

Methods Views of hospital physicians caring for people with conditions causing chronic breathlessness were explored in a South Indian hospital as part of a service improvement project. Three semi-structured focus groups were conducted in English, audio-recorded, transcribed and subjected to thematic analysis.

Results Fifteen clinicians participated, representing oncology, palliative care, cardiology and respiratory specialties. Three major themes (Impact, Invisibility and Purpose) and 12 sub-themes were generated by the data.

Chronic breathlessness as defined, was seen as prevalent with a huge impact on patients, their families, carers and clinicians. In non-palliative care clinicians, a sense of therapeutic helplessness with a lack of awareness or ability to manage chronic breathlessness was observed in association with active avoidance. This, a perceived lack of assessment tools and lack of clear clinical pathways allowing access to palliative care contributed to the invisibility of people with this symptom.

Most participants were in agreement about the name of chronic breathlessness syndrome. All agreed that focussed systematic identification would foster education regarding assessment, management and monitoring and would support service development and research.

Conclusions Chronic breathlessness syndrome is recognised in clinical practice in Southern India but risks being invisible due to lack of awareness, particularly of interventions to manage the breathlessness itself. A named and defined syndrome was seen as a way to improve identification and management of chronic breathlessness.

98 THE SYMPTOM BURDEN AND QUALITY OF LIFE IN CANCER PATIENTS IN GAZA, PALESTINE: A CROSS-SECTIONAL STUDY

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Background Cancer is the second leading cause of death in Palestine. Cancer patients usually suffer high levels of physical and psychological symptoms. In Gaza, there are no studies assessing symptom burden and quality of life (QoL) using validated tools. The aim of this study was to assess symptom burden and QoL in a representative sample of cancer patients accessing outpatient services in the Gaza Strip.

Methods A cross-sectional, descriptive survey was used. The Lebanese version of the Memorial Symptom Assessment Scale (MSAS-Leb) and the Arabic version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) were used to collect data from cancer patients accessing oncology outpatient services at Al Rantisi Hospital or European Gaza Hospital (EGH) from July to August 2019. Analysis is ongoing including modelling to derive determinants of symptom prevalence and QoL.

Results Data were collected from 385 cancer patients (93% response rate) at Al Rantisi Hospital and EGH. The majority of participants were women with breast cancer and the mean age was 52 years. The most commonly reported physical symptoms were lack of energy and pain and the most common psychological symptoms were feeling nervous and feeling sad. A higher level of burden of global distress, physical, and

psychological symptoms was found in patients categorised as either 'Divorced/Widowed/Widower', with less than secondary school education or low income. The physical and role functioning domains of the EORTC QLQ-C30 were found to have the lowest score and cognitive functioning the highest.

Conclusions A high symptom burden was identified across participants. There remain many unresolved problematic symptoms for patients with cancer that affect their QoL. Utilising such systematic assessment of symptom burden and QoL can help to inform guidance and protocols for treatment and follow up of cancer patients in this context.

99 THE ROLE OF CIVIL SOCIETY IN THE PROMOTION OF PALLIATIVE CARE: CASE OF PALLIATIVE CARE ASSOCIATION OF RWANDA (PCAR)

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The concept of Palliative care in Rwanda was initiated in 2004, after realization of the need for Palliative care services for the patients with chronic illnesses like cancer and HIV/AIDS. The 1st Palliative Care introduction course was held for health professionals from hospitals and NGOs in 2006.

The role of PCAR in promotion/Provision of PC in Rwanda; 1) Advocacy :(Policy level)

Contributed to the development of Rwanda National Stand-alone palliative care policy, development of standard and guidelines on PC, development of Five year National strategic and implementation plan on PC, availability and accessibility of strong opioids and for integration of PC at all levels of health care. 2)Capacity strengthening; trained 168 trainers (TOTs) of health professional in referral and District Hospitals, 250 Health care professional trained from from different Hospitals and 100 Community health workers. 3) Service Delivery: Started a Hospice and Home palliative care and reached 120 patients, provided to 88 patients: comfort fund, Bereavement support and home based care.

Key Results Government integrated PC into all levels of Health system, Availability of Syrup Morphine, was put on essential drugs list, revision of law concerning the use of Narcotic drugs (allowing Nurses to prescribe Morphine)

Way forward Establish partnership between churches, Rwanda Correctional Service (prisons), and private hospitals.High-level lobbying: government institutions to understand PC (Parliament),Resource mobilization both inside and outside the country. Continuous in-service training on PC, Annual Stakeholders meeting to monitor the implementation of national PC policy, and scale up PC services especially home and hospice care.

100 HOW DO COMMUNITY-BASED PALLIATIVE CARE PATIENTS IN THE USA VIEW EMERGENCY HEALTH CARE PLANS?

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Background Advance care planning (ACP) improves the quality of life, reduces hospital admissions and increases choice for patients with life limiting conditions. ACP includes advance statements, health care power of attorney and emergency

health care plans (EHCPs). They provide concise clinical recommendations for use in an emergency while also aiming to empower patients. There is however no research evaluating the views of palliative care patients on EHCPs.

