

An increasing number of patients with motor neurone disease (MND) in the UK and Ireland are using assisted ventilation to control symptoms and prolong life. A small proportion of these are initiated on long term tracheostomy ventilation (TV). NICE guidelines dictate that MND patients should routinely receive specialist palliative care input, yet research into the management of TV MND patients in the hospice setting is limited. Objective

The aim of this study was to explore the extent to which hospices and specialist palliative care units (SPCUs) in the UK and Ireland currently manage MND patients using assisted ventilation, especially TV.

Methods A literature review was used to guide the development of an electronic questionnaire which was sent to medical directors or lead physicians in all hospices/specialist palliative care units in the United Kingdom and Republic of Ireland. The questionnaire was sent to 184 units.

Results The response rate was 41.3% (n=76). 97% units admit MND patients on non-invasive ventilation (NIV) but only 33% admit TV MND patients (n=22). However 40% of respondents indicated that community palliative care support was provided to TV MND patients. 61 respondents indicated adequate expertise in the management of NIV, while only 6 indicated adequate expertise in managing TV. While the majority of respondents (96%) indicated that Advance care planning was routinely offered to the MND patients, less than half routinely included conversations regarding ITU admission (40%) or invasive ventilation (39%). Only 11 (14%) of respondents indicated having personal experience of withdrawal of TV in MND patients.

Conclusion This study has highlighted a perceived lack of expertise in the management TV MND patients within hospices/SPCUs with less than half of units allowing admission for TV MND patients. There is a need for further research in this area.

163 EVALUATION OF CAN-GUIDE (CANCER-GOAL USE IN DECISIONS): A DECISION MAKING SUPPORT PACKAGE TO ENHANCE SHARED DECISION MAKING IN PROGRESSING CANCER

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Introduction National guidelines recommend that shared decision making be employed where several treatment or supportive care options are available to the patients with cancer. Shared decision making is associated with positive outcomes for patients including reduced decision regret surrounding their treatment and reduction of unrealistic expectations. Optimising shared decision making in situations where cancer is no longer curable may facilitate the discussion about not only the aims of treatment but also the patient's life goals and how their treatment options may affect these.

Aim to evaluate the Cancer-Goal Use In DEcisions (Can-GUIDE) web-based communication/decision aid as a resource for facilitating goals of care conversations and shared decision making in the context of incurable cancer.

Method A pre-test post-test pilot study to assess the benefit of Can-GUIDE on patient experience and shared decision making. The quality of the decision making process is currently

being assessed by determining the effect on patient decision self-efficacy, decision conflict, preparation for decision making and perceived involvement in shared decision making with their clinician. Oncology clinician opinion will be sought to determine whether patient responses to the package helped guide GOC conversations within their consultations. Furthermore, GPs will be surveyed to determine the usefulness of receiving a tool documenting GOC conversations within oncology consultations. The views of all participant groups surrounding the usability and acceptability of Can-GUIDE are also being investigated.

Results Currently, 14 patients have been recruited for the study with 4 withdrawn due to progressing disease or non-compliance with protocol. Data collection is due to complete March 2018 with a total of 40 patients recruited.

Conclusions If our pilot results demonstrate the potential value of Can-GUIDE a fully powered randomised controlled trial will be conducted to test its effectiveness on improving patient-centred outcomes.

164 BEYOND EARLY INTERVENTION – INTEGRATED WORKING IN A BRAIN TUMOUR CLINIC

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Background An increasing body of evidence supports early palliative care involvement in oncology as improving quality of life, advance care planning and decision making. Patients with brain tumours experience high symptom, social and psychological burden and those with lower grade tumours may struggle to access palliative care services earlier in their disease trajectory. This tumour site has not been studied in any previous work on early intervention or joint working. This service review looks at a joint oncology/palliative care, consultant delivered, brain tumour clinic.

Methods Records of 133 consecutive consultations (82 patients) were analysed for demographics, diagnosis, clinician seen, primary purpose of appointment and additional topics addressed. For a cohort of patients from each diagnostic group, all consultations since diagnosis were reviewed to establish any patterns of engagement over time and disease progression.

Results 43.6% of consultations were with the palliative care consultant (PCC). Longitudinally, 81.8% of patients saw the PCC at least once. Whilst PCC (60.3%) and oncologist (62.6%) had a similar proportion of complex consultations (those dealing with at least one additional topic) for the oncologist these were concentrated in new patient consultations and treatment decisions (63%) and for patients with glioblastomas (60.1%); whereas for the PCC, complex consultations were distributed across all tumour types except pituitary and predominantly occurred in routine reviews (76.5%). Levels of complexity were comparable in patients with lower grade gliomas or meningioma to those with glioblastomas.

Conclusions This analysis demonstrates a high level of complex need in patients with brain tumours and particularly for those with lower grade tumours over the very prolonged course of their disease. Integrated working appears to facilitate early involvement of palliative care and collaborative care,