The role of palliative medicine in end stage symptom control of dyspnoea in patients with Duchenne muscular dystrophy.

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Background Duchenne Muscular Dystrophy (DMD) is a progressive muscle wasting disease. It is the most common type of muscular dystrophy in the UK. Those affected usually die in their late 20s or early 30s due to cardiac or respiratory problems. As the disease progresses they may need management of symptoms arising from complications of late disease, such as pain. This poster looks into the joint services provided by the community palliative team at Shrewsbury and Telford Severn hospice and the Oswestry neuromuscular clinic caring for five patients with advanced Duchenne muscular dystrophy.

Methods The notes from the clinic consultations of the five patients involved were used and the consultations noted, along with the proposed management plan. Subsequent clinic follow ups were looked into to review response to the management plan and note any amendments to treatment that were made.

Results The five patients presented with pain as their main symptom. Different choices of analgesia were tried with different responses. All patients reported improvement in their symptoms after starting analgesia with some requiring a combination of analgesics. In addition to this, some of the patients required input from other services regarding other aspects of patient care, such as the respiratory team for sleep studies and Telford Severn hospice and the Oswestry neuromuscular clinic caring for five patients with advanced Duchenne muscular dystrophy.

Conclusion As there are no guidelines for management of DMD, management may involve trials of different analgesia for pain management in addition to involvement of a multi-disciplinary team to address other care issues. As palliative medicine involves symptomatic treatment of patients with advanced and terminal disease and holistic care, there is a role for palliative medicine in management of patients with end stage Duchenne muscular dystrophy.

Cannabis use in a rural palliative care community: a survey

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Interest in Cannabis as a medicinal product is growing globally; recent scheduling review of Cannabis by the Chief Medical Officer puts forward a strong case for the therapeutic benefit of cannabis-based medicinal products. We have noticed an increased number of questions, from patients and carers relating to Cannabis use. More patients appear to confide in us about their use of Cannabis. The incidence of Cannabis use in a palliative care population is little known.

We undertook a sequential survey of fifty patients referred into and triaged as requiring domiciliary review by the Severn Hospice Nurse Outreach team. Each patient was asked at the end of the usual initial assessment whether they would take part in the anonymous survey.

Results 50 consecutive patients referred to the Shropshire community palliative care team (outreach specialist nurses) 36 patients completed the survey.

Of 36 questionnaires completed 8 patients declined completion. 10 patients (almost a third of those completing the survey) had considered using Cannabis, 18 had not.

The study population (n=36) were mainly aged over 70 (n=21). Gender split was fairly equal. Of those who had considered cannabis (n=10), the main reason was for pain relief (n=6). Other reasons included general wellbeing and treatment/cure. Half of those who had considered cannabis were on chemotherapy. Ages in the ‘cannabis curious’ group tended to be younger – with 40% aged less than 70. Half of these had researched Cannabis using only Media sources.

Conclusions In a survey of 50 palliative care patients in a rural county of England asked ‘Have you considered the use of Cannabis’ most had not. Of 10 patients who said they had considered it, the most commonly cited reason was Pain relief.

Symptom control of dyspnoea in patients with cystic fibrosis

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Background Cystic fibrosis (CF) remains an incurable condition in respiratory medicine. One of the main symptoms is dyspnoea. CF is a multi-system disorder and treatment of pulmonary symptoms tends to focus on medication which can be nebulised therefore minimizing the systemic side effects. Traditionally in palliative medicine opioids are effective at relieving dyspnoea however nebulised opioid is not routinely recommended. In patients with CF who are at risk of gastrointestinal complications such a distal intestinal obstruction syndrome (DIOS), administration of nebulised opioids has been sporadically reported to improve dyspnoea and minimize the risk of constipation.

The aim of this systematic review was to examine the role of nebulised opioids in improving dyspnoea in patients with CF.

Methods Medline (1946–2018) and Embase (1974–2018) were searched. Eligible studies met the following criteria: patients with CF, patients >13 years of age

Results 70 studies were eligible. Three studies fulfilled the criteria for review. The three studies described different case reports of nebulised opioid in patients with CF. The ages ranged from 13 years to 48 years. All patients had end stage respiratory failure due to CF. Two patients received nebulised morphine and one patient received nebulised fentanyl.