Objectives The objective of this pilot study was to describe the views of community-based palliative care patients in USA on EHCPs.

Methods The study was conducted in February 2018 with community based palliative care patients in Greater Cincinnati, Ohio, USA. Patients were recruited if they had completed an EHCP and it had been valid for at least 1 month. There was 2 parts to the study: a written quantitative survey and a face to face interview. The study was approved by the health system's Institutional Review Board.

Results Demographics - 7 out of 10 patients eligible participated in the study (Survey 6 patients, Interview 3 patients).

Survey Results 100% patients felt an EHCP guided them during an emergency and they would recommend them to other patients. 100% patients did not share their EHCP with other professionals.

Interview Themes: Patients were overwhelmingly positive of EHCPs: they helped in preventing unwanted hospitalisation and aided symptom management. They described the time to write an EHCP as reasonable.

Conclusion The results of this study demonstrate that patients use EHCPs to guide their care during an emergency. This reaffirms the place of EHCPs in the advance care planning process. Patients did not share EHCPs with other professionals but this may be due to EHCPs being new to the health system. Finally, as this was a pilot study, further large scale research is required to further determine patients' views.

101 A SIMPLE ACT OF KINDNESS CAN DO MORE THAN MEDICINE: PALLIATIVE CARE TRAINING FOR COMMUNITY HEALTH WORKERS IN RURAL MYANMAR

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Introduction Chin State, a very remote and mountainous state, is the most impoverished in Myanmar. Health and Hope has trained 834 community health care workers (CHWs) from over 550 villages across Chin and neighbouring Rakhine state to address basic healthcare needs in their communities. The current project involves the selection and training of Area Coordinators (ACs) to provide support, ongoing training and supplies to a group of CHWs in their geographical area. Palliative Care is underdeveloped and resourced in Myanmar, which ranked 76th out of 80 countries in the Economist 'Quality of death' index. There is no known provision in Chin State.

Method A half day workshop was delivered to 23 ACs which aimed

- To improve understanding of issues facing patients at the end of life
- To introduce palliative care and a holistic approach
- To improve confidence in looking after patients at the end of life

Results None of the participants had previously heard of palliative care. ACs reported that most had looked after patients at the end of their lives with many difficult and distressing

stories involving huge suffering. Verbal feedback at the end of the workshop demonstrated that they had acquired a good understanding of palliative care and a holistic approach in several key areas and had improved in their confidence of caring for patients at the end of their lives.

Conclusion There is a significant need for palliative care in Myanmar, due to a high level of serious health related suffering and poor current provision. A short training package delivered to CHWs improved understanding of palliative care and confidence in looking after dying patients. Additional education, training and resources could further equip the team with the potential to make a significant impact on the lives and deaths of those in Chin and neighbouring states in Myanmar.

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102 USE OF TAPENTADOL FOR PAIN MANAGEMENT IN PALLIATIVE CARE: A RETROSPECTIVE CASE NOTE ANALYSIS OF HOSPITAL INPATIENTS

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Background Tapentadol is a relatively new centrally-acting analgesic medication. Tapentadol is approved for the treatment of severe chronic pain and may reduce the need for strong opioids and reduce side effect burden. However, there is limited data about the use of tapentadol in palliative care. This project aimed to evaluate use of tapentadol in a hospital specialist palliative care unit.

Methods This project included the following: 1) Retrospective case note review of tapentadol use in all inpatients receiving care in a UK hospital specialist palliative care unit over a 12 month period. The primary outcome was whether pain improved following tapentadol use. The following information was collected: reason for initiation, initial dose, titration regime, side-effects, treatment duration, discontinuation reason and quality of discharge information.

2) Anonymised survey of healthcare professionals working within the palliative care team regarding their knowledge about, and use of, tapentadol.

Results Tapentadol was used in 10 individuals. Mean age 65 years; 6 (60%) were male and 4 (40%) were female, all patients had cancer. There was an improvement of pain in 5 (50%) patients; this was identified through electronic clinical records. Nine (90%) received a starting dose of 50 mg BD. The final dose given was 50 mg BD in 5 (50%) people, followed by 100 mg BD in 4 (40%) and 150 mg BD in one (10%). Tapentadol was discontinued in five (50%) due to side effects, inability to swallow and renal failure. Eleven healthcare professionals completed the questionnaire. Of the respondents, 5 (45%) had prescribed or given advice on prescribing tapentadol and 10 (91%) indicated that they would like further training.

Conclusion Tapentadol was used in small number of individuals who all had cancer pain. Our data suggests that tapentadol may be beneficial in palliative care. More research and staff education is important to ensure effective use.