

The Need for Sustaining Hope during Communication of Unfavourable News in the Care of Children with Palliative Care Needs: The Experience of Mothers and Health Professionals in Jordan

Authors : Maha Atout, Pippa Hemingway, Jane Seymour

Abstract : A preliminary systematic review shows that health professionals experience a tension when communicating with the parents and family members of children with life-threatening and life-limiting conditions. On the one hand, they want to promote open and honest communication, while on the other, they are apprehensive about fostering an unrealistic sense of hope. Defining the boundaries between information that might offer reasonable hope versus that which results in false reassurance is challenging. Some healthcare providers worry that instilling a false sense of hope could motivate parents to seek continued aggressive treatment for their child, which in turn might cause the patient further unnecessary suffering. To date, there has been a lack of research in the Middle East regarding how healthcare providers do or should communicate bad news; in particular, the issue of hope in the field of paediatric palliative care has not been researched thoroughly. This study aims to explore, from the perspective of patients' mothers, physicians, and nurses, the experience of communicating and receiving bad news in the care of children with palliative care needs. Data were collected using a collective qualitative case study approach across three paediatric units in a Jordanian hospital. Two data collection methods were employed: participant observation and semi-structured interviews. The overall number of cases was 15, with a total of 56 interviews with mothers (n=24), physicians (n=12), and nurses (n=20) completed, as well as 197 observational hours logged. The findings demonstrate that mothers wanted their doctors to provide them with hopeful information about the future progression of their child's illness. Although some mothers asked their doctors to provide them with honest information regarding the condition of their child, they still considered a sense of hope to be essential for coping with caring for their child. According to mothers, hope was critical to treatment as it helped them to stay committed to the treatment and protected them to some extent from the extreme emotional suffering that would occur if they lost hope. The health professionals agreed with the mothers on the importance of hope, so long as it was congruent with the stage and severity of each patient's disease. The findings of this study conclude that while parents typically insist on knowing all relevant information when their child is diagnosed with a severe illness, they considered