31 PATIENTS', RELATIVES' AND HEALTH PROFESSIONALS' DIRECT EXPERIENCES AND PERCEPTIONS OF BISPECTRAL INDEX (BIS) MONITORING IN A UK HOSPICE: A QUALITATIVE INTERVIEW STUDY FOR I-CAN-CARE

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10.1136/spcare-2019-mariecuriepalliativecare.31

Background Research interest is growing in using EEG-based tools, such as Bispectral Index (BIS) technology, to assess levels of sedation for palliative care patients. To date, little research has investigated using BIS in palliative care practice, but previous exploratory work for our I-CAN-CARE programme asked clinicians, patients, and relatives whether using BIS in palliative care would be acceptable in principle.

Aim To explore the direct experiences and perceptions of palliative care patients, their relatives, and clinicians regarding BIS monitoring in a UK hospice.

Methods We trialled the use of BIS with hospice inpatients, and then conducted semi-structured interviews with them, their relatives, and hospice clinicians. Interview transcripts were analysed following the framework method.

Results Ten patients, two relatives, and ten clinicians participated in individual interviews. Most (as in our previous hypothetical study) considered BIS monitoring non-intrusive. Some patients commented that after the sensor had been applied to their foreheads they were 'not aware' of it. Patients and clinicians commented that, although noticeable, the BIS device and sensor were small and easily handled, and felt that the monitoring did not affect patients' daily routines, nor care activities. After trialling BIS monitoring, participants said that they would have no objections to BIS being used as part of routine care, provided that it was beneficial for patients.

Conclusions Our participants perceived BIS technology as acceptable and feasible for monitoring hospice inpatients' consciousness levels. This indicates that further exploration of how this technology might contribute to palliative care practice would be appropriate, and valuable.

32 THE TWO SIDES TO COUGH STORIES AND THE TRUTH IN BETWEEN: A QUALITATIVE STUDY OF IDIOPATHIC PULMONARY FIBROSIS (IPF) PATIENTS AND THEIR CLOSEST FAMILY MEMBERS

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10.1136/spcare-2019-mariecuriepalliativecare.32

Background Idiopathic Pulmonary Fibrosis (IPF) is a progressive condition of the lung with no known cause or cure. Whilst treatments slow disease progression, symptom control remains paramount to improving quality of life. Cough is a predominant symptom, however, the underlying mechanism is unknown and medications seldom provide relief (Hope-Gill et al. 2003). This study aims to characterise the way patients and their family perceive cough and the impact on their daily lives.

Methods Eligible patients had a diagnosis of IPF and a chronic cough. A convenience sample was drawn from an ongoing cross-sectional study and consented to face-to-face interviews

in the outpatient setting or at home. Thematic analysis was used to analyse the transcripts.

Results 12 patients (9 male), aged 45–84, with a history of IPF spanning 1–57 months and 11 family members (females) participated. Patients and family see cough as marker of disease. Cough initially motivated patients to seek health advice which led to the diagnosis and from this, cough is perceived as a reminder of the condition and used as a measure of disease progression. There are degrees of understanding, acceptance and ability to cope with cough, depending on family members, friends and societal awareness of patients' condition. Cough also generates resentment, anger and denial, some of which stems from lack of communication.

Conclusions Patients and family use cough to monitor disease progression. However, the lack of a clear link between the two makes it challenging for clinicians to support patients to manage IPF. Communication and information sharing between patients, family and clinicians enhance coping mechanisms.

33 WHAT ARE THE BEST SETTINGS AND METHODS FOR RECRUITMENT INTO A RANDOMISED TRIAL IN SEVERE BREATHLESSNESS?

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10.1136/spcare-2019-mariecuriepalliativecare.33

Limited drug treatments exist to relieve severe breathlessness in advanced disease. Antidepressants warrant consideration due to potential effects. However, trials are challenging.

We aim to test the feasibility of a larger randomised mirtazapine trial, focusing on best settings and methods for recruitment. The BETter Treatments for Refractory Breathlessness (BETTER-B feasibility) trial was a randomised, double-blind, placebo-controlled mixed-methods feasibility trial in London, Nottingham, Hull/York in adults with advanced diseases and modified Medical Research Council breathlessness scale (mMRC) scores of 3/4.

We screened 409 patients, randomising 64 participants (30 mirtazapine, 34 placebo), averaging 1.8 patients per centre pcm. Existing antidepressant use was the main reason for ineligibility. 63% needed help completing questionnaires. Missing data were low. Participants (47 men) had a mean age of 72 (range 51–90) years. Primary diagnoses: chronic obstructive pulmonary disease (COPD) (40, 67%), interstitial lung disease (ILD) (19, 32%), cancer (1), heart failure (4). Several had multimorbidity.

A 6.4:1 (16%) screen to recruit conversion suggests recruiting people with stage 3/4 mMRC breathlessness is possible. We consider screen to recruit ratios for different settings and diagnoses. Cancer patients were difficult to recruit. Achieving recruitment requires dedicated research teams.

