, ALD (HCV), first interview*)

Not dwelling on it

Many participants also consciously averted their focus away from their situation so as to not add to their own, and others', worries.

What's the point in thinking about it the now, because it's just going to stress me out. It's going to make me feel even worse about myself and everybody else around me. (*Rebecca, 37, ALD, third interview*)

Comparing self to others

While there was a reluctance to contemplate the details of their own situation, many participants found it helpful to compare their illness experience to that of others.

Despite their own poor wellbeing, they generally considered themselves more privileged than others.

There's always somebody worse than yourself. (*Fay, 84, NAFLD, first interview*)

Participants' inpatient episodes proved particularly useful for making comparisons, as they afforded an opportunity to observe the plight of others with liver disease.

When you're in and out of hospital all the time, it kind of makes you stop looking at yourself and think, "Well look at all these people that are a lot worse off than I am." (...) And that kind of spurs me on a bit, because I think, "Now what am I making all this noise about?" (*Kate, 41, cryptogenic LD, second interview*)

Those with ALD also compared themselves to other heavy drinkers. These participants typically concluded that a weaker constitution or predisposition must have contributed to their illness developing.

Sometimes I do think maybe my liver was or is weaker than other people's, because I've seen the amount of people that, it's incredible how much they drink and they've never been in hospital and they never go jaundiced and they drink every day. (*Ben, 35, ALD, second interview*)

Focusing on a positive outcome

Another prominent coping strategy was a conscious mental focus on a positive future outcome. Given the advanced and incurable disease status of all participants, this stance must be considered a deliberate cognitive and emotional distancing to enable better coping in the face of uncertainty.

As far as I'm concerned I have a problem. I've got a liver that doesn't work and the only way it's going to be fixed is if they take it out and give a new one, and that's what's going to happen. I don't know when it's going to happen, but it's going to happen. And after that life's going to be hunky dory. And there is no doubt in my mind whatsoever that anything other than a positive outcome is going to be. (*Kate, 41, cryptogenic LD, third interview*)

A key strategy to maintaining a positive mindset was to put their faith in healthcare professionals and their abilities and commitment to achieving the best possible outcome.

I don't really worry about my health because I'm in good hands here. As far as I'm concerned they know what they're talking about. Whether they do or not that's another matter. (*Mary, 66, autoimmune hepatitis, first interview*)

Taking responsibility for health improvement

At the same time, there was an appreciation that one also needed to make a personal effort towards health improvement.

What's the point in coming in here, getting them to do all of this for me, if I'm not even going to help them, you know? (*Aidan, 58, ALD, first interview*)

Consequently, participants spoke of committed attempts to adhere to their medication regimes, dietary stipulations, and refraining from alcohol consumption. They also looked towards popular lifestyle advice to support their health further. Indeed, in the absence of understanding and guidance regarding their illness as described in Chapter 5, many participants resolutely put their energy into improving their condition by pursuing self-care strategies of their own design.

I don't think that every time they drain [the fluid] off that they're getting me back to where I was. I think there's just a bit, a bit heavier, a bit heavier. So I'm actually putting myself onto a diet to try and lose some weight to see if that'll help. (*Thomas, 75, NAFLD, first interview*)

This eagerness to better their situation made some push themselves to unsafe levels.

[Friend] says, "You're trying too much for it to make yourself better Mary. Let yourself get better in its own time." I says, "I can't wait that long." But I feel I can't wait that long. I want to get better yesterday, not today or the morn. (*Mary, 66, autoimmune hepatitis, first interview*)

Faith

Three of the 15 patient participants declared an active faith from which they drew strength to help them cope with their illness. While most denied any form of spirituality, some participants did indicate a level of spiritual engagement in the context of their illness.

I believe there's someone looking after me, but I always talk about it as a guardian angel. (*Sarah, 38, ALD (HCV), third interview*)

It's very difficult to articulate it, because it's not what most people would think of as a faith. It's more an attitude. (*John, 68, ALD, first interview*)

6.3 Social relationships

With few exceptions, levels of social contact remained poor or declined over time. This means that those already isolated from their previous social networks remained socially isolated throughout their illness. Several factors contributed to this isolation. Some participants lived a distance from family and close friends due to previous life choices. Others were estranged from their relations. This scenario was true across disease causes and was not exclusive to those with troubled backgrounds such as alcohol dependency. Indeed, participants with alcohol problems were just as likely to have the support of a loving family as those without.

For some participants, their failing health meant that levels of activity and social contact decreased as they became increasingly less motivated, energetic and able to travel around.

Polly: I'm a quiet person, eh? I mean, I never go out. Yes.

BK: Has that always been like that or just since you got ill?

P: No, just since I got ill.

(Polly, 68, NAFLD, first interview)

The loss of an active working life also contributed to this segregation from previous social networks, as did frequent hospitalisation.

Julie: We have a lot of parties for people's birthdays, engagements, anniversaries and things like that. (...) And it's a shame you [Rebecca] can't go to them, eh? (...) She's usually in the hospital at the time. She couldn't go to my 60th. She couldn't go to her brother's 40th. What else now, Rebecca? What else did you miss?

R: Everything.

(Rebecca, 37, ALD, and Julie, mother of Rebecca, first interview)

In contrast, some ALD participants were able to improve social contact over time; this was usually due to their condition stabilising with sustained abstinence. This motivated dedicated efforts to rekindle intimate relationships after previous estrangement due to alcohol problems or ill health.

I'm meeting my friends a lot more regular as well and I'm trying to see my family as much as I can. *(Sarah, 38, ALD (HCV), third interview)*

6.3.1 Discussing the illness

Patient participants were acutely aware of the pressure their illness was putting on those close to them. They consequently avoided adding to this burden by hiding their emotions and worries from them.

I don't hide the problem from people, I hide the feeling from people. I'm always conscious that other people get quite upset by the things you tell them, so I tend to kind of keep my feelings to myself a bit or hold back and try and pick my moment. *(Kate, 41, cryptogenic LD, second interview)*

There was also great reluctance to discuss the illness with others beyond the immediate family circle.

I wouldn't be prepared to tell my friends what I've been through, you know? Maybe it will come in time with [best friend], maybe I'll be able to tell her, but not at the moment. *(Carol, 45, ALD, first interview)*

For some, avoiding discussion additionally provided a means of keeping the illness at bay as much as possible.

I don't like talking about it because I don't want to be reminded of it. *(Ben, 35, ALD, first interview)*

6.4 Support needs

When asked directly about their support needs, several participants reported feeling well supported and managing fine with available resources.

I feel like I'm, you know, I've been supported at the moment pretty well. *(Carol, 45, ALD, first interview)*

However, not everybody agreed that all their needs were well attended to.

I feel as though it's a bit of a shambles, is how I feel about it. I know everybody's busy and I know, you know, all this, but I think if I wasn't the type of person that I am, if I had been on my own with nobody else there to support me, i.e. no husband and no family, then I think I would have probably gone into a shell and not come out again. *(Kate, 41, cryptogenic LD, second interview)*

I feel I'm neglected. *(Mary, 66, autoimmune hepatitis, second interview)*

Indeed, even among those expressing satisfaction with the support they were receiving, their narratives revealed a range of needs that appeared in fact poorly addressed.

6.4.1 Types of support need identified

Practical support needs

As highlighted in Section 5.3, the physical complications associated with advanced liver disease posed a number of practical challenges which needed negotiating on a daily basis and for which assistance was frequently required.

[My sister], she'll like go down the post office for me if I feel like, I'm unwell in the morning and like, maybe get my money for me and get shopping and stuff. She'll Hoover for me if I've got a sore back. (*Rebecca, 37, ALD, third interview*)

Sarah, who lived alone and had no immediate support available to her, anticipated struggling with basic household tasks in the wake of her latest discharge.

When I get out of hospital it's gonna be difficult, you know? I won't be able to carry a lot of messages home, plus I won't be able to cook, I won't be able to stand and cook very long either. So it's gonna, you know, be quite basic foods. (*Sarah, 38, ALD (HCV), first interview*)

Many participants required assistance with personal hygiene due to being rendered inflexible by ascites or problems with their balance. Several also required support with attending medical appointments. This not only related to needing to be transported to them due to frailty and mobility problems, but also to the ability to compute the information being discussed.

[Friend] sits in with basically everything that I do, because my memory's a bit funny at the moment (...) and [friend] will pick up on things that I don't pick up on. (*Mary, 66, autoimmune hepatitis, second interview*)

Many participants' homes became increasingly unsuitable as their condition deteriorated. Negotiating stairs in particular became a problem as they struggled with poor mobility, imbalance and breathlessness due to ascites. Mary had enquired about the option of installing a stairlift in her home, but to no avail.

Walking up these stairs and back down again kills me. (...) They'd no even listen to me when I spoke about that electric chair. (*Mary, 66, autoimmune hepatitis, second interview*)

Patients' physical support needs generally increased as their condition, and thus abilities, declined over time. At the start of his study involvement for example, Martin was solely supported by his wife Cora. By his third interview nine months later, Martin's condition had deteriorated to a point where he needed professional care at home four times daily.

Psychological support needs

Participants' accounts indicated a lack of psychological and emotional support in relation to living with advanced liver disease. Indeed, patients voiced dissatisfaction with healthcare professionals' approaches to addressing their psychological needs.

They just gave us anti-depressants and I don't want anti-depressants. (*Mary, 66, autoimmune hepatitis, second interview*)

Several participants expressed their appreciation of the chance to discuss living with their illness as part of the research interviews and wished for access to more such opportunities.

It's good to be able to talk to someone you know is listening, you know, rather than just, 'Aye I've got this wrong with me, I've got that wrong' and they're away talking about football or something, or just not taking it in. (*Aidan, 58, ALD, first interview*)

Exposure to other patients and an opportunity to compare illness experiences with them was considered particularly beneficial.

What Kate's really wanting is probably just somebody to talk to about how she's feeling, how her condition is developing. Debate, almost, the fact that she's feeling this way, and does this other person feel the same and stuff like that. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

The need to speak about their situation was also heightened by participants' reluctance to further burden their loved ones, as mentioned earlier in Section 6.3.1.

I don't know what there is that could support Ben, because as he says he needs somebody to talk to, because he's really only got me and [son] and as he says he doesn't want to keep boring me, (...) venting off to me all the time. So he starts to keep it inside and then he explodes because he's built up all of this in his head. (*Tamsin, partner of Ben, 35, ALD, second interview*)

Abstinence support

Those with a history of alcohol misuse had additional support needs in relation to helping them overcome this damaging habit to enable their liver condition to stabilise. There was a sense that care professionals did not appreciate the reality of living with alcohol dependency.

You've got to have something in place to support you to come off alcohol. It's alright for doctors and that to say to stop drinking and then we'll get you treatment. (...) If you stop drinking, what else is there to stop you going back to it? (...) It's really difficult to give up alcohol because it's like your friend, you know? (*Sarah, 38, ALD (HCV), third interview*)

Many ALD participants had previously accessed alcohol support services. There was consensus, however, that available services were not always suited to their needs, especially with regard to them having to cope with serious illness in addition to their alcohol problems.

I got referred to an alcohol referrals group, but they weren't very helpful. (...) Because of the shock of the illness and everything I kind of withdrew and isolated myself into myself and they kind of gave up quite quickly, perhaps just felt that I didn't want the help. But it's not that I didn't want the help, it's just I wasn't coping particularly well. (*Sarah, 38, ALD (HCV), first interview*)

In addition, the time delay between hospital discharge and referrals being picked up by community-based services was considered too long.

In the past the alcohol liaison team would refer Ben to [local town], but by the time they got in touch with Ben and sent a letter and an appointment it was a good few weeks later. It might be good if they could get in earlier and give you a bit of a boost as soon as you're home, like a follow-up phone call, "Well you were in hospital because of this, how are you doing? Is there anything I can help you with?" (*Tamsin, partner of Ben, 35, ALD, first interview*)

The professionals interviewed were in agreement that current support arrangements for those with additional alcohol problems were inadequate. Ongoing support once abstinence was achieved was similarly considered unsuitable for some, thus putting their new-found stability at risk once more.

6.4.2 Barriers to accessing support

The interviews served to identify a number of barriers to accessing support. Having to proactively ask for support from others proved a challenge for several participants, due to a lack of confidence or reluctance to impose on others. Moreover, many did not like the idea of accepting outside support even when this was offered to them.

They're wanting me to have a carer that comes in to get you out of bed and help you wash, but I'm not wanting that. No, I have been independent too long. (*Fay, 84, NAFLD, third interview*)

We're not a couple that want people to come into our house. (*Jeff, husband of Polly, 68, NAFLD, first interview*)

There was also concern about the potential costs involved in accepting outside help.

I don't know what care I'll get when I go [home]. [Friend] says put in for a home help but then I'd have to pay for a home help. (*Mary, 66, autoimmune hepatitis, first interview*)

Physical access to support services where these were available proved another barrier, as many participants relied on others to take them places due to their poorly condition. Interestingly, distance was also a barrier where participants considered support services too local or familiar.

Rebecca: There's a place along the road actually (...).

Julie: That's for all [neighbourhood], aye. The thing is you walk into it, Rebecca, and you ken half the folk.

R: I know. I don't want to broadcast all my stuff.

(*Rebecca, 37, ALD, and Julie, mother of Rebecca, second interview*)

A lack of knowledge of what support services were available emerged as another barrier. Many participants felt unable to articulate what support they would value most as they were unaware what may be available to them. Michael questioned the availability of support services specific to the needs of those living with liver disease, and in particular outside of large cities.

I don't think it exists. That's my point, you know? I don't think there is anything in between there for liver disease or... You can go to Macmillan for cancer care, which I get because it is one of the bigger, you know, illnesses out there, I understand that. But there is nothing specifically around what Kate is going through just now, particularly in a rural place. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

Even where local, disease-specific support services were available, this information was not always communicated by care professionals. For many months Sarah had been unaware that there were organisations local to her, which supported people living with hepatitis C like her. She only found out about these services by chance after mustering the strength to seek counselling for her psychological problems.

It wasn't till the counsellor had said that there was organisations out there to provide support that I even thought about it. It never even went into my head that there's actually organisations to support people [with HCV]. But as I say, by the stage I was able to ask the doctor for it I probably didn't need it as much as what I could've done with it, you know? (*Sarah, 38, ALD (HCV), third interview*)

However, professionals themselves appeared unaware of which support services may be available to those with advanced liver disease.

I don't know of many support services. That's a bit of a worry actually, considering that I'm the last point of contact for people. (...) Are there any specific services for folks with liver conditions? I don't know any of them if there are any. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

The barriers to accessing support identified in this study related mainly to personality factors, access and a lack of awareness. There is thus scope to address some of these issues to improve the patient experience in advanced liver disease.

6.5 Discussion of findings

The above results illustrate the everyday challenges participants faced beyond the physical aspects of their condition and as the illness progressed over time. Again, uncertainty emerged as a key factor in their experiences. In line with Brashers et al. (2003), a number of personal and social sources of uncertainty could be seen to add to their illness burden. The threats upon their sense of self first described in Section 5.5.4 emerged as disruptive to their entire biography (Bury, 1982). Participants employed a number of coping strategies to manage the uncertainties they felt in relation to their condition and wider circumstances. Beyond these uncertainties, the data revealed several domains in which support proved inadequate. I will now examine each of these issues in turn.

6.5.1 Personal sources of uncertainty

Having advanced liver disease impacted on participants' wider life circumstances such as employment and finance, with a negative effect on their psychological wellbeing, sense of self, and close relationships. This was especially true for younger participants. This mirrors previous research with cirrhotic patients (Marchesini et al., 2001, Roth et al., 2000), but differs from people with COPD (Small and Graydon, 1993), possibly on account of this constituting a relatively older patient group.

Financial concerns were mainly linked to uncertainty about one's social role and the future. The impact of chronic illness on financial wellbeing and the loss of a productive working life can trigger a gradual loss of positive self-images; maintaining a positive and life-affirming view of one's self requires daily reaffirmation to that effect (Charmaz, 1983). This was difficult to achieve for those with an increasingly reduced ability to actively engage in everyday life. In addition, the resultant challenge of having too much time uninterrupted by the 'trivia of daily life' encouraged increased reflection and thus questioning of one's identity (Charmaz, 1997).

For those with ALD, overcoming their harmful drinking habits posed an additional challenge and source of uncertainty, as they worried about their ability to remain abstinent long-term. Their anxiety appeared considerably greater than that expressed by people with COPD who found themselves unable to stop smoking (Eklund et al., 2012). The implications of not achieving abstinence were at the forefront of most ALD participants' minds. This added significant psychological pressure which they struggled to cope with, in turn threatening this very goal. This observation is a useful reminder for healthcare professionals to be mindful of the wider psychosocial context of these patients' lives as their liver problem, however advanced, may not in fact constitute their key priority. Likewise, compliance in ALD has been linked to communication, understanding and the person's social environment (Blaxter and Cyster, 1984). With the patient's social environment generally outwith professionals' sphere of influence, enabling a clearer understanding of their condition and its

implications and providing opportunities for clarification are consequently important facilitators towards the desired behaviour change.

6.5.2 Social sources of uncertainty

Social uncertainty was a key feature of the lived experience of advanced liver disease. Experiences and perceptions of stigma, the changing nature of familiar relationships, and increasing social isolation constituted social sources of uncertainty in this sample. Similar experiences have been described by HIV-positive adults (Brashers et al., 2003). These findings confirm the importance of the social dimension in a person's illness experience (Charmaz, 1983, Radley, 1994, Radley and Green, 1987).

Stigma

Stigma, while not always directly experienced, was acutely felt by participants (Scambler and Hopkins, 1986). The sociocultural aspect of living with advanced liver disease was especially evident in this context (Kleinman, 1988), with participants' experience of stigma borne out of public ignorance and prejudice regarding the nature of liver disease as well as its largely invisible character. The common assumption that their liver disease was caused by alcohol misuse has previously been shown to rile liver patients (Vaughn-Sandler et al., 2014, Wainwright, 1997).

Participants recounted instances of enacted and felt stigma in both their clinical care and everyday life. This finding parallels the patient experience in lung cancer (Chapple, Ziebland and McPherson, 2004), and reflects accounts by liver patients reported elsewhere (Sogolow et al., 2010, Vaughn-Sandler et al., 2014). Stigma in the healthcare setting has been linked to patients being less likely to access care and having a poorer quality of life (Earnshaw and Quinn, 2012, Vaughn-Sandler et al., 2014). Therefore, while subjective perceptions of stigma may be unavoidable, care professionals must educate themselves about the many causes of chronic liver disease beyond those related to substance misuse, and be mindful of how their language and actions may be received by liver patients.

The anticipation of stigma and associated fear of social rejection constituted a further source of uncertainty. Participants managed this by avoiding potentially stigmatising situations and adopting a “policy of non-disclosure” (Scambler and Hopkins, 1986, p38). This was true of all participants regardless of their actual disease cause. This finding again reflects the actions of other cirrhotic patients (Vaughn-Sandler et al., 2014), and echoes findings in the realm of HIV infection (Carricaburu and Pierret, 1995). Where non-disclosure of their illness was challenged, participants went to great lengths to ensure that others knew that their illness was not subject to an alcohol problem or were selective in the detail that was being disclosed. Avoiding disclosure not only serves to manage uncertainty by limiting the likelihood of stigmatisation, but also supports a patient’s preferred self-image by enabling them to present as a person not exclusively defined by their illness (Charmaz, 1997). In addition, participants censored disclosure of information to discourage discussion of their condition. This may indicate another attempt at upholding uncertainty to protect their self from deep-seated fears they themselves harboured about their situation.

Social isolation

Social isolation in this sample was widespread and persistent, irrespective of disease cause. Physical limitations, repeated hospitalisation, unemployment, embarrassment and the anticipation of stigma contributed to even those with previously good social contact becoming increasingly isolated. However, the ability of those with ALD to influence their illness experience was again demonstrated in this respect. While in most cases social relationships diminished over time, a gradual improvement in the psychological wellbeing of Sarah and Ben, prompted by sustained sobriety, motivated a proactive approach by both to actively seek out and maintain familiar relationships.

Social networks are an important source of validation for a person’s sense of self. Consequently, experiencing social isolation can be detrimental to the maintenance of one’s self-concept (Charmaz, 1983). A disruption of social relationships is not merely due to restrictions inflicted by the illness, however, but may in part be actively imposed by the ill person (Bury, 1982). This was evident in the present study, where several participants deliberately isolated themselves by restricting their

social contact. Given their awareness of the stigmatising reputation of liver disease, this can be understood as another way of managing the uncertainty they perceived in relation to social encounters and the potential for embarrassment or rejection on account of their illness. Likewise, their actions may reflect a conscious ‘pulling in’ in order to retain some control in their lives and reduce distractions and pressures to preserve strength for coping with their illness (Charmaz, 1997).

Managing information flow, avoiding disclosures and deliberate distancing from others are thus all means by which ill people can exert some control over their uncertain situation (Charmaz, 1997, Mishel, 1988). In this study, participants employed these approaches to safeguard their identity, exposure to information, emotional response and quality of life more widely.

6.5.3 Biographical disruption

Biographical disruption, as described in Section 2.3.2, could be witnessed in the accounts of all participants (Bury, 1982). This resonates with previous findings in advanced liver disease (Brown et al., 2006), but contrasts with the illness experience in COPD (Pinnock et al., 2011). At the same time, different characteristics of the concept were evident. For Mary and Thomas for example, biographical disruption was dramatic and traumatic. Indeed, by the time the tangible complications of advanced liver disease had set in (for many the point of diagnosis or conscious acknowledgement of their illness) the illness was often too disruptive and uncertain to allow participants to hold on to their previous self and retain biographical continuity. Nevertheless, many older participants appeared to cope more stoically with their biographical disruption than younger counterparts. This finding is consistent with previous research in liver disease (Marchesini et al., 2001) and reflects similar observations in stroke patients (Pound, Gompertz and Ebrahim, 1998). This easier acceptance did not appear to relate to their living with more co-morbidity, with liver disease just another condition to deal with - its nature was too disruptive and tended to dominate their other health challenges. They did, however, express a greater sense of acceptance on account of their older age, with ill health simply a feature of this life stage.

Kate's relatively longer experience of living with chronic liver disease compared to most other study participants evidenced not just one, but two biographical disruptions. The first came at the time of diagnosis 10 years prior with what was then a manageable, relatively unobtrusive illness experience. Biographical disruption at that point was short-lived, with Kate formulating a new self which accommodated the new circumstances (Frank, 1993). However, she experienced another disruption when her illness deteriorated into decompensated cirrhosis, and the appearance of disabling complications resulted in inpatient episodes and an inability to work. Repeated disruptions of biography have also been observed in other chronically ill or disabled people over time (Larsson and Grassman, 2012). The present finding supports the notion that biography is in fact a continual process of dynamic revision (Williams, 2000).

Receiving a diagnosis of ALD did not immediately disrupt the lives of some participants like Sarah and Ben, whose biographies had already been upset by alcohol dependency. This echoes the experience of haemophilic men, who considered their HIV infection merely a continuation of their already challenging biography (Carricaburu and Pierret, 1995), and supports the notion that existing difficult life circumstances may lessen the impact of a new illness diagnosis (Lawton, 2003). However, biographical disruption did occur in ALD patients eventually, typically through a tangible brush with death due to their deteriorating condition. They initially managed to retain relative continuity by accommodating developments into their already difficult life circumstances. Once the physical complications of advanced liver disease and their management started to noticeably disrupt their lives, however, maintaining continuity became impossible. Participants were forced to rethink their previous status and contextualise their diagnosis. This finding again mirrors the patient experience in haemophilia (Carricaburu and Pierret, 1995). In this context then, biographical disruption could be seen to encompass an element of biographical reinforcement.

For a few ALD participants, this series of events resulted in an active reworking of their identities and the setting of new priorities. For John and Sarah, and at a later stage in the study for Ben, being faced with advanced, life-limiting illness acted as a

catalyst for biographical disruption towards the positive, their actions reflective of a quest narrative (Frank, 1995). These participants determinedly worked on mastering sustained sobriety, while, given their advanced disease state, remaining aware of the enduring uncertainty regarding future outcomes. They could thus be seen to appraise this uncertainty as an opportunity to re-evaluate their lives and formulate priorities for the future. This finding evidences the potential of uncertainty as a positive force for personal growth (Mishel, 1990).

In summary, the data afford the following observations regarding the concept of biographical disruption in the context of advanced liver disease:

1. The findings support the assertion that the severity of biographical disruption experienced is subject to person-specific factors (Lawton, 2003, Williams, 2000).
2. Biographical disruption was sometimes a positive experience, leading to the creation of a new self which not only accommodated, but sought to transcend the illness.
3. Biographical disruption constituted a gradual process which required tangible symptoms to take effect, and one that could happen more than once. This highlights the temporal aspects of this concept.

6.5.4 Coping with uncertainty

Coping relates to a person's efforts to master harmful, threatening or challenging circumstances. In the context of illness, Hinton (1984, p228) suggested that, "the question of coping does not arise until the condition becomes manifest and its lethal nature subsequently recognised." The experience of advanced liver disease described in this and the previous chapter supports this statement.

Participants' levels of coping varied with age, symptom severity and over time, and related to the uncertainty inherent in participants' circumstances. Uncertainty challenges a person's ability to cope with and successfully adapt to chronic illness (Hilton, 1992). As highlighted, uncertainty did not necessarily constitute a negative experience among this sample. Nevertheless, uncertainty drove participants' choice

of coping strategies, which reflected a tendency to appraise uncertainty as an opportunity in order to manage emotions and keep negative cognitive stimuli at bay. This approach is possibly due to a lack of scope for reducing uncertainty given the general complexity and ambiguity of the illness.

Managing the amount and flow of information has already been highlighted as one means by which participants sought to control uncertainty to preserve hope and protect their sense of self, and this finding echoes the literature (Brashers, Goldsmith and Hsieh, 2002, Mishel, 1988). Taking one day at a time also served to manage the self in the face of uncertainty, as narrowing their focus on daily illness management allowed them to avoid contemplation of the wider consequences of their situation (Charmaz, 1997). Positive thinking was another tactic employed for managing uncertainty, despite constituting a rather optimistic sentiment given participants' advanced disease stage. This finding thus supports Mishel's notion of illusion as a cognitive process underlying the appraisal of uncertainty as an opportunity (Mishel, 1988). Adopting a stance of unrealistic optimism can be a protective strategy for people faced with relatively uncontrollable disease (Fournier, de Ridder and Bensing, 2002), and has been reported in patients rejected for liver transplantation (Heyink et al., 1989). Positive thinking and living for the day have also been noted as coping strategies used in COPD and heart failure (Small and Graydon, 1993, Winters, 1999). Placing their confidence and trust in healthcare professionals was another coping strategy used by participants. Viewing clinicians as able to control one's illness has been recognised as a strategy which can reduce uncertainty in the chronically ill (Madar and Bar-Tal, 2009).

As described in the previous chapter, participants' self-image was affected by physical changes related to their disease and a gradual loss of their independence and previous abilities. A loss of self ensued, both in relation to their previous sense of self and in the context of wider social and cultural norms. This constituted a significant contributor to poor psychological coping, and was consistent with the observation that, "In a society which emphasizes doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life." (Charmaz, 1983, p191) In this context, downward

comparison is one way in which a person may bolster their sense of self and manage uncertainty by neutralising their circumstances. This coping strategy has previously been observed in patients rejected for liver transplantation (Heyink et al., 1989), and was employed by participants in the present study. They compared themselves to fellow liver patients during hospital stays, and overall considered others less fortunate. Making comparisons with others in similar circumstances facilitated the evaluation and legitimisation of their feelings, actions and experiences in relation to their illness. This helped to alleviate uncertainty, strengthen self-esteem, and thus improve subjective wellbeing.

Self-managing advanced liver disease

Patients' yearning for more and improved self-management guidance constituted a task-oriented approach to coping with their uncertain circumstances, and highlighted again the limited information they perceived to hold about their condition. This resonates with reports that cirrhotic patients lacked adequate knowledge to allow them to effectively self-manage their illness (Volk, Fisher and Fontana, 2013), but that they were eager to do so (Wainwright, 1997). Similar findings exist for patients with COPD (Wortz et al., 2012). The lack of opportunity for patients with advanced liver disease to engage in self-care despite its benefits for disease progression has been observed before (Volk et al., 2010).

Three models of self-management have been proposed: medical, collaborative, self-agency (Koch, Jenkin and Kralik, 2004). In the present study, the medical self-management model dominated. Participants accepted responsibility for supporting disease management and were generally committed to the lifestyle changes and medication regimes stipulated by healthcare professionals. Interestingly, despite this model effectively discounting individuals' life contexts and self-agency, participants' desire for more extensive guidance in this respect indicates that this model was in fact preferred over a more collaborative approach.

In the absence of satisfactory levels of medical self-management, several participants had adopted a self-agency approach to the everyday management of their condition, mostly based on popular lifestyle advice and remedial actions of their own design.

Participants engaging in direct action by making up their own self-care approaches suggests a coping strategy designed to actively reduce uncertainty (Mishel, 1988), and is thus counter to their overall tendency to maintain uncertainty in preference of negative certainty. Direct action is a coping strategy rarely seen in catastrophic illness (Mishel, 1988). Its presence in the context of this study may be explained by the data indicating that participants generally lacked awareness of the devastating nature of their condition.

Having structures and routines to follow can help to create a ‘cocoon of certainty’ which moderates the effects of uncertainty (Brashers, 2001). Being able to take an active role in their illness management has been shown to diminish uncertainty in people with heart failure (Winters, 1999). I would also argue that this action-focused approach helps to reinforce people’s focus on the present as described earlier, and therefore additionally supports their coping in line with this preferred stance. It has been suggested that sometimes healthcare professionals can unwittingly fuel an ill person’s loss of self by failing to provide adequate or appropriate advice, thus leaving the person unaware of options for treatment or support that could facilitate a more active participation in daily life (Charmaz, 1983). I would therefore argue that any absence of self-care opportunities beyond those already commonly instructed, such as abstinence and dietary change, should be communicated to patients in order to reduce any anxieties in this respect.

