

alcoholic, fatty, viral and other chronic liver diseases and liver cancer.

**Results:** The number of people who die with liver disease as UCOD has risen from 9,231 in 2001 to 12,538 in 2011, averaging 10,850 (2% of all deaths). On average ~16,000 people (3.4% of all deaths) died each year with liver disease as either UCOD or a CCOD. The most common UCOD are alcoholic liver disease and liver cancer (0.8% and 0.5% of all deaths). Deaths from liver disease are more common in males and age at death is young (90% are under 70 years old, one in ten of all deaths in 40-49 year olds). More (2.3 fold) people die of liver disease from the most deprived quintile (3,148 p.a.) than the least deprived (1377 p.a.). 71% of people with liver disease as UCOD died in hospital compared with 56% for all causes of death. Hospital death rates varied from Viral liver disease (86%) to liver cancer (48%).

**Conclusions:** Liver disease patients differ from the majority of dying patients due to young age, deprivation and hospital as a place of death. Life threatening, acute-on-chronic exacerbations, co-morbidities and psychosocial problems frequently complicate their end of life care. More focus needs to be given in the hospital setting to recognition of and preparation for the possibility of death in liver patients as this is where most will end their lives.

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### Gatekeeping in Palliative Care Research: A Systematic Review of Reasons

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**Introduction:** Research in palliative care is essential to improve therapies. Study reports indicate that gatekeeping -a phenomenon that patients who are eligible for inclusion are not approached for participation- hampers palliative care research.

**Aim:** To identify who are gatekeepers in palliative care research and to list their reasons for gatekeeping in order to work towards a thoughtful patient centred approach of gatekeeping

**Method:** A 'review of reasons' was conducted, according to a well described model that integrates the systematic PRISMA approach and the identification of reasons using strategies common in qualitative research.

**Study identification:** After screening of 700 unique papers published from 2000, 24 papers were relevant to the research question. Qualitative software (NVivo) supported the systematic identification of gatekeepers and their motives.

**Findings:** Six types of gatekeepers were identified: doctors, nurses, research ethics committees, management and researchers. The most mentioned reason for gatekeeping was the fear of burdening a vulnerable patient. This reason was often reinforced by the pursuit of comfort and well-being, in line with palliative care goals. Other reasons for gatekeeping were feeling uncomfortable by disclosure of health status, to avoid family burden, having doubts about the importance or quality of the study, logistical obstacles and a range of reasons related to personal attitude and expertise. The reasons mentioned often appeared to be a result of intuitions.

**Conclusions:** A variety of actors, including researchers, experience situations in which they felt it would be inappropriate or even harmful to approach an eligible patient. Intuitions more than considerations seemed to underlie the reasons mentioned. There is a need for a normative framework to evaluate gatekeeping.

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### Emotional Impact of Transferring Advanced Cancer Patients from Oncology to Palliative Care

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**Objectives:** To assess the opinion of cancer patients (pts) transferred to the Palliative Care Outpatient Clinic (POC). Specifically, we sought patient opinions on the information they received about the transfer, their experience between the moment their oncologist informed them of the transfer but before the initial consultation at POC, and their expectations of care at the POC.

**Material and methods:** Opinion survey in consecutive pts referred to POC. Prior to the 1<sup>st</sup> POC visit, nursing staff contacted pts by telephone to schedule an appointment and resolve doubts.

**Results:** Of 274 pts enrolled, 269 signed the informed consent form & were evaluable. Mean age was 67 and 65% of pts were male. Most pts (85%) were referred from Medical Oncology. M1 was 68%, median PPS 70%, and 42% of pts received anticancer treatment. Median time from diagnosis was 1.3 years. Pt feelings regarding the transfer were: liked (27%); indifferent (67%); didn't like (2%); don't know (7%). Although most pts (67%) reported that

the oncologist explained the transfer rationale, the remaining pts answered “don’t remember” (17%), “No” (10%), or “don’t know” (6%). Pt reported “Reason for consultation” were pain (43%), shared care/follow up (25%), to prevent problems (12%), to manage problems other than pain (9%), and don’t know (11%). When informed of transfer to POC, 23% pts reported unease/worry, although this decreased to 16% after a mean of 3 days ( $P=0.009$ ). Before the first consultation, 91% believed the POC would help them while 9% expected to get worse.

**Conclusions:** In a group of pts with advanced cancer and early intervention, transfer to POC is perceived with calm (liked or indifferent=84%), with most pts (91%) expecting to be helped. The main perceived reason for referral was pain, although shared follow up and prevention of future problems were also perceived as important. Early contact before the consultation could positively influence pts emotional state.

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#### **From the Spectacular to the Subtacular; Experience of Hospital Care for Patients with Advanced Respiratory Illness Following Emergency Admission**

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**Background:** Despite the increase in emergency admissions of patients with lung cancer and Chronic Obstructive Pulmonary Disease (COPD), little is known about the patient experience in hospital. Understanding this is important to ensure that services are organised and patients receive high quality, compassionate care.

**Research aims:** To explore the experience of patients with advanced Lung Cancer and COPD following emergency admission.

**Design and methods:** Qualitative, critical case study involving semi-structured interviews with 39 patients (15: COPD, 24: lung cancer), 50 health care professionals and 20 family/informal carers. Patients were recruited from three hospitals in England. Interviews took place after emergency admission and following discharge or transfer to a hospital ward. Interviews were transcribed and analysed thematically.

**Results:** Patients were satisfied with their initial emergency treatment but expressed concerns about care in the subsequent phase of hospital admission particularly lack of attention to their individual needs, lack of recognition

by staff of the expert family, poor communication about management plans, and lack of continuity between primary and secondary care.

**Interpretation:** Findings offer important insights into hospital care near the end of life. Despite processes in place to prevent emergency admission, the nature of advanced respiratory disease predisposes patients to emergency admission. The initial treatment of the acutely ill patient was likened to a ‘spectacular trajectory’ of care however once stabilised, this is replaced with a ‘subtacular’ approach which involved less direct input and a lack of attention to continuing supportive and palliative care needs. This has implications for hospitals providing end of life care where more attention needs to be given to the organisation and delivery of care.

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#### **Living and Dying with Advanced Chronic Liver Disease: Negotiating Uncertainty**

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

**Aims:** To explore the dynamic physical, psychosocial, spiritual and information needs of patients and their family and professional carers, and to review their use of health, social and voluntary services.

**Methods:** Qualitative, multi-perspective, serial in-depth interviews. Patients with different causes of liver disease were recruited in hospital. They and their family carers were interviewed up to 3 times over one year. Single interviews were undertaken with case-matched professionals. Interviews were recorded, transcribed and analysed using grounded theory methods and NVivo 9.

**Results:** 15 patients and their carers were recruited and 53 interviews conducted. Uncertainty was the key theme experienced across all domains and by all participants: patients, family carers and professionals. This 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. The ubiquitous uncertainty meant that a care planning approach was hard to introduce.

**Conclusion:** This is the first serial interview study of this patient group. It identifies uncertainty as the pervasive