identified to act as a point of contact should the participant lose capacity to consent to further assessments. Once recruited to the study the researcher ensured regular contact with both participant and consultee throughout their inpatient stay.

Results A total of 101 people have participated in these studies over a 2-year period. The high recruitment rate (83%, n=101/121) demonstrates a willingness of the hospice to take part in end of life research; this is consistent with previous work about palliative care research participation. Feedback has been positive with patients, caregivers and staff through the entire research process.

Conclusions The advance consent process is an effective way to facilitate research participation at the end of life. People with palliative care needs want to participate in studies which include assessments in the dying phase of their illness. Caregivers have shown great desire to support research. Researchers should consider the potential to use the advance consent process to improve research participation for people who are dying.

95 HOME PARENTAL NUTRITION FOR PALLIATIVE PATIENTS. A REVIEW OF FIVE YEARS OF EXPERIENCE AT MILTON KEYNES UNIVERSITY HOSPITAL

Jane Wale, Lynfa Lanzon-Miller, Marrison Marwood. *Milton Keynes University Hospital, University of Buckingham Medical School*

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Background Parenteral Nutrition (PN) is the intravenous administration of nutrition and can be used in patients whose gastrointestinal tract is unable to function. It is a treatment that is relatively easy to initiate, but it is a difficult treatment to continue outside of hospital and can also be, ethically and morally, a difficult treatment to stop. Recent ESPEN guidelines (2016) state that 'the bioethical aspects of feeding patients with advanced disease should be considered.... There are data showing benefits of home artificial nutrition in cancer patients even in advanced cancer patients. Home parenteral nutrition is a complex therapy and selecting patients for this treatment a demanding task'.

Method Patients for whom home parenteral nutrition had been a goal were identified. A retrospective review of these patients' clinical records was undertaken.

Results Between 2014 and 2019 six palliative patients had PN commenced at Milton Keynes University Hospital, a medium sized District General Hospital. One further patient had PN started at a tertiary centre. All patients had ongoing bowel obstruction secondary to peritoneal metastases. The mean age of patients was 49 years (range 35–81 years). The average time from starting PN to hospital discharge was 47 days for the MKUH patients compared to 14 days for the patient who was started on PN at a tertiary centre. The average time from starting PN to death was 435 days (range 28 – 1825 days). One patient remains alive, 2 died in the hospital, 2 in the hospice, 2 at home.

Conclusion Carefully selected palliative patients can benefit from home PN, but in a district general hospital this requires a lengthy hospital admission to achieve. The decision to start PN should be multidisciplinary and the goals of treatment should be clearly defined and reviewed regularly.

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96 UNDERSTANDING THE MEANING ATTRIBUTED BY JORDANIAN PARENTS OF CHILDREN WITH CANCER TO THEIR ILLNESS: A PHENOMENOLOGICAL STUDY

Maha Atout, Abd Al-Hadi Hasan, Rabia Allari, Amani Alkharabsheh, Mahmoud Thalgi, Nourreen Shivji. *Philadelphia University*

10.1136/spcare-2020-PCC.116

Background Jordanian culture is a variant of Arab-Islamic culture that comprises two intertwined strands: the interpretation of Islamic religion and vernacular Arab culture. Few studies have been conducted in the Middle East to explain the way culture shapes and reflects parents' lived experiences and interactions with their children, particularly concerning the meaning and philosophy of disease.

Methods The aim of this study was to explore the lived experiences of Jordanian parents of children with cancer. The study investigated the cultural meaning of illness and how it affected parents' lived experiences of their children's illness. The study adopted a hermeneutic phenomenological approach informed by the philosophy of Martin Heidegger and used semi-structured interviews. The study was conducted in one paediatric oncology unit in one Jordanian hospital.

Results Twenty-five interviews were collected from 24 mothers and one father. During the interviews, the parents expressed that their spiritual beliefs helped them accept their child's disease. Showing patience towards the suffering of their children was perceived as an important value the parents tried to stick to despite the deep suffering the children were experiencing. All the parents demonstrated a thankful approach as they perceived that everything that happens to their child is according to destiny. The beliefs the parents held about their child's illness were perceived to positively affect the way they interacted with them. This was especially so in sensitive situations, such as their reactions to initial diagnoses and receiving bad news.

Conclusion The findings of this study will inform the education of health professionals and increase their understanding of the beliefs and practices demonstrated by the study's participants and their integration into supportive patient plans.

97 HOW DO PHYSICIANS IN SOUTH INDIA RECOGNISE, ASSESS AND MANAGE CHRONIC BREATHLESSNESS AND IS CHRONIC BREATHLESSNESS CONSIDERED A SYNDROME OR DIAGNOSIS?

Matilda MM Barnes-Harris, Miriam J Johnson, Sunitha Daniel, Venkateswaran Chitra. *Hull York Medical School, Wolfson Palliative Care Research Centre, University of Hull, Amrita Institute of Medical Sciences Amrita University*

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Background Chronic breathlessness syndrome has been recently defined to help clinicians actively seek and patients legitimately present with persistent breathlessness, and to drive service development and research. There are many evidence-based interventions emerging. However, the naming and defining process did not include views from low to middle-income countries, where chronic breathlessness is a significant issue.

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

Yousuf ElMokhallati, Enas Alaloul, Mohammed Shatat, Tasneem Shneewra, Saad El Massri, Omar Shaer, Matthew Allsop. *University of Leeds, Ministry of Health (Palestine), Islamic University (Palestine)*

10.1136/spcare-2020-PCC.118

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)

Rose Gahire, Grace Mukankuranga. *Palliative Care Association of Rwanda (APCAR)*

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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?

L Srivastava, R Krueger, B Rose. *PalliaCare Cincinnati, Hospice of Cincinnati, Trihealth*

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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