6.5.5 Patient support needs

Participants displayed a range of support needs relating to their condition. The physical challenges associated with the disease necessitated practical support with various everyday activities, such as household tasks, personal hygiene and transportation. Practical support needs increased over time. This finding supports the suggestion that homecare needs may be underestimated in this patient group (Roth et al., 2000). Likewise, hospitalised COPD patients expressed uncertainty about how they would manage at home after discharge (Small and Graydon, 1993). Similar concerns were also raised in the present sample and borne out by the level of practical support need evidenced.

Support for people with ALD seeking to overcome alcohol dependency was perceived as inadequate by patients, lay carers and professionals alike. A lack of consideration was seen to be given to the considerable impact of abstinence on that person's emotional and social world, individual personality factors, and patients' additional burden of living with advanced disease. As mentioned earlier, the need to achieve abstinence in itself constituted a major stressor in these patients' lives. However, all participants, regardless of their particular stage and context of illness, desired better psychological support. A need for psychological support was evident from the point of diagnosis and related to the need to come to terms with not only the condition itself, but its pervasive impact and consequences. Nevertheless, support of this nature remained largely absent.

This psychological burden adds to that identified in the previous chapter and lends further support to the widespread low mood and depression reported in cirrhotic patients (Bianchi et al., 2005). Patient participants' care appeared to focus predominantly on disease management. Alcohol dependency, where this featured, received some but overall inadequate attention, meaning that related psychological or emotional problems similarly remained unresolved. The psychological wellbeing of patients without alcohol problems went largely ignored, despite evidence of low mood and depression. Some participants reported taking anti-depressants, yet anxiety and low mood suffused their accounts. This suggests an urgent need for routine psychological assessment of these patients, particularly of those with underlying alcohol problems, and increased attention on alleviating what appears to be a considerable psychological illness burden.

Relatedly, social support can provide the ill person with an opportunity to discuss and contemplate their illness and express emotions and feelings, which may facilitate increased clarity and understanding of their situation. Social support thus benefits health-related quality of life (Sherbourne et al., 1992). However, in this study participants could be seen to hold back from confiding in their loved ones so as to not burden them, which suggests that intimate relationships may perhaps be too close to be helpful for expressing emotions and feelings in the context of serious illness. At the same time, wider social engagement became increasingly scarce for reasons

outlined earlier in Section 6.5.2, leaving few opportunities for them to gain emotional support from another source. Some felt that the interview itself provided the sort of opportunity to talk which they would value in general. Some expressed a need for confirmation that their feelings were valid and mattered.

Given the evident need and expressed desire for psychological support in this study then, emotionally neutral sources of social support must be considered. Several participants were keen to compare their experiences and feelings with others in the same circumstances to help them make sense of what was happening to them. As highlighted earlier, social comparison can strengthen a person's sense of self and help alleviate uncertainty. Peer support may thus present a possible means of effective social and emotional support for this patient group.

Barriers to accessing support identified in this study were manifold. Individual reasons were: personality attributes, not wanting to impose on others, and giving up one's independence. This supports previous findings that independence is key to those with life-limiting illness (Cotterell, 2008). Perceived cost, distance and transportation were further barriers to accessing support. Additionally, both patients and professionals showed poor awareness of available sources of support. While personality-based factors may be difficult to address, there is scope to improve the awareness of supportive resources by mapping these and educating patients and their families about their availability and any associated costs. Given the many varied challenges people with advanced liver disease experience that may affect their ability to physically access services, support provision should show sufficient flexibility in its set-up and delivery to facilitate maximum reach and uptake.

6.6 Concluding remarks

This chapter has added some rich detail to our understanding of the lived experience of advanced liver disease. In addition to the medical sources of uncertainty described in Chapter 5, personal and social sources of uncertainty emerged as extensive and influential (Brashers et al., 2003). Moreover, the different types of uncertainty could be seen to interconnect (Brashers, 2001). For example, uncertainty experienced in

relation to their condition caused uncertainty regarding one's sense of self (e.g. the 'working self'), financial wellbeing and social relationships.

In addition to further evidence of a potentially divergent experience by ALD patients related to achieving sobriety, age differences emerged both in relation to some of the life-related stressors reported and patient coping. Patients' coping strategies were largely aimed at managing the pervasive uncertainty. Orientating towards one day at a time, avoiding active contemplation of the illness, managing information flow (seeking versus avoiding), and evading potentially stressful social interactions were all ways in which this was achieved. Faced with the possibility of negative outcomes, this suggests a shared tendency to appraise the uncertainty of their circumstances as an opportunity. It also resonates with the notion that, "the erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action" (Bury, 1982, p176). In addition, guidance to enable greater self-management of their illness was desired but lacking.

Biographical disruption proved a prominent feature in this condition. The data advances our understanding of this concept by highlighting its characteristics in the context of advanced liver disease. This includes the observation that biographical disruption does not always constitute a negative event. Adding to the high level of information need identified in the previous chapter, this patient group also exhibited extensive practical, psychological and social support needs. Psychological and social support in particular are key to helping patients manage uncertainty and thus achieve improved wellbeing, but both were found lacking. The data in this and the previous chapter thus evidence all three areas of 'work' the chronically ill person is said to have to contend with: illness work, everyday life work and biographical work (Corbin and Strauss, 1985).

Chapter 7: The patient experience of care

The previous chapter confirmed and extended the finding that uncertainty dominated life with advanced liver disease. This uncertainty proved pervasive, multi-faceted and interconnected. Its impact has thus far been noted in relation to the physical experience of the disease and the management of everyday life.

This chapter describes patient participants' use of services to support them with their illness, and their perceptions of the extent to which these services met their needs. It first shows the types of services people engaged with and their care relationships within these settings. It then presents participants' experiences and perceptions of their medical care. The chapter concludes with a discussion of these findings in relation to existing research and theory.

7.1 Contact with services

Due to some of the disease-related physical challenges such as extreme fatigue and poor motor function and mobility, travel to medical care services proved a challenge for several participants.

The GP, he wasn't wanting to come down and see me. He says, "Is there any way you can go up and come up and see me." There isn't, I cannae walk that way. And he says, "Well, why don't you get a taxi up?" I says, "Well, are you going to pay for the taxi?"
(*Fraser, 60, ALD, first interview*)

Accessing the hospital proved particularly challenging because, as a regional base with a large catchment area, people often had to travel a considerable distance. This posed a problem not only for patient participants, but their lay carers too.

My mum and dad (...) had to depend on other people coming in [to town] to bring them in because my mum doesn't drive, my dad can't drive now, and it was just a nightmare.
(*Carol, 45, ALD, first interview*)

Arranging patient transport to travel the distance was fraught with difficulty for patients and professionals alike.

They've been good in arranging patient transport, but you've got to sort of kind of plead with them a wee bit, you know? (*Carol, 45, ALD, second interview*)

If she was to be admitted the next day for a blood transfusion (...) we had to pretend it was an emergency ambulance, because you can't pre-book an ambulance for the next day. (*GP of Polly, 68, NAFLD*)

7.1.1 Contact with secondary care

All participants had a named liver consultant allocated to their case, whose outpatient clinic they were called to attend every few months. Many participants felt positive about their designated consultant.

I get on well with him and he gets on well with me. (*Fraser, 60, ALD, first interview*)

He's a brilliant doctor. He is brilliant. (*Mary, 66, autoimmune hepatitis, second interview*)

At the same time, people were often unclear about how to access their consultant in case of a query.

"Get in touch with my secretary," and things like this. I haven't the foggiest idea how to get hold of his secretary. (*Kate, 41, cryptogenic LD, first interview*)

He said, "Oh, I wish you had let me know about that." How was I to do that, because he is surrounded by secretaries and people who answer phones and all that, and they've got their agenda and that is, seems to be to prevent you from talking to him at all. (*John, 68, ALD, second interview*)

In addition to outpatient clinic appointments, many participants also regularly accessed inpatient services. Appendix 4 shows the number of hospital admissions (related to their liver disease) for each patient during their study involvement, and for those who died also at 6 months and 12 months prior to their death. Participants' experiences and perceptions of their inpatient care will be described in Section 7.2.

7.1.2 Contact with primary care

Primary care involvement in their liver disease care varied across participants, but was generally limited compared with their engagement with secondary care. Participants viewed the role of the GP mainly as providing referrals or prescriptions.

I see my GP maybe once a month or twice a month, but I never really go because I'm ill. It's usually because I need another sick line or I'm needing new medication or something like that. (*Sarah, 38, ALD (HCV) second interview*)

This narrow understanding of the role of the GP resulted in a general perception that there was little value in seeking their support and advice.

BK: So are you going to pursue trying to get an appointment with your GP do you think?
Nadia: Do you think there's any point?
(*Nadia, 58, ALD (HCV), first interview*)

Most participants saw the practice nurse when attending their local practice for occasional blood tests. District nursing input was limited across the sample; only Donald and Martin mentioned the involvement of a district nurse in their home care.

7.1.3 Contact with allied professions

During inpatient stays, some participants had specialist input by occupational health practitioners, dieticians and, where necessary, a physiotherapist. Those with alcohol problems underlying their liver disease were also seen by the hospital-based alcohol liaison team, whose role was to assess individuals' readiness for abstinence and refer them to community-based services as appropriate. In particularly critical cases the alcohol liaison nurse would continue to see a patient on an outpatient basis. This was the case for Ben, who was at first uncertain what the purpose of these meetings was.

BK: Did you find the involvement of the alcohol liaison person helpful? (...) What's the support that she's providing at the moment?
Ben: I'm not quite sure. I was going to ask yesterday but I thought it was quite rude. (laughs) We just had a chat for about an hour.
(*Ben, 35, ALD, first interview*)

However, over time Ben started to appreciate the value of the nurse's involvement.

She's making me feel a lot more positive about myself, giving me things to work on and like, about how to cope with it all. (...) She's basically there for to ask her things that like, explain more what the doctors mean like, like, if I want to ask any questions she can sort of answer them. And she can show me my [blood] levels and that on the computer if I want to have a look at them. Basically it's just somebody to talk to as well about how it's all affecting me. (*Ben, 35, ALD, third interview*)

It was credit to this intense therapeutic support by the alcohol liaison nurse that, by the end of his study involvement, Ben was at last successful in achieving sustained abstinence from alcohol and consequently a stabilisation in his liver condition.

Only two participants had had contact with community palliative care services, arranged by their GPs in recognition of their poor prognosis. This referral initially caused uncertainty and alarm due to the popular perception that palliative care constituted a service for cancer patients.

That Marie Curie nurse, oh I wasn't happy about that. But then that's when they told us it's not just for cancer patients, it's for everybody. I said, "Oh, that's fine." (*Martin, 77, ALD (NAFLD), third interview*)

7.2 Medical care

Participants' medical care was predominantly delivered in the secondary care setting. They had regular, usually 6-monthly, outpatient appointments at their consultant's clinic to monitor their condition. They also attended for outpatient endoscopy procedures to prevent potential gastrointestinal bleeds. As highlighted earlier, many patients also had regular admissions to the hospital ward. This was commonly for non-acute events such as draining of their ascites, but occasionally involved acute exacerbations such as bleeds or anaemia.

7.2.1 Hospital experience

Given the regularity with which many of them attended hospital, several participants expressed a sense of 'coming home' to the ward.

It kind of feels like home. It's my second home. (laughs) (*Rebecca, 37, ALD, second interview*)

When I go into the hospital, oh I'm a real kent face now. When I walk in I know the doctors, I know the surgeons, I know them all. (*Martin, 77, ALD (NAFLD), first interview*)

Kate valued her care at the regional hospital so much that she chose to travel a long distance from her home in preference over accessing more local hospitals.

Over the years I've had two or three bleeds where I've ended up in hospitals in other places. (...) Not really been that terribly enamoured with the care that I'd received, so I've always tried to keep coming back to [regional hospital] because I like it here. It feels like coming home. (*Kate, 41, cryptogenic LD, first interview*)

Not everyone was so positive about their hospital experience, however. Repeat admissions for paracentesis were experienced as particularly irksome by several participants. Some were growing weary of having to undergo the same initial procedures, like being weighed and having blood taken, at the start of every admission. Further upset was caused by conflicting instructions given by doctors and nursing staff as to the correct protocol to follow for getting booked onto the ward.

Thomas: It was supposed to be that, “Oh well ok, we know all about you and that now, if it happens again you phone up the ward and, you know, we’ll get you in right away or the next day” sort of thing. So we try that. “Oh you can’t do that! Oh no no no, you’ve got to go through emergency or you’ve got to go through your own doctor.”

BK: Who told you that?

T: This was the nurse that answered it on the ward.

(Thomas, 75, NAFLD, first interview)

Despite many speaking of the liver ward as a ‘home from home’, participants described a real desperation to be able to leave as soon as possible.

You’ve got the nurses, but you do have that feeling of aloneness when you’re in a hospital. (...) It’s a horrible feeling just lying there and you’re so ill and you just pray to be out. *(Ben, 35, ALD, second interview)*

The amount of time spent waiting for things to happen added to their frustration, and fostered a perception that being in hospital made one worse and slowed recovery.

I don’t want to go back into hospital again. Every time I went into hospital, I actually felt iller when I came out than when I went in. (...) You’re just sitting there vegetating and the air’s not healthy (...) You’re never going get better sitting doing nothing, you know? *(Sarah, 38, ALD (HCV), second interview)*

7.2.2 Perceptions of the quality of care

Many patient participants felt that doctors were doing a good job in caring for them through their illness.

Anybody you phone, the doctor, the nurses, the hospital, never a problem. *(Martin, 77, ALD (NAFLD), third interview)*

Just got to thank everybody involved actually because it’s overall really, really good. *(Kate, 41, cryptogenic LD, third interview)*

Lay carers were equally satisfied with the care that had been offered to patients.

Everybody supported Fraser. Even the nurses in the hospitals, the doctors, they were really, really kind to him. I mean, you could probably get people who say, "Oh he's just a drunk, don't bother," you know? He got all the attention that he needed in [hospital] and [by] the carers at home. (*Betty, neighbour of Fraser, 60, ALD, bereavement interview*)

However, participants whose accounts displayed the greatest uncertainty regarding their situation tended to hold a less favourable view of their medical care.

BK: How do you feel about the care that you've been getting so far?

Nadia: Terrible.

BK: Terrible. Is that in hospital or in general?

N: Just the whole thing, just the way I've been dealt [with].

(*Nadia, 58, ALD (HCV), first interview*)

The medical profession has a lot to be desired as far as I'm concerned. I don't feel as though I've been treated well by them. (*Thomas, 75, NAFLD, first interview*)

Quality of hospital care

Participants were generally pleased with the staff they encountered at the hospital.

That ward I go in, they're awfully nice. (*Polly, 68, NAFLD, first interview*)

Some participants, however, recounted instances where they had been made to feel ignored and insignificant by ward staff.

A nurse comes along and she opens up the locker and she gives me pills out and she doesn't speak. And she puts them on the table and then she walks away. By this point it's now about 10.30pm at night and I've been in the ward since 6.30pm and nobody has actually said a word. Not one word. And I'm getting more upset and more upset and more upset until the flood gates just open and out it comes and I think, "Jesus, I'm just insignificant." (*Kate, 41, cryptogenic LD, first interview*)

Nursing staff were perceived as not always sufficiently caring and lacking understanding of the realities of alcohol dependency and mental ill health. Moreover, some participants recounted incidents during their hospital stays which they considered outright neglectful.

He gets a bath every morning and he gets three different creams on cos he's got bad psoriasis. He was in the [hospital] and he come out, you want to have seen the mess that man was in. (...) He wasn't getting a shower every day and he wasn't getting his creams every day. (*Betty, neighbour of Fraser, 60, ALD, first interview*)

Rebecca was fed up with the amount of times she was being asked to accommodate student doctors during her inpatient stays.

You just feel like a guinea pig in there. (...) You get them one after another, one after another, one after another. (*Rebecca, 37, ALD, second interview*)

For many participants, paracentesis was the main reason for their repeat admissions to hospital. As this procedure required inpatient treatment, it constituted a disruptive event for patients and lay carers alike. Regular shortfalls in staff or draining equipment and being rendered weak and poorly after the procedure saw many participants in hospital for several days at a time.

BK: This is now Saturday and nothing's happened you said?

Aidan: That's it. Thursday night, well I think I got in here about half five or so by the time I got into the ward, getting into bed, the doctor came round he says, "Well I know what you're in for and I can see what it's doing, but as you know there's not a team of staff nurses at nightshift to look after, take your bottles away and empty them and such like so," he said, "we don't do it at night." (...) Yesterday I seen the doctor in the morning, it was a doctor I'd never seen before, and he just told me what I already knew. And then the two doctors that was going to do the drain (...) they said, "Aidan, we'll see you in a wee while, we'll be back to get it done." (...) I never heard a word after that, never seen them again. (...) And then I seen him this morning and (...) he said, "We'll get it done today," he says, "but the thing is," he says, "there's five people waiting on the same thing, so we're going round to pick who's going to get done and who's not, because we're short of..." Seemingly he was telling the nurse, you know, it's a long needle that they put in and they're running short of them. (*Aidan, 58, ALD, first interview*)

Opinions differed on how to best handle routine admissions of those with recurrent ascites requiring regular draining. Fay expressed a preference for scheduled appointments, while such an arrangement had previously proven unworkable for Martin. Thomas' GP considered the hospital's approach of leaving it to patients to judge when further draining was required inappropriate and an unnecessary source of uncertainty.

Leaving it until his ascites then built back up again and he had to go back in, to me I think (...) it just left him (...) unnecessarily symptomatic for long periods of time, and also I think it probably left him and his family with too much uncertainty, so he'd be sitting at home for a week or two at a time going, "Oh, should I, should I really be going, calling the ward and going back in?" (*GP of Thomas, 75, NAFLD*)

Quality of primary care

Several participants had a good relationship with their GP, who would visit them at home to check on their health, and considered them approachable and supportive.

The help I've had with my GPs has been great, you know? I can't fault them really. (*Carol, 45, ALD, second interview*)

However, some criticised their GP's support due to a perceived lack of motivation and empathy.

It's just a job to him. (...) If it's just something like a bug he can prescribe something for you, that's fair enough. But to actually do anything over and above, you just don't get that from [GP]. (*John, 68, ALD, third interview*)

I went to my GP and I told him my esteem was on the floor. "What do you want me to do about it?" I went, "Nothing," and I walked out the surgery. (*Mary, 66, autoimmune hepatitis, first interview*)

Many participants also felt that their GP lacked confidence and knowledge in matters relating to their liver disease.

I'm not sure that the GP actually gets all the ins and outs of it because (...) I said, "I'm on the transplant list," and he said, "Now how long are you going to have to wait for a liver then?" which I thought was a very strange thing for a doctor to ask. (*Kate, 41, cryptogenic LD, third interview*)

When he first came he didn't know very much about this drainage, he was asking me questions. (*Martin, 77, ALD (NAFLD), third interview*)

This poor disease-specific understanding is likely to be a contributing factor to GPs' limited involvement in participants' liver care. Indeed, some GPs were seen to deliberately hold back on their involvement and leave their patients' liver care in the hands of secondary care professionals.

He tended to seem to want to take a back seat and leave it in the hands of the consultant. So apart from monitoring my bloods that was about it, you know? (*John, 68, ALD, second interview*)

7.2.3 Doctor-patient communication

A key factor in the care experience of any patient is the nature and quality of the communication between the patient and their professional carers. Professionals' communication with patient participants generally aimed to promote a positive outlook. Michael considered this the right approach for professionals to take.

He was very upbeat and positive and 'everything's going to be fine, don't worry about it', and all that kind of stuff, which is absolutely the right thing for a GP to say. (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

At the same time, several participants expressed a preference for professionals' frankness about their condition.

I'm very practical. I don't take well to people bullshitting me basically. So the doctor and [consultant] have always been quite open and honest with me and I do appreciate that. (*Kate, 41, cryptogenic LD, first interview*)

Being truthful proved a delicate balancing act for professionals, however.

You're trying to kind of be honest with them, but you don't want to be completely terrifying and lose their faith/confidence in you as well. (*Consultant of Fraser, 60, ALD*)

Indeed, Sarah's experience with her GP exemplified this challenge for professionals.

I stopped going to her. She was just so negative and I found it really... I want them to be honest but I don't want them to, you know, be so negative. I'm trying my best, you know? (*Sarah, 38, ALD (HCV), third interview*)

A number of factors contributed to participants' experiences of ineffective doctor-patient communication. Importantly, the time available during medical appointments was seen as too limited for effective information exchange.

You're sitting in the surgery and you're aware that you've got a 10 minute slot and everything's all about timing and, you know, there's another 20 people with coughs and colds outside waiting to see him and he's running late and all that's going on in your head. (*Kate, 41, cryptogenic LD, second interview*)

Participants appreciated that this lack of consultation time was due to professionals needing to attend to the needs of others also. Nevertheless, it discouraged them from asking questions or from opening up about their concerns.

You just get the feeling that the doctors are unapproachable because they're so busy. You feel like you can't say, "Doctor, can we have 5 minutes," because you feel you're holding them back and why should I be more special to get more of your time than everybody else. (*Ben, 35, ALD, first interview*)

The choice of language used by professionals also impacted significantly on the perceived quality of doctor-patient encounters. Several participants felt that explanations were often too medicalised to be readily understood by them.

What they're saying is, "Right, your potassium level's at such and such, your sodium level's at such and such," what else, "your blood count was this, your blood pressure was that." All these different things, and they don't actually tell me what it means. It is good? Is it bad? Is it happy medium? I don't know. (*Rebecca, 37, ALD, second interview*)

A few participants recounted instances where a professional's inappropriate choice of words had left them feeling uncertain or alarmed.

Every time I went to the doctor or to see the specialist or something, I was coming away thinking I was dying. (*Sarah, 38, ALD (HCV), second interview*)

Several participants also commented on what they considered poor bedside manners during their stays on the hospital ward. Some doctors discussed patients among themselves in front of the person, thus fuelling people's sense of being insignificant.

All these things were getting said about me and it was like I wasn't there, you know? (*Kate, 41, cryptogenic LD, first interview*)

Participants also criticised hospital staff for regularly approaching and advising them on their care without prior introduction, leaving them uncertain which authority these instructions were coming from.

You often don't know where their advice is coming from (...) and I always felt it was sort of a bit impolite to say, "Hey hold on a second, who are you?" I don't think you should have to do that. (*John, 68, ALD, first interview*)

Problems with doctor-patient communication were thus manifold and had great potential for adding further uncertainty to the overall illness experience.

7.2.4 Continuity of care

Participants highlighted issues relating to continuity in their care relationships and in the provision and coordination of their care.

Continuity in care relationships

Continuity in seeing the same GP for their liver-related care varied across participants. Some benefitted from a continuous relationship with one key primary care contact. This was often the case for those with an underlying diabetic condition like Martin and Thomas, who had often already been known to the same practitioner on account of their ongoing diabetic care. Others had acquired a named contact by virtue of that professional taking a particular interest in their case.

[GP] did come round to speak to Rebecca once and says, ken, "Could I take on your case?" (*Sue, sister of Rebecca, 37, ALD, third interview*)

However, several participants did not benefit from one consistent primary care contact.

BK: You don't have one sort of doctor that...

Fay: No, no. They change all the time.

(Fay, 84, NAFLD, third interview)

Similarly, many participants were lacking relational continuity with their designated consultant.

Sometimes I get him and sometimes I get somebody else. *(Rebecca, 37, ALD, first interview)*

If you didn't get so many different people. (...) Every time I go to the clinic you see, they've got a list of names and you just get the one that takes your file through. *(Fay, 84, NAFLD, first interview)*

Changes in their care arrangements left some participants uncertain as to the status of their relationship with their named consultant.

I don't really know who's in charge. One time it was [consultant], now it's another doctor. *(Fay, 84, NAFLD, third interview)*

I don't know whether he's even my consultant anymore, because he passed me into the care of the transplant team. *(Kate, 41, cryptogenic LD, second interview)*

Indeed, Fraser was alarmed by an unexpected change in his consultant care, interpreting this as an indication of a declining condition.

Fraser: I usually have my own consultant coming down but it's [another consultant] that's coming down. Now I thought, "There's something going on here."

BK: What do you mean?

F: Well, why is it [designated consultant]'s no coming, why is it [other consultant] coming? It must be pretty bad.

(Fraser, 60, ALD, second interview)

Discontinuity of care also existed on the hospital ward, with many participants commenting on the frequent turnover of nursing and clinical ward staff.

A lot of the nurses were really, really nice but (...) they swap around even though they're at the same nurses' station. John's her patient one day and he's not her patient the next day. *(Jane, partner of John, 68, ALD, first interview)*

Every day it's different people coming in to see you. (...) You just start thinking this wee team knows my case and then they change them the next week. *(Ben, 35, ALD, first interview)*

While some did not perceive the regular staff turnover as a problem, most participants expressed a desire for better relational continuity in their liver care.

I see an awful lot of doctors and professional people who I don't really know who they are sometimes. (...) I just feel sometimes that it'd be quite nice just to, you know, have that one person who can say, "Hey, how's it going?" (*Kate, 41, cryptogenic LD, third interview*)

Relational continuity of care was thus wanting across both primary and secondary care settings. Discontinuity in their medical care relationships could be seen to add further uncertainty to the patient experience.

Continuity in care provision and coordination

Patients received follow-up care through attendance at outpatient clinics at the hospital and a regular monitoring of their bloods commonly conducted in the primary care setting. Some participants, however, questioned the usefulness of these appointments.

It's just basic. They just ask how I've been feeling, have I had a drink, are you eating well? And then they'll put you on the bed and have a wee prod about and then take your blood and that's it. (*Ben, 35, ALD, second interview*)

Attendance at follow-up appointments proved challenging for many as this could be impeded by illness-related factors as well as a lack of support.

BK: So what is the reason that you don't always make it along to the clinic appointments?
Rebecca: Well, like, good and bad days. (...) It's to do with the jaundice as well, more so, you know, people staring. (...) But other times it's because I just can't make it. I've not got the energy or I'm constantly (...) on the toilet and haven't slept. Loads of things, eh? Or I've not got anybody to go with me.
(*Rebecca, 37, ALD, second interview*)

People's ability to attend appointments was also affected by their frequent admissions to hospital.

I hadn't seen him in the clinic for a wee while, because he's been in and out of hospital.
(*Consultant of Fraser, 60, ALD*)

Non-attendance at medical appointments thus contributed to the poor relational continuity of care described earlier. However, the reverse also held true, with guaranteed access to one's key professional an incentive for attendance.

There's no point, because he's always in the hospital anyway. (...) If it was [named consultant] we would go, because we'd like to see him again, but it's just his clinic. (*Cora, wife of Martin, 77, ALD (NAFLD), third interview*)

Despite doubting their overall value, being offered regular check-ups reassured participants that a close eye was kept on their condition.

If they're doing scans and different things all the time then they'll pick up on anything else wrong, you know? (...) And even blood tests, the blood tests can pick up on something wrong as well. So it's not too, you know, I'm not too worried about it. (*Sarah, 38, ALD (HCV), third interview*)

Gaps between follow-up appointments were considered unhelpfully long, however. GPs in particular expressed concern at the lack of follow-up from liver specialists.

What tended to happen was he would be in hospital very unwell, have fluid, his ascites drained off and then he'd come out and I'd say, "So when's your next follow-up appointment?" and he would say, "Oh, I'm seeing [consultant] in three or four months," and to me that didn't seem appropriate and he, it seemed far more appropriate that he was seen on a more regular basis. (*GP of Thomas, 75, NAFLD*)

Patients also expressed frustration about the long gaps between clinic appointments, as they made them feel forgotten about.

If I am being 100% honest with you, I don't really feel that I'm being supported at all by the hospital. It's almost like you go away and that's you forgotten about till you come back again. I've had no contact with anybody at all apart from coming to the clinics. (*Kate, 41, cryptogenic LD, second interview*)

In many cases, aftercare plans appeared lacking or poorly communicated.

Nadia: When I came out of hospital all I got was a letter just saying what my tablets are and I've got to get a blood check, and that's what I done. Other than that pffff.
BK: So are you due to go back to see somebody in the clinic at some point?
N: Not that I know of. I've not got a clue. Nobody told me, I don't know.
(*Nadia, 58, ALD (HCV), first interview*)

Where aftercare plans had been mentioned to participants, these were not always followed through.

Three times he was in that hospital when he took the hypos and the doc says, "Oh we'll have to get your stomach drained." (...) Three times. Even our doctor said, "We'll get your...", "and they never done it. (*Martha, wife of Donald, 74, HCC (NAFLD), bereavement interview*)

Effective continuity of care provision was also affected by the quality of interprofessional communication. This topic will be discussed in Chapter 9 in the context of professionals' accounts of supporting people with advanced liver disease. Overall, however, continuity of care in this sample proved to be consistently inadequate, both in terms of care relationships and provision, throughout the illness trajectory and added a further dimension of uncertainty to the illness experience.

7.3 Discussion of findings

Three particular areas of interest emerged from the above findings. These pertain to participants' experiences and perceptions of their medical care, the quality of doctor-patient communication, and the continuity and consistency of patient care. According to the study findings, improvements are indicated in each of these areas. These improvements relate to reducing the uncertainty these issues contribute to the illness experience, and the overall management and co-ordination of patient care in advanced liver disease.

7.3.1 Patients' experiences and perceptions of their care

Participants' ongoing care for their liver disease was mostly located in the hospital setting. A named liver consultant was allocated to each person's care. However, there was a perception that one's designated consultant was difficult to contact, even where this had not been attempted before. Some consultants had invited patients to contact them in case of any questions; however, this was not considered a realistic offer. Participants could be seen to fashion excuses for not attempting this route such as not knowing how to contact the consultant's secretarial staff or anticipating gate-keeping. In the context of uncertainty theory, this may again be reflective of the ongoing 'knowing versus not knowing' conflict seen in the previous chapters. Their stance of being unable to make contact may again represent a deliberate generation of illusion intended to maintain uncertainty for the sake of protecting their sense of self (Mishel, 1988). This provides another example of patients employing uncertainty as an opportunity to help them cope with their illness. However, other findings may also contribute to this apparent reluctance to take up professionals' offers of support. Participants' actions may reflect a deliberate minimising of their need for answers in

light of professionals' perceived busy-ness as well as their tendency to view others as being worse off than them.

Primary care involvement in patients' liver care was comparatively limited. Several participants had a positive and active relationship with their GP, although this was usually on account of pre-existing chronic conditions. Many participants, however, had little contact with their named GP, or primary care professionals more widely. This was in part due to long delays in getting an appointment with their named GP, but also because patients held a narrow interpretation of the GP role. GPs were mainly considered a source for referrals, prescriptions and sick lines. There was little appreciation of what further support they might be able to provide in relation to patients' liver condition.

