• Mean ‘pain’ score changed from 1.9 to 1.2, with 47% of the 125 patients with pain improved
• Mean ‘breathlessness’ score improved from 1.1 to 0.8, with 48% of the 64 patients with breathlessness improved
• Mean ‘anxiety’ score changed from 1.9 to 1.3, with 42% of the 73 patients with anxiety improved
• Mean ‘feeling depressed’ score changed from 1.5 to 1.0, with 52% of the 56 patients with depressed mood improved
• Mean ‘information needs’ score changed from 1.2 to 0.9, with 78% of the 36 patients wanting more information improved.

Conclusions For the first time in UK, an inpatient hospice has systematically used routinely-collected outcomes date to demonstrate the marked positive impact of the clinical care provided.

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Free papers 4 – 6: education & communication

4 PROGNOSTIC COMMUNICATION WITH FAMILIES OF PATIENTS AT THE END-OF-LIFE IN A HOSPICE: A QUALITATIVE INTERVIEW STUDY

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Background Research has consistently shown that patients at the end-of-life and their families value honest communication about prognosis. In the final hours and days of life, communication with families is particularly important, as at this point patients are often unable to communicate. This study aims to understand experiences of end-of-life prognostic communication from the perspective of hospice clinicians and relatives of patients.

Methods Semi-structured interviews and a focus group were carried out with five senior hospice clinicians and twelve relatives of patients who died in the same hospice in the previous 3–6 months. Thematic analysis was used to identify relatives’ and clinicians’ perspectives on what is important to them during end-of-life prognostic communication.

Results Clinicians suggested that as long as the family were aware that the patient was dying, it was not always necessary to raise prognosis. They felt repeatedly talking about timelines could cause families to become fixated on prognosis. When they did raise prognosis, this was often for practical reasons, such as ensuring relatives could stay overnight to be present if the patient died. They described using relatives’ own descriptions of the patient’s deterioration to help them understand the prognosis, and emphasised the importance of being honest about the uncertainty. Relatives appreciated this honesty and were aware that it would not be possible to be given an exact timeline. Some described information on what to expect during the dying process as helpful, but others felt this information was lacking.

Conclusions Relative and clinician accounts of prognostic communication were generally aligned, with a focus on providing an awareness that the patient was dying whilst highlighting prognostic uncertainty. Clinicians should be aware that some relatives want further information about what changes to expect in order to be reassured that the patient’s symptoms are a part of the natural dying process.

5 QUALITY IMPROVEMENT– DEVELOPMENT OF AN INTERACTIVE STAFF EDUCATION SESSION TO RAISE CONFIDENCE IN DISCUSSING LGBTQ+ ISSUES IN THE HOSPICE SETTING

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Background People who identify as LGBTQ+ are at an increased risk of certain serious health conditions including types of cancer and so it is vital that this group of people feel able to access palliative care services. In 2014, Marie Curie commissioned research which highlighted a lack of evidence about LGBTQ+ people’s experience of palliative care. A recent study identified that individuals may feel unable to spontaneously disclose their identity to healthcare staff due to prior experience of discrimination. Therefore, it is important that all staff feel confident in talking to patients about sexual orientation.

Method Review of patient records to identify how many patients admitted to hospice over the past 6 months have been asked their sexual orientation. Development of a 3-hour interactive LGBTQ+ staff training programme. Review of written feedback from these sessions to analyse how this was received by staff.

Results Over the past 6 months, 146 patients were admitted. 52% had been asked their sexual orientation. Small group LGBTQ+ teaching sessions were provided, where interactivity was promoted with activities such as a quiz and word-search. Feedback indicating that this was a valuable learning opportunity for staff. Quotes included, ‘more aware of LGBTQ+ terms that patient may use and what they mean’, ‘increased awareness and has made me more confident to ask’, ‘session highlighted the importance of continuing to treat patients as individuals’.

Discussion Marie Curie has made great strides both locally and nationally to ensure LGBTQ+ patients feel welcome. New training sessions have been provided to ensure that all staff feel confident in being able to openly discuss LGBTQ+ issues and feedback from this has been extremely positive. We plan to re-review the data in 6 months to ensure that more patients are being offered the opportunity to disclose their sexual orientation on admission.

6 BRIDGING THE GAP – AN EDUCATIONAL INITIATIVE TO IMPROVE COMMUNICATION AND DECISION MAKING AT END OF LIFE CARE AT A DISTRICT GENERAL HOSPITAL AND ITS LOCAL AREA


Background and introduction North Middlesex University Hospital (NMUH) is a district general hospital that serves the culturally and ethnically diverse London boroughs of Haringey and Enfield. In a May 2018 questionnaire, NMUH staff reported that spiritual, religious and cultural factors frequently
play a pivotal aspect of end of life care and that their own knowledge could be better in addressing these factors. An educational initiative called Bridging the Gap was established with two distinct arms (community and medical staff) to improve communication and decision making at end of life care in NMUH and its local area.

