Oral Presentations

Parallel session 1.1 – Evidence at the core; questions, routes to answers and reflections (Monday 6 November 2023, 13:30 – 14:45)

0-01 IDENTIFY UNANSWERED QUESTIONS FOR PALLIATIVE AND END OF LIFE CARE RESEARCH – A JAMES LIND ALLIANCE PRIORITY SETTING PARTNERSHIP REFRESH PROJECT

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Background In 2015, Marie Curie and partners reported the results of the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) that identified the top 10 unanswered research questions in palliative and end of life care. Prioritised questions were mapped onto funded research (Fordham, Candy, McMillan, et al. Health Open Res. 2020; 2(17): 17) and have been influential in the field of palliative and end of life care research, informing strategic funding opportunities for palliative and end of life care research in the UK, and also providing insights into public opinions of palliative and end of life care (Nelson. Health Open Res. 2020; 2(15):15).

Aims To undertake a refresh of the Palliative and end of life care Priority Setting Partnership to identify current priorities for palliative and end of life care research, in partnership with the JLA and other organisations.

Methods Sequential surveys open to members of the public and health and social care professionals to elicit potential research questions. A range of approaches will be used to try and reach a diverse sample. Identified questions will be checked against existing research and prioritised. The final priorities will be identified through a workshop attended by people affected by dying, death and bereavement and health and social care professionals. A group of people with lived experience has been set up to inform the project across all stages.

Results Interim findings from the first survey will be shared, including emerging topics and characteristics of the sample recruited to date.

Conclusions This work will explore, from the perspectives of people affected by dying and bereavement and health and social care professionals, what the current priorities for palliative and end of life care should be. This will provide vital insights to inform the direction of future research and ensure that research is shaped by the voices of those it is intended to benefit.

0-02 THE DEVELOPMENT OF A TOOL TO STREAMLINE ANALYSING AND DISPLAYING PATIENT CENTRED OUTCOME MEASURES IN END OF LIFE CARE SERVICES


10.1136/spcare-2023-HUNC.2

Patient Centred Outcome Measures (PCOMs) such as Phase of Illness or IPOS are highly valued for individual patient level clinical care but seldom used to test or demonstrate cumulative impact of an end of life care service in more strategic conversations (Bradshaw, Santarelli, Mulderrig, et al. Palliat Med. 2021; 35(2): 397–407). PCOMs enable a service to demonstrate quality personalised care alongside more traditional activity analysis such as the avoidance of acute bed days and admissions.

We aspired to build a tool to streamline analysing and sharing aggregate PCOMs for end of life care services; both to enable easier cumulative measurement of quality care beyond individual patient experiences and to assist with suitable adaptations and scale of service models. The project team identified four widely used PCOM measures to build an alpha version of the tool in PowerBI (Pearson, et al. Pro Microsoft Power Platform. 2020). Whilst building the overarching tool, it was identified that different organisations and service teams had different levels of resource and expertise. We thus produced three additional resources alongside the tool to ensure it is pragmatic for a variety of organisations outside of academic research. The tool has a Creative Commons License to ensure all organisations can shape and use the tool for their own needs.

The tool and the supporting materials are publicly available and ready for use. We anticipate having preliminary results from tool use in Summer 2023. We have started to use the tool’s analysis and visuals with three partner organisations to explore how best they can collect, analyse, display and share PCOMs. We aspire to share the initial results from this process and our evaluation of the tool’s strengths and weaknesses by November 2023.

Conclusions from our initial design of the tool have highlighted that this methodology can be used for wider PCOMs. A dynamic dataset that is attractively presented and easily interrogated can effectively engage clinicians in service improvement.

0-03 UNCOVERING THE EVERYDAY EXPERIENCES AND EMOTIONAL ENGAGEMENTS OF CLINICAL AND NON-CLINICAL HOSPICE STAFF

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Appreciating the everyday experiences of hospice staff can help to illuminate their emotional engagements and needs for emotional support. Existing research on emotional work in healthcare and hospice contexts tends to focus on clinical staff, such as doctors and nurses. This study adopted an ethnographic approach to uncover the day-to-day working lives of both clinical and non-clinical hospice staff. In doing so, the findings appreciate the subtle, sensory and intimate practices of hospice staff.

The study involved 6 months of observations and 18 in-depth interviews in a hospice situated in the North of England. Since then, consultation work has also been carried out to consult with staff on the findings and develop recommendations for the emotional support of hospice staff in various roles.

This paper will draw on quotes and fieldnotes to illuminate the everyday work of hospice staff. The findings appreciate the small practices, such as silence, touch and the preparation of food, to highlight how such acts are less acknowledged, yet