Relatedly, despite advanced disease and very poorly overall health, some participants did not consider themselves 'ill enough' to warrant a more involved relationship with their GP. Given the pervasive and relentless nature of their condition as well as the frequency of hospitalisations, this finding is unlikely to constitute evidence of adaptation and normalisation similar to that observed in other chronic illnesses. Rather, I feel that this mindset is more likely to again be a reflection of participants seeking to preserve their valued self by insisting on a healthier vision of their person.

The data indicate that the holistic care role of the GP is not appreciated by patients, which is consistent with findings elsewhere (Beernaert et al., 2014). Their perception may be borne out of previous experiences of primary care encounters, which are typically time-pressured and symptom-focused and thus not generally geared towards the holistic needs of the chronically ill (Wagner, Austin and Von Korff, 1996). Indeed, participants' frustration with GPs' apparent lack of knowledge and confidence regarding liver disease suggests an expectation that consultations should focus on the physical aspects of their condition. This notion finds support in other research (Deveugele, Derese and De Maeseneer, 2002). Moreover, the perceived lack of GPs' competence regarding liver disease is in itself likely to constitute a reason why participants did not tend to seek out their GP for support. This contention receives backing from research in motor-neurone disease (Hughes et al., 2005).

Finally, there was evidence of some involvement of allied health or social care professions during inpatient episodes, but scarcely any such support in the community setting. (The dearth of palliative care input noted will be elaborated upon in Chapters 8 and 9.) This reinforces observations in previous chapters that patient care in this group was predominantly focused on urgent or acute care to the detriment of their psychosocial wellbeing. The value of attending to patients' holistic needs was illustrated by Ben's improved illness experience as a result of the ongoing, individualised support offered by the alcohol liaison nurse. Furthermore, all of those who had received input from allied professions commented positively on the experience. This again highlights the importance of identifying ways in which the psychosocial needs of people with advanced liver disease may be addressed within current medical structures and cultures. As much of everyday chronic illness management happens in the person's home, the potential of harnessing existing primary care and community-based resources should be explored.

Sources of dissatisfaction in patients' care

Despite numerous reports suggesting that hospital-based care in liver disease is inadequate (Ghaoui et al., 2014, Kanwal and El-Serag, 2013, Moore and Sheron, 2009, Juniper et al., 2013, Williams, 2005, Williams, 2009), most participants in this study considered the overall quality of their medical care to be satisfactory. However, this finding may be influenced by the fact that this sample was recruited and received their main liver care from a specialist unit, thus giving access to expertise less likely to exist in a general hospital (Williams, 2009).

Nevertheless, participants also reported instances of inadequate care in the hospital setting. While not as traumatic as acute events, non-acute admissions caused much uncertainty and upset due to conflicting instructions regarding the admission process, treatment delays and consequent length of time in hospital, as well as the overall inconvenience of frequent hospitalisation to the patient and their family. Several participants felt ignored, neglected and devalued in their encounters with hospital staff, reflecting care experiences relayed by cancer patients and their family carers (Janssen and Macleod, 2010). Given patients' increasing social isolation, as described in Chapter 6, occasional social encounters such as medical appointments or

inpatient stays can take on a significant role in that person's life. The doctor-patient relationship considered in this context highlights how critical its experience can be to the patient's sense of self (Charmaz, 1983). A positive encounter with someone the ill person considers significant can strengthen their self-concept, while a negative experience can threaten their identity and leave them feeling demeaned and discredited (Coyle, 1999). Indeed, perceptions of poor care may contribute to depression, hopelessness and declining health among people awaiting liver transplantation (Brown et al., 2006).

Patient satisfaction with primary care is determined by the nature and quality of the doctor-patient relationship and the professional's skill (Calnan et al., 1994). In this study, several participants perceived their GPs as somewhat reticent in their support relating to their liver condition. This observation may be linked to GPs' apparent lack of understanding and confidence with regard to the disease. Perceptions of doctors as lacking competence negatively influence patients' views of the overall quality of their care (Janssen and Macleod, 2010). Indeed, compared with generalists, healthcare professionals holding specialist knowledge engage in more active care and achieve improved patient outcomes in a range of conditions (Harrold, Field and Gurwitz, 1999). Uncertainty theory posits that the more credible the patient perceives a healthcare professional, the less uncertainty they will experience in relation to their illness (Mishel, 1988). A lack of trust in GPs' abilities therefore means that GPs are less likely to be able to alleviate patients' perceptions of uncertainty and consequently improve their overall wellbeing; the opposite may in fact be true.

In this study, people generally valued their medical care and put their faith in their healthcare professionals. At the same time, the medical system constituted a major source of frustration, confusion and uncertainty. These findings support the contention that medicine as a system is both support and hindrance to patients' quest for meaning (Bury, 1982). Current models of medical care are focused on disease management and the data suggest that this holds true for the care of people with advanced liver disease. However, especially in chronic disease this approach is too limited (Larsen, 2013). The present study is consistent with the wider chronic disease literature in highlighting the pervasive, individual nature of the illness experience

and its impact on all domains of the affected person's life. Adopting a more patient-centred care management approach in organ failure can also reduce patient uncertainty (Dudas et al., 2013), and is therefore indicated in advanced liver disease.

7.3.2 Doctor-patient communication

The quality of communication between patients and healthcare professionals proved an influential factor in patients' perceptions of their medical care. Importantly, a number of issues were found to contribute to experiences of ineffective doctor-patient communication. Lessons from patient satisfaction research show consistent reports of dissatisfaction with information-sharing in all care settings, insufficient opportunities to discuss concerns, and a lack of assurance or suitable advice (Coulter and Fitzpatrick, 2000). All these issues, as well as others, were identified here.

In the present study, short appointment times were found to limit opportunities to discuss patients' concerns and assess their psychosocial support needs (Dugdale, Epstein and Pantilat, 1999). Research with patients awaiting transplantation highlighted their lonely suffering (Bjørk and Nåden, 2008). The authors questioned whether this was due to patients not communicating their distress to professionals, or professionals lacking awareness, knowledge or interest in this respect. The present data suggest that the former may be the case, owing to patients' acute awareness of time constraints as well as a lack of opportunity to share such information in a brief consultation encounter, a stance of seeing others as worse off, and inconsistent care relationships. Likewise, GPs appreciate the importance of attending to patients' holistic support needs, but perceive a lack of time and skill to actually do so (Grant et al., 2004).

It is clearly a challenge to impart and discuss all necessary information to the appropriate depth and in the most suitable manner within the typical medical encounter. According to uncertainty theory, access to relevant education constitutes one of the key elements providing structure in the context of uncertainty and can exert a positive impact on its appraisal (Mishel, 1988). Section 6.4.2 highlighted a current lack of awareness by both patients and professionals regarding complementary sources of support for this patient group. In light of systemic

consultation time restrictions then, healthcare professionals may still be able to alleviate uncertainty by raising their own and patients' awareness of, and enabling better access to, complementary sources of information and support, e.g. leaflets, websites, and charitable or community-based support organisations, to those living with advanced liver disease.

Participants described some healthcare professionals displaying poor interpersonal skills; an issue also noted by others (Janssen and Macleod, 2010). A lack of introductions and poor bedside manners for example impacted negatively on participants' sense of self as well as their perceptions of their overall care. The use of unsuitable language related to both a poor choice of words that alarmed patients unnecessarily, and to overly medicalised explanations that rendered their meaning inaccessible to patients. Despite the ambiguity and uncertainty such poor quality communication generates, there is a tendency by both patients and professionals not to ask for clarification (Deveugele, Derese and De Maeseneer, 2002). The discrepancy in language used by professionals and patients has been recognised previously (Ong et al., 1995). In this study, its problematic nature was first indicated in Section 5.2 in the context of receiving a diagnosis of 'cirrhosis', which suggested an erroneous assumption by professionals that a shared understanding existed as to the meaning of this term (Hadlow and Pitts, 1991). However, the inappropriate use of medical jargon could be seen to remain a challenge throughout participants' illness journeys.

Participants indicated an appreciation for both positivity and frankness from professionals in relation to their illness. This finding is consistent with previous research in ALD (Blaxter and Cyster, 1984) and other conditions (Parker et al., 2007, Sell et al., 1993). However, professionals in this study commented on the challenge of striking the delicate balance between honesty and tact. The difficulty of achieving this was highlighted by Sarah's experience, who changed her GP after deeming that person's approach to be too negative. Viewed in the context of uncertainty theory, her action may again be understood as a means of managing uncertainty. The rather realist, frank approach of her first GP promoted negative certainty and led her to interpret her situation as a danger. This prompted a coping response that saw her

take direct action by seeking out an alternative care professional. The more positive approach employed by Sarah's new GP promoted uncertainty to be appraised as an opportunity and in turn facilitated a sense of hope, which served to improve her psychological wellbeing. This finding again demonstrates the critical role healthcare professionals play in mediating patients' experiences of uncertainty.

Multiple aspects of doctor-patient communication could thus be seen to constitute further sources of uncertainty in the overall illness experience in advanced liver disease. Where communication proved to be of poor quality, it had the potential to negate the positive influence a credible authority like a care professional could exert on patients' perceptions of uncertainty (Mishel, 1988).

7.3.3 Continuity of care

Continuity of care reflects the coherence and quality of a patient's care over time (Gulliford, Naithani and Morgan, 2006). Three interrelated dimensions of continuity of care have been identified: relational continuity, management continuity and informational continuity (Haggerty et al., 2003). The relative emphasis on dimensions varies between settings and conditions, but all constitute important elements in the care of people with long-term conditions (Waibel et al., 2012). In this study, continuity of care was found to be inconsistent, fragmented and inadequate in all three dimensions and throughout participants' illness journeys.

Relational continuity

Continuity in care relationships was poor across primary and secondary care settings, and both inpatient and outpatient care. This was true in relation to both the longevity and the consistency of care professionals involved in supporting the participants. Despite patients generally having a designated consultant contact, actual contact with that person varied greatly due to the sharing of responsibilities across specialist care teams. Those with rarer types of liver disease were more likely to have contact with their named consultant. Changes in designated care contact were poorly communicated and experienced as disruptive, confusing and alarming, thus adding further uncertainty to the patient experience.

A caring relationship can foster feelings of safety, trust and respect in the patient (Janssen and Macleod, 2010). The degree of trust and confidence patients feel about their relationship with a healthcare provider is important given its influence on their experience of uncertainty and thus their overall ability to manage their illness (Mishel, 1988). A steady, trusting care relationship encourages patients to disclose sensitive information and raise concerns or questions. It also reduces the need for unnecessary and repeated sharing and interpreting of patient data. As such, relational continuity constitutes a key factor in achieving informational continuity.

An absence of relational continuity makes the development of trust and confidence in the doctor-patient relationship less likely, to the detriment of all involved and the quality of the care provided. However, relational continuity is only beneficial if the care relationship is a positive one. The study data have already shown the harmful impact experiences and perceptions of stigma, excessive negativity, unsupportiveness, and poor interpersonal and communication skills by professionals can have on the patient. Having access to multiple perspectives must also be considered advantageous for successful care management, especially where these involve different disciplines (Mellinger and Volk, 2013). In this study, however, the lack of relational continuity was strongly felt, with many participants looking for that 'familiar face' as they moved within and between care settings. This situation also fostered uncertainty regarding the who and how of seeking help when necessary.

The current organisation of healthcare systems around teamworking does not promote the provision of a single caring relationship. The involvement of multiple care providers does not need to constitute a problem, however, as long as their involvement is complementary and well co-ordinated. Nevertheless, I feel that the disruptive, all-encompassing and importantly long-term nature of conditions like advanced liver disease favours access to one steady, reliable and trusted source of advice and support for patients and their families along their illness journey. The importance chronically ill patients attach to having a continuing care relationship over time has been noted previously (Waibel et al., 2012). Moreover, access to a single co-ordinating care professional can positively affect preventable

hospitalisation (Billings and Teicholz, 1990), and is a key factor in providing good end-of-life care (Lynn, 2001).

In many comparable conditions this central supportive, and often co-ordinating, function is provided by a nurse specialist, but this role is scarce in the realm of liver disease (Williams, 2009). At the same time, relational continuity has been found to improve with increased GP consultations (Gulliford, Cowie and Morgan, 2011). This again points to the value of developing currently underused primary care resources to better support the ongoing care of people with advanced liver disease. Indeed, contrary to what the present data intimate about participants' dissatisfaction with GPs' condition-specific understanding, when it comes to relational continuity patients are willing to forego clinical expertise in favour of a familiar, trusted family clinician (Haggerty et al., 2013).

Management continuity

Management continuity refers to how coherently patient care is organised within and across care settings and providers, and the extent to which provision is complementary. Patient interviews in this study highlighted mainly issues relating to the co-ordination of care within the hospital setting on account of the bulk of participants' ongoing care taking place in this environment. Issues relating to care co-ordination between settings featured in the professional interviews, however, and will therefore be discussed in Chapter 9 in the context of care professionals' views on providing care in advanced liver disease more generally.

In the present study, ongoing patient care consisted of infrequent outpatient clinic appointments, which participants judged too short and symptom-focused to be of benefit for them. The unlikelihood of getting to see their named consultant on those occasions added to this negative perception. Moreover, these appointments, typically several months apart, were considered too infrequent. GPs felt that the unpredictable and fluctuating nature of the disease as well as patients' advanced disease status warranted more regular attention from liver specialists. Patients, on the other hand, felt forgotten about in the intervening time; an experience reinforced by their limited engagement with primary care services as highlighted earlier.

Infrequent clinic follow-up and reliance on patient-initiated attendance at primary care make it more likely that complications and deterioration of the condition are detected late. As mentioned in Section 5.5.3 for example, some of participants' physical complications such as problems with motor function or sleep may indicate the presence of subclinical levels of hepatic encephalopathy (HE) (Groeneweg et al., 1998). At the same time, they may be linked to transient episodes of overt HE which would benefit from targeted care at the time, but which go undetected on account of the long gaps in follow-up. More regular care contact is also important in the context of patients' increasing social isolation highlighted in Chapter 6. As mentioned earlier, social isolation can make the care relationship more significant to the ill person (Charmaz, 1983). More frequent interaction with care professionals can also serve to improve patients' opportunities for social contact (Charmaz, 1997), which may impact positively on their psychological wellbeing.

Despite their scarcity, clinic appointments served to reassure participants that their condition was being monitored. Their existence, albeit infrequent, therefore constituted an important means of reducing patient uncertainty. However, attendance at appointments could be impeded by a number of illness-related factors such as poor overall health, physical stigmata of the disease rendering patients embarrassed in public, hospital admissions, or a lack of support with respect to access to appointments or their immediate after-care. Patient attendance at follow-up clinics is an important health behavioural indicator, but the factors affecting attendance are still poorly understood (O'Carroll, 2011). The present data describe various physical and psychosocial issues that may impact on patients' ability to attend medical appointments. These factors sit alongside those discussed earlier with regard to participants' perceptions of the value of these consultations and their preference for being able to see their designated consultant when attending. All of the above factors are thus important barriers to achieving management continuity.

These findings again point towards the value of a better sharing of care activities across settings, and the promotion of patients' utilisation of primary care resources in order to facilitate closer monitoring and support of both their condition and holistic support needs. Improving the frequency of care in decompensated liver disease by

sharing patient care between gastroenterologists and primary care professionals has shown to impact positively on patient outcomes (Bini et al., 2001, Morando et al., 2013). Potential improvements in the current care pathways for people with advanced liver disease will be considered in more detail in Chapter 9 in the context of care professionals' views on that matter.

Informational continuity

Informational continuity pertains to continuity in both disease- and person-focused documentation and accumulated understanding across individual care providers and care episodes (Haggerty et al., 2003). This dimension of continuity is thus influenced by the quality and consistency of both care relationships and care management as described in the previous sections. In addition, informational continuity is likely to be affected by the duration and quality of medical consultations and the manner in which information is shared with patients. Participants' views of their medical care and doctor-patient communication presented earlier in this discussion are consequently also of relevance here. Finally, informational continuity will be affected by the quality and effectiveness of interprofessional communication. This particular issue will be considered in Chapter 9 in the context of professionals' experiences of supporting people with advanced liver disease.

7.4 Concluding remarks

The literature in advanced liver disease highlights a need to enhance the current care provision for this patient population, but research on patients' own views and experiences in this context is lacking. This study contributes insight by exploring patient participants' use of care services and their perceptions of that care. Most considered their overall medical care satisfactory, but also described sources of dissatisfaction and uncertainty in this respect. Unlike in other organ failure, the care of these patients centred predominantly around hospital-based services. Primary care services were underused and undervalued. Care provision in advanced liver disease presented as largely symptom-focused, episodic and reactive, and thus constituted a poor fit with the long-term support needs of chronically ill people.

Complexity in the organisation of treatment and healthcare as well as inadequate information-sharing are both indicated in illness uncertainty. Furthermore, trust and confidence in one's healthcare provider is key to reducing uncertainty in the ill person (Mishel, 1988). Poor doctor-patient communication and relations as well as discontinuous care can thus foster uncertainty in a patient, which in turn challenges their ability to manage their illness more generally. Inadequate follow-up and intervention management, poor facilitation of self-management, and insufficiently managed psychosocial needs may lead to undesirable patient outcomes (Wagner, Austin and Von Korff, 1996). Likewise, bedside manners, listening, time, continuity and consistency of care, competence, clear and sensitive information-sharing, and empathy are important aspects in patients' experiences and perceptions of their care in advanced disease (Janssen and Macleod, 2010). All these factors were found wanting in this study.

Chapter 8: Deterioration and death

The previous chapter marked out the care experience in advanced liver disease as another issue beset with ambiguity and complexity. Thus far then, uncertainty has been seen to permeate the physical and psychosocial domains of the illness experience, persist from illness onset, and extend through patients' everyday life at home and their experiences in the care setting.

This chapter focuses on patients' accounts regarding their future with advanced liver disease. It first presents their experiences of receiving a prognosis. It then illustrates their expectations and concerns regarding the future, and their thoughts on death and dying from their illness. It also describes some patients' end-of-life experiences as related by their lay carers in bereavement interviews. The chapter concludes with a discussion of these issues in relation to the wider literature.

8.1 Prognosis

Prognosis constituted the 'elephant in the room' in the context of advanced liver disease. The issue of receiving a prognosis was subject to great uncertainty. The unpredictable nature of the disease was one aspect of this.

It's very difficult to pinpoint when they're coming to the end, because they're generally not very well for quite a long time and then they get slightly worse and you're never really sure. (*GP of Martin, 77, ALD (NAFLD)*)

Sometimes people are given, "You'll only live for a year," or that kind of thing, but I suppose you have to be quite cautious about it because, for example, I would never have thought Ben would have survived this. His bilirubin was so high it was death defying. How he survived this beggars belief. (*Alcohol liaison nurse of Ben, 35, ALD*)

This uncertainty was also played out in the differing prognoses offered by healthcare professionals. Some GPs felt that liver specialists were being overly optimistic in their judgement of patients' prospects.

They said two or three years (...) I told them I thought that was very optimistic and I thought we were looking at a matter of months. And I think it was probably four or five months before he died that he came in to speak to me and I said, "Look, I think six months or a year is more an accurate time period." (...) I suppose I saw him regularly and I knew what he was like beforehand. (*GP of Thomas, 75, NAFLD*)

However, participants tended to trust liver specialists' opinions over those of their GP. This may be due to specialists' disease-specific expertise, but also because their more optimistic outlook helped patients feel more hopeful.

I was really quite worried about it for a while, the illness, but I kind of went to my [liver consultant] and went, you know, "Be truthful and tell me," and he was actually quite positive. Because the [GP] I had went to before, she'd told me, "Make happy memories now, because you don't know how long you've got." And that really, that played on my mind a lot (...) so I asked [consultant] and he told me that it could be decades before I'm affected and my quality of life could be great for decades, you know? (*Sarah, 38, ALD (HCV), third interview*)

In only a minority of cases had the topic of their prognosis been broached with participants. Where participants had received an explicit prognosis, it had been experienced as a rather shocking and upsetting event.

You're absolutely shattered, it's like running into a brick wall, you know? "My God," you know, "what am I gonna do?" (...) I actually told the doctor the next visit I was in, I says, "Well if it's that bad then life's not worth living." I was actually contemplating suicide. (*Thomas, 75, NAFLD, first interview*)

Most commonly it was those with alcohol problems who had received a prognosis. This had usually come in the form of a stark warning that continued drinking would kill them within months.

[The consultant] basically says if I keep on drinking I'll be dead in 6 months (...) which was a harsh statement but had to be said because, well, you need to be shocked into knowing how serious it is. Cos it is serious. I mean, your liver is serious. (*Sarah, 38, ALD (HCV), first interview*)

The last time they virtually told me my liver would get back to normal, and it did. Whereas this time it won't. I have been warned, well warned, "If you drink again, you will die." So if I do drink again, I'm signing my own death certificate. (*Ben, 35, ALD, first interview*)

Participants in this study were split on whether they wished to be told their prognosis or not. Some appreciated clarity on the matter.

The last time I went to see the specialist I was just like, "Just go and be honest with me and just tell me exactly," you know? (*Sarah, 38, ALD (HCV), second interview*)

Others preferred to remain ignorant about their future prospects.

BK: So have the doctors told you anything about what to expect, how things might develop with time?

Donald: No, I'll no ask him. (...) I don't want to ken.
(*Donald, 74, HCC (NAFLD), first interview*)

BK: When you say you don't want to know, what is it that specifically that you don't want to know?

Rebecca: My lifespan.
(*Rebecca, 37, ALD, third interview*)

Giving and receiving a prognosis then was a further issue beset with uncertainty; this was true for both patients and professionals. As a result, patients' prognoses were rarely discussed.

8.2 Contemplating the future

Participants also differed in the way they felt about their future prospects. Some were rather worried about what lay in store for them.

BK: Do you worry at all where it might end or where it might take you?

Aidan: Oh aye I do, aye.
(*Aidan, 58, ALD, first interview*)

When I'm on my own I keep taking wee panic attacks because I start thinking about the future. (*Ben, 35, ALD, third interview*)

Others tried to stay hopeful that things would turn out fine for them in the long run.

BK: So are you feeling reasonably confident about the future?

Carol: I have to. I just have to.
(*Carol, 45, ALD, second interview*)

Yet others had stopped looking towards the future, their deteriorating condition making them resigned to an inevitable decline.

I don't see a future. (*Nadia, 58, ALD (HCV), first interview*)

The uncertainty and unpredictability inherent in the illness trajectory in advanced liver disease contributed to participants' difficulties in envisaging their future.

If there's an episode, let's call it an episode, of any description you kind of start to worry about is this progressing? Is it getting worse? You know, what's going to happen next? (...) And as time goes on that impact and fear and worry and whatever starts to become more frequent, because the events start to become more frequent as you move along through time. (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

At times I panic. Things are happening too quick so I'm panicking. (*Mary, 66, autoimmune hepatitis, second interview*)

8.2.1 Returning to work

Worries about the future were not limited to likely developments in relation to participants' health. In contemplating their future, the issue of if and when they would be able to return to work preoccupied the minds of younger participants. All were eager to work again, but there was uncertainty whether they would be able to.

The way I'm feeling at the moment, I don't know if I'll be back at work. (*Carol, 45, ALD, first interview*)

What chance have I got when all these fit people and able people can't get a job, and students with degrees and everything, fit and healthy? Christ, I'm not long out of hospital about dead, what chance have I got of getting some sort of job? (*Ben, 35, ALD, second interview*)

For participants with ALD, this uncertainty also related to their ability to halt the progression of their illness by achieving sobriety long-term. Given their poor state of physical and psychological health, however, some were resigned to the fact that they would never be able to work again.

I know I'm not going to be able to get a job. (...) I couldn't cope with a job. (...) Health-wise issues and how I'm feeling and...I know I wouldn't. If I actually had a job it maybe would give me a wee bit of drive, but I don't think it would last for long. (*Rebecca, 37, ALD, third interview*)

8.2.2 Liver transplantation

Kate was the only study participant for whom a liver transplant became a tangible possibility in the course of the study. For the majority of participants liver transplantation was contraindicated due to co-morbidities or continued drinking. Some participants considered themselves too old to even contemplate taking up such an option should it be offered to them.

I'm 77 and I'll be 78 when, this time I've got, four to six months, I says, well I'm no that fussy really. Even my grandchildren, they've all grown (...) I wouldn't bother anymore. (*Martin, 77, ALD, first interview*)

Others felt that they were undeserving of a new liver on account of the self-inflicted nature of their condition.

Rebecca: I don't deserve it. (...)

BK: You feel you don't deserve it or you've been told you don't deserve it?

R: No, I feel I don't deserve it. (...) It's self-inflicted.

(*Rebecca, 37, ALD, second interview*)

Interestingly, receiving a transplant was not considered a final safety net in the battle against their deteriorating condition. On the contrary, participants appeared particularly fearful of the thought of undergoing transplantation.

That's always been my biggest fear, probably more than, I wouldn't say more than dying but on a par with dying. I don't think I could handle that if I was told that I needed, my liver was kaput and I needed a transplant. (*Ben, 35, ALD, second interview*)

Mary was similarly alarmed at the thought of requiring a transplant.

I said, "Are we talking, down the road, transplant then?" It was me that brought it up. [Consultant] says, "Yes." Well, my mouth went..." (drops jaw). I says, "Oh God almighty." (*Mary, 66, autoimmune hepatitis, second interview*)

Mary never did get assessed for transplantation, however, as she died suddenly only one week after this conversation. Her story thus exemplifies the uncertain nature of advanced liver disease and the difficulty of determining a prognosis as indicated earlier in this and previous chapters.

8.2.3 Contemplating death and dying

While issues around death and dying were rarely raised in the interviews, many participants acknowledged at some level that death was a possible outcome. In particular, brushes with death during acute exacerbations and observations of deterioration in one's condition promoted participants' reflecting on this and existential issues more generally.

I've never thought about death so much since I've...you know, you don't think about it at my age. But since all this has happened I've been thinking about it. We've all got to think about it one day, but normally not till you're about 80. (*Ben, 35, ALD, third interview*)

For younger participants especially, contemplating death proved a frightening process.

You always plan your life ahead and you think, “Oh well, this year I’m going to do this and next year I’m going to do that,” and kind of reality is beginning to sink in a little bit that if this all goes tits up there won’t be next year. Jesus. (*Kate, 41, cryptogenic LD, first interview*)

There was a suggestion that some participants mentally acknowledged their imminent demise, but refrained from voicing this publicly.

I think she knew herself, you know, but she didn’t want to say to me. (*Jeff, husband of Polly, 68, NAFLD, bereavement interview*)

In the context of the research interviews, participants’ level of willingness to engage in a consideration of death and dying remained constant throughout their study involvement. Martin for example, despite having received an explicit prognosis of four to six months and being fully accepting of his fate, remained reluctant to acknowledge this aspect of his illness in his interviews. In contrast, Fraser was consistent in his expression of a wish to die soon and see the end of his suffering.

I wish honestly, I wish somebody would just give me a jag and put me to sleep and that’s it. That’s what I do. (*Fraser, 60, ALD, second interview*)

In others, the threat of death inspired an unflinching strong will to live despite their unpredictable and poor condition.

I’m quite a determined person. I refuse to sit down and die, you know what I mean? (*Sarah, 38, ALD (HCV), first interview*)

The uncertainty inherent in advanced liver disease could thus be seen to both prompt and influence participants’ considerations of death and dying in relation to their illness.

8.3 Planning for the future

Given the many uncertainties they experienced relating to their illness, most participants felt unable to make plans for the future.

You can’t turn around and plan for the future or nothing, you know? (*Jeff, husband of Polly, 68, NAFLD, first interview*)

In contrast to their counterparts, Kate and Michael tackled the uncertainty of their situation head on by making plans around both a positive and a negative outcome.

It's not an easy thing to talk about, but the reality is you have to make plans, both positive and negative plans, because in these situations things can happen and change very, very quickly. You don't want to be in a position where something really bad happens and you don't know what the answers are to what Kate wants for her estate so to speak, or her family or funeral arrangements (...) So it's definitely something that should be done. Absolutely. But equally it's nice to plan for the future as well, you know? (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

The week after I got out of, from the [transplant] assessment week, I went home and wrote a massive, massive long letter to my husband. And he knows it's there and he knows where it is, and it's telling him what to do with me and what to do with all my things should the worst come to the worst. And that was quite difficult. However, it's done. It's done. (*Kate, 41, cryptogenic LD, second interview*)

Some of the older participants had also made plans for the future. Their plans focused solely on a negative outcome, however.

Just about maybe a couple of months before she died we were talking about different things, you know, she told us what she wanted if anything happened to her. (*Jeff, husband of Polly, 68, NAFLD, bereavement interview*)

Martin and his wife Cora had made wills and funeral arrangements prior to Martin's diagnosis with decompensated liver disease. Despite these plans being in place and Martin accepting of the fact that he only had a short time to live, he was reluctant to plan for the time of his final deterioration.

It was really tricky to have conversations with him about being less well or planning for when he died. I think a lot of the barrier to that was because of his ascitic taps being done, it was just the next one after the next one. "That will keep me alive, that is all I have to do, I can't think beyond that. Two weeks will come, I'll be symptomatic, I'll need the tap done. Marie Curie can't give me a tap, so I'm not going to Marie Curie." So because we don't do invasive procedures as you would on wards, my feeling was that that's why he was not wanting to go there. (*Community palliative care nurse of Martin, 77, ALD*)

8.4 Experiences of death and dying

Nine of the 15 patient participants died during their involvement in the study. Of these, eight died in hospital following either acute or routine admissions. Only Donald died at home, in line with his and his family's wishes. Interestingly, Donald was the only study participant whose disease cause was primary liver cancer. His end-of-life care arrangements had been put in place with the help of his GP and community palliative care services. His wife Martha was pleased about the care and support provided by both professions in Donald's final days.

