Dying from liver disease: the importance of end-of-life discussions

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Introduction

Over the past 50 years, deaths from liver disease have risen dramatically, whereas deaths from many other major diseases have fallen (Williams et al, 2014). Liver disease is now the third largest cause of premature death in the UK, with alcohol related liver disease accounting for nearly 40% of these deaths (National End of Life Care Intelligence Network (NELCIN), 2012). With advanced liver disease comes the associated complications of varices, hepatic encephalopathy and ascites, and death from liver disease can be sudden and catastrophic.

It has been acknowledged that 'supportive and palliative care needs in people with liver disease often go unrecognised and unaddressed' (Kimbell et al, 2018). End-of-life care and wishes can be a difficult subject to broach to patients and their loved ones, but it is one that nurses are often best placed to undertake. Therefore, when considering the overall care of patients with liver disease, it is necessary to incorporate anticipatory and concordant end-of-life plans.

Liver death rates

Since the 1970s, death rates from liver disease have exponentially increased by over 400%, whereas death rates from other causes have lowered (Public Health England (PHE), 2018). Between 2001 and 2009 alone, there was a 25% increase in liver-related deaths in the UK, and in 2014 there were approximately 11 600 deaths attributable to liver disease (PHE, 2018). Liver disease is now the fifth biggest cause of death in the UK, making it the only major cause of death that is continuing to increase year on year (British Liver Trust (BLT), 2017; Williams et al, 2018). There are many causes of liver disease, but the main attributable factors are alcohol, obesity and viral hepatitis. All of these are preventable (NELCIN, 2012). Other factors include the genetic conditions haemochromatosis and autoimmune liver disease.

Liver disease in the under 65s is now the third major cause of premature death, with alcohol-related liver disease accounting for around 37% of all liver deaths (NELCIN, 2012). Because of this, being diagnosed with or dying from liver disease is often associated with a stigma. Furthermore, the increasing incidence of advanced liver disease presents a major public health issue and potential palliative burden to the health service (Faull et al, 2012).

Complications of liver disease

Liver cirrhosis leads to portal hypertension, which carries the complications of ascites, varices and hepatic encephalopathy (HE).

Varices

Variceal haemorrhage is a major cause of mortality and one of the most distressing complications for patients to experience or loved ones to witness (National Institute for Health and Care Excellence (NICE), 2013). Therefore, people dying from liver disease can have complex end-of-life care needs that require hospital admission to deal with complications.

Around 70% of these patients die in hospital (NELCIN, 2012). This can make end-of-life discussions and planning challenging. However, these discussions can be even more difficult for those with alcohol-related liver disease, who are often younger and, in some instances, compounded with drug dependence and/or mental health problems, with no social or family support (PHE, 2017).

Hepatic encephalopathy

Hepatic encephalopathy is a complication of decompensated liver cirrhosis and manifests as altered levels of consciousness, ranging from forgetfulness through to confusion and, in severe cases, coma. HE is graded from 0–4 (Table 1). HE can occur suddenly, and its manifestation can be alarming. Therefore, patients and their loved ones should be forewarned of the potential complications of liver disease before they occur.

Table 1. Grades of hepatic encephalopathy

Grade	Description
Grade 0 (minimal)	Changes to mentation and affect (such as reduced coordination or concentration); no clinical evidence
Grade 1 (mild)	Short attention span; mood changes (such as depression or irritability); sleep disturbances
Grade 2 (moderate)	Forgetfulness; fatigue; slurred speech; inability to do basic arithmetic; apparent confusion; ability to respond to verbal commands
Grade 3 (severe)	Confusion; bizarre behaviour; sleepiness; responsiveness to verbal stimuli
Grade 4 (coma)	Coma; potential irresponsiveness to painful stimuli
Source: European Association for the Study of the Liver (2010)	

Ascites

Ascites is the abnormal accumulation of fluid within the peritoneal cavity. There are many causes of ascites, but it is most commonly due to cirrhosis of the liver causing portal hypertension (Douglas et al, 2013). The development of ascites is an indicator that liver cirrhosis has progressed from compensated (or stable) cirrhosis to decompensated cirrhosis (BLT, 2017), which is a sign of end-stage liver disease. Many litres of fluid can accumulate in the peritoneal cavity, causing discomfort and pain, as well as more serious complications, such as breathing difficulties, hydrothorax and spontaneous bacterial peritonitis. For patients with decompensated liver disease, if liver transplantation is not an option, this is an appropriate time to discuss advance care planning. Patients with decompensated cirrhosis have a 40% possibility of dying at 1 year from diagnosis and a 50% chance of death at 2 years (EASL, 2010).