Six participants per arm stopped treatment prematurely; 4 mirtazapine, 5 placebo experienced serious adverse events (SAE); 1 (placebo) suspected as medication related. One

participant per arm died, both unrelated to intervention. Qualitative data suggests feasibility and acceptability.

A randomised double-blind phase III trial of mirtazapine is feasible and acceptable in patients with COPD/ILD, with low toxicity, and is warranted.

34 NURSING STAFF ATTITUDES TO CLINICALLY ASSISTED HYDRATION AT THE END OF LIFE IN A HOSPICE SETTING

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10.1136/spcare-2019-mariecuriepalliativecare.34

Background Clinically assisted hydration (CAH) at end of life is a contentious issue (Cabañero-Martinez et al, 2016) There is disagreement as to its benefits and this can lead to a lack of concordance between medical and nursing opinions, with nurses feeling unable to challenge doctors (Churchman, 2010; Van Der Riet, 2008; Mayashita, 2007). Prior to introducing a feasibility study on CAH (Davies, 2018) on one hospice site, an unpublished survey of nursing staff revealed widespread dissatisfaction with the standard practice of not routinely offering CAH. Following completion of the study a staff survey was undertaken to see if attitudes had changed.

Aims To determine if nurses feel coerced into accepting the current hospice policy on CAH. To examine how nurses interacted with families when asked about CAH. To explore staff engagement with research on CAH.

Method A semi-structured questionnaire sent to all nursing staff including HCA's, with closed and open-ended questions. The responses were analysed using descriptive statistics and thematic analysis.

Results The responses indicated that;

The majority accept standard care without feeling coerced (68%).

Nurses felt they could challenge accepted practice (62%).

An overwhelming majority felt the hospice should be engaged in research on CAH (80%).

Nursing staff expressed the following;

Nurses wanted to be more involved in decision making around CAH.

Many felt that a standard practice should be replaced with individual patient decisions. Staff were frequently asked about CAH and felt able to discuss the risks and benefits with families.

Conclusions Overall, nurses accepted hospice standard practice on CAH and did not feel coerced. A few opposed further research, most welcomed it to establish an evidence base.

35 PAIN IN ADVANCED DISEASE: INITIAL FINDINGS FROM A QUALITATIVE INTERVIEW STUDY WITH BRITISH SOUTH ASIANS IN LEEDS AND BRADFORD, UK

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10.1136/spcare-2019-mariecuriepalliativecare.35

Background Population projections indicate that by 2051, the Black, Asian and Minority Ethnic (BAME) populations of England and Wales will rise to 3.8 million people aged 65

years and over, and 2.8 million aged 70 and over (Lievesley, 2010). This has important implications for palliative care services. Current evidence on ethnicity and palliative care is limited, and is often solely focused on access to services (Calanzani et al., 2013). Evidence is particularly limited for British South Asian populations (Shabnam, et al, 2019). South Asians have a high burden of life-limiting and chronic diseases compared to other groups (Nair and Prabhakaran, 2012). This study focuses on pain management, the impact of culture, and the quality of services for British South Asians with advanced disease.

Aim To explore the attitudes and perceptions of British South Asians with advanced disease concerning pain, pain management, and expression of pain; and to examine the differences in service provision.

Methods Qualitative interviews (N=25) with individuals who have serious life-limiting disease, are experiencing pain as a symptom, or having their pain controlled, and are from a South Asian background currently living in Leeds or Bradford UK. Fieldwork was undertaken in 2019. Interviews were audio recorded, transcribed verbatim and analysed using NVivo and Thematic Analysis (Braun and Clarke, 2006).

Discussion Key themes: experiences of pain and pain management related to cultural background; help-seeking behaviour and barriers; strong pain management at the end of life; and differences between those utilising specialist palliative care services and those receiving care elsewhere.

36 PREFERRED AND ACTUAL PLACE OF DEATH IN PATIENTS WITH HAEMATOLOGICAL MALIGNANCIES

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10.1136/spcare-2019-mariecuriepalliativecare.36

Patients with haematological malignancies are more likely to die in hospital than those with other cancers (Cohen et al. 2015), but little is known about their preferred place of death and the discussions surrounding this. This study aimed to investigate this using data from the Haematological Malignancy Research Network (www.HMRN.org); a population-based cohort that, since 2004, has collected detailed information on all newly diagnosed patients across 14 hospitals (catchment populations ~4 million). Additional data for the present study were collected from the medical records of 892 HMRN patients (>18 years) who died 2011–2012.

Fifty-eight percent of patients died in hospital (home, 20%; care home, 11.9%; hospice, 10.2%). Half had a preferred place discussion recorded, with the majority of these having more than one discussion. At the discussion nearest death, the most common preferred place was home (44.9%) followed by hospice (20%), hospital (19.5%), and care home (15.6%). However, preferences varied over time; for patients whose final recorded preference was hospital, 14.3% had the same preference at their first discussion. When home was the final choice, 80.4% also chose home at their first discussion. Patient involvement was less common during final discussions. Almost all of those who wanted to die in hospital did so, yet only half of those who wanted to die at home achieved this.