Top marks, definitely. They were perfect. I mean they were in there in the morning, afternoon and night. Then [GP] come in every day. I mean, that was over four days but that felt like weeks. Oh no, the nurses were perfect. (*Martha, wife of Donald, 74, HCC (NAFLD), bereavement interview*)

As mentioned previously, Martin was the only other participant to benefit from similar arrangements with community palliative care services to allow him to die at home. However, these plans were not in fact followed through at that critical time and he died in hospital following an acute admission. Interestingly, while Martin was eventually persuaded to accept palliative care input in his own home, he was not prepared to completely relinquish his end-of-life care to a hospice. His designated palliative care nurse suspected that his fortnightly hospital admissions to drain his ascites had lured him into the illusion that these treatments were prolonging his life.

He didn't want to go into Marie Curie, but he was quite happy to be in an acute setting, which is quite unusual. A lot of people don't want to go near the hospital. But I think he almost viewed that (...) as a life line. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

At the same time, there was a sense that hospital was in fact an appropriate place for some these patients to be in their dying phase. While it was not possible to ascertain the circumstances around all the participants who died in hospital, the bereavement interviews conducted suggest that the lay carers of those who had died in hospital did not regret this experience.

The staff at [local hospital] were, to be honest, they were brilliant, you know? (...) They put her into a wee room for about a fortnight (...) and I took some photographs (...) and we had them on the window ledge and everything, you know? They were definitely quite good, you know? (*Jeff, husband of Polly, 68, NAFLD, bereavement interview*)

Fraser's consultant agreed that liver patients dying on the hospital ward was not necessarily a negative event, given the familiarity that usually existed between patients and ward staff on account of their repeat admissions.

To some degree I think that's a reasonable thing because I think we know them and, you know, for Fraser we were more of a family, you know, or not a family is the wrong term to use but, you know, he knew all of us lot better than anybody else, and I think you know, he would have been comforted by being in with us. (*Consultant of Fraser, 60, ALD*)

8.5 Discussion of findings

The above findings illustrate participants' views and experiences in relation to anticipating, contemplating and planning for deterioration and death. Again, each of these areas was subject to considerable uncertainty which affected participants' perceptions and actions. Discussing prognostic and end-of-life issues, facing an uncertain future, and contemplating and planning for death emerged as particularly challenging issues.

8.5.1 Discussing prognosis and the end of life

Prognosis constituted a further source of uncertainty in participants' illness stories, and one that was shared by patients and professionals alike. Prognostication in chronic liver disease is complex and dependent on several person and disease-specific factors (Propst et al., 1995). Determining a precise prognosis on an individual basis is therefore difficult. Doing so is further undermined by the fluctuating, unpredictable nature of chronic liver disease, and the potential of those with lifestyle-related aetiologies being able to alter the illness pathway through behaviour change.

Guidance has been put forward to help healthcare professionals manage prognostic uncertainty in non-malignant disease including advanced liver disease (Highet et al., 2013). Nevertheless, it is important that professionals acknowledge and explain to patients the uncertainty that remains in providing a prognosis in relation to their specific circumstances (Hancock et al., 2007b). In this study, conversations between patients and professionals about the patient's prognosis were mostly absent. This mirrors the experience of patients with other types of organ failure (Barclay et al., 2011, Davison, 2010, Murray et al., 2002). Professionals are more likely to conduct prognostic conversations with cancer patients than with people with other progressive types of illness (Exley et al., 2005, Heyland et al., 2009).

Participants in the present study were more likely to have been given an indication of their prognosis if their liver disease was related to alcohol misuse. The data relating to ALD participants presented so far suggests an illness experience that is in some respects more in line with the cancer experience than with other causes of liver

disease. Like cancer patients, people with ALD have a concrete diagnosis, an opportunity to overcome their disease which would facilitate are more stable, slower disease progression, and a relatively more predictable life expectancy based on their ongoing drinking behaviour. This makes prognostication in this particular liver patient group easier to gauge, and may be the reason why such conversations were more likely to occur in this context. Alternatively, care professionals may use prognostic conversations as a motivational tool to shock ALD patients into behaviour change, i.e. abstinence, to curb disease progression. As this option is not available to people with liver disease of other causes, it might offer another explanation as to why professionals generally omitted similar conversations with them.

Characteristics of prognostic and end-of-life conversations

Where conversations had taken place about participants' prospects, the study data indicated that the opinions of liver specialists were regarded more highly than those of GPs. In the context of prognostic predictions, their disease-specific expertise combined with a tendency to express more optimism about future developments. This disparity between specialists and generalists has been reported previously (Christakis and Lamont, 2000). Specialists' communication therefore served to alleviate patient uncertainty regarding future developments by promoting a sense of hope, which might further explain participants' tendency to favour their input.

At the same time, actual developments observed in several participants' illness journeys support the view expressed by GPs in this study that specialists were in fact being unrealistic in their verdicts. Research elsewhere confirms that healthcare professionals are inclined to consciously misjudge patients' survival (Lamont and Christakis, 2001). At the same time, promoting a sense of life remaining open-ended has been found to aid coping (Johnston and Abraham, 2000). Expressing over-optimism to nurture hope in the patient, as employed by liver specialists in this study, should therefore not be considered inherently harmful. It is critical that patients' overall volatile health status remains acknowledged, however, and that professionals undertake advance care planning to allow for a sudden deterioration in a patient's condition. Indeed, having prognostic conversations can facilitate the advance care planning process (Heyland et al., 2009). The topic of advance care planning will be

examined more closely in Chapter 9 in the context of professionals' views on caring for people with advanced liver disease.

Barriers to prognostic and end-of-life conversations

Professionals agree that people with progressive, life-limiting conditions deserve open dialogue about their prognosis and end of life, but remain reticent to initiate such discussions for reasons such as a lack of time, personal apprehension, and uncertainty about the illness trajectory (Hancock et al., 2007a, Hancock et al., 2007b). All these factors were indicated in the present data and may therefore have contributed to the relative absence of such conversations between participants and their care providers. Similar barriers to prognostic communication exist in heart failure (Barclay et al., 2011, Hjelmfors et al., 2014) and COPD (Momen et al., 2012). Previous research also suggests that professionals tend to rely on patients to raise such matters, and that they interpret an absence of questions as an indication that patients do not wish to have this information (Hancock et al., 2007a). However, the present study has already identified several factors which are likely to affect patients bringing up issues of personal concern during medical encounters, such as a poor understanding of their condition, lack of confidence, discontinuity in their care relationships, and the symptom-focused, time-pressured and infrequent nature of consultations. The widespread coping strategy of focusing on one day at a time is also likely to work against patients raising issues about their future with professionals.

It has been suggested that prognostic accuracy in progressive disease is subject to not only clinical uncertainty, i.e. actual limitations in current medical knowledge, but also to 'functional uncertainty' (Davis, 1960). Uncertainty in this context is deployed to provide a critical function, that of informational gatekeeping. As such, uncertainty is actively preserved by professionals even where prospects are relatively clear in order to make their ongoing care efforts and relations with a patient more manageable. This again highlights not only the influence professionals may exert on the patient experience of uncertainty, but also hints at patients' uncertainty being actively manipulated at times in order to achieve a favourable outcome for other stakeholders in their illness. The idea of 'functional uncertainty' thus provides a

further explanation for the relative absence of prognostic conversations observed in this study.

Patients and their families consider prognostic information important and their desire for it is high (Davison, 2010, Lowey et al., 2013, Parker et al., 2007). However, participants in this study were split in their wish to know details of their life expectancy and what to expect in the future. Similar differences have been noted in patients with a range of conditions including advanced cirrhosis (Heyland et al., 2009). This finding may reflect participants' strategic coping by employing a stance of denial with respect to their future prospects. Similarly, participants may have sought to protect their sense of self by limiting their exposure to such information. This indicates another instance of uncertainty being appraised as an opportunity and thus actively maintained in the context of their illness.

However, participants' poor understanding of their condition and liver disease more widely as described in Chapter 5 suggests an alternative explanation. It is conceivable that people did not in fact appreciate the life-limiting nature of their condition and thus did not feel a need to consider their prognosis. This notion has some support from research in heart failure and COPD, where patients demonstrated little awareness of the deadly nature of their illness (Lowey et al., 2013, Murray et al., 2002, Pinnock et al., 2011). Poor awareness in this respect may also have been influenced by the fact that advanced liver disease is a chronic illness predominantly managed in the acute care setting, as demonstrated in the previous chapter. This experience may shape people's perceptions of their illness as one that is treatable long-term, thereby enforcing their ignorance (or possibly denial) regarding the likely terminal nature of their condition.

The above finding consequently underlines the importance of prognostic and end-of-life conversations being initiated by the care professional, while at the same time giving due attention to cues indicating patients' preparedness to engage with this topic. Inappropriate and poorly timed prognostic conversations can foster uncertainty and anxiety (Rogers, Karlsen and Addington-Hall, 2000). Conversely, effective communication of such challenging issues can promote understanding, acceptance

and adjustment in the patient (Fallowfield and Jenkins, 2004). In light of the rapid and erratic trajectory in advanced liver disease, I believe that healthcare professionals should start raising awareness of potential deterioration with the patient from the point of diagnosis. This is particularly critical where that person's liver condition is already decompensated, as their eventual decline is guaranteed. This notion receives support from a systematic review indicating that patients want prognostic information at the time of diagnosis or shortly thereafter (Parker et al., 2007). However, it is imperative that professionals be sensitive to patients' needs and preferences in this respect, tailor such conversations to the individual case, and ascertain patient understanding (Hancock et al., 2007a, Hancock et al., 2007b).

8.5.2 Facing an uncertain future

Uncertainty relating to disease progression and future prospects left many participants feeling anxious, while others chose to remain hopeful in the face of their uncertain circumstances. The same uncertainty also affected participants' ability to envisage their future. This observation has also been made in COPD, where patients are similarly unable to plan for the future on account of the unpredictability of their condition and its uncertain trajectory (Small and Graydon, 1993). Given the relatively more pervasive and traumatic consequences of the illness on their lives, younger participants expressed more anxiety about the uncertainty shrouding their future. This finding is consistent with the literature in other conditions indicating a greater negative impact of chronic illness on the lives of younger patients (Hummel, 2013).

The anxieties expressed over one's future also provide further evidence that people with advanced liver disease experience biographical disruption, as noted in Section 6.5.3 (Bury, 1982). Uncertainty draws the ill person's attention to what is a normally taken-for-granted future (McCormick, 2002), and highlights to them the unsettling impact of their illness upon previous expectations and plans for their future. Younger participants were particularly concerned about the likelihood of them one day being able to return to work. There was also uncertainty over the necessity of undergoing liver transplantation at some point in the future.

Interestingly, liver transplantation was not considered the ultimate safety net in the context of a precarious existence. Conversely, its contemplation appeared to create considerable uncertainty and fear. Although professionals had raised this issue with only a few participants in this sample, there was widespread awareness of the dangers inherent in this intervention. Moreover, those with ALD considered their chances of being selected for transplantation poor given the self-inflicted nature of their illness. This negative perception is in fact borne out by research into public attitudes towards the allocation of scarce organ resources to people with alcohol problems (Rodrigue et al., 1998), although it does not reflect the views of clinicians (Neuberger et al., 1998). Nevertheless, it again indicates the acute sense of stigma participants perceived, as highlighted in Chapter 6. What is more, several ALD participants considered themselves undeserving in comparison with patients they regarded innocent victims of their liver condition. Numerous studies have explored liver transplant candidates' views of facing transplantation while waiting for a donor organ. Research into how liver patients more generally view and rationalise the possibility of requiring a transplant in the future is lacking. In light of the anxiety this issue appears to cause in this patient group, and in particular for people with ALD, this topic warrants further exploration in order that any uncertainties, misconceptions and concerns may be addressed and the psychological burden on patients alleviated as they progress through the illness.

8.5.3 Death and dying in advanced liver disease

Contemplating death

Patients with primary liver cancer are reported to experience a constant fear of death (Fan and Eiser, 2012). The present data suggest that this is not necessarily the same for people with other causes of liver disease. This discrepancy in findings may be explained by the relatively greater societal awareness of the implications of a cancer diagnosis compared to that of liver disease. Nevertheless, while rarely openly acknowledged, participants' accounts indicated a general awareness of the potential for deterioration towards death. This finding reflects observations in heart failure patients, who were similarly uncertain of their prognosis but recognised the severity of their ill health (Boyd et al., 2004). Given participants' poor understanding of the

life-limiting nature of advanced liver disease, their awareness was prompted by episodes of exacerbation serving as a reminder of the volatile nature of their situation, as well as a sense of a slow but steady deterioration in their condition. Those with ALD were additionally conscious of the explicit threat of impending death if they failed to stop drinking. Thus, different sources of uncertainty related to their condition could be seen to promote existential contemplation in participants.

Recognising the precariousness of their situation injected participants with fear and determination alike. Some actively avoided overt contemplation of death. This can again be understood as a way these people managed the uncertainty that existed over this issue, which related to both an uncertainty regarding one's prognosis and participants' general understanding of the implications of a diagnosis of advanced liver disease. In avoiding thinking about death, uncertainty was again employed as an opportunity and served as a way of protecting not only their own sense of self, but the wellbeing of their loved ones also.

Planning for death

Uncertainty also played a key role in participants' ability and intent to plan for future eventualities. This was a task rarely undertaken in this sample. Research in similarly unpredictable conditions like heart failure and COPD suggests that patients wait for health professionals to prompt them when the time is right to plan for death (Lowey et al., 2013). No such expectations were expressed by participants in this study, however. Older participants had commonly prepared for death by making a will, although this had usually been undertaken in recognition of their age and general life stage rather than their illness. Some participants again chose to embrace the uncertainty surrounding death as an opportunity in this respect, however. Kate and her husband Michael for example opted to make plans for both a positive and a negative future outcome. Similarly Martin, despite being aware and accepting of his short prognosis, used his repeat hospital admissions for paracentesis to avoid engaging with the issue of his imminent decline. In this context, ongoing restorative care could be seen to interfere with patients' willingness to engage with their death. It offered a source of stability within an illness experience dominated by uncertainty, and a welcome distraction from thinking about the future by facilitating a focus on

the present. This fact has also been observed in the experiences of cancer patients (The et al., 2000).

End-of-life care planning was generally absent among participants. Even where arrangements had been put in place, it did not guarantee these plans being followed through; a finding that resonates with previous observations of this kind (Rhee, Zwar and Kemp, 2013). There was a lack of appreciation among the participants of when death was imminent, which was exacerbated by the lack of prognostic discussion highlighted earlier and the ‘rescue culture’ of modern healthcare (Gott et al., 2013). As intimated previously, continued active treatment served as an additional challenge to patients truly appreciating the life-limiting nature of their illness, and consequently as a barrier to the implementation of appropriate end-of-life care. Being accepting of one’s death facilitates the provision of end-of-life care (Zimmermann, 2012). Clearly then, in order to accept death the person needs not only to be fully aware of and understand the terminal nature of their illness, but be supported by care structures which enable this process to take place.

Place of death

Lack of appropriate planning, of coordinated care and services, and regular acute exacerbations meant that most participants died in hospital. This is consistent with recent figures suggesting that nearly three quarters of liver deaths in England occur in the hospital setting (National End of Life Care Intelligence Network, 2012). Hospital deaths are also common in other organ failure (Murray et al., 2002). Numerous surveys suggest that most people prefer to die at home and current end-of-life care policies strive for this to happen wherever possible and appropriate. In the present study, however, there was a sense among lay carers and professionals alike that the hospital was in fact not a wholly inappropriate place for liver patients to die. Indeed, the bereavement interviews with lay carers indicated positive experiences of patients dying in hospital.

Care professionals agree that death should be facilitated in a familiar environment (Reyniers et al., 2014b). The previous chapters as well as the hospital admissions data presented in Appendix 4 highlight the frequency with which participants

attended hospital as inpatients and explain the resultant sense of ‘homecoming’ for many. Similar sentiments have also been expressed by patients with kidney disease (Gott et al., 2013). In the case of advanced liver disease then, hospital constitutes a familiar and trusted environment for many patients. This is particularly true when one recognises the considerable number of individuals in this patient group living in difficult social circumstances related to drug or alcohol misuse. For these individuals, their home environment may not constitute the safest or most supportive environment to accommodate their end-of-life care. The acute hospital setting on the other hand, a familiar surrounding with valued care relationships, may represent a ‘safe haven’ and thus a more appropriate place of death (Reyniers et al., 2014a). The increasing social isolation witnessed among participants in this study provides further support for this notion. Moreover, hospital admissions at the end of life may not always be inappropriate or unwelcome (Morris et al., 2013). Indeed, if the patient requests being admitted to hospital then doing so must be considered justified (Reyniers et al., 2014b). This may in fact be the reason for Martin dying in hospital despite care plans to enable him to die at home being in place. The expectation, borne from previous experience, that he would be well cared for at the hospital may have driven the decision to have himself admitted in favour of contacting his GP or community palliative care nurse. Unfortunately the data did not allow an insight into patient participants’ views on the matter. However, feedback from the members of the study’s lay advisory group lends support to this idea, by confirming that they valued and trusted their hospital-based care and healthcare professionals to the extent that they would be perfectly accepting of hospital as their place of death.

The above suggests a somewhat divergent stance from that currently dominating the literature around preferred place of death. Taking a person’s place of death as a proxy for the quality of the death experience is clearly too simplistic. Given the unpredictability and frequency of acute exacerbations in advanced liver disease and the current paucity of community-based palliative care provision for this patient group, deaths in the hospital setting in this group are likely to remain common (Clark et al., 2014). Moreover, a considerable number of people with advanced liver disease are averse to the idea of receiving care in a nursing home (Roth et al., 2000), and

might in fact be too young to qualify for such provision. Professionals working in acute hospital care have previously commented that contrary to popular opinion their setting is able to ensure a good death (Gott et al., 2013). At the same time, findings in this and other studies indicate that hospital care is currently too focused on continued life-prolonging interventions and that professionals lack appropriate communication skills (Reyniers et al., 2014a). It is therefore imperative that staff in acute hospital services are upskilled accordingly (Barclay and Arthur, 2008). Barriers relating to the current organisation and culture of the acute care setting also need addressed to ensure that hospitals and their staff are adequately equipped to deal with the needs of the person at the end of their life (Gott et al., 2011).

8.6 Concluding remarks

Issues around death and dying in the context of advanced liver disease were beset with further ambiguity and uncertainty. Notably, uncertainty in this regard existed not only for patients, but professionals alike. Uncertainty was a key barrier to effective prognostic and end-of-life communication and planning in the care setting. Similar to other conditions that are subject to an uncertain disease course, patients' needs in this respect were poorly attended to. ALD patients could again be seen to constitute an exception, however. The need for professionals to take the lead in initiating prognostic and end-of-life conversations, and to do so early on in the illness trajectory, was indicated.

There was little appreciation among patients of the life-limiting nature of their condition, and in turn a lack of due consideration of or planning towards possible decline and death. At the same time, patients saw their future shrouded in uncertainty, which added to their psychological burden. The prospect of needing a liver transplant in the future presented a particular threat in this respect and warrants further attention. Finally, the data make an important contribution to current debates regarding preferred place of death and the appropriateness of the acute hospital setting as a provider of end-of-life care. The questions it raises in this regard indicates avenues for further research.

Chapter 9: Caring for people with advanced liver disease

The previous chapters described the patient experience in advanced liver disease. Uncertainty emerged as an enduring and pervasive characteristic of this experience. Uncertainty affected all stages of the illness: from diagnosis to the everyday experience of living with advanced liver disease to issues around contemplating and planning for death. Moreover, uncertainty was observed in all settings within which life with the illness had to be negotiated – home, care settings and the wider social environment. There was also an indication that uncertainty was not only a feature of the patient experience in advanced liver disease, but that it was similarly felt by lay and professional carers.

This chapter focuses on the experiences of lay and professional caregivers with regard to caring for people with advanced liver disease. The first part of this chapter outlines the experiences and perceptions of patients' lay carers with regard to caring for someone with liver disease at home, and the support they received in this respect. The second part of the chapter describes the views of professionals on the challenges they encountered in providing care for people with advanced liver disease, and their thoughts on how existing services for this patient group might be improved. Finally, there follows a discussion of these findings in relation to the empirical and theoretical literature.

9.1 Lay carer experience

As described in Section 4.1.2, 11 lay carers nominated by patient participants agreed to be interviewed. The majority of them were family members living with the patient. When given the option, most patient and carer participants chose to be interviewed together, to which I agreed respecting their wishes. The data obtained gives an indication of some of the challenges faced by carers in the context of advanced liver disease.

9.1.1 Being a carer

Given patients' complex support needs described in the previous chapters, it is not surprising that carers felt the strain of their role.

I'm emotional. You know, it gets you down sometimes. (*Cora, wife of Martin, 77, ALD (NAFLD), second interview*)

This strain was felt not just by them, but gradually affected wider family networks.

It's not just about us, it's about the wider family circle as well. They start to worry more and there's more contact and more stress and it almost pulls people together a little bit for the wrong reason. So you do tend to see people more often because they worry and they stress. (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

It does put a strain on the whole family trying to support him and trying to say the right thing and knowing when to butt out and when to try and help. (*Tamsin, partner of Ben, 35, ALD, second interview*)

A variety of concerns played on carers' minds, causing feelings of uncertainty. Some worried about being faced with challenges beyond their capabilities.

I worry about him in case he falls or, ken, has an accident, and I can't help him, ken? I couldn't lift Fraser up. (*Betty, neighbour of Fraser, 60, ALD, first interview*)

Michael was mindful of the fact that he needed to make plans in preparation for Kate's likely deterioration, but felt uncertain about the best course of action.

I'm now thinking about my work side of things that if Kate's well, great, if she's not will we need care packages? Financially, how does that affect me? When does it affect me? (...) Do I work for another few months? Do I need to stop and sell and move into something smaller and so I can afford to get support? What finances are out there? (*Michael, husband of Kate, 41, cryptogenic LD, first interview*)

At least in relation to patients' physical condition, however, carers felt reassured by the medical care provided.

The only worry is on the, his own mental side of things, his mood and trying to move on in his life, trying to live with it and accept what's happened and try and move forward. I'm more worried in that way, but with regard to the liver and seeing the liver doctors, I'm not really worried about that because I'm sure they'll flag up if anything's amiss. (*Tamsin, partner of Ben, 35, ALD, first interview*)

Coping strategies

Carers' coping strategies were motivated by the practical and emotional complexity of their caregiving role.

I have to give my boss reminders every so often that I've got to go and do this today, or, you know, there's an appointment coming up. Even then there's a daily challenge of feeling guilty about not being at work and the impact that it has on them. And the challenge of not being with Kate because of the impact that it has on her. And in between that the impact it has on me because I'm worried about work and I'm worried about Kate. (laughs) So it's quite a hard one to manage, but you just have to get on with it and deal with it and try and bury your feelings towards both sides of it. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

Carers' coping approaches by and large mirrored those of patients. They similarly dealt with the uncertainty of the situation by adopting a stance of simply 'getting on with it' and hoping for the best.

I'm not a defeatist. I don't crack up. I might have a few tears sometimes with worry, but at the end of the day you've just got to face it and get on with it and hope for the best. (*Julie, mother of Rebecca, 37, ALD, first interview*)

At the same time, carers were conscious of protecting patients from further burden by withholding their own concerns from them.

Not that I can't talk to Kate but it does make you a little bit, you got to suck it up yourself a little bit and try and get on with it, because Kate doesn't want to hear negative thoughts and attitudes which is quite right, but then equally I've still got to deal with it. I've still got to deal with the stuff that chucks around your head, you know? (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

Being able to go to work served as an escape from the strains of the caring role.

I think having [son] and my job keeps me going. (*Tamsin, partner of Ben, 35, ALD, first interview*)

BK: What helps you cope? Are you spiritual at all?

Cora: I'm working.

BK: You're working? Ok.

C: I work. I was gonna give up my job eh, and Martin said no and the family said, "No, keep working as long as you can."

(*Cora, wife of Martin, 77, ALD (NAFLD), second interview*)

In contrast, some felt that having to go to work only added to their worries.

You don't particularly want to be there because you'd rather be with Kate to see her through things and look after her. And you're kind of torn between financially having to go and work to earn money to pay the mortgage versus looking after Kate. (*Michael, husband of Kate, 41, cryptogenic LD, first interview*)

Similar to patient participants, faith did not seem to generally be part of carers' coping repertoire. However, Michael felt that his challenging circumstances had reawakened a sense of spirituality in him.

I haven't been to church for a very long time. But interestingly, and I'm sure it happens to many, many people who go through illnesses like this, is you do start to question, you know, stuff like that. (...) In fact the last 2 or 3 times we've been down, I've gone into the church in the hospital just for even just 10 minutes. It's peaceful, it's quiet. I don't know if it is a particularly religious thing or not, but it just lets you gather your own thoughts sometimes. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

Putting the patient first

Carers' lives were increasingly centred around patients' needs.

I'm never out. If I'm on my way out I go up to the shop there to get a paper and that, or down to the clinic. It's only down the street. But I'm never, otherwise I'm never out. (*Jeff, husband of Polly, 68, NAFLD, first interview*)

By necessity, this meant carers curbing their own activities, isolating them from their own social networks.

Any spare time that I have I tend to be with Kate as opposed to possibly going and doing my own thing, going to the gym or spending time with friends or whatever. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

At the same time, a number of carers' accounts suggested that guilt played a key role in this context.

I tend not to organise that much because I feel guilty saying, "I've got this," and "I've got that." (*Tamsin, partner of Ben, 35, ALD, second interview*)

9.1.2 Carers' support needs

When asked directly about their own support needs, many carer participants were uncertain what kind of help would benefit them.

BK: What sort of thing do you think might help you?

Jeff: I don't know. I just, I've been a person I've never relied on nobody. (*Jeff, husband of Polly, 68, NAFLD, bereavement interview*)

Given the unpredictability of the illness and its progression, carers felt similarly uncertain about the support they might need to help them care for the patient in the future.

If she becomes confused and such like, then would I have the skill and ability to deal with that? 'I don't know' is the answer, I may need some help with that. If her liver deteriorates and her muscles start to waste more she may need some personal care and stuff like that, you know, possibly. (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

Indeed, Cora greatly appreciated receiving professional help at home when Martin's condition deteriorated to a point where she no longer felt able to cope.

Now that I've got the four carers in a day I feel I can cope now. (...) Especially when he was, when he couldn't walk, you know, when his mobility was going downhill, I was beginning to panic. And with him falling...It was one week, remember, you fell three times and I thought 'oh', you know? It was getting to me. And anyway, that's why we got the help, the extra help. So it's great now, it really is. I've no problems now. (*Cora, wife of Martin, 77, ALD (NAFLD), second interview*)

Others wished for psychological and emotional support to help clarify their thoughts and worries.

Just sometimes you want be able to offload. "Am I thinking the right things? Am I being too negative? Is what I'm going through and thinking the right thing to be thinking or not? Are the facts actually 100% right or wrong?" (...) Do I make it worse than what it is?" (*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

While carers felt uncertain about their own support needs, psychological support needs were evident throughout their experience. Practical support needs emerged with patients' increasing debility.

9.1.3 Support provision for carers

Most carer participants had little involvement with, or direct support from, the patients' care professionals. There were two reasons for this. Some patients, like Donald and Thomas, chose not to involve their lay carer in medical appointments to protect them from upsetting information. Therefore, while many professionals considered it part of their role to support carers, they did not always get the opportunity to engage with them. However, some carers benefitted from being able to access the patient's GP by virtue of being registered with the same practice.

I specifically asked to have [the same GP] the last time I was there for my appointment because I knew he knew Kate's circumstances, and when I brought it up he understood and knew what was going on and stuff, so that was quite nice to be able to get that facility. (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

Sue: [GP] has been absolutely brilliant for Rebecca and well, for my side as well.

I: So is she somebody that you kind of confide in as well?

S: Aye.

(*Sue, sister of Rebecca, 37, ALD, third interview*)

At the same time, professionals appeared to give little proactive attention to the specific needs of their liver patients' lay carers. Indeed, Fraser's consultant admitted that supporting carers was not a priority within his remit.

I particularly see my remit as the patient rather than the carers and the family I suppose, if we want to put it as harshly as that. My priority is obviously them, while informing the carers and so on, but it's not something I've got a lot of experience or knowledge about to be honest. (*Consultant of Fraser, 60, ALD*)

Information-sharing between professionals and carers also appeared to rely predominantly on the initiative of carers themselves.

Sometimes when she's in the hospital they don't tell me much, you know, you've got to ask. (*Julie, mother of Rebecca, 37, ALD, first interview*)

Not everybody felt confident enough to approach staff with their questions, however.

The staff are very nice. It's just my own personal shyness and (...) just feeling that I don't want to cause any hassles. (*Tamsin, partner of Ben, 35, ALD, first interview*)

Some made a point to attend clinic appointments in order to keep abreast of developments for themselves.

If I wasn't there I wouldn't know a lot of stuff. (*Michael, husband of Kate, 41, cryptogenic LD, third interview*)

Despite being relatively neglected within the current care provision, caregivers felt assured that they would receive support from care professionals if they requested it.

BK: Do the professionals at any point ever sort of take you to the side and give you attention particularly?

Michael: No. I've never asked for it though to be fair and (...) I'm quite sure if I asked for that I'm quite sure they would do that for me.

(*Michael, husband of Kate, 41, cryptogenic LD, second interview*)

The accounts proffered by lay carers described an experience marked by strain, uncertainty and isolation. There was little contact with care professionals and carers' support needs were largely neglected. Psychological and information needs were evident throughout the carer experience. Carers' practical support needs increased over time in line with patients' deteriorating condition, as did their social isolation.

9.2 Professional carer experience

This section describes the experiences relayed by the 11 case-linked healthcare professionals interviewed for this study. To recap, this group comprised of eight general practitioners, one consultant hepatologist, one hospital-based alcohol liaison nurse and one community palliative care nurse. It presents their views on caring for people with advanced liver disease, the challenges of doing so, and their perspectives on potential areas for improvement.

9.2.1 Providing professional care in advanced liver disease

GPs professed to having little expertise in treating people with advanced liver disease.

I'm talking from a position of a sort of lack of knowledge really, you know? (*GP of Donald, 74, HCC (NAFLD)*)

Having never really dealt with somebody with non-alcoholic fatty liver disease to this, at this stage, I found it difficult to be absolutely certain about what I was telling them being true or not. (*GP of Thomas, 75, NAFLD*)

Not everybody considered having a limited understanding of advanced liver disease a problem, however.

