

**Discussion:** Based on these results, a new visitation period in the morning was officialized. An official protocol to standardize medical information during visit times is currently being developed and workshops including role-play to improve communication are scheduled to begin October 2024.

#### Professional Consensus Grids – ‘Getting the first opinion right’

*Emily Harrop<sup>1</sup>, Laura Nohavicka<sup>1</sup>, Charlotte Holland<sup>1</sup>*

<sup>1</sup>Oxford University Hospitals / Helen & Douglas House

**Background:** Critically ill children are cared for by numerous paediatric specialists simultaneously. When difficult decisions need to be made, the messaging can thus appear inconsistent to families. It can be easy of them to focus only on the most apparently optimistic language, such as the impression of a ‘stable shift’ from a bedside nurse. This is likely to contribute to the development of conflict between parents and health-care professionals.

**Aim/Research question or hypothesis:** We discuss the use of an active process of professional consensus building to ensure clear messaging and promote coherent decision making. This may provide a clear way forward in of itself or may highlight the needs for other interventions such as ethical review, mediation or second opinion.

**Methods:** The palliative care team is often invited to support care planning for life-threatened children on intensive care units. These cases were addressed by holding multidisciplinary meetings with a structured format, identifying the specific clinical issues, allowing each team to present their summary, finally leading to a chaired discussion to reach an agreed consensus of the child’s clinical options.

**Results:** This approach allowed a clear multi-professional view of the child’s holistic clinical picture to be communicated between professionals, as well as with parents. In many cases this provided an agreed way forward, where decision making had been stalled and conflict was a risk.

**Discussion:** We have adopted this approach within our tertiary children’s hospital, whenever a child’s decision-making is impaired by complexity. It has led to increased clarity about best interests, the need for ethical review, the role of a second opinion (if consensus is not clear) and the place for mediation, if the communication with family remains a challenge. The technique has been shared with the Nuffield Council on Bioethics, who included it in their 2023 guidance on Managing Disagreements in the Care of Critically Ill Children.

#### Media interviews in palliative care settings

*Mark Taubert<sup>1</sup>, Caitlin Cahill<sup>2</sup>, Eva Cahill<sup>3</sup>, Olivia Gibbs<sup>1</sup>*

<sup>1</sup>Cardiff University, <sup>2</sup>Velindre University NHS Trust, <sup>3</sup>School of Journalism, Cardiff University

**Background:** Palliative care professionals are increasingly being asked to give interviews, and be part of documentaries for TV, radio and online outlets. This can be important in giving our view on sometimes emotional or controversial topics, and also reducing stigma around topics like death and dying.

**Aim/Research question or hypothesis:** What are the pitfalls when agreeing to talk on camera or microphone? How do we safely bring patients/carers into this space, without compromising their care? The presentation aims to address some of the common areas of miscommunication with the media, including consent, vetting, contractual arrangements and safety.

**Methods:** Literature review of 4 key databases from 1999–2024 for relevant published papers, incorporating the words ‘media interviews’ and ‘palliative care’. Review of available media workshops and seminars for palliative care professionals and key areas they focused on, and these were identified and aggregated into subheadings/topics.

**Results:** Key topics that came up in our search were as follows: Preparation, vetting, consent to record versus consent to broadcast/publish, patient safety, contractual arrangements with interviewers or media companies, Trust and Health & Safety arrangements.

**Discussion:** Main areas that were found in this literature and course review are discussed and will be highly relevant to anyone considering engaging with media outlets. We provide a list of themes. The main author has considerable experience with worldwide media outlets and will integrate personal experience into the findings.

Understand why a journalist is doing the interview/report

Consider your/your organisation’s own agenda and objectives in agreeing Steps to take to prepare for different types of media exposure (interviews, comments, blogs, podcasts, requests to write)

Small-print in many media interview contracts

Importance of asking to see (for written content) what title will be used for the article with your name in/on it,

Importance of asking which images they plan to use alongside this output (incl in social media postings)

#### Children’s Palliative Care: Make some noise!

*Lizzie Chambers<sup>1</sup>, Alex Daniels<sup>2</sup>, Howard Kinyua<sup>1</sup>, Cassie Thompson<sup>1</sup>, Barbara Steele<sup>1</sup>, Julia Downing<sup>1</sup>*

<sup>1</sup>International Children’s Palliative Care Network, <sup>2</sup>ICPCN

**Background:** Children’s Palliative Care is an underdeveloped and often misunderstood specialty, with recent data showing that almost half of countries have very little service provision, funding, policy, education or research capacity. These shortfalls are often compounded by poor access to medicines for children and the gaps are greatest in Low and Middle-income countries where the need is highest. To close this gap it is therefore imperative that focussed awareness-raising and advocacy campaigns are designed and delivered to maximum effect.

**Aim/Research question or hypothesis:** To demonstrate effective approaches to raising awareness of the needs of children with palliative care needs and for the global development of services to support them.

**Methods:** The evaluation of three international advocacy campaigns will be shared as case studies, drawing out the critical success factors of each.

**Results:** The evaluations show the importance of 8 critical success factors for delivery of a successful campaign: 1) Clear aims and objectives 2) Data and evidence 3) A targeted audience able to make the required change happen 4) Clear actions for the identified audience to take 5) The right language and messaging about children’s palliative care 6) A focus on telling the child and family story 7) Working with partners, champions and networks 8) Evaluation – being able to measure change and impact over time.

**Discussion:** There are many challenges when advocating for children’s palliative care, not least the lack of evidence base and poor understanding of what it is, such as the prevailing misunderstanding that it is about care at the end of a child’s life or just for children with cancer. There are however many strengths to draw on when campaigning in this arena – we have a committed network of champions around the world and the potential to harness powerful and emotional stories from children and families.

#### Palliative approach to relieving suffering at home: Clinical Case

*Patricia Coelho<sup>1</sup>, Rosa Silva<sup>1</sup>, Pedro Melo<sup>1</sup>, Maria José Lumini<sup>1</sup>, Paulo Marques<sup>1</sup>*

<sup>1</sup>CINTESIS@RISE, Nursing School of Porto ESEP

**Background:** Palliative needs can develop complications during the illness and are at risk of very intense physical and psychosocial symptoms, which require specialised and personalised assessment and management. Drawing up a care plan from a comprehensive and holistic perspective to satisfy needs and desires is key to preserving autonomy, reducing suffering and optimizing care and its quality.

**Aim/Research question or hypothesis:** To describe the importance of the palliative approach in relieving suffering in the face of complex interventions focused on symptom control, emotional management and psychosocial support.