Methods and results In the first phase of the community arm, religious, spiritual, cultural and social care leaders from the local community were invited to a pilot session and two workshops. Here, they were introduced the medical, moral and ethical considerations that doctors and other medical staff contend with when providing end of life care. 37 leaders from 13 distinct groups attended these events and there was an improvement in participants’ confidence and familiarity towards DNAR, ACP and end of life care discussions.

In the medical staff arm a workshop was arranged for NMUH staff and community palliative care teams, where the Greek, African & Caribbean and Muslim perspectives towards end of life care were explored and practical steps of how to manage their specific needs were discussed. Confidence rating of participants in managing these perspectives improved from 2.68/5 to 4.47/5.

Conclusions In the community arm, different approaches need to be employed to engage hard to reach leaders whilst simultaneously arranging seminars and forums to disseminate information to the wider public via established contacts from the previous workshops. For the medical staff arm there are more perspectives prevalent (Jewish, Turkish, Eastern European) in the local area that need to be explored via future workshops.

Free papers 7 – 9: qualitative studies

7 WORK STRESSORS FACED BY HEALTH PROFESSIONALS WORKING WITH CHILDREN WITH PALLIATIVE CARE NEEDS: MULTIPLE CASE STUDY APPROACH FROM JORDAN

Maha Atout, Noureen Shivji, Philadelphia University

Background A broad overview of the existing literature reveals that nurses often feel inadequately trained or prepared in terms of the communication skills needed to deal with the difficult situations. The purpose of the current study was to explore the experience of communication in the care of children with palliative care needs, from the perspective of physicians, nurses, and mothers in Jordan.

Methods This study employed a collective qualitative case study approach. It was conducted in three paediatric units in a Jordanian hospital. Each case comprised a child aged 1–12 years, their most involved family carer (mothers), physician(s) and nurse(s). Two data collection methods were employed: participant observation and semi-structured interviews with three categories of participants: mothers, physicians, and the nurses who cared for the children that participated in this study.

Results The study was based on 15 cases, with a total of 197 observational hours and 60 interviews (conducted with 15 mothers, 12 physicians and 21 nurses). The findings indicate that the healthcare professionals struggled to communicate with families of children with life-limiting or life-threatening conditions. For instance, many found it difficult to communicate with parents when delivering an initial diagnosis, when the child’s health deteriorated, or if the child’s death was imminent. Doctors also reported feeling blamed for the ineffectiveness of treatment plans and cited this as their primary difficulty. Nurses also revealed that work pressure often limited their ability to provide optimum patient care and to communicate effectively with patients and their families. Other nurses reported difficulty in offering emotional support.

Conclusions The continuous education and specialised training for professionals, which provides staff with specialised communication skills and emotional support for children and parents is imperative in improving the clinical practice in the healthcare settings with limited access to specialist palliative care.

8 ‘HE MATTERED AS A HUMAN BEING’: PALLIATIVE HEALTHCARE PROFESSIONALS EXPERIENCES AND VIEWS ON PALLIATIVE CARE DELIVERY TO THE HOMELESS

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Background International evidence suggests there are barriers to homeless patients accessing healthcare, including palliative services, despite poor health outcomes and the average age of mortality in the UK homeless being 30 years younger than the mainstream population. The literature calls for in-reach palliative services to hostels, shelters and the streets to meet the palliative need. These conclusions arise from research with homeless staff, but the perceptions of palliative healthcare professionals had not been explored to see if this is achievable in practice.

Method A novel peer-reviewed online survey allowing quantitative and qualitative responses was distributed to 227 adult hospices listed with Hospice UK. Any palliative health professional working within these services was eligible to participate.

Results 129 palliative healthcare professionals responded. Participants included consultants, specialty doctors, nurses, clinical nurse specialists, social workers, physiotherapists, occupational therapists and counsellors. All 12 regions of the UK were represented. There was a wealth of palliative experience (two thirds had over 10 years’ experience) but minimal training in palliative care specifically for people experiencing homelessness. Notable challenges to supporting this group included difficulty engaging community services (e.g. GP registration, safe provision of controlled medications), difficulties over discharge destinations from hospices if not an end-of-life admission, and challenging client behaviour. Respondents felt palliative care should extend support to this population through supporting homeless services as well as engaging the multi-disciplinary team. This may require flexibility to established referral pathways and ways of accessing palliative care.

Conclusion Flexibility and collaboration with homeless organisations and multi-disciplinary health care teams is imperative to ensure equitable palliative delivery to homeless populations. More training and education is needed for palliative care workers to understand caring for this population and for homeless staff to understand palliative care services. Further research is needed to understand how to achieve this care delivery in practice.