If you ask me if I know enough about the subject probably not, but I think being a GP is often about knowing a man who can, so I think that's fair enough. (*GP of Kate, 41, cryptogenic LD*)

Nevertheless, there was evidence that a lack of confidence in one's expertise on the subject could hinder GPs' decision-making regarding a patient's care.

He did have quite marked ascites and I'm never quite sure exactly what the feeling is about draining ascites (...) and once or twice I thought maybe I should phone the liver people and see if they'll take him in and drain off his ascites, and it never happened for some reason, you know? (*GP of Donald, 74, HCC (NAFLD)*)

Perhaps as a result of GPs' limited disease-specific knowledge, they largely opted for a reactive approach to caring for their patients with advanced liver disease.

Kate hasn't come to me saying, "Look, I feel that this is..." you know, "I'm unsupported." I think had she done that, you know, had she felt that there wasn't enough going on I might have started to, sort of looked into it a bit more, but things in her case have been ok so I haven't really taken it any further. (*GP of Kate, 41, cryptogenic LD*)

Some also felt that patient care was affected by factors outwith their control, such as a patient's willingness to engage with services.

GP: I think that some needs are unmet, but often they are unmet because of circumstances outwith the medical control.

BK: Right. Could you give an example?

GP: Just people who drink. We know that their liver disease is going to be terminal and they really just don't want help.

(*GP of Carol, 45, ALD*)

Likewise, the quality of hospital care was perceived as a potential barrier to effective patient care.

Far more people just refuse to go into hospital or self-discharge, and it's just their hospital experience is more negative than it used to be. (...) It does affect our ability to look after patients. If somebody with end-stage liver disease has to lie in a corridor bed for 4 hours, it massively affects my ability to persuade them into hospital the next time. (*GP of Rebecca, 37, ALD*)

There was also consensus that the relatively younger age of liver patients could make their care more difficult.

Quite often folk are at the stage really where you think this person would be better in some sort of supported care, sheltered accommodation type scenario, but often they are too young for that. (*GP of Rebecca, 37, ALD*)

9.2.2 Interprofessional communication

Services commonly communicated about patients through written correspondence.

This process, however, could be slow and the information related of poor quality.

Still seems to be the case, you know, of getting a clinic letter dictated and then it gets put in a pile to be signed at some point and then seen again at some other point and then sent to us. You know, a few weeks later we will get a letter by which time the patient may have been in ill umpteen times or back into hospital. (*GP of Sarah, 38, ALD (HCV)*)

I didn't feel as if we were really given enough information from the liver unit. It was, it, lots of the discharge summaries were just quite short and to the point and quite factual, there wasn't really much made about what discussions had been made with Thomas and his family about follow-up. (*GP of Thomas, 75, NAFLD*)

Despite these frustrations, many GPs considered their relations with hospital-based colleagues good and did not feel the need for more direct contact. Few GPs had discussed their patient's care directly with the patient's named consultant, but those that had had valued the exchange.

I think all of us are aware that consultants tend to be busy and that can then make bleeping and ringing difficult. (...) So consultants who are willing to respond on email is really good, and [Rebecca's consultant] does. (*GP of Rebecca, 37, ALD*)

While GPs expressed their dissatisfaction at the limited information shared by secondary care professionals, there was an acknowledgement that primary care communication could also be improved upon. Martin's GP recognised that he had most likely failed to communicate Martin's anticipatory care plan to his hospital team, thus contributing to him ultimately dying in hospital instead of his home.

BK: Would they have been aware that things had been put in place in the community?
GP: It would have been in his discharge summary but no, I didn't formally let them know and maybe the family didn't either, and then obviously that is where the conflict comes from. So yes, possibly a fault of ours as well for just not communicating well with them. (*GP of Martin, 77, ALD (NAFLD)*)

There was agreement across the care professions that communication relating to patients with advanced liver disease was poorer than that in oncology.

Compared with maybe someone going through kind of the palliative stages of cancer I thought the communication really didn't stack up to how good communication we would probably get from, say, oncology or the palliative care services or something like that. (*GP of Thomas, 75, NAFLD*)

There never seemed to be a consistent person who I would speak to from [the hospital]. When he was admitted he would go to the same ward I think, and I would speak to different people, but there was never anyone who seemed to take ownership from the [hospital] who would be a link. (...) Oncologists, we all get letters from all the time. We will have phone calls with them and discuss patients with them. But there was no one for Martin. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

9.2.3 Advance care planning

Identifying the appropriate time

The majority of professionals interviewed had not conducted anticipatory care conversations with their liver patients. The unpredictable nature of the condition made it difficult for them to pinpoint the appropriate time at which to raise this issue.

In non-cancer cases it can be much more challenging, you know, just judging when to have that discussion and...because it would be very easy for the patient just to be left with the feeling that, you know, 'there's nothing you can do for me' whereas there's obviously a lot that you can do for someone and the palliative management just can't cure them. (*GP of Donald, 74, HCC (NAFLD)*)

Carol's GP had not yet had an anticipatory discussion with her when she died, as she did not have a 'terminal' phase.

[Carol] was very positive and she didn't think, she actually thought she would just get better, so it didn't seem appropriate to talk about that because she wasn't unwell, she was still functioning. (...) At no time did I feel that she was imminently about to die and needing to embark on any terminal care. (*GP of Carol, 45, ALD*)

Fraser's consultant raised this topic with patients only when they had clearly entered their dying phase, by which point conversations could be difficult to conduct.

BK: What would normally be your sort of trigger point for initiating those sort of conversations?

Consultant: Well, I think when you are clear people are dying, you know? I mean [Fraser] was still coming in for a period of time, getting drained, going back home again, you know, mobile, eating, drinking, whatever, independent, but (...) there's a different group of patients who come in and they're very jaundiced or have encephalopathy or, you know, liver failure effectively. The difficulty is with these patients is that often by the time that you know they are dying they're often too confused or unwell or sleepy to actually have that conversation so, you know, it can be difficult.

(*Consultant of Fraser, 60, ALD*)

GPs also seemed reluctant to discuss details about patients' likely disease progression and outlook. When specialists decided to withdraw futile treatment for Donald, it paved the way for his GP to discuss the likely turn of events, if not actual timescales.

Well it happened very early and it meant we could have that discussion quite early and it was a very general discussion about, you know, sort of obviously trying to avoid sort of likely timescales and things. (...) There was an early awareness of the likely outcome, just not a sort of discussion around timescales or, you know, how things were likely to progress. (*GP of Donald, 74, HCC (NAFLD)*)

Likewise, even after Kate had been included on the liver transplant register, her GP avoided discussing end-of-life needs and options with her.

No, I haven't actually. And I suppose that just reflects the fact that, you know, she's remained upbeat. (...) I would wait until she brought it up rather than kind of get into that, you know? (*GP of Kate, 41, cryptogenic LD*)

Reflecting on Thomas' experience of living and dying with advanced liver disease, his GP regretted not having responded to his palliative care needs in good time.

Three or four months prior we should maybe have been thinking of involving the palliative care team for a bit more support at home when he wasn't in the hospital, but that didn't happen. Well, it didn't happen partly maybe because of my uncertainty as to exactly what his prognosis was, and it didn't happen because the secondary care team didn't appear to flag that up as something they thought was then appropriate, which I suppose kind of maybe left me a little bit uneasy in the fact that we probably hadn't taken a holistic approach as we would normally do with someone in the palliative stages of their condition. (*GP of Thomas, 75, NAFLD*)

Advance care planning at the primary/secondary care interface

Another reason for the absence of timely advance care planning conversations appeared to be GPs' reluctance to contradict secondary care specialists.

Maybe I should have written a letter to the consultant to say, "Look, we're treating this as palliative care, is it possible to step back on the thing?" But somehow you don't feel that it's your place to say that, because they're under the care of a liver specialist who obviously knows what they're doing. (*GP of Martin, 77, ALD (NAFLD)*)

He'd been told on the ward that there was a hope or expectation that he would survive two, three, four years. And in those circumstances as a GP it is quite difficult to then say, "Look, we should be filling out a DNAR form," and all that, and it's quite difficult for us to do that because it sends out the signal that we don't really believe what the hospital are saying. (*GP of Thomas, 75, NAFLD*)

At the same time, GPs wished conversations about progression and prognosis to be conducted by their specialist colleagues.

I think when it was apparent that this was really him entering, being in liver failure due to it, I don't know whether he was, he did sit down with the consultant and it was just never fully taken on board and he...but I felt somebody in a very senior position should have sat down a little bit sooner with him and his family and had a full discussion about really where we were going with this. (*GP of Thomas, 75, NAFLD*)

The continued routine treatments provided by the hospital also put GPs off considering patients' palliative care needs.

BK: Was there any particular point or event from where you felt that she needed a palliative care approach or maybe put her on the register?

GP: No, not particularly, you know? I mean they kept transfusing her, so they didn't say, "Stop transfusing her." So, you know?

(GP of Polly, 68, NAFLD)

Indeed, specialists' tendency to continue routine treatments until the final stages of the illness caused GPs uncertainty about the status of their patient's condition.

We have this increasing number of patients that are towards the end of their lives that are basically being managed by us, almost solely by us. They're still being admitted to hospital for acute things. It's confusing for them and it's confusing for us about what's happening. *(GP of Martin, 77, ALD (NAFLD))*

Martin was one of only two participants who had benefitted from palliative care arrangements through his GP and community palliative care services. However, this process too was hampered by his continued routine admissions for paracentesis.

He was a tricky one to keep in the community because he had so many taps done. He'd be constantly in and out of hospital, and it was really difficult to coordinate our meetings around that. *(Community palliative care nurse of Martin, 77, ALD (NAFLD))*

Despite having arrangements in place to allow Martin to die at home according to his wishes, he died in hospital following an acute admission. Martin's GP felt that the habit of turning to the hospital for support may have interfered with the care plans put in place for him.

All these plans for things he had to die peacefully at home, actually when he had the [gastrointestinal] bleed instead of maybe calling the GP and maybe getting things sorted he probably felt it was ok for him to go to hospital, because he was so used to it. So that's why he ended up in hospital. *(GP of Martin, 77, ALD (NAFLD))*

Advance care planning then was largely absent in this sample. This omission was a result of uncertainty related to several factors: appropriate timing, GPs' lack of expertise, poor interprofessional communication, distribution of care responsibility across settings, and the ongoing active and curative care provided by hospitals.

9.2.4 Improving service provision in advanced liver disease

There was consensus among all the professionals interviewed that palliative care for people with advanced liver disease deserved improved attention and effort.

Chronic liver disease is a perfectly valid reason for, you know, patients being managed in a palliative way and having access to, you know, the range of palliative care services that anyone else would. (*GP of Donald, 74, HCC (NAFLD)*)

However, the uncertainty inherent in the disease made the provision of palliative care in this patient group especially challenging. There was also a recognition that the right pathways for effective palliative care in liver disease had yet to be defined.

It's different with cancer patients because (...) the cancer pathways are pretty clear. Actually, when you decide to go on a palliative care pathway it's pretty good for that, the hospital tend to step back a little bit and we kind of take over. It works quite well. But with other palliative care diseases it's very difficult. (*GP of Martin, 77, ALD (NAFLD)*)

There isn't an obvious, you know, move-on place from us, you know? There are patients that we are confident are not going to get better and get out of hospital, but because we've known them so well and there isn't really another facility, you know, hospice facility we've occasionally been able to access but not frequently, they tend to die with us, (...) but it is an acute busy medical hospital and it's not always the best place for these people to be looked after. (*Consultant of Fraser, 60, ALD*)

In contrast, the community palliative care nurse felt that the ability to support people with advanced liver disease already existed, but that the importance of palliative care provision for these patients needed to be championed by liver specialists themselves.

I think we have the ability to meet the needs, but I think we need to spread the word a bit more and encourage people. (...) You need someone who is an expert at liver disease that says, "These patients have a need that maybe we could meet better when they get to this point, so let's try and do it and let's make it big for us." (...) There is a big drive in heart failure, we get lots of heart failure patients. Big campaign between British Heart Foundation and Marie Curie, who are working together to try and promote that for people with heart failure. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

There were various areas in which professionals appreciated support or improvement. Most commonly, they wished for more access to specialist advice.

GPs do need some, you know, guaranteed access to specialists. (...) Some specialties do have sort of email-based advice lines which, you know, are helpful (...) even if you're just needing some advice about medication changes, symptom control, or whether or not you do need to refer somebody back or not, whether or not they need to be admitted, you know, in a planned way. So no, just an on-going commitment to providing access to specialist advice is always important. (*GP of Donald, 74, HCC (NAFLD)*)

Several GPs mentioned the usefulness of specialist nurses available in other specialities, although they were uncertain whether these in fact already existed in the realm of advanced liver disease.

I think they probably, well, might have this for hepatitis C anyway, but you know for sort of liver disease in general whether, you know, nurse specialists - having said that they probably do exist and maybe we don't use them as much as we should do - are quite a good link with services (...) you know, a kind of linking service like that with a nurse specialist (...) that GPs can access freely just for advice. (*GP of Sarah, 38, ALD (HCV)*)

Some wished for disease-specific education to build knowledge and confidence.

I think specific education would be really good, yes, because as I said, I do have two other Hep C patients which are on my caseload and we would have patients who would have liver disease and other co-morbidity. So I think something more formal would be beneficial, yes. I don't know how they would run that, or who would run that, but yes. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

Professionals also called for improved interprofessional communication.

It's always good to have, you know, more written information, perhaps we could have had a bit more of that. (*GP of Kate, 41, cryptogenic LD*)

In particular, GPs wanted to be informed of what long-term plans their specialist colleagues were pursuing in relation to a patient's care.

I guess it's just a more consistent approach in the hospital with regards to the management of this patient. We like to be kept informed about what's happening, which they did. But we actually weren't informed of the plan, which they often don't do, you know, the ongoing plan. (*GP of Martin, 77, ALD (NAFLD)*)

There was also a wish for guidance from liver specialists regarding when to initiate palliative care conversations with their patients.

Really a little bit more communication would be all that would be necessary, and giving us an idea of what they think is to be the prognosis and kind of we respond to these kind of triggers, and yes we'll, we're more than happy to take on lots of the palliative type discussions and maybe it will be more appropriate from us rather than the liver unit, but it's really getting the triggers to say that that's really what we should be speaking about now. (*GP of Thomas, 75, NAFLD*)

The community palliative care nurse felt that having a direct link to hospital-based staff would help improve the overall care of the mutual patient.

Communication between treating teams, I think that was a big one for me, not having a link directly with the hospital. It's always a bit tricky, you're all trying to work towards the same goal and keep someone happy and comfortable and that, but if the chain is broken and people aren't communicating you are effectively stuffed. (*Community palliative care nurse of Martin, 77, ALD (NAFLD)*)

Finally, some felt that having referral pathways directly to the liver unit would promote better patient care.

If you could directly admit to the ward and say, “You will know where you’re going, you are going up to ward X, that’s the ward you know, I can get you straight in there,” then it helps in getting people acute care when they need it. (*GP of Rebecca, 37, ALD*)

Professionals across healthcare settings were thus in agreement on the need for enhanced service provision for people living and dying with advanced liver disease. The interviews identified several areas for improvement at both strategic and operational levels that provide a starting point for further discussion in this respect.

9.3 Discussion of findings

While both participant groups profiled in this chapter - lay and professional carers - constituted small study samples, the inclusion of their views benefitted this study in two ways. Firstly, it provided a helpful means by which to illuminate and contextualise the experiences and perceptions relayed by patient participants. Secondly, the views of carers served to highlight several personal and structural challenges in providing appropriate care to people with advanced liver disease. Similar to patients, uncertainty also emerged as a key feature in carers’ accounts.

9.3.1 The experiences and support needs of lay carers

The multi-dimensional sources of uncertainty pervading patients’ illness experiences as described in Chapters 5 to 8 were also the foundation of many carers’ anxieties. Caregivers worried about their capacity to provide appropriate care, especially in the event of the patient’s deterioration. Only patients’ ongoing medical care constituted a source of reassurance in this respect. A lack of information and concerns about one’s caring ability have been noted as considerable sources of stress for carers of people on the liver transplant list (Miyazaki et al., 2010). Having to manage the needs and distress of the wider family circle in addition those of the patient and their own augmented this strain, as did the financial burden caused by patients’ inability to work and carers needing to curtail their own professional activities to accommodate their caring role. Their own employment provided both respite and additional strain.

The considerable financial and emotional burden experienced by carers of people with cirrhosis has been highlighted previously (Bajaj et al., 2011, Roth et al., 2000).

Given their similarly uncertain experience, carers were found to display similar coping approaches to those used by patients. They generally chose to simply 'get on with it' and, like patients, consciously concealed their personal concerns so as to not add to the illness burden. Carers also prioritised patients' needs to the detriment of their own. This was in part driven by feelings of guilt, and contributed to carers becoming increasingly socially isolated themselves. At the same time, the data highlighted that carers were also acutely aware of the stigmatising reputation of liver disease. Therefore, while only hinted at in some carer interviews, it is conceivable that their choosing to forego social contact may in part have been driven by an uncertainty surrounding people's reactions in relation to their circumstances.

The support and behaviour of those close to the ill person play a critical role in preserving, bolstering or discrediting that person's sense of self (Charmaz, 1983). Evidently, the stress related to the patient's illness left carers overwhelmed and in need of support themselves. This would have challenged their ability to provide patients with the necessary positive validation of their self-image. Biographical disruption was also witnessed among carers in this sample, forcing them to reconsider professional activities and future plans in order to accommodate the needs of the patient (Bury, 1982).

Carers' support needs

Carers felt uncertain about their own support needs. They did, however, speak of a possible need for practical support in the event of patients' condition deteriorating. This finding echoes previous research, which found carers prioritising improving the needs of the patient over self-care (Lasker, Sogolow and Sharim, 2005). Increased practical support needs were indeed indicated in some carers' accounts where the patient's physical condition had declined to a point where they were unable to manage without professional help.

The need for psychological support for caregivers was evident throughout the study. Uncertainty regarding the nature and potential development of the patient's condition made some wish for opportunities to validate their thoughts and feelings on the matter. This need was reinforced by the fact that carers opted to withhold their concerns from the patient, and had progressively fewer opportunities to confide in members of their wider social network. The need for psychological support for lay caregivers receives backing from research in primary biliary cirrhosis. A content analysis of an online message board used by PBC patients' friends and family showed that socio-emotional topics dominated their discussions (Lasker, Sogolow and Sharim, 2005).

Similar to patients, the range of concerns impacting on the lay carer experience points towards the utility of a multi-disciplinary approach to their support, encompassing clinical, psychological and social work expertise. Targeted professional support for caregivers was found to be lacking in this study. They relied on their own initiative to keep abreast of developments affecting the patient and to seek support for themselves. However, doing so could be hampered by a lack of confidence, which also related to the stigma associated with the condition. The discontinuity of patient's care highlighted in Chapter 7 further impedes carers' access to information (Guy, 2006). Being left out of the loop thus fosters their uncertainty and isolation. Carers have previously reported struggling to obtain information regarding the patient's condition and prognosis (Rogers, Karlsen and Addington-Hall, 2000). Carers in this study sought to, where possible, attend medical appointments with the patient in order to gain access to information they would otherwise be unlikely to receive. However, caregivers' information needs differ from those of patients and increasingly so as the illness progresses (Parker et al., 2007), and so this route is consequently unlikely to satisfy their demands.

Good palliative care must include targeted support for patients' lay carers (Hudson, 2013, Shipman et al., 2008). Healthcare professionals in this study acknowledged the importance of supporting caregivers, but considered the patient their primary concern. This view is understandable given the focus of clinical training, the time constraints of medical consultations, and their limited opportunities to engage with

carers as alluded to earlier. However, carers' anxieties may negatively affect their ability to provide appropriate support to the patient. Reducing their feelings of uncertainty and promoting better coping is thus key to achieving improved outcomes for both patient and carer. While carers in this study felt assured that they would be given help if they asked for it, there is a need to proactively improve access to information and support that is tailored to their specific requirements. A few carers expressed their appreciation for being able to access support from the patient's GP through being registered at the same general practice. Families commonly being registered with the same GP supports palliative care provision in the community (Barclay, 2001), and highlights again the value of enhancing the role of primary care in supporting people with advanced liver disease and those that care for them.

9.3.2 The views of professional carers

This sample was predominantly made up of general practitioners. Many issues raised therefore pertain to the particular circumstances and challenges that exist within the primary care setting. While this limits conclusions in this area, the repeated indications over previous chapters that liver patients and their families would be well served by improvements in their community-based care render the views of GPs of particular value to this study.

Providing professional care in advanced liver disease

GPs acknowledged their limited knowledge of advanced liver disease. This finding confirms the perceptions of patient participants described in Chapter 7. The findings in Chapter 7 add to this by showing that patients saw little value in seeking GP support for their liver disease-related care, thereby further reducing GPs' opportunities to engage with this patient group. These factors combined to leave GPs feeling uncertain when faced with a patient in the advanced stages of liver disease, and impacted on their confidence to proactively support them.

Caring for people with advanced liver disease was considered a complex endeavour, and one that was affected by patients' willingness to engage with care providers. The quality of interprofessional communication between care settings added to these challenges. A typically slow information transfer by written correspondence proved

unhelpful given the erratic pathway of the disease and the frequency of patients' admissions. In addition, the information shared by specialists on a patient's ongoing care was often considered too limited. These factors left primary care practitioners uncertain as to the appropriate and timely follow-up of these patients in the community. The lack of continuity in patients' care identified in Chapter 7 further contributed to these communication difficulties, and proved a particular barrier to the effective involvement of allied care providers. Having direct email contact with a liver specialist proved a great help for the few GPs who had this facility. All agreed that interprofessional communication compared poorly with that in other specialties.

Poor communication and information exchange as well as inequities between different conditions have previously been noted as barriers to effective palliative care provision (McIlfatrick, 2007). Inadequate interprofessional communication affects patients' perceptions of the quality of their care (Cotterell, 2008). Moreover, recent research with people with advanced liver disease suggests that improved interprofessional communication may be a determining factor in reducing mortality and healthcare costs in this population (Morando et al., 2013). The development of electronic registers shared between primary and secondary care constitute an important step towards improving the speed of information transmission. This must be considered key to facilitating appropriate and timely care for people with uncertain and erratic illness pathways like that in advanced liver disease.

Advance care planning

Advance care planning in Scotland entails the development of a written anticipatory plan, which details a patient's care goals and preferences in the event of a sudden deterioration in their condition (Murray, Sheikh and Thomas, 2006). Holistic, goal-focused patient care is increasingly recognised as preferable over disease-focused care, and is especially appropriate for those with limited life expectancy (Reuben and Tinetti, 2012). Failing to discuss patients' goals means that their most appropriate care is not assured (McGrew, 2001). Advance planning also reduces the burden on the patient's family as it avoids the need to make important decisions close to the patient's death, which is typically a fraught and upsetting time (Wright et al., 2007). Advance planning is especially relevant in conditions like advanced liver disease

where patients may experience episodes of mental incapacity, and is one reason why this process should be undertaken early in the illness trajectory (Larson and Curtis, 2006). Discussions in this regard should be conducted by a trusted, knowledgeable professional over multiple sessions and in response to a patient's willingness to contemplate the topic (Conroy et al., 2009, Hjelmfors et al., 2014).

Advance care planning was largely absent in this study. A number of factors contributed to this situation. Professionals felt uncertain about the appropriate timing in the face of an unpredictable illness trajectory, a common observation in organ failure research (Barclay et al., 2011, Exley et al., 2005, Pinnock et al., 2011). Professionals differ in their interpretation of the term 'end of life' and the time period it signifies (Shipman et al., 2008). GPs' uncertainty in this respect, alongside a lack of confidence on account of their limited liver expertise, further contributed to their reluctance to address advance care planning. Similarly, specialists tended to only recognise the need to plan for a patient's forthcoming death when patients were often already too unwell to engage in such conversations.

Delaying care planning conversations until a terminal phase, as typically occurs in cancer, reduces the opportunities for patients to ascertain important information and engage in decision-making and preparation in a timely manner. It also has financial implications, as in the UK those with a terminal prognosis are entitled to claim special disability benefits which would help alleviate some of their and their carers' concerns, especially with regard to the potential costs involved in accessing additional care or aids. Current UK guidance on end-of-life care includes in its definition of 'approaching the end of life' any patient with an advanced, progressive, incurable condition (General Medical Council, 2010). It has been suggested that in advanced liver disease the onset of signs of decompensated disease such as ascites or gastrointestinal bleeding present clear trigger points for end-of-life discussions (McGrew, 2001). Generalists may benefit from using prognostic indicators to aid their decision making (Boyd and Murray, 2010, Shipman et al., 2008). More generic clinical markers to trigger conversations have also been suggested (Quill, 2000).

As well as their uncertainties relating to limited expertise and appropriate timing, GPs in this study were reluctant to initiate advance care planning discussions for fear of taking away patients' hope and causing anxiety. Consequently, they opted to wait for patients to raise questions in this regard, an expectation which was subject to several barriers identified earlier in Section 8.5.1. While GPs' sentiments are understandable, they are inconsistent with the ethical principle of autonomy guiding professional conduct in healthcare, whereby patients have a right to informed decision-making about their care (see Section 3.8). Their concerns also appear misplaced. A systematic review of interventions in palliative and end-of-life care indicates that advance care planning does not harm patients and may even be experienced as positive (Lorenz et al., 2008). This notion has support from research into advance care planning in kidney disease (Davison and Simpson, 2006).

GPs' relative lack of knowledge and confidence also played out in a reluctance to discuss details for fear of contradicting their specialist colleagues. Moreover, there was uncertainty about whose role it was to initiate advance care conversations. In this sample, GPs felt that the primary responsibility for this lay with specialists, with appropriate follow-up provided in the primary care setting. A similar sentiment has been expressed by specialist nurses in heart failure. Despite feeling competent in conducting end-of-life discussions with patients, they consider it the responsibility of specialists to do so and do not wish to interfere with this process (Hjelmfors et al., 2014). Current advance care planning guidance in the UK suggests that such conversations should be undertaken by a trustworthy individual who is knowledgeable about the condition (Conroy et al., 2009). Given their limitations in this respect, this view confirms the perceptions of GPs in this study that specialists are best placed to take the lead. The earlier finding that patients tend to trust the opinions of specialists over those of their GPs lends further support in this respect. However, the discontinuity in patient care described in Chapter 7 indicates that current care arrangements for people with advanced liver disease do not lend themselves to facilitating an appropriate, patient-centred advance care planning process in the secondary care setting. This issue demands further consideration.

Patients' continued hospital treatments, even if actually palliative in nature such as blood transfusions, further contributed to GPs' uncertainty as to the appropriateness and timing of undertaking advance planning with them. They also challenged the management of patients' care in the community. Ceasing ongoing curative care only when death is deemed certain can be too late for initiating care planning as patients may already be too unwell. Conversely, attending to patients' holistic supportive and palliative care needs early and in parallel with disease-focused treatment can serve to counter overzealous treatment and promote quality of life in advanced, progressive disease (Murray, 2009). Indeed, while medical care tends to focus on prolonging life, managing a patient's end of life satisfactorily should be considered a success in itself (Wright et al., 2007). It is thus imperative that patients are given the opportunity to engage with their future care planning early and frequently throughout their illness.

However, as seen in the present study, even where an existing anticipatory care plan existed its implementation was not guaranteed. The data suggests that this process may have been hampered by poor information exchange between professionals and care settings. Individual and organisational factors were also indicated. The multi-factorial challenges in implementing advance care planning decisions have been noted (Rhee, Zwar and Kemp, 2013). Issues relating to poor information transfer should be eradicated with the introduction of shared electronic patient registers.

Professionals' views on improving care provision

All interviewees agreed on the need to enhance service provision for people living and dying with advanced liver disease. There was a consensus that it was easier to organise appropriate supportive and palliative for people with cancer than for those with non-malignant disease, a view also reported elsewhere (Exley et al., 2005). Professionals expressed a need for a clear, structured care pathway similar to those in operation in cancer care. An agreed, shared care plan would provide a framework and consistency in these patients' ongoing care. The data indicates that this is especially important in relation to clarifying care roles and responsibilities across the primary and secondary care interface, and in particular regarding the management of ongoing acute care in parallel with supportive and palliative care.

There was uncertainty as to the options for referral as patients deteriorated. Patients whose care needs became too complex to manage at home were challenging to place, as their relatively younger age meant that they often did not qualify for services such as nursing home care. Likewise, hospices were considered to have limited capacity to support this patient group. Furthermore, the uncertainty regarding a clear terminal phase in liver disease makes it difficult to determine the most appropriate time at which to make a hospice referral. Interestingly, contrary to the perceptions of the other professionals, the community-based palliative care nurse participating in this study felt that community palliative care services had the capacity to attend to the needs of this patient group. It has previously been argued that palliative care can be easily accommodated within standard liver disease management (Sanchez and Talwalkar, 2006). As such, what is required is not an introduction of new structures, but a renaming and rethinking of current practice, with the most critical factor that palliative care is recognised as a valid and important concept by all professionals involved (Dunn, 2006). This notion ties in with professionals in this study arguing for the need to more vociferously champion the care needs of people with advanced liver disease similar to recent endeavours seen in other conditions, so as to prompt their consideration and active promotion across all care settings.

Improving interprofessional communication and support was considered a key factor in enhancing current care provision in advanced liver disease. With modern healthcare operating in a context of scarce resources, this may be most usefully achieved by way of developing better electronic information transfer. However, the data suggest that there is also a need to improve on the quality and detail of the information shared. Interviewees spoke highly of the availability of specialist nurses in other conditions and advocated for a similar role in advanced liver disease. Specialist nurses offered not only a consistent point of contact, but also a source of disease-specific expertise when aspects of care or referral criteria required clarification. Some professionals also highlighted an interest in more disease-specific education, although the value of developing specialist knowledge in generalists is disputed (Wagner, Austin and Von Korff, 1996).

One model of care that may inform suitable care pathways in advanced liver disease is that currently used in heart failure (Volk et al., 2010). For the last decade, community-based heart failure nurses have been operating in the UK. Some of these also engage in palliative care support. While heart failure patients' medical management remains mainly located within secondary care, this care model facilitates their holistic, long-term care in the primary care setting. This approach also promotes better continuity of all aspects of care, which is likely to impact positively on the extent of uncertainty experienced by patients, lay carers and professionals alike. However, despite its virtues, a model of care that serves patients with various long-term conditions including multi-morbidity would be more advantageous and should be investigated.

9.4 Concluding remarks

Uncertainty also constituted a core feature in the experiences and perceptions of both lay and professional carers. In many ways this uncertainty related to the same issues already noted in patient participants' accounts such as the uncertain and unpredictable nature of the condition, poor disease-specific understanding, inadequate information-sharing and communication, and confusing, discontinuous care arrangements. As such, all stakeholders in advanced liver disease emerged as operating in a context of uncertainty, ambiguity, complexity and lack of direction.

The accounts of lay carers evidenced their need for information and psychological support at all stages of the patient's illness, while their practical support needs and social isolation increased over time. The needs of lay carers of people with advanced liver disease are relatively neglected and should be given more focused attention. This is not only an important undertaking in its own right, but is also key to achieving a good end-of-life experience for patients and a better bereavement experience in due course. The disruptive impact of chronic illness on carer biographies is currently lacking in the literature and may warrant further attention.

The professional care of people with advanced liver disease compared poorly to that of other conditions. Both service provision and advance care planning were impeded by the complexities of the condition itself as well as existing care and

communication structures. GPs emerged as a currently disempowered group and should be enabled to play a greater role in attending to the holistic care needs of these patients. At the same time, the data suggest that advance care planning conversations in advanced liver disease might be best initiated by specialists.

Several areas for service improvement were put forward. At a strategic level, professionals advocated for clearly defined care pathways and a more vocal promotion of the needs of this patient group. At an operational level, improved interprofessional communication and support to strengthen current practice, refinement of procedural pathways and referral criteria, and access to disease-specific education were indicated. Learning should be sought from recent service improvements in comparable conditions such as heart failure.

The final chapter to follow will integrate and reflect on all the results presented in the previous chapters as well as on the study methodology employed, and put forward recommendations for future practice and research.

Chapter 10: Integration of findings, implications and recommendations

This study sought to broaden our understanding of the experience of living and dying with advanced liver disease. Current trends in some of the risk factors associated with chronic liver disease as well as diminishing donor organ resources indicate a dramatic increase in the number of patients living and dying with the disease in the coming years. At the same time, supportive and palliative care provision is traditionally focused on the needs of cancer patients and ill-equipped to effectively support those with non-malignant illnesses. Consequently, this study was informed by the following research objectives:

1. To explore the dynamic experiences, priorities and support needs of people with advanced liver disease, their lay carers and key health or social care professionals, and in particular their physical, psychosocial, existential and information needs in the last year of life.
2. To explore the use of health, social and voluntary sector services by this group and the extent to which existing services are perceived to meet their needs.
3. To contribute to the methodological knowledge base regarding the effectiveness of longitudinal, multi-perspective qualitative methods in end-of-life research.

The first section of this chapter will integrate the empirical study findings presented in Chapters 5 to 9 in order to address research objectives 1 and 2. It will also respond to objective 3 by setting out my learning and conclusions regarding the effectiveness of using longitudinal, multi-perspective qualitative research methods with this patient group. This section will be followed by a consideration of the limitations of the study, and a discussion of its contribution to theory and policy. Finally, I draw on the present findings to put forward recommendations for current care practices as well as potential directions for research.

10.1 Integration of study findings

10.1.1 Research objective 1: Experiences, priorities and support needs

Pervasive, enduring, multi-dimensional uncertainty defined and unified the experiences of all stakeholders in this study – patients, lay carers and professionals. Uncertainty is characterised by ambiguity, vagueness, unpredictability and incomplete information (Mishel, 1981), which were at the heart of each of their accounts through time. This uncertainty was multi-dimensional and individually complex. Medical sources of uncertainty were experienced across all three groups and related to the vague and unpredictable nature of the disease, individuals' limited understanding of the condition and its likely progression, poor communication, and discontinuity of care. Patients and lay carers were additionally faced with several personal and social sources of uncertainty (Brashers et al., 2003), which further unsettled their illness experience. Moreover, these factors combined to result in a loss of patients' sense of self. Finally, uncertainty not only defined all stakeholders' experiences, but was a key mediating factor in relation to their perceptions and actions in the context of the illness.

Insofar as can be deduced given the small size and make-up of the study sample, the physical and psychological experience of living with advanced liver disease was largely uniform across patients regardless of the underlying cause of their liver disease. Some exceptions to the shared patient experience of advanced liver disease must be noted, however. Age differences were indicated in relation to patients' coping, the biographical disruption of their lives as well as their considerations of death and dying. Moreover, the ability of ALD patients to influence their illness and thus overall illness experience through sustained sobriety must be recognised. This saw some embark on a divergent trajectory to that of their counterparts, with subsequent differences in their physical, psychosocial and existential experiences. Furthermore, those with ALD were additionally burdened with the challenge of achieving abstinence, a matter which dominated their psychological illness experience and necessitated additional support.

All participants considered fatigue and ascites the most disruptive physical complications related to their illness. Motor co-ordination and mobility were also widespread. Surprisingly, pain as an enduring feature of their advanced illness was universally absent. Patients' physical experience generally evidenced a slow but steady decline over time, which was interspersed with relatively short-lived routine exacerbations such as ascites, and more dramatic acute exacerbations such as gastrointestinal bleeding, both of which required inpatient treatment.

Advanced liver disease constituted a prominent feature in the lives of those affected. The effects of their debilitating complications as well as a significant treatment burden marked by an extensive and complex medication regimen, medical check-ups, blood tests and regular hospital admissions kept their condition firmly in the foreground. Even where the condition was controlled by a modification of harmful behaviour, the challenge of maintaining sobriety served as a daily reminder of the damage done and the uncertainty of sudden deterioration remained. This meant that patients were unable to normalise and adapt to their illness over time.

The experiences of debilitating physical complications and pervasive uncertainty combined to produce a substantial and enduring psychological burden throughout. This burden was added to by a social experience marked by stigma, the changing quality of familiar relationships, and increasing social isolation. The psychosocial experiences of patients and their lay carers were comparable, and perhaps as a result they were seen to employ similar coping strategies which principally focused on managing the ubiquitous uncertainty of their situation. There was little explicit consideration of existential issues by patients and lay carers, although their turmoil in this respect was evident throughout. Issues around death and dying were beset with further ambiguity and uncertainty and as a result were largely disregarded by patients, carers and professionals alike.

There was overlap as well as variance regarding the information and support needs of patients, carers and professionals. Lack of information and the quality of communication were concerns raised by all three groups. Patients generally desired more information about their condition and its likely progression, guidance and

opportunities to take on more self-care, and increased recognition and support of their psychological needs. Lay carers similarly showed a need for increased information-sharing and psychological support, but also required advice and reassurance regarding the care they provided for patients. There was a lack of awareness across all groups with regard to available support resources for these patients. Patients and carers were particularly interested in opportunities to engage with peers. GPs, who made up the majority of the professionals interviewed, prioritised better access to specialist knowledge regarding symptom management in advanced liver disease. This disease-focused concern suggests a lack of recognition of the widespread multi-dimensional impact of the condition on the lives of those affected, and evidently conflicts with patients' and carers' priorities. Psychosocial support in particular is key to the successful management of uncertainty and thus better coping, but was notably absent for both patients and carers.

The opinions and experiences of professionals, regardless of discipline, converged on most matters relating to the care of this patient group. Their perceptions were mainly informed by the complexities inherent in the condition and the care structures they operated in, which rendered care provision for these patients a challenge in all settings. GPs in particular emerged as a currently disempowered group on account of a lack of exposure, confidence and competence relating to caring for people with advanced liver disease and uncertainty regarding their role in these patients' care.

10.1.2 Research objective 2: The use and fit of services

Both inpatient and outpatient care of patients with advanced liver disease was primarily located in the hospital setting. Primary care services were undervalued as a source of support by patients and consequently underused. However, patients' lack of appreciation of the holistic care role of the general practitioner must be considered alongside GPs' apparent preoccupation with disease management as mentioned above, and highlights a need for better delineation of the GP role in the care of these patients. Involvement of allied professions was generally absent. Palliative care involvement relied on a recognition that a patient may be imminently dying and in light of all three parties' uncertainty in this respect was rarely facilitated.

Patients and carers were generally in agreement that the overall medical care provided was satisfactory. However, they also described sources of dissatisfaction and uncertainty in this respect. Patients perceived GPs as lacking confidence and competence in relation to liver disease, and this impression was confirmed by the GPs in this study. All three participant groups felt that the overall quality of care was affected by limited and poor quality information exchange between care professionals as well as between clinicians, patients and carers. Inadequate as well as contradictory information from different care sources, limited confidence in some of their care providers, a lack of continuity and consistency of care, and inadequate management of their psychosocial needs constituted key sources of uncertainty for both patients and carers.

This study highlights the experience of advanced liver disease as one in which care needs constantly alternate between acute care and chronic illness management. In general, patient care was symptom-focused, episodic and reactive, both in primary and in secondary care settings, and was consequently poorly aligned with the chronic multi-dimensional needs of this patient group. While patients' acute medical care appeared largely adequately organised, the data suggest that their ongoing care in the community was lacking structure and dedicated focus. In addition, the relatively younger age of this patient population is incompatible with current systems for long-term care provision.

Professionals considered the care of people with advanced liver disease to compare unfavourably with that of other conditions, and in particular towards the end of life. The complex nature of the condition itself as well as current structures of care and interprofessional communication impeded their care provision overall, but in particular the process of advance care planning. Uncertainty was again a key barrier in this respect and resulted in a notable absence of prognostic and end-of-life conversations, and consequently an absence of anticipatory care in this patient group. At the same time, professionals were vocal about the current inadequacy of palliative care provision in advanced liver disease. Patients and carers did not generally comment on their expectations in this respect, possibly on account of their general lack of appreciation for the life-limiting nature of their condition. With all except one

of those patients who passed away during the study dying in hospital, palliative care activity was thus limited to their final days in that setting.

The concerns of patients and carers regarding service improvements related mainly to improved communication and information-sharing as well as relational continuity of care. In contrast, professionals put forward several areas for improvement at both practice and policy levels. Recommendations in relation to current care provision based on the findings of this study will be presented in Section 10.4.1.

10.1.3 Research objective 3: Using longitudinal, multi-perspective methodology in end-of-life research

Employing a qualitative longitudinal, multi-perspective research design proved a challenging but ultimately successful means by which to meet the objectives of this study. My reflections on the study design and conduct in general were outlined in Chapter 4 and indicate a number of learning points for future research. In this section, I respond to research objective 3 by specifically considering the benefits and challenges of using a longitudinal, multi-perspective approach in the context of advanced liver disease.

Exploring multiple perspectives

In this study, I sought the views of patients, their lay carers and case-linked care professionals. Doing so generated context-rich accounts of how living with advanced liver disease is experienced, negotiated and interpreted by different stakeholders. The addition of the professional perspective on their patient's care, but also on that of people with advanced liver disease more generally, served to link the complex and varied needs of patients and lay carers with the current challenges and barriers faced by professionals in the care setting. Inferences and recommendations drawn from the data may therefore be argued to be more meaningful, as they are grounded within key stakeholders' realities.

Conducting single versus joint interviews

Most patient/carer dyads in this study were interviewed in pairs. In a number of cases, however, circumstances meant that some of their interviews were conducted individually or that one person was out of the room for a portion of an interview.

This afforded an opportunity to reflect upon the difference in accounts proffered by each party when interviewed singly or jointly. It was for example evident that individuals in joint interviews were more likely to hold back thoughts and emotions in order to protect the other's feelings. While this might be looked upon as a limitation, I also noted real benefits in conducting joint interviews. Given these patients' advanced disease status, they commonly suffered from poor mental focus due to fatigue, a mild encephalopathic episode, or periods of relapse into alcohol. Consequently, their memory of events was prone to inconsistency, distortion or vagueness. Having their carer present on those occasions allowed them to jog patients' memory or clarify their accounts, thus benefitting the overall data generation.

One disadvantage to joint interviewing was that it proved difficult for the carer's story to be heard. Even when asked directly about their own needs or challenges, many carers quickly reverted the focus of the conversation back to the patient. It may be that they were reluctant to reveal their own struggles with the situation in front of the patient so as to not cause feelings of hurt, guilt or worry. It may also be the case that they did not feel that their own difficulties warranted any real attention in the face of the great challenges faced by the person they cared for. As a result, there is comparatively less information on the carer experience in advanced liver disease that can be gleaned from the data.

Observations of data development over time

A longitudinal study design allows the consideration of changes in participants' narratives (Lewis, 2007). There was clear evidence of the longitudinal format of the study prompting changes in participants' stories over time. In particular, being able to build a relationship over time, and to revisit and explore issues with participants on multiple occasions was key to the development of both the content and depth of narratives over time. Some of the generic benefits in this respect have already been described in Section 4.4.2. As explained in Section 3.5.1, interviews were based on a loose guide to facilitate maximum flexibility in letting participants raise issues of key importance to them. Faced with the unexpected absence of mentions of pain in patients' accounts for example, the longitudinal study format allowed the interview

guide to evolve accordingly, so that pain was incorporated for targeted follow-up in future interviews. As pain typically constitutes a core feature in advanced chronic disease, the longitudinal design thus facilitated the capture of what must be considered key information in the realm of end-of-life research.

Considerations of timescales

This research followed patient and carer participants over 12 months, which proved to be an appropriate timespan for investigating the needs and experiences of this study population. It allowed observation of the lived experience of advanced liver disease over a number of months in most cases, but included some participants who died during the study period. This allowed an insight into events leading up to their death, supplemented by retrospective accounts of their final days from lay and professional carers where available. The average length of study enrolment for patient participants was 7.7 months (see Table 3, Section 4.3, for details of each patient's length of enrolment).

As indicated earlier, follow-up interviews were scheduled flexibly to capture key changes in the trajectory while being sensitive to the needs of the participant at that time. This approach proved successful with this study population. Advanced liver disease is characterised by an erratic illness progression. Taking a flexible approach to timing follow-up interviews ensured that I was able to respond to critical events or changes in participants' trajectories. It also meant that I was able to gain multiple interviews from some participants I would have otherwise lost to a sudden death had I followed a fixed schedule.

Where distinct trigger events in a patient's illness experience were lacking, it proved difficult to determine when to schedule the next interview. The unpredictability in non-malignant disease means it is not always the sickest patients who die first (Fox et al., 1999). Leaving longer intervals between follow-up interviews could therefore mean a loss of participants to the study. However, choosing relatively short intervals could result in a lack of discernible progression or change in participants' stories, thus limiting the insight gained from their experiences. Moreover, determining a time point for follow-up did not guarantee that interview taking place. Interviews had to

be rearranged repeatedly owing to fluctuations in patients' condition and frequent readmissions to hospital; delays of several weeks were common and added to the challenges of conducting this research.

Building and maintaining relationships

Keeping in touch with participants was critical to the successful conduct of this study. I kept in touch with participants through bi-monthly telephone calls. This proved time-consuming, as participants would be frequently too unwell to chat or unavailable due to a return to hospital. However, I did benefit from my regular attendance at the liver unit in this respect. I often saw participants as they returned to the ward and was thus able to keep abreast of changes in their condition or circumstances that way. In future research, where participants may be recruited from settings other than a liver ward and catching up with them at times of admission is therefore not an option, it may be beneficial to arrange monthly telephone conversations to increase the opportunities to keep engaged with participants.

Regular contact with participants was not only key to keeping informed about their developments. As alluded to earlier, it also served to foster a closer relationship with participants, which positively impacted on the range and quality of data obtained. Participants also shared a lot of additional information during these interim conversations, both about their situation and their feelings about it. This supplementary information often informed the content of follow-up interviews, allowing me to clarify and explore some of these issues later within a formal interview context. As indicated earlier, it also provided useful additional insights about those participants who I had only been able to interview once or twice, thus adding to my observations of developments over time. As I had not sought ethical approval to record my telephone conversations with participants, I kept thorough field notes of their content and my thoughts and reactions, which provided important contextual information during data analysis. Future studies should consider seeking ethical approval to request participants' permission to record these interim telephone conversations in order to benefit from the additional pool of data.

Developing closer relationships with participants over time was also found to have an unexpected positive effect on recruitment. Some nominated lay carers had initially declined participation in the study. However, increased familiarity with me through my telephone calls fostered an interest in the study, and they subsequently agreed to take part. Interviewing participants at home also contributed positively here as carers would not only meet me in person, but also see for themselves what the interview process entailed.

Being able to build rapport with participants over time also facilitated the opportunity to request bereavement interviews with lay carers some months after the patient's passing. Recruiting bereaved carers for a one-off interview having had no prior contact with that person is likely to be challenging. The longitudinal aspect of this study made this aspect more amenable to investigation as I was able to benefit from the relationships that had developed. Nevertheless, not all lay carers I approached about a bereavement interview were willing to participate.

It is conceivable that the opportunity to nurture relationships also aided participant retention. As stated earlier, no participant opted to leave the study despite some rather upsetting interview encounters. On the contrary, several participants were positively eager for their follow-up interviews to come around. Thus, I believe that the longitudinal design of the study promoted participant retention. At the same time, developing close relationship with participants raised some ethical challenges at times. An example of such a scenario which presented during the course of the study is given in Appendix 7.

Data management and analysis

Keeping in touch with participants on a regular, continuous basis as well as the random and often spontaneous scheduling of interviews made keeping up with interview transcription and preparation for follow-up interviews challenging. Preparing for subsequent interviews required a thorough familiarisation with and broad, preliminary analysis of the content of the previous conversation. This was therefore a considerable and time-pressured task, which had to be undertaken alongside continuous recruitment and data collection. Receiving support with

interview transcription provided considerable relief in this respect. Any future study of similar design would benefit from outsourcing interview transcription to allow the researcher to remain responsive to the study's organisational needs.

10.2 Limitations of this study

While this study offers advancement on our understanding in the realm of advanced liver disease, it is subject to a number of restrictions. Section 1.4 set out the scope of this study, the boundaries of which must be borne in mind. In addition, the following limitations need to be recognised:

- This study was conducted in a specific locality of the UK, with all patient participants receiving their liver-related care from the same regional hospital. Their experiences and services may therefore differ from other localities in this country and elsewhere.
- Similarly, patient participants were recruited from a specialist inpatient liver unit. Their care experiences may therefore differ from those of patients accessing general hospitals, which are likely to have comparatively limited disease-specific expertise.
- In the absence of a single agreed definition of advanced or end-stage liver disease, the study's inclusion criteria constitute an empirical measure that may not be representative of this patient population at large. Relatedly, while ascites is the most common physical complication in cirrhosis of the liver affecting nearly 60% of patients with compensated liver disease within 10 years of diagnosis (Ginés et al., 1987), not everyone will develop this complication.
- Identification of potential research participants by different ward staff is likely to have introduced selection bias as well as an element of gatekeeping, for example excluding people considered too poorly to participate. (However, this particular issue was circumvented by the longitudinal study format, which meant that some patient participants deteriorated during their study involvement, thus enabling the stories of those nearing death to be heard too.)

- Self-selection bias among patient participants must be recognised. For example, patients who cope with their illness through denial or disavowal are less likely to engage with research (Thorne and Paterson, 2000). Similarly, as described in Section 5.4, some patients did not feel able to comment on their condition on account of their poor understanding and thus declined participation.
- Carers' bereavement interviews and professionals' accounts of caring for patient participants and their families were likely to be subject to recall bias.
- There were a number of voices missing in the study sample, namely:
 - Ethnic minorities and those on the margins (e.g. the homeless or severely socially deprived). Both groups are traditionally hard to reach and were poorly represented on the hospital ward I recruited from. Moreover, while chronic liver disease is widespread in the homeless population (Davis et al., 2011), the specific complexities of this group as well as the use of a longitudinal format requiring long-term study involvement mean that homeless participants were not pursued.
 - Secondary care professionals and allied professions. Asking patient participants to nominate the professionals to be interviewed meant that there was no control over the type of professions that would be represented, resulting in a sample that was dominated by GPs.

10.3 What this study contributes

In responding to the study's research objectives in Section 10.1, this study contributes new insights to both empirical and methodological understanding. The study adds to what is currently only limited understanding of the experience and associated challenges of living, dying and caring in advanced liver disease. It also contributes to the emergent knowledge base with regard to the effectiveness of qualitative longitudinal, multi-perspective methods in end-of-life research by testing and describing their utility in the realm of advanced liver disease. In this section I will delineate the specific contributions this study makes to existing understanding and theory, and suggest some implications for policy.

10.3.1 Contribution to theory

A small number of previous studies noted the presence of uncertainty in the experiences of people with advanced liver disease. However, this study contributes new understanding in this regard by bringing to the fore an enduring dominance and influence of uncertainty across all dimensions, throughout the illness trajectory, and affecting patients, carers and professionals alike. Furthermore, in this study the challenges of life with advanced liver disease were regularly managed by an appraisal of uncertainty as an opportunity. This finding not only confirms the notion that uncertainty is not in itself a negative phenomenon (Mishel, 1990), but also that reducing uncertainty is not necessarily a person's desired goal (Brashers et al., 2000). This finding then has implications for the way in which uncertainty in chronic illness is understood and addressed in clinical encounters and therapeutic interventions.

Similar to other chronic illness, biographical disruption emerged as a key phenomenon in relation to the psychological experience of both patients and lay carers (Bury, 1982). The study contributes to current understanding of this concept by describing for the first time its characteristics in the context of advanced liver disease. Importantly, this includes the observation that biographical disruption does not always constitute a negative event. To my knowledge this notion, and the experience of biographical disruption in the carer experience, have not previously been noted in the literature. These findings thus suggest further exploration to establish their potential for extending our understanding of this core theoretical concept in chronic illness research.

The study contributed some interesting new insights regarding patients' physical experience of advanced liver disease specifically. Challenges with motor coordination and mobility have so far only had scant acknowledgement in the liver literature, but emerged here as a pervasive and key concern. The observation that pain was only of marginal concern among this group contrasts several previous studies in advanced liver disease and indeed much of the wider chronic illness literature. Both these findings warrant further investigation. The study also highlights the pervasiveness and complexity of the complications experienced, and the relative

impact of specific problems on the quality of life of patients and their families. Moreover, the qualitative longitudinal format of this research offered new insight into the severity as well as the unpredictable and enduring nature of some of these complications, for example fatigue. Overall then, the findings of this study have served to extend current understanding of the nature and relative importance of some of the physical challenges of advanced liver disease, and draw attention to some areas requiring follow-up.

While the current literature in advanced liver disease acknowledges that care provision for this patient group is in urgent need of improvement, there is scant research on patients' own views in this regard. This study thus adds insight by eliciting participants' experiences and perceptions of their care service use. The shortcomings in care provision identified in the present study may support current endeavours to identify pathways for improved patient care across settings and care providers in advanced liver disease (Mellinger and Volk, 2013, Morando et al., 2013, Wigg et al., 2013).

The finding that dying in hospital may not necessarily be inappropriate for people with advanced liver disease challenges current debates regarding preferred place of death and the appropriateness of the acute hospital setting as a provider of end-of-life care. This finding therefore has implications for current theoretical discourse and research in this respect, and may stimulate considerations regarding current care practices in this setting.

Finally, the benefits and challenges of employing a qualitative longitudinal, multi-perspective study design in the context of advanced liver disease were outlined in Section 10.1.3, and echo those highlighted in other conditions (Kendall et al., 2009). The overall success of this methodology in meeting the aims of this study as well as the specific learning its use generated with regard to this particular patient group therefore adds to the methodological knowledge base in end-of-life research, and may usefully inform the design and conduct of future research in the realm of advanced liver disease.

10.3.2 Contribution to policy

Scotland's national action plan, *Living and Dying Well*, sets out the government's vision for a patient-centred approach to delivering equitable, consistent and timely palliative and end-of-life care for all patients (Scottish Government, 2008b). Many of this study's findings can be seen to reflect and reinforce its priorities, in particular with respect to the early identification of patients who may need palliative care, advance care planning, interprofessional information transfer, and the provision of palliative and end-of-life care in acute hospitals (NHS Scotland and Scottish Partnership for Palliative Care, 2012). What is more, the study provides a patient and carer perspective on how care may be usefully improved, and as such offers valuable insights to the new national strategic plan for palliative care currently under development in Scotland.

The study shows that the aspiration of ensuring equitable access to palliative care regardless of condition is still unmet as far as liver disease is concerned. Access requires the timely identification of a person's palliative care needs. The Gold Standards Framework, a widely used UK programme designed to support community-based healthcare teams with the identification, organisation and quality of care of those requiring palliative care with any life-limiting condition, provides guidance in a number of non-malignant conditions but omits liver disease (Royal College of Practitioners, 2006). The recently validated SPICT (Supportive and Palliative Care Indicators Tool) includes a section to aid the identification of liver patients coming towards the end of their lives (Highet et al., 2013), but it is too early to gauge its long-term impact in this regard.

I am thus in agreement with a recent suggestion that focus should be shifted from asking, "Is it time yet?" to "What are the problems and who can manage them?" (Johnson and Gadoud, 2011, p41). This study contributes insight in this regard. Importantly, this insight is provided through the views and experiences of those whose welfare sits at the heart of this challenge. The study also highlights the need to clearly define integrated care structures for people with advanced liver disease so as to better support professionals in providing appropriate care to these patients.

Furthermore, options need to be explored that allow for the specific characteristics of this group, particularly their younger age and propensity to die unexpectedly in hospital, to be better accommodated in the current management of care provision. A recent English publication has made first inroads in this respect by applying the care pathway put forward in the national End-of-Life Care Strategy (Department of Health, 2008) to the needs of those with advanced liver disease (Kendrick, 2013). However, further development is needed.

As advocated by the professionals interviewed, there is a need to champion the considerable needs of this currently disadvantaged patient group in order that their supportive and palliative care needs may be better recognised and more effectively addressed. Given the increasing numbers of these patients and thus relative urgency of this endeavour, this should ideally involve a joint effort between government, health boards and third sector services as successfully employed in other conditions such as cancer or, more recently, heart failure. Some progress to this effect was recently made in England with first steps towards the formulation of a national strategy for liver disease, but similar efforts are still lacking in Scotland.

Finally, more realistic societal discourse about liver disease must be promoted. This relates to greater awareness-raising regarding its insidious nature and a dispelling of myths in order to reduce its stigmatising reputation. This will not only improve the psychological burden of those living with the disease, but may also facilitate better access to funding and support for liver-related projects. This endeavour will benefit from engagement with the media. Lessons may be learned from HIV/AIDS, a similarly stigmatised condition, which has over time been successful in promoting better public understanding.

10.4 Recommendations for practice and research

10.4.1 Developing practice

The data indicate a number of areas for practice development regarding the care of this patient group and their families. These relate to improvements with respect to communication, support provision, care arrangements and professional training.

Communication

- Explaining the insidious nature of liver disease and its potential consequences when discussing raised liver function tests may help some individuals better appreciate the potential dangers of continued harmful behaviours such as excessive alcohol consumption, and prevent their deterioration towards liver failure.
- Given the impact of patients' poor understanding of their condition on their overall illness experience, there is a need to better educate patients and their families about the typical features and progression of advanced liver disease. While this should be done early on in the illness trajectory, opportunities to ask questions and clarify issues should be provided and encouraged at all times. In this context, the data showed that it is important that professionals are mindful of the language they use in order to avoid causing confusion and anxiety. In light of the time pressures of medical consultations, this process may be aided by a better use of information booklets and other sources of complementary information.
- Relatedly, professionals should be upfront with patients about the uncertain aspects of their illness, such as likely prognosis and pathway. Being aware of inevitable uncertainty is important and empowering in itself and is likely to aid coping. Acknowledging the enduring uncertainties related to the condition may also facilitate the introduction of advance care planning conversations by encouraging the idea of 'hoping for the best, but preparing for the worst'.
- Professionals should seek to remedy patients' uncertainties regarding the legitimacy of their complications by educating them about common problems they may encounter, in particular fatigue and difficulties with motor co-ordination and mobility.
- Professionals should assess patients' perceptions of uncertainty (whether they appraise issues as negative or positive) to make information and interventions complementary to the person's approach and thus support their coping.

- Given the erratic and rapid trajectory of advanced liver disease, professionals should alert patients and their families to the danger of eventual deterioration at or around the time of diagnosis, and especially where this coincides with the first signs of decompensation.
- Optimal pathways and quality of interprofessional communication must be defined and enhanced to enable improved integration of care between primary and secondary care settings. Avenues for better electronic data sharing should be explored. Communication pathways also need to be clarified and strengthened with community-based palliative care services and other allied professions in order that their involvement can be maximised. As communication in cancer care was deemed effective by all professionals interviewed, lessons should be learned with regard to its set-up and management.
- Specialists should ensure that they keep primary care colleagues abreast of their long-term care plans for a patient. They should also advise when key conversations, e.g. about prognosis or end-of-life care wishes, have been conducted with the patient and specifically when a palliative care approach is indicated, so that this can be followed up in the community.

Support provision

- The data confirms that chronic illness requires extensive amounts of ‘work’ by the patient relating to illness, everyday life and biography (Corbin and Strauss, 1985). In light of these findings, professionals should take account of the effort of work required by patients to master everyday life, and focus support on extending their opportunities to remain engaged in life for as long as possible.
- There is a need for emotionally neutral sources of support, and in particular peer support. In light of the finding that both patients and professionals lack awareness of available resources, current sources of support in the care setting, community and online should be identified, coordinated and mobilised so that they can be promoted accordingly. Gaps in provision should be noted and ways of addressing these within existing resources considered. Given patients’

problems with accessing services due to their condition, support provision should be flexible in both set-up and delivery.

- Relatedly, the information and support needs of lay carers should be given focused attention so as to promote their own wellbeing as well as that of the person they care for.
- ALD patient participants' preoccupation with the need to overcome their alcohol dependency highlights the need for professionals to remain alert to the wider psychosocial context of these patients' lives, as their liver disease may not in fact be their priority concern. (This of course also holds true for those with other causes of liver disease and may similarly relate to other health issues, especially in older patients.) This shows the reality of living with advanced liver disease to be complex and reminds of the importance of holistic, goal-centred patient care.