Prognosis and scoring systems

Prognosis is closely related to the severity of the underlying disease. In the complex management of such an array of symptoms, it is possible to predict survival rates and disease trajectories with the support of well-established scoring classifications, such as the Childs-Pugh classification, the model for end-stage liver disease (MELD) and the UK end-stage liver disease (UKELD) model (Medici et al, 2008).

The MELD scoring system is primarily used to predict mortality for patients on a waiting list for liver transplant. However, studies have revealed adding serum sodium to the MELD scoring system, as in UKELD, provides a better prognostic indicator of mortality before and after liver transplantation (Aroori et al, 2010). Hepatology units use both the Child-Pugh scoring systems and the UKELD score to determine priority for liver transplantation (Cheung and Cheung, 2013). The Child-Pugh score uses clinical features, such as:

- Serum levels of bilirubin
- International normalised ratio (INR)
- Degree of ascites
- Grade of HE.

While increasing symptom burden does correlate with increasing disease severity, sudden changes in symptoms and the speed of deterioration can create much uncertainty for patients living with advanced liver disease and those managing their care (Kimbell et al, 2015). However, uncertainty neither explains nor excuses professional failure to have timely conversations about the future with patients with advancing liver disease. In fact, prognostic indicators should enable timely conversations, and best-practice guidance encourages carers to be proactive towards conversations about their future care, wishes and preferences (Wright et al, 2018).

Timely identification of patients

In view of liver disease's increasing symptom burden and palliative care needs, which can go unrecognised, patients with advancing disease need to be identified in a timely manner (Poonja et al, 2014). To ensure care, assessment and planning are truly patient-focused and proactive, early patient identification can be guided using disease trajectories, classifications and frameworks, such as the AMBER care bundle in acute hospitals and the Gold Standard Framework (GSF) developed in primary care (GSF, 2011; Etkind et al, 2015). To help professionals identify these patients the AMBER and GSF frameworks ask the following surprise question: 'would you be surprised if the individual patient may die within the next 12 months?'. This is asked in the understanding that the next 12 months' journey is likely to be unpredictable, but there should be many potential contact points ahead where professionals have the time and to plan for these conversations (Thomas et al, 2016; Wright et al, 2018).

Proactive patient identification contributes to the kind of quality care that is characterised by:

- A person-centred approach
- Open and honest communication
- Treating individuals with dignity and respect (Health Education England (HEE), 2017a)

The national quality standards for end-of-life care draw on evidence to emphasise that all health and social care staff involved in end-of-life care, regardless of professional role, are under a particular expectation to deliver individualised care (Department of Health and Social Care (DHSC), 2009; NICE, 2004; Leadership Alliance for Care of Dying People (LACDP), 2014; Care Quality Commission (CQC), 2016; HEE, 2017b).

The CQC (2016) reviewed national statistics on the delivery of end-of-life care, finding significant inequalities in the care delivered, with reduced access to advance care planning in those who were more vulnerable, either through demographics, dementia or dying from comorbidities other than cancer. This may mean that, for many dying from liver disease, individualised end-of-life care may not be achievable, and their wishes may go unidentified and unexplored. To combat these inequalities, missed opportunities need to be reduced, and not failing people who may be in their last year of life means identifying them sufficiently early.

Preferred place of death

Preferred place of death has historically been a performance indicator in the UK, with PHE's (2017) end-of-life care profiles aiming to reduce the overall number of deaths in acute hospitals. This is based on the understanding that most patients would rather die at home than in a hospital, and so the acute setting is not the ideal place for end-of-life care. As liver disease advances, with increasing symptom burden and severity, crisis points requiring hospital admission become more common, which can be very frightening for patients and their families. For example, a patient might experience a catastrophic variceal haemorrhage at home, necessitating emergency hospital admission for urgent lifesaving treatment and/or symptom management. For patients who wish to die at home, hospital admissions can still be unavoidable. This patient and/or family can change their minds, and a death in a hospital should not be considered a failure, when the patient received high-quality end-of-life care at the point of admission.

Open and honest discussions about treatment plans and symptom management should be prepare health professionals and loved ones for a likely death, whether it occurs with or without medical intervention and whether or not it happens at home. Professional accountability means that among a nurse's core duties are candour and respect when it comes to balancing ethical principles (General Medical Council (GMC), 2010; Nursing and Midwifery Council (NMC), 2015).