Care arrangements

- Given the study data indicating their significant impact on psychosocial wellbeing, patients should be routinely assessed for potential difficulties with motor co-ordination and mobility and offered support where appropriate.
- Being able to self-manage one's illness is an important means of managing uncertainty. Patients' expressed willingness to share responsibility of their condition and take on self-care activity should be considered and incorporated into treatment plans. Similar to the importance of acknowledging the enduring uncertain aspects of the condition as stated earlier, patients should be made aware of any absence of self-care opportunities beyond those already instructed in order to alleviate their anxieties in this regard.
- Care in advanced liver disease is currently focused on acute care and symptom management. This study highlights the importance of addressing patients' and lay carers' abundant psychosocial needs. The widespread low mood identified and its impact on patients' quality of life suggests a need for their routine psychological assessment, and in particular those with underlying alcohol

problems. At the most basic level, ascertaining and attending to patients' uncertainties with respect to their illness experience will go some way towards improving their psychological wellbeing.

- Much of everyday chronic illness management takes place in the person's home. However, this study suggests that primary care and community-based services in this patient group are currently underused. Opportunities for developing and promoting these resources should be explored. Moreover, the manifold barriers to patients attending services identified in this study indicate that rather than relying on patient-initiated contact, practice-led approaches to follow-up care such as telephone calls, telemedicine, or offering an appointment or home visit might be beneficial (Wagner, Austin and Von Korff, 1996, Wasson et al., 1992).
- Relatedly, there is a need to promote the holistic nature of general practitioner care in order to encourage uptake of this apparently undervalued resource. Although patients seemed put off by GPs' lack of liver expertise, there may be little value in developing their specialist knowledge (Wagner, Austin and Von Korff, 1996). Moreover, the data suggest that patients consider their medical care satisfactory, but lack focused support of their psychosocial and existential needs. GPs and primary care services more generally should develop and promote their strengths in this regard and thus foster a more patient-centred approach to the care management of this patient group.
- Cognitive behavioural therapy has been suggested as a potential way of alleviating fatigue and assisting patients to better deal with the associated emotional distress (Blackburn et al., 2007, O'Carroll, 2011). This avenue should be explored further, and highlights the potential for increased involvement of psychologists in the care of these patients. Engagement of psychologists in end-of-life care is currently underdeveloped, but can provide a wealth of important support (British Psychological Society, 2008).
- Patients' frequent admissions for routine interventions such as paracentesis were found to interfere with advance care planning and their care in the community.

Resources and opportunities should be explored in which such routine procedures may be undertaken in the community setting, for example at hospices. Good practice in this respect exists, but relevant literature is scarce. Lessons learned should be shared to inform developments in this regard.

- We should seek to learn from care pathways used in diseases with similar uncertain characteristics and pathways such as heart failure. In particular, the utility of a generic specialist liver nurse role should be considered as professionals deemed this a success in other conditions. This role might take the lead in managing and co-ordinating patients' ongoing care in the community, which would address a number of the shortcomings identified in their care provision, with additional support from palliative care specialists.

Professional training

- The choice of language used by some professionals was indicated in patients feeling stigmatised, confused and uncertain. Professionals should be reminded, and their confidence and skills developed, with regard to effective doctor-patient communication. This includes the importance of ascertaining patient understanding and encouraging patients to ask questions or raise sensitive issues. The data identified several reasons why patients are unlikely to do so off their own back, so professionals should take the lead in this respect while remaining sensitive to patients' needs and willingness to engage with certain topics, especially with regard to advance care planning and end-of-life conversations.
- As highlighted earlier, professionals need to educate themselves about the resources available to support patients and their families in the community and promote these.
- Given the number of hospital deaths in this patient group, there is a need to ensure that acute hospital staff are upskilled to recognise imminent death and discuss related matters effectively and sensitively with patients and their families.

10.4.2 Directions for future research

The findings of this study point towards a number of potential directions for research, both with respect to improving the care of people with advanced liver disease and some of the theoretical concepts that served to explain the data. In addition to research which addresses some of this study's limitations outlined in Section 10.2, key areas to consider are as follows:

- The findings of this study and wealth of potential avenues for service improvement identified in the previous section point towards the utility of follow-on focus group research with key stakeholders such as clinicians, managers and commissioners. This research would aim to discuss the study findings and suggested service improvements, determine priorities for action, and identify ways of trialling and evaluating these.
- Uncertainty emerged as the key mediating factor in the psychological wellbeing of patient and lay carers. This suggests value in utilising uncertainty theory to inform and trial both educational and behavioural interventions to alleviate the effects of uncertainty by addressing some of its modifiable sources. Alternatively, interventions may be trialled which seek to support patients to better accept and live with the enduring uncertainty inherent in their condition. All of these constitute potentially important non-pharmacological approaches to ameliorating the pervasive low mood common in this patient group.
- The study sample included only one participant with primary liver cancer (HCC), who also died shortly after his first interview. As such, there was little insight into how these patients' illness experience compares with that of people with other liver disease causes. However, there was a suggestion that support provision in particular may differ due to the 'cancer label'. The literature also indicates potential differences in the way HCC is experienced (Fan and Eiser, 2012). There may thus be value in investigating more closely the similarities and differences in the illness experience of those with HCC and other causes of liver disease in order to identify potentially divergent care and support needs.

- This study similarly intimates that the illness pathway of those with ALD may in some respects bear close similarities to that of cancer patients. Also, ALD patients' experiences were similar to those with other aetiologies in many respects, but differed in some important ways. This may indicate divergent needs from the wider liver disease population and is thus an area which warrants further investigation.
- There is a dearth of research into how people perceive and rationalise the idea of potentially facing liver transplantation in the future. Better understanding in this realm may be beneficial as it was found to create much anxiety among patient participants, and especially those with ALD.
- The data raises questions regarding preferred place of death and the appropriateness of the acute hospital setting as a provider of end-of-life care in advanced liver disease. How the hospital setting is viewed as a potential place of death by this patient group would benefit from dedicated research. This would add to the wider academic and clinical discourse on achieving a 'good death', and help to inform end-of-life care arrangements which are appropriate and sensitive to the specific needs and wishes of people with advanced liver disease.
- Focused research relating to the concept of biographical disruption is indicated, both with regard to its potential to instigate positive change and the disruptive impact of chronic illness on carer biographies (Bury, 1982). Research in this realm will serve to clarify and develop further this seminal concept in the chronic illness literature and research.

10.5 Final statement

Since embarking on this research in 2010, recognition has grown with respect to the neglected care needs of people with advanced liver disease, and research activity in this realm is gaining momentum. This study found the current support and care for this patient group to be lacking from diagnosis to bereavement. Ubiquitous uncertainty made advance care planning especially important, yet impeded that very process.

This study is timely and important, adding the neglected perspectives of patients and carers, and informing how their quality of life and care in their last months of life may be improved. It evidences an urgent need to ensure that people living and dying with advanced liver disease and their families benefit from appropriate, equitable and timely access to supportive and palliative care.

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Appendices

Appendix 1: Publication: Co-authored editorial

Appendix 2: Publication: First-authored, peer-reviewed literature review

Appendix 3: Interview topic guides

Appendix 4: Overview of patient demographics and hospital admissions

Appendix 5: Notifications of ethics and R&D approval

Appendix 6: Example of evolving coding structure

Appendix 7: Example of an ethical challenge in qualitative longitudinal research

Appendix 1: Publication: Co-authored editorial

BOYD, K., KIMBELL, B., MURRAY, S. & IREDALE, J. 2012. Living and dying well with end-stage liver disease: time for palliative care? *Hepatology*, 55, 1650-1651.

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Living and Dying Well With End-Stage Liver Disease: Time for Palliative Care?

Chronic liver disease is a major cause of mortality worldwide. In the United Kingdom, liver deaths have been increasing for 30 years and currently constitute the fifth highest cause of mortality.^{1,2} Liver transplantation is only available to a subset of patients who meet strict criteria. Comorbidities and limited donor organ supplies mean that many patients will not receive a graft and so stand to benefit from palliative care delivered in parallel with optimal disease-focused treatment.³

End-stage liver disease (ESLD) is the final decompensation phase in the liver trajectory. It is characterized by episodic, acute exacerbations, often requiring hospitalization. Life-threatening complications, such as variceal hemorrhage or hepatoma, combine with multiple debilitating symptoms, including ascites, extreme fatigue, pruritus, and cachexia.⁴ Patients may also experience cognitive decline, ranging from mild chronic impairment to severe hepatic encephalopathy and coma. Many suffer from psychological distress and depression.⁵ Advanced liver disease generally affects younger people of working age. Financial and social problems as well as the stigma of liver disease can have a profoundly negative impact on the quality of life of the patient and their family.⁶

Given the plethora of complex physical, psychological, existential, social, and family problems that are the norm in advanced liver disease, it is perhaps surprising that so little attention has been paid to understanding and addressing the wider illness experience of these patients and families.^{3,7,8} The hepatology literature has largely focused on the clinical complications of liver disease and treatment options that may improve both prognosis and quality of life.⁹ Health-related quality-of-life research is starting to provide insights into the burden of advanced liver disease and how people cope with waiting for transplantation.^{10,11} The liver illness

trajectory is very different from that found in a typical progressive cancer, the disease paradigm for which most palliative care provision has been developed.¹² These patients face an uncertain illness trajectory with the possibility of improvement, if they can stop drinking, or rapid deterioration and death during an acute admission for a life-threatening complication. Palliative care may be viewed incorrectly as only applicable once the patient is in the final days of life and all other treatment options have been exhausted.

Palliative care policies in the United Kingdom and internationally aim to ensure that patients with any life-limiting illness who are approaching the last months of life are identified and assessed.¹³⁻¹⁵ Given the lack of a clear "terminal phase" and the difficulties of accurate prognostication at an individual level, patients who are likely to be "at risk of dying" from advanced liver disease in the next year are candidates for palliative care.^{3,8} We suggest that clinical judgement informed by generic indicators, such as recurrent, unplanned hospital admissions and multimorbidity, can help trigger a review.^{16,17} Disease-specific prognostic tools, such as the Child-Pugh or Model for End-stage Liver Disease scores, are evidence-based markers of some of the major complications of decompensated disease, and patients on the transplant waiting list also have end-stage disease. Palliative care has well-defined, supportive care goals related to optimizing quality of life and addressing information needs about the illness and prognosis alongside symptom control, psychosocial support, and spiritual care of the patient and their family.^{3,8} Continuity of care consistent with the patient's wishes should then be provided through effective care planning. Goals, interventions, and plans for managing progressive deterioration or a potential episode of acute decompensation can be agreed upon with patients and families and communicated to all those providing care.^{14,15}

In addition, expertise in symptom control for patients with other types of organ failure is more advanced, whereas a robust evidence base for safe prescribing in liver disease, with its complex pathophysiology and pharmacokinetics, is lacking. Pain may be caused by comorbidities, liver disease complications, or hepatoma. There are no long-term studies of paracetamol (acetaminophen) use in patients with cirrhosis, but at a reduced dose, it is the safest option for mild pain.¹⁸ Opioids can be problematic in a population

Abbreviation: ESLD, end-stage liver disease.

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with a high prevalence of substance abuse and are considered a risk for encephalopathy, so careful assessment followed by individualized management and regular review are needed. Opioids should be given in smaller doses and at less frequent intervals in patients with liver disease. Constipation must be managed actively. Two reviews suggest that fentanyl may be the best-tolerated opioid for moderate-to-severe chronic pain, but there is no low-dose oral formulation for dose titration or breakthrough pain.^{19,20} Codeine and tramadol are not recommended. If the patient's renal function is not compromised, immediate-release oral morphine may be tolerated and the liquid preparation allows titration with very small doses. An alternative is the more potent, oral opioid, hydromorphone. Morphine and hydromorphone are metabolized by glucuronidation. This is impaired to a lesser extent than the metabolism of drugs cleared by the cytochrome pathways, such as oxycodone. Some clinicians use oxycodone for patients with hepatorenal failure intolerant of morphine who require a low-dose, immediate-release opioid. These patients need to be monitored very closely.⁸

There is a clear, timely need to generate a better understanding of the experiences and needs of those living and dying with advanced liver disease. Though their experiences may resemble that of people with other types of organ failure, much less is known about the archetypical illness trajectory of ESLD. When asked directly about their care preferences, many patients with end-stage organ failure, including those with liver disease, expressed a clear wish for a palliative care approach that focuses on reduction of morbidity.²¹ There is growing professional and public recognition that palliative care should be available on the basis of need, not diagnosis; prognostic paralysis should not delay the assessment of needs, and integrated, well-planned, holistic care shared by different teams and specialties in primary and secondary care should be the norm for any patient with a life-limiting illness and their family. Clear guidance exists for the palliative care of nonmalignant end-stage disease in the kidney, lung, and heart. There is currently a pressing need and opportunity to develop programs of research to inform the development of such guidelines for liver disease.

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Appendix 2: Publication: First-authored, peer-reviewed literature review

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What is the patient experience in advanced liver disease? A scoping review of the literature

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ABSTRACT

Background There has been a dramatic increase in liver disease over recent decades, with morbidity and mortality rates predicted to rise significantly. In order to effectively support this growing patient population we need to understand the experiences, key issues and priorities of people living and dying with advanced liver disease.

Aims To establish what is currently known about the patient experience of advanced liver disease.

Methods Scoping literature review. We searched MedLine, Web of Science, CINAHL and PsychINFO databases. Eligibility criteria: original research and review papers written in English since 1990 relating to the adult patient experience of advanced liver disease. Papers focusing on treatment development, acute liver failure or post liver transplantation were excluded.

Results 240 abstracts were identified and 121 articles reviewed in full. Patients with advanced liver disease experience many physical and psychosocial challenges, often of a greater severity than those reported in other advanced conditions. They are affected by gastrointestinal problems and fatigue, with both linked to higher levels of depression. Socio-demographic variations in the patient experience occur. Only two studies explored the holistic patient experience.

Conclusions Our knowledge of the patient experience in advanced liver disease is mainly from quality of life instruments and quantitative research. There are methodological limitations in the existing research such that the holistic patient experience is not well described. Qualitative longitudinal research has great potential for contributing to our understanding of the complex needs and experiences of patients living with advanced liver disease.

INTRODUCTION

There has been a dramatic increase in liver disease over recent decades, bucking the trend of falling mortality rates for most

major diseases. For example, while UK-wide standard death rates for ischaemic heart disease and cerebrovascular diseases between 1970 and 2010 fell by 71% and 72%, respectively, death rates for chronic liver disease and cirrhosis rose by nearly 300%.¹ In the UK, liver disease is currently the fifth most common cause of death² and by 2030 more people may die from liver disease than heart disease.³ The average age of death from liver disease is 59, and in England more than one in 10 of deaths of people in their 40s are now attributable to the disease.⁴

The role and importance of psychosocial factors in the patient's experience of having various illnesses have received increased attention over the last two decades. In light of the continued growth of this patient group, it is imperative that we understand the experiences and priorities of people living with advanced liver disease in relation to their illness beyond simply their medical care in order to ensure that they, and their family carers, are adequately cared for and their holistic needs met.^{5, 6}

We thus undertook a narrative scoping literature review to establish what is currently known about the patient experience in advanced liver disease.

METHOD

Design

This review was informed by the methodological framework of Arksey and O'Malley for scoping the literature.⁷ We chose this type of review to gain an overview of the breadth and extent of literature in a developing field.^{8, 9}

Search strategy

Literature searches were conducted in MedLine, Web of Science, CINAHL and

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PsychINFO databases. The search was conducted in an iterative manner, with search terms and strategy evolving as familiarity with the literature increased and key papers were identified. Searches were also adapted to suit the different formats of the individual databases.

Table 1 outlines the keywords and terms selected and searched for in abstracts.

Results were supplemented through hand-searches of key journals, grey literature, internet resources, websites of key organisations, bibliographies and reference lists. Email alerts were set up for key journals. We also asked specialists in hepatology, palliative care, general practice and specific liver diseases to inform us of any work they knew of in this field.

Selecting articles for inclusion

Due to time and budget constraints we included only articles written in English since 1990 that related to the adult patient experience of advanced liver disease. The selection of articles was based on initial screening of titles for duplicates, relevance and false hits. Editorials or commentaries were excluded, as were papers where their main focus was on treatment development, acute liver failure or outcomes relating to the patient experience post liver transplantation. We did however retain qualitative studies exploring experiences post liver transplantation where findings also made reference to the patient experience prior to the intervention. We retained original research and review papers only.

Data extraction and analysis

Selected papers were summarised, grouped according to their key focus, for example, health-related quality of life (HRQOL), transplantation or psychological aspects of the disease, and charted using an Excel data sheet.

RESULTS

A preliminary pool of 240 abstracts was identified and scrutinised for relevance and 121 articles were reviewed in full (figure 1).

The majority of papers was located in HRQOL research in general as well as relating to liver

transplantation, and employed a variety of quantitative assessment instruments. Generic tools such as the Short Form SF-36 questionnaire and disease-specific tools such as the Chronic Liver Disease Questionnaire were used to assess physical and psychosocial factors.¹⁰

Qualitative studies were less common. Of the 13 papers identified, six focused on patients' experiences of liver transplantation. The remainder pertained to specific types of liver disease, in particular primary biliary cirrhosis (PBC). Only one study employed a longitudinal design. Table 2 provides an overview of the qualitative studies retrieved. A more detailed consideration of the nature of the identified literature in general follows in the Discussion section.

The following sections outline the key findings in relation to patients' experiences of living with advanced liver disease. In light of the large number of final papers reviewed it is not possible to report on each paper in this article. Findings are grouped into three broad areas: physical experience, psychological experience and socio-demographic variations.

The physical experience of advanced liver disease

Conducting HRQOL research with 575 patients with end-stage liver disease and/or their surrogate decision-makers, Roth *et al* found that these patients suffered substantial levels of pain, which compared with those reported by advanced cancer patients and exceeded those of patients with chronic obstructive pulmonary disease and chronic heart failure.¹¹ Pain was particularly marked in cirrhotic patients with additional hepatocellular carcinoma.¹² Due to the impact of patients' liver damage on their ability to metabolise analgesics however, managing their pain proved challenging.¹³

Liver impairment also compromises the effective processing of nutrients. As such, malnutrition was found to be widespread among patients with advanced liver disease.¹⁴ Panagaria and colleagues compared the nutritional status of participants with alcoholic and non-alcoholic liver disease, alcohol addicts and healthy controls. Features of malnutrition such as nutrient and calorie deficiencies were seen in all liver disease patients regardless of aetiology, but were particularly frequent and severe in those with alcoholic liver disease.¹⁵ Malnutrition was also linked to a number of

Table 1 Keywords and search terms

	OR	OR	OR
AND	<i>Disease-specific terms</i>	<i>Stage-specific terms</i>	<i>Psychosocial terms</i>
	Cirrhosis	Decomp*	Patient experience
	Advanced liver disease	End of life	Illness experience
	End stage liver disease	Palliati*	Quality of life
	Liver failure	Terminal	
		Advance care planning	
		Hospice	
		Death	
		Dying	

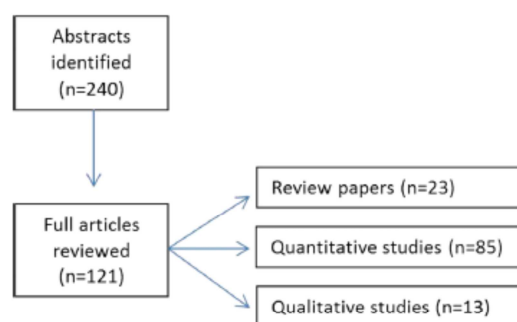


Figure 1 Process and outcome of literature search.

gastrointestinal complications in cirrhotic patients, which may progressively impair their HRQOL.¹⁴

Patients with advanced liver disease experienced higher levels of fatigue than healthy controls.^{16–17} Fatigue was particularly well investigated in the realm of PBC where it constituted a major debilitating symptom.¹⁸ Comparative research by Jones *et al*¹⁹ using the Fatigue Impact Scale however suggested that its negative effect on patient well-being was similar across different types of liver disease. Wainwright²⁰ interviewed transplant survivors on their experience of living with the disease prior to the intervention. Patients described a range of gastrointestinal symptoms as well as mental impairments, but felt particularly frustrated with the physical limitations brought about by their high levels of fatigue. Respondents recalled gradually losing their independence as their health deteriorated to the point where transplantation became the only life-saving option; they perceived themselves as ‘not living’ during that time. Relatedly, Cordoba and colleagues²¹ described extensive sleep disturbance in cirrhotic patients, unrelated to any cognitive impairment. The level of sleep problems in advanced liver disease compared with that of chronic renal failure patients²¹ and was significantly higher than that of healthy controls.²²

Surveying a sample of 544 patients with cirrhosis, Marchesini *et al*²³ found that, compared with the general population, liver disease patients perceived most areas of their daily life affected by their illness, particularly the physical domain. Interestingly, respondents reported feeling significantly more affected by relatively minor symptoms such as muscle cramps and pruritus than some of the major, possibly life-threatening complications. Male participants also highlighted their sex life as a great concern in relation to their well-being. Sexual problems such as erectile dysfunction or reduced libido were a common occurrence in male patients with advanced liver disease,²⁴ and in particular among patients with hepatocellular carcinoma.²⁵

The psychological experience of advanced liver disease

Patients with advanced liver disease reported more substantial levels of psychological distress than patients with other types of organ failure^{11–26} and age- and gender-matched controls.²⁷ Indeed, it was suggested that psychological distress was the best predictor of quality of life in patients with liver cirrhosis.²⁸ Impairment in patients’ psychological well-being was linked to the gastrointestinal symptoms associated with advanced liver disease²⁹ and to high levels of fatigue in female PBC patients.³⁰

Depression was particularly prevalent.³¹ The assessment by Bianchi *et al*²⁷ of depression in cirrhotic patients found that over that half of their sample were depressed. Moreover, few patients had a known history of depression, thus suggesting that their liver disease was impacting on their mental health. In addition, the researchers found that 69% of participants suffered from some type of sleep disorder which affected their psychological ill health.

Depressed liver disease patients reported significantly more adverse outcomes compared with their non-depressed counterparts such as adaptive coping, physical pain, perceived quality of life and a higher level of pessimism.³² In addition, those with a greater psychological burden were more likely to experience stigma, which in turn can reinforce mental and emotional distress.³³

Hepatic encephalopathy was one of the main cognitive complications in patients with advanced liver disease, with neurological symptoms affecting patients’ attention, memory and psychomotor functions. While few patients were found to develop severe cognitive decline, many experienced some cognitive impairment at a subclinical level,³⁴ although reported prevalence rates varied widely.³⁵ Subclinical hepatic encephalopathy was shown to have a profound impact on liver patients’ quality of life and daily functioning, highlighting the value of routinely assessing and treating subclinical levels of cognitive dysfunction in this population.³⁶

Table 2 Patient experience in advanced liver disease: qualitative studies (or studies containing a qualitative element) retrieved

Author(s)	Year of publication	Study aims	Methodology	Study population	Disease causes represented	Key results
Bjork and Näden ⁵¹	2008	To explore patients' experiences of being accepted and waiting for liver transplant	<ul style="list-style-type: none"> ▶ Interviews ▶ Data analysis as per Kvale (1996)⁵⁹ 	21 patients on transplant waiting list; 17 male, 4 female Average age 46 years (27–62)	Mostly (?) posthepatitis and primary sclerosing cholangitis (PSC) (not clear from description)	<ul style="list-style-type: none"> ▶ Overwhelming lack of energy; perceived linear relationship between lack of energy, physical limitations and mental distress ▶ Great uncertainty related to life and death ▶ Plethora of physical problems and discomfort, anxiety and lonely suffering expressed
Bladbum <i>et al</i> ⁶⁰	2007	To explore psychological parameters in fatigued and non-fatigued primary biliary cirrhosis (PBC) patients	<ul style="list-style-type: none"> ▶ Semistructured interviews (plus various validated psychological scores) 	24 patients Gender split not stated Average age 57.9 (±8) years	PBC	<p>Results linking to specifically to qualitative portion of study not given. Overall key results:</p> <ul style="list-style-type: none"> ▶ High fatigue linked to higher levels of distress and perceived quality of life and lower self-efficacy for undertaking everyday activities
Bomschlegel <i>et al</i> ⁶²	2011	To describe the unmet needs of people with hepatitis C	<ul style="list-style-type: none"> ▶ Telephone interviews ▶ Data analysis method not stated 	180 patients; 98 male, 82 female. Overall age range or mean age not stated but 77% of sample between 42 and 61 years	Hepatitis C	<p>Unmet information needs relating to:</p> <ul style="list-style-type: none"> ▶ Basic information about the virus ▶ Available support groups ▶ Counselling about preventing further liver damage and transmission prevention
Brown <i>et al</i> ⁶³	2006	To explore what meaning people with liver failure ascribe to the experience of waiting for a transplant	<ul style="list-style-type: none"> ▶ Interviews ▶ Phenomenological data analysis ▶ 9 interviews with 6 participants (details of follow-up not stated) 	6 patients on transplant waiting list; 4 male, 2 female. Age range 46–63	Hepatitis C, alcoholic liver disease, cryptogenic liver disease	<ul style="list-style-type: none"> ▶ Illness experienced as transformative and disruptive ▶ Lack of positive care felt to contribute to depression, hopelessness and worsening health ▶ Pervasive experience of loss relating to perceived loss of personal control and freedom, important roles, and increasing disability ▶ Feelings of frustration and boredom, sense of isolation and loneliness ▶ Patients develop new perspectives on time

Continued

Table 2 Continued

Author(s)	Year of publication	Study aims	Methodology	Study population	Disease causes represented	Key results
Fan and Eiser ³⁷	2012	To explore how patients perceived the impact of hepatocellular carcinoma on their lives and coped with its demands	<ul style="list-style-type: none"> ▶ Semistructured interviews ▶ Interpretative phenomenological analysis 	33 patients; 22 males, 11 females. Mean age 54.24 (31–76)	Hepatocellular carcinoma	<ul style="list-style-type: none"> ▶ Many physical symptoms and psychological distress ▶ Disrupted social relationships ▶ Adjustment to illness a dynamic process influenced by physical health, stage of disease, patients' illness perceptions and coping strategies ▶ Illness understanding added to patients' sense of control ▶ Observed transitions in patients' coping
Forsberg <i>et al</i> ⁵⁴	2000	To explore the subjective experiences of the meaning of having a liver transplantation	<ul style="list-style-type: none"> ▶ Interviews ▶ Phenomenological analysis ▶ Interviews covered experiences pretransplant and post-transplant 	12 patients 1 year post-transplant; 3 males, 9 females. Mean age 51 years (24–63)	PSC, Laennec's cirrhosis, hepatitis, PBC, metabolic disease	<p>Pretransplant experience:</p> <ul style="list-style-type: none"> ▶ Feelings of grief and fear of the unknown ▶ Existential thoughts common
Johnson and Hathaway ⁵⁵	1996	To explore the lived experience of end-stage liver failure and liver transplantation	<ul style="list-style-type: none"> ▶ Interview ▶ Phenomenological analysis 	1 patient post-transplant; female. Age 62	Not stated	<p>Pretransplant experience:</p> <ul style="list-style-type: none"> ▶ Uncertainty ▶ Feelings of loss of control related to increasing dependence, confusion/disorientation, anger/frustration and fear ▶ Positive impact of spirituality, faith and social support
Jorgensen ⁵⁶	2006	To understand the lived experience of fatigue for the people with PBC	<ul style="list-style-type: none"> ▶ Interviews ▶ Interpretative phenomenological analysis 	8 patients; 1 male, 7 females. Age range 38–60	PBC	<ul style="list-style-type: none"> ▶ Experience of fatigue all-encompassing and overwhelming, insidious and difficult to control ▶ Patients plan lives around fatigue to preserve energy ▶ Struggle to maintain normality ▶ Feelings of dysphoria and general apathy
Lasker <i>et al</i> ⁵⁷	2005	To explore the responses of family and friends to chronic liver disease including gender differences	<ul style="list-style-type: none"> ▶ Survey, open-ended questions, posts to a Friends and Family listserv 	52 spouses, family members or friends	PBC	<ul style="list-style-type: none"> ▶ Males less affected than females by loved one's illness ▶ Giving emotional support and being more accommodating seen as most important support strategies ▶ 54.5% overall access internet-based support, but more females than males

Continued

Table 2 Continued

Author(s)	Year of publication	Study aims	Methodology	Study population	Disease causes represented	Key results
Lumby ⁵⁰	1997	To explore the experiences of surviving a liver transplant	<ul style="list-style-type: none"> ▶ Focus groups and storytelling ▶ Analysis using NUDIST software ▶ Longitudinal study (over 2 years) 	8 patients post-transplant; 2 males, 6 females. No ages given	No details given but a variety	<ul style="list-style-type: none"> ▶ Male support action-oriented, female socio-emotional Pretransplant experience: <ul style="list-style-type: none"> ▶ Range of physiological states ▶ Trust in medics even where poor care management ▶ Attempts to maintain independence throughout illness ▶ Facing both life and death, but hope dominates
Montali <i>et al</i> ³⁹	2011	To explore the illness experience of women with PBC from a gender perspective	<ul style="list-style-type: none"> ▶ Semistructured interviews ▶ Interpretative phenomenological analysis 	23 female patients; mean age 59 (39–77)	PBC	<ul style="list-style-type: none"> ▶ Denial of patients' sick role by family and health professionals, trivialisation of fatigue, lack of consideration of patients' needs ▶ Fear of rejection and losing their social role ▶ Need for biographical continuity
Robertson ⁵⁸	1999	To explore patients' perspectives on the effect of transplantation on quality of life	<ul style="list-style-type: none"> ▶ Semistructured interviews ▶ Cluster analysis 	5 patients post-transplant No gender split or ages given	No details given	<ul style="list-style-type: none"> Pretransplant experience: <ul style="list-style-type: none"> ▶ Physical symptoms impeded independence and limited activities and social life ▶ Quality of life perceived as poor ▶ Little acknowledgement of possible death
Wainwright ²⁰	1997	To explore patient experience of chronic liver disease	<ul style="list-style-type: none"> ▶ Interviews ▶ Grounded theory 	10 patients post-transplant (reporting on pretransplant experience) No gender split or ages given	No details given	<ul style="list-style-type: none"> ▶ Main debilitating complaint fatigue ▶ Many gastrointestinal symptoms, some mental impairment ▶ Negative feelings due to physical limitations ▶ Experience of stigma regardless of aetiology ▶ Wish to retain independence and self-manage illness

Finally, a recent qualitative interview study by Fan and Eiser³⁷ explored the illness experience of 33 patients with hepatocellular cancer. Patients' adjustment to the illness was found to be a dynamic process influenced by their physical health, the stage of the disease, the patient's illness perceptions and their coping strategies. It appeared that understanding the nature of their illness, especially its causes, prognosis and treatment plans, was particularly important in promoting these patients' sense of control.

Socio-demographic variations

Both age and gender differences were reported in the HRQOL of individuals with advanced liver disease. Patients with liver disease constituted a relatively young patient population compared with other major diseases.²⁻¹¹ Age was found to be significantly correlated with worsening HRQOL in patients with cirrhosis.³⁸ In the survey research by Marchesini *et al*,²³ the impact of cirrhosis was experienced more acutely among the younger participants. This may be reflective of the relatively more widespread impact of the disease on younger patients' lives in terms of their employment, family life and adjustment to a diagnosis of a life-limiting illness, compared with older patients who are already beyond the most active phase of their lives. In addition, male participants cited paid employment and sexual function as their main issues in relation to their illness, while female respondents highlighted their home life and social life as primary concerns, suggesting gender differences in the way the illness is experienced.

DISCUSSION

Summary of main findings

Patients with advanced liver disease experience many physical and psychosocial challenges, and often of a greater severity than those reported in most other chronic diseases. Patients are particularly affected by gastrointestinal problems and fatigue, with both linked to higher levels of depression.

Our review found the literature limited in the extent to which it was able to describe the lived patient experience of advanced liver disease. Some physical and psychological support needs can currently only be inferred from more clinically-focused research. While there has been some interest in the psychosocial experience of undergoing liver transplantation, we found only two studies that explicitly explored the everyday, holistic patient experience in advanced liver disease: one study of hepatocellular carcinoma³⁷ and one study exploring the experiences of female patients with PBC.³⁹

We currently lack understanding of these patients' main concerns and priorities in relation to their illness. We also do not know how patients with advanced liver disease experience their medical treatment and care, and in particular their supportive and

palliative care, and to what extent the support provided is perceived to meet their needs and goals. Similarly, there is currently little insight into liver patients' social, emotional, existential or information needs, or how these change over time. All of these are likely to have a significant bearing on the perceived quality of life and overall illness experience of both the patient and their family, and may be especially pertinent as their illness progresses towards liver transplantation or death.⁴⁰ This is of particular interest in light of ongoing concerns regarding poorer availability of supportive and palliative care services for patients with non-malignant life-limiting diseases compared with cancer patients.⁴¹

Methodological considerations

HRQOL research employing survey-based methods has contributed a great deal to our quantitative understanding of symptom burden and psychological distress, and provides the basis of many recommendations to more effectively target treatment and care for liver disease patients. Moreover, assessing liver patients' HRQOL does not just serve as an assessment measure in its own right, but has also been found to be a useful predictor of mortality.⁴² The approach however is not without its critics.⁴³⁻⁴⁴ Indeed, patients themselves have previously commented that preformulated questionnaires give no opportunity to make personal comment on their subjective illness experience.⁴⁵⁻⁴⁶

The literature focused on liver transplantation uses the same or similar quantitative assessment tools as HRQOL research to examine and compare patients' quality of life before and after transplantation. The qualitative liver transplantation literature identified relates to a very particular set of circumstances: awaiting transplantation. Many patients with advanced liver disease do not qualify for transplantation on account of comorbidities, general frailty, or continued drinking or drug-taking. While much can be learned from the insights from these patients awaiting transplantation, their experiences may not reflect those of the wider patient population with advanced liver disease. Indeed, marked differences between transplant and non-transplant patients have been observed.⁴⁷

A number of the studies recruited patients with different causes of liver disease. Their results indicate some variation in HRQOL and related factors, suggesting that there may be differences between aetiologies in the way advanced liver disease is experienced. This implies that it may be inappropriate to extrapolate from one type of liver disease to another and to suggest that there exists a universal patient experience in advanced liver disease. While there is much aetiology-specific research into the patient experience with PBC and hepatitis C for example, there is a paucity of similar insights in the realm of non-alcoholic fatty liver disease. This consideration is also important given that PBC affects disproportionately more women,

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pointing towards potential gender differences in the patient experience.

Limitations of this review

This review gives an overview of the knowledge that has been generated by liver disease research over recent years, including insights into some of the types and extent of challenges patients with advanced liver disease face in everyday life. However, while we gained an overview of the extent and nature of the literature, we did not conduct a systematic appraisal of the quality of the individual studies or the effectiveness of any particular intervention. Given the large body of material yielded by the search it was not possible to provide an overview of all reviewed articles. Imposing timescale and language criteria on the search and omitting citation searches mean that potentially relevant articles may have been missed. Also, both literature search and review were undertaken by an independent researcher and as such are subject to potential bias.

Implications for future research

Current research in liver disease is predominantly cross-sectional and quantitative. The typical organ failure trajectory is marked by an erratic progression towards death⁴⁸ and liver patients' quality of life deteriorates with increasing disease severity.²⁶ This suggests that the patient experience is likely to differ dynamically along the liver disease pathway. It is important to understand how people experience these fluctuations in their condition to allow changing needs to be recognised and responded to with acceptable and effective care. Qualitative longitudinal research which explores and captures the changing nature of these patients' health in depth has the potential to provide useful insights in this respect.⁴⁹ Our review found only one qualitative study using a longitudinal approach to explore patients' experiences of liver transplantation.⁵⁰

There is currently only a very limited amount of qualitative research in this area. Of the 121 articles identified, only 13 employed a qualitative research design. Many are situated in the liver transplantation literature and therefore not necessarily representative of the wider patient population with advanced liver disease. Moreover, they commonly employ a retrospective design, asking transplant survivors to recall their experiences prior to transplantation, and are therefore subject to the biases inherent in this approach.

This area would therefore benefit from future research which is generic (ie, not aetiology- or transplantation-focused), prospective, longitudinal and qualitative. Potential differences in the patient experience in relation to demographic factors, such as age and gender, and disease aetiology, also warrant further exploration.

CONCLUSIONS

There are many physical and psychosocial challenges for people living with advanced liver disease. However, no research has been identified describing the holistic lived patient experience of advanced liver disease in depth. There is a lack of insight in key areas such as patients' perceptions of their treatment and care. Existing qualitative research is very limited compared with heart, lung and kidney organ failure illnesses, despite surveys suggesting that the patient experience in advanced liver disease is more challenging and associated with multi-morbidity. Given the erratic and unpredictable trajectory of this disease, it is imperative that a longitudinal, patient-centred approach is taken to illuminate the dynamic illness experience. Thus far, no research has been undertaken which seeks the views of the patient who experiences and manages this condition on a daily basis. Insights have either been provided from a professional perspective or generated from predetermined standard questions. Only by letting patients' illness stories be told in their own words, and allowing them to speak freely and focus on the aspects of this experience of greatest importance to them, will we be able to confirm whether or not their needs are sufficiently supported through current care structures and pathways. In light of the rapidly increasing number of people predicted to be living and dying with advanced liver disease in coming years, this area deserves urgent attention.

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Contributors Both authors devised the research question and formulated the search strategy. BK performed the searches, identified eligible studies, extracted data and drafted the first sections of text. Both authors contributed to the penultimate and final draft. BK is the guarantor.

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Review

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Appendix 3: Interview topic guides

PATIENT INTERVIEW GUIDE (v.1, 01/06/11)

Topic area	Questions / Prompts
Background	
The person	Tell me a little about yourself - Family? Work?
Illness to date	How long have you had this illness? When and how did you find out about it? What were you told about it? (cause, treatment, prognosis) How did you deal with this? What has happened since? (How is it managed? Has it stayed the same, got worse?)
Current situation	
Symptoms/complications	How are you feeling at the moment? Are there any current physical problems? How do they make you feel? Are they different at different times/days? What has happened since the last time (interview)? (treatment/care, hospital admissions etc) Do you understand what the medication/tests/treatments are for? How do they make you feel?
Practicalities	How do you manage your life on a day-to-day basis? Are there any things you have difficulty with due to your illness? (household, getting around etc) How do you manage them? Where do you get practical support from and what type of support is it? Who looks after you at home? How do you feel about this?
Relationships	What is your relationship with your carer like? How does your illness affect your relationship with your (other) family members? With friends? Do you feel you can/want to talk to them about your illness? How do you feel about doing so? Wider social network? Do you still get out and about? Have you experienced any stigma? Have you had any positive experiences related to your illness?
Feelings	How do you feel within yourself? How does this compare to before the illness? How do you feel about what is happening/your illness? Do you ever feel low or depressed? Do you worry about anything? How do you cope with this? Does anyone help you cope? (how?) Has anyone ever asked you how you feel living with the illness? Do you share your feelings with anyone/do others know how you feel? What do you particularly value in life? Has this changed since becoming ill? Would you consider yourself a spiritual person?

Services / support	<p>How do you feel about the care you receive? Has anyone ever asked you what your main issues/priorities are? Do you tend to see the same people? (consultant, GP etc) Do you feel they adequately understand your needs? If not, how could this be improved? Who tends to be your first port of call and why? Has anyone ever asked you what support you need at home? What services have you used? (NHS, social work, charities, patient support group, faith group etc) How did you find out about them? What are your experiences with them? Are you aware of other services available that you are not using? Why not? How did you hear about them? How do you feel they might be useful to you?</p>
Information needs	<p>Do you feel well enough informed about your illness? What do you know about your illness? Where do you get information from? What areas are you less sure about? How do you feel about asking doctors/nurses questions about your illness? Are you encouraged to ask questions? In which ways do you prefer to receive information about your illness? (conversation, leaflet, internet)</p>
Future	
Planning/Preparing	<p>Do you ever think about the future? What do you expect will happen? How does this make you feel? Has anyone spoken with you about the future? Has anyone asked what you would like to happen if you illness was to get worse? What would you like to happen? What type of help would you want? Can you talk to your carer/family/friends about this?</p>
Improving QOL	<p>How do you feel the quality of your life could be improved? What would make life easier for you? How could services be improved for liver patients more generally? Anything particularly good/bad?</p>

CARER INTERVIEW GUIDE (v.1, 01/06/11)

Topic area	Questions / Prompts
Background	
The person	What is your relationship to X (<i>patient</i>) (e.g. family/friend/neighbour; duration of relationship)? Tell me a little about yourself What is your own health like?
Illness to date	How have things been for you since X became ill? How did you come to become the main carer? What sort of help or support does X need? How do you feel about providing this care?
Current situation	
Being a carer	Are there any particular problems for you as carer? (e.g. physical, understanding, other commitments, own health) Do you have any concerns about the care you provide? (safety, appropriateness, effectiveness) Do you worry about any particular aspects of X's illness (e.g. symptoms, unexpected changes, treatment)? How have sudden changes in the X's condition been handled previously? Has anything positive come out of taking on the caring role?
Relationships	How has your relationship to X changed since taking on their care? How openly are you able to talk to X about the illness/their feelings/family affairs? How openly are you able to talk to X about any problems or concerns you have with being their carer? How has X's illness affected family life in general? (if applicable) And your social life?
Feelings	How do you feel in yourself these days? Do you have good and bad days? How do you feel about being a carer to your ... (<i>relationship to patient</i>)? Do you worry about what might happen in the future? Who can you talk to about how <u>you</u> are really feeling? What helps you cope with things?
Services / support	Where do you get your own help or support as a carer from? How did this support come about? (if arranged) Are you in contact with any health or social work professionals about X's illness? What sort of help or support do they give you? What do you find particularly helpful? Do they give you the opportunity to ask questions or discuss how you feel? Has anyone ever asked you what your main issues/priorities are? Has anyone ever asked you what support you need at home? Are you included in discussions between X and professional carer? How do you feel about this?

	<p>Do you that feel you and X are getting enough help, information and support? If not, what could be improved?</p> <p>What other type of support would you find helpful?</p> <p>Are you aware of any other services that offer support to people like you caring for someone with a serious illness (NHS, social work, charities, support group, faith group etc)? How did you hear about them? Have you or are you using any of them? What are your experiences with them?</p> <p>Have you thought about what kind of help you might want in the future/if X's illness fails to get better?</p>
Information needs	<p>What have you been told about X's illness? (cause, treatment, prognosis)</p> <p>What are your main sources of information?</p> <p>Has anyone discussed with you what you can expect as a carer?</p> <p>Has anyone discussed with you what is likely to happen in the future?</p> <p>Do you feel you are getting enough information about the illness, the treatment, the future? What areas are you less sure about?</p>
Future	
Planning/Preparing	<p>Have you thought about why this has happened, the meaning of life...?</p> <p>Do you ever think about the future? What do you expect will happen? How does this make you feel?</p> <p>What would you like to happen? What type of help would you want? Can you talk to others about this?</p>
Improving QOL	<p>Have you any other suggestions about how the needs of people in your situation might be better met? How can services be improved (for patient/for carer)?</p> <p>How could the quality of <u>your</u> life be improved?</p> <p>What is the one thing that would make life easier for <u>you</u> at present?</p>

PROFESSIONAL INTERVIEW GUIDE (v.1, 01/06/11)

Topic area	Questions / Prompts
Relationship with patient/carer	<p>Can you tell me about your involvement in the care of patient X and carer Y?</p> <p>How long have you been X's professional carer?</p> <p>What is the type of support you provide?</p> <p>Do you also have a care/support responsibility or role for Y?</p>
Care provision	<p>As far as you know, who is most involved in the care of X (e.g. GP practice, community nurses, social services)?</p> <p>From your point of view, what are the main issues or problems in providing support for X and Y?</p> <p>How well do you feel their needs are being met? How could this be improved?</p> <p>Did you change your care of X in response to any recent hospital visits/admissions?</p> <p>Do you have a care plan in place for managing acute complications?</p> <p>Would you consider X for inclusion in a practice palliative care register? What informs this decision? How would this impact on the support provided?</p>
Communication with patient/carer	<p>Are there any problems or particular areas of concern for you as regards X's treatment/care?</p> <p>How well do you feel X and Y are coping with their situation?</p> <p>How do you see the illness impacting on their lives?</p> <p>Do they talk to you about their needs, concerns, values?</p> <p>Do you feel they are getting enough help and support? Do X and Y speak about their experiences with this help/support?</p> <p>How was it arranged?</p> <p>Have you discussed the illness or prognosis with X and/or Y?</p> <p>Are there any issues you choose not to discuss with them? Why?</p> <p>Do you think X will continue to be able to be looked after at home in the future? Do you have any concerns in this respect? (physical/mental, carer wellbeing, shortage of appropriate home-based services...) Do you think that Y is able to care for them adequately?</p> <p>Have you talked with X and Y about care arrangements for when the illness progresses? Have you discussed their end-of-life care and preferences? Do you keep a record of their wishes? What happens to this information?</p>
Communication with other services	<p>What information have you received about X's illness, treatment and prognosis and from what source?</p> <p>How do you link with other services involved in X's care? How effective do you find this communication between services? Is there anyone you feel you should link more closely with? What in your view are the barriers to making this happen?</p> <p>What services/support/people/interventions have been especially good or helpful?</p> <p>How do you feel services could be improved to more effectively meet X's/Y's needs?</p>

Appendix 4: Overview of patient demographics and hospital admissions

The following table outlines supplementary patient-related information such as participants' individual DEPCAT and MELD scores at recruitment in order to give additional context to the experiences described. It also provides additional care-related information by showing the number of hospital admissions over different time periods. The range of number of admissions over time in this sample must be noted, with the majority reflecting routine admissions for paracentesis. Overall, these figures illustrate the increasingly disruptive nature of the disease as patients approach the end of life and confirm the need for improved support at that time.

Patient	Age	Primary (secondary) aetiology	DEPCAT (1 least dep - 7 most dep)	MELD at recruitment	Admissions prior to recruitment	Months in study	Admissions during study involvement	Status at end of study	Admissions 6 months pre-death	Admissions 12 months pre-death
John	68	ALD	4	14	0	12	0	Alive	----	----
Sarah	38	ALD, HCV	5	20	4	12	3	Alive	----	----
Mary	66	AIH	4	20	6	5	5	Dead	6	9
Fraser	60	ALD	5	17	6	7	6	Dead	6	10
Fay	84	NAFLD	4	9	1	11	13	Dead	8	15
Donald	74	HCC (NAFLD)	7	17	1	1	0	Dead	4	6
Martin	77	ALD (NAFLD)	6	9	3	9	21	Dead	15	25
Thomas	75	NAFLD	3	21	4	6	9	Dead	12	15
Ben	35	ALD	4	24	4	12	5	Alive	----	----
Aidan	58	ALD	5	13	6	6	7	Dead	8	13
Kate	41	Cryptogenic	3	10	0	8	5	Alive	----	----
Nadia	56	ALD, HCV	4	13	0	6	0	Alive	----	----
Carol	45	ALD	3	16	0	7	2	Dead	3	3
Polly	68	NAFLD	3	15	7	5	9	Dead	12	14
Rebecca	37	ALD	7	26	3	9	2	Alive	----	----

Table 5: Overview of patient demographics and hospital admissions

Appendix 5: Notifications of ethics and R&D approval

Lothian NHS Board

South East Scotland Research Ethics
Committees
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
www.nhslothian.scot.nhs.uk



Enquiries Emily Pendleton
Direct Line 0131 465 5676
emily.pendleton@nhslothian.scot.nhs.uk

05 August 2011

Mrs Barbara Kimbell
PhD Student
University of Edinburgh
Centre for Population Health Sciences
General Practice section
Teviot Place, Edinburgh
EH8 9AG

Dear Mrs Kimbell

Study title: Exploring the needs and experiences of patients with advanced liver disease: a qualitative, longitudinal, multi-perspective study
REC reference: 11/AL/0351

Thank you for your letter of 20 July 2011, responding to the Committee's request for further information on the above research and submitting revised documentation. Please note the Committee that reviewed the study are now known as South East Scotland Research Committee 1 (SESREC 1) not LREC.

The further information was considered in correspondence by a sub-committee of the REC at a meeting held on 2 August 2011. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites



Headquarters
2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		
GP/Consultant Information Sheets	1	01 June 2011
Interview Schedules/Topic Guides	1	01 June 2011
Investigator CV		
Letter of invitation to participant	1	01 June 2011
Other: interview carer	1	01 June 2011
Other: interview professional	1	01 June 2011
Other: recruitment flow chart	1	01 June 2011
Other: letter recruit professionals	1	01 June 2011

Other: Identifying patients for supportive		
Participant Consent Form	2	11 July 2011
Participant Information Sheet: professional	1	01 June 2011
Participant Information Sheet: Letter recruit carer	1	01 June 2011
Participant Information Sheet: patient	2	11 July 2011
Participant Information Sheet: carer	2	11 July 2011
Protocol	1	01 June 2011
REC application		01 June 2011
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/AL/0351	Please quote this number on all correspondence
------------	--

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Janet Andrews
Chair

Email: emily.oconnor@nhslothian.scot.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]

"After ethical review – guidance for researchers" [SL-AR2]

Copy to: Ms Gemma Watson
Ms Karen Maitland, NHS Lothian

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

CPP/MJ /approval

28/07/2011

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Director:

Professor David E Newby

Dear Ms Kimbell,

Lothian R&D Project No: **2011/R/PSY/04**

Title of Research: Exploring the needs and experiences of patients with advanced liver disease; a qualitative, longitudinal, multi-perspective study.

REC No: 11/AL/0351

CTA No: N/A

Eudract: N/A

PIS: version 2 dated 11 July 2011
Carer information sheet, version 2 dated
11 July 2011
Health/social care professional information
sheet, version 1 dated 1 June 2011

Consent: Patient, version 2 dated 11 July 2011
Relative/friend, version 1 dated 1 June 2011
Professional, version 1 dated 1 June 2011

Protocol No: version 1 dated 1 June 2011

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Following a Research Ethics Committee final favourable opinion, final copies of all project documentation (with revised version numbers) should be sent, with the Research Ethics Committee letter of favourable opinion, to the R&D office. Management approval will only be valid after favourable opinion has been received.

Following funding award, confirmation of award should be sent to the R&D Office. Management approval will only be valid after the funding award confirmation has been received.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'CPhillips'.

Dr Christine P Phillips
Deputy R&D Director

cc Paul Dearie, QA Manager

Appendix 6: Example of evolving coding structure

First two pages of coding structure after coding of first patient case

Nodes

Name	Sources	References
<input type="radio"/> Attendance at healthcare	3	4
<input type="radio"/> Being normal	1	2
<input type="radio"/> Being unaware of severity of illness	1	1
<input type="radio"/> Burdening others	4	10
<input type="radio"/> Carer	3	3
<input type="checkbox"/> Being a carer	3	12
<input type="radio"/> Feeling isolated	1	3
<input type="radio"/> Needing to work	3	10
<input type="radio"/> Putting the patient first	2	7
<input type="checkbox"/> Doctor-carer communication	2	5
<input type="radio"/> Feeling included	1	3
<input type="radio"/> Changing outlook on life	3	9
<input type="checkbox"/> Complications related to disease	0	0
<input type="radio"/> Ascites	3	5
<input type="radio"/> Fatigue	4	27
<input type="radio"/> HCC	2	3
<input type="radio"/> 'Intangible' symptoms	1	1
<input type="radio"/> Motor problems	2	2
<input type="radio"/> Pain	1	2
<input type="radio"/> Varices	1	1
<input type="checkbox"/> Weight loss	2	7
<input type="radio"/> Appetite	2	9
<input type="checkbox"/> Contact with allied services	0	0
<input type="radio"/> Social work	2	4
<input type="checkbox"/> Coping	4	21
<input type="radio"/> Accepting your limitations	0	0
<input type="radio"/> Concerns about physical appearance	1	1
<input type="radio"/> Focusing on a positive outcome	2	2
<input type="radio"/> Getting emotional	0	0
<input type="radio"/> Giving into illness	1	1
<input type="checkbox"/> I just have to get on with it	2	3
<input type="radio"/> Everybody's dealt their hand	2	4
<input type="radio"/> Keeping a level head	1	1
<input type="radio"/> Losing one's independence	2	2
<input type="radio"/> Talking about it	0	0
<input type="radio"/> Trying not to think about it	2	4
<input type="checkbox"/> Deterioration of condition	3	26
<input type="radio"/> Expecting the worst	1	2
<input type="radio"/> False sense of security	1	6
<input type="radio"/> Psychological deterioration	1	1
<input type="radio"/> Diagnosis	1	8

Nodes

Name	Sources	References
<input type="radio"/> Doctor-patient communication	1	1
<input type="radio"/> Accepting doctors' limitations	3	17
<input type="radio"/> Appreciating doctors' frankness	2	3
<input type="radio"/> Being conscious of time restrictions	2	2
<input type="radio"/> Feeling unsupported	1	3
<input type="radio"/> Focus on disease vs holistic needs	2	5
<input type="radio"/> GPs have limited disease knowledge	2	6
<input type="radio"/> Miscommunication	2	6
<input type="radio"/> It was like I wasn't there	1	1
<input type="radio"/> Lack of information	3	6
<input type="radio"/> Receiving conflicting information	3	7
<input type="radio"/> Promoting a positive outcome	1	4
<input type="radio"/> Putting faith in professionals	1	2
<input type="radio"/> Relationship with consultant	3	10
<input type="radio"/> Relationship with GP	3	8
<input type="radio"/> Emotions	2	2
<input type="radio"/> Becoming more negative	1	1
<input type="radio"/> Feeling frustrated	1	4
<input type="radio"/> Feeling guilty	2	4
<input type="radio"/> Feeling low	2	4
<input type="radio"/> Feeling pathetic	1	1
<input type="radio"/> Feeling scared	3	4
<input type="radio"/> Feeling uptight	1	1
<input type="radio"/> Hiding emotions from others	2	3
<input type="radio"/> Wishing life away	1	2
<input type="radio"/> Existential	1	2
<input type="radio"/> Acknowledging death	3	9
<input type="radio"/> Becoming conscious of time	1	1
<input type="radio"/> Faith	1	1
<input type="radio"/> Hoping for the best	3	6
<input type="radio"/> Making the most of time	2	20
<input type="radio"/> Spirituality	1	1
<input type="radio"/> Time passing quickly	1	1
<input type="radio"/> Filling a long day	2	3
<input type="radio"/> Losing motivation	2	5
<input type="radio"/> Good days, bad days	3	8
<input type="radio"/> Hospital experience	2	4
<input type="radio"/> Contact with nurses	1	1
<input type="radio"/> Doctors keep changing their minds	1	3
<input type="radio"/> Feeling insignificant	1	3
<input type="radio"/> Feels like coming home	1	1
<input type="radio"/> Lack of introductions	2	3

First two pages of coding structure at end of initial coding phase

Nodes

Name	Sources	References
<input type="checkbox"/> A - BECOMING ILL	0	0
<input type="checkbox"/> Aetiology	3	5
<input type="checkbox"/> AIH	1	2
<input type="checkbox"/> Alcohol	14	29
<input type="checkbox"/> I got told but I didn't listen	12	22
<input type="checkbox"/> It'll never happen to me	3	3
<input type="checkbox"/> Cryptogenic	1	4
<input type="checkbox"/> Hepatitis C	5	28
<input type="checkbox"/> Feeling embarrassed	1	2
<input type="checkbox"/> I'm not a drinker	4	6
<input type="checkbox"/> NAFLD	5	7
<input type="checkbox"/> Diagnosis	22	47
<input type="checkbox"/> First symptoms	14	27
<input type="checkbox"/> Denying first symptoms*	6	8
<input type="checkbox"/> It was a bit of a shock	6	7
<input type="checkbox"/> B - LIVING WITH LIVER DISEASE	0	0
<input type="checkbox"/> Care experience	0	0
<input type="checkbox"/> Communication	0	0
<input type="checkbox"/> Doctor-carer	11	36
<input type="checkbox"/> Doctor-patient	11	14
<input type="checkbox"/> Appreciating doctors' frankness	7	9
<input type="checkbox"/> Comfortable asking questions	9	13
<input type="checkbox"/> Consultant communication	11	15
<input type="checkbox"/> GP communication	12	20
<input type="checkbox"/> Miscommunication	19	34
<input type="checkbox"/> Being stigmatised	4	9
<input type="checkbox"/> It was like I wasn't there	3	4
<input type="checkbox"/> Lack of introductions	4	7
<input type="checkbox"/> Professionals are busy	9	16
<input type="checkbox"/> Promoting a positive outcome	7	11
<input type="checkbox"/> Interprofessional	19	64
<input type="checkbox"/> Trusting specialist over GP	5	7
<input type="checkbox"/> Contact with services	0	0
<input type="checkbox"/> Alcohol liaison nurse	11	21
<input type="checkbox"/> Consultant	0	0
<input type="checkbox"/> Contacting consultant	3	5
<input type="checkbox"/> Relationship with consultant	13	16
<input type="checkbox"/> Lack of continuity	13	26
<input type="checkbox"/> Dietetics	5	9

Nodes

Name	Sources	References
○ District nurse	3	6
☐ ○ GP	0	0
○ A doctor that cares	20	44
○ Contradicting specialists	4	5
○ Getting an appointment	6	8
○ Happy to take a back seat	3	5
○ Just wasn't helpful	3	7
○ Not terribly knowledgeable	11	18
☐ ○ Relationship with GP	7	8
○ Bad relationship	3	5
○ Good relationship	11	23
○ Lack of relationship	3	4
○ Role of GP	13	15
○ Marie Curie PC nurse	4	13
○ Occupational therapy	3	4
○ Physiotherapy	3	3
○ Social work	5	9
☐ ○ Hospital experience	28	61
○ Access issues	6	14
○ Being discharged prematurely	6	7
○ Contact with nurses	14	23
○ Feeling insignificant	3	4
○ Feels like coming home	9	14
○ You're always waiting for something	6	10
☐ ○ Medical care	33	65
○ End of life care	7	26
○ Lack of follow-up	12	26
○ Reassured by check-ups	5	12
○ Seeing lots of different doctors	17	32
☐ ○ Undergoing medical procedures	3	3
○ Endoscopy	13	18
○ Paracentesis	13	50
○ Wasting doctors' time	2	5
☐ ○ Experiencing the illness	3	3
☐ ○ Changing outlook on life	5	12
○ Making the most of time	3	20
○ Positive impact of illness	7	12
☐ ○ Coping	28	55
☐ ○ Burdening others	13	24
○ Hiding emotions from others	6	9

Appendix 7: Example of an ethical challenge in qualitative longitudinal research

As indicated in Section 4.7, the deeper connection which developed between researcher and researched as a result of the longitudinal nature of this study at times challenged professional boundaries. Lonely and isolated participants in particular thrive on the non-judgemental, sympathetic role of the researcher providing a rare opportunity to speak openly about their feelings and concerns (Watson, Irwin and Michalske, 1991). Research interviews exploring individuals' 'intimate sphere' are particularly prone to being considered therapeutic engagements by some participants (Birch and Miller, 2000). A lack of appropriate community-based support services can contribute to the threat of such 'privatisation' of the research relationship and the development of over-dependence on the part of the participant (Hemmerman, 2010).

Some of these issues were borne out in this study. For example, both Sarah and Fraser would occasionally phone me to see how I was getting on, while eagerly pushing for their next interview to take place. Ben freely admitted that he found our interviews cathartic and that being able to speak openly and honestly with someone about "all that stuff in his head" made him feel better. Our catch-up telephone conversations were also significantly longer than with other participants for that reason. He would give me a detailed run-down of what had been happening over the previous weeks and share his feelings on the situation. It did not feel appropriate to cut him short on these occasions and of course this information was also of value to the study in terms of timing the next visit and planning follow-up questions. However, granting him so much of my attention appeared to have blurred the boundaries of our relationship over time, as he subsequently asked whether I would consider visiting him and his partner informally, as 'friends', as he really enjoyed and benefitted from our conversations.

In situations such as these the task of relationship maintenance was a challenging one as I had to be mindful of the ethical boundaries I was subject to. I had to be careful not to compromise trust and rapport whilst being supportive of participants' needs. Thankfully Ben appreciated the professional limitations placed upon our relationship

and was happy to continue with the study despite my declining his request, although I did feel that he was more distanced and guarded with me after this incident.

This example demonstrates the unpredictable, evolving, situated and relational nature of ethical decision-making in qualitative longitudinal research, which adds to the challenges of appropriate research conduct by requiring the researcher to be alert to and react to any unforeseen ethical dilemmas as they arise.