In liver disease, therefore, place of death may not necessarily be an appropriate marker for whether quality end-of-life care has been achieved. For some patients dying from advancing liver disease, hospital may be the best and preferred outcome, and for others it may not be. This underlines the need to make sure care is individualised and person-centred. Advancing liver disease often comes with rapid deterioration, which presents much uncertainty and makes conversations on advance care planning especially important.

As well as the need to discuss advance care planning, care coordination is essential to minimise duplication and ensure information is shared promptly between health professionals. Complex needs often require high-quality care in a variety of settings, requiring frequent medical attention as death approaches. Therefore, for each patient, will it is necessary to identify contacts for advice on palliative care and liver disease, both in and out of hours, as recommended by the National End of Life Care Programme (NELCP) (2013) for patients with liver disease.

Reviewing care plans

As their illness progresses, liver patients require regular review of care planning, and discussions of wishes and preferences. Nurses are in a prime position to have conversations with patients and their families about end-of-life care. Tailoring individual emergency care plans should ideally involve those health care professionals who know the patient well and consider what potential outcomes are most likely. Discussing preferred manner and place of death is the cornerstone of modern treatment plans, such as the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) (Pitcher et al, 2017). ReSPECT discussions should:

- Start as early as possible
- Link in to ongoing conversations
- Give ample opportunities to discuss possible treatments that can be given—not just those that may be withheld, such as resuscitation (ReSPECT Working Group, 2017).

Care plans are created through conversations between patients and health professionals, covering future care and treatments that they may want or may wish not to have in a future emergency. This helps to balance and frame these often-difficult conversations. The completed form stays with the patient and is made available to health professionals who called in an emergency, either at home or in hospital. It may contain broader goals of individualised care and encourages open and honest conversations about future uncertainties, and it captures what is important to the patient as he or she approaches potential crisis points and dying. Such emergency treatment plans may also contain the discussions and decisions about cardiopulmonary resuscitation, along with goals and ceilings of emergency treatment and care. To support autonomy and mental capacity assessment, the earlier these conversations can be had prior to any cognitive deterioration, the more likely that these open and honest conversations can support best-interest decisions when needed at a later point (UK Government, 2005).

Nurse training

It is of paramount importance to enhance nurses' skills in dealing with complex end-of-life care in patients with liver disease, as nurses are at the heart of providing a person-centred and individualised approach to care. Evidence suggests that professionals' and patients' acknowledgement of death allows sensitive discussions around end-of-life issues and concerns (Anderson et al, 2013). While holistic, person-centred care and equal partnership working should be at the heart of nurses' skills and abilities (HEE, 2017a), not all nurses always feel either confident or competent when it comes to having these conversations.

Having identified that nurses caring for liver patients need to be equipped to help support many complex situations, attention to providing the underpinning education and training in communication skills is essential to increase both confidence and competence in having these conversations. Recent developments in conversational analysis have shown that both professionals and patients are hesitant to introduce the topic of end-of-life discussions, for numerous reasons (Pino and Parry, 2018). During consultations, patients are often reluctant to ask for an estimated prognosis or broach the subject of dying, instead waiting for open opportunities to appear. Patients can be encouraged by understanding their perspective and readiness to hear more (Pino and Parry, 2018). Nurses often fear that raising this topic may not be their role or responsibility, this it is something that all health professionals involved in end-of-life care share responsibility for, and nurses are most suitably placed than other colleagues, being more likely to know their patients and associated loved ones well. However, nurses need to feel confident and have appropriate support and training. Being able to see the impact of real patient interactions with regards to end-of-life talk adds both authenticity and greater emotional impact to new learning, which can help build confidence (Parry et al, 2018).

Conclusion

Understanding an individual's personal context, situation and choices, as well as finding out what is important to their quality of life, is paramount (HEE, 2017b). Some patients with decompensated liver disease may have had a lifestyle that already isolated them from loved ones, and, while it is good to identify if patients have important loved ones in their lives, it cannot be assumed that everyone has a family, carers or friends, or that they would choose anyone to be involved in their lives or their care, and this may or may not be a concern to them. What is important for nurses is to identify and recognise an individual's circumstances and focus on a person-centred approach (LACDP, 2014). Where appropriate, nurses can offer and signpost to befriending services and community care coordinators, as well as encourage engagement in advance care planning and escalation of treatment plans, in order to capture patients' wishes about what is important to them and to make sure they are shared and taken into consideration.

Patients with advanced liver disease, as well as their loved ones, face considerable challenges. Nurses are able to support them in managing these challenges by supporting quality of life until death and balancing the patients' preferences and wishes with the need to prepare for crisis and the eventuality of death. As such, these patients need anticipatory, concordant end-of-life plans to be incorporated into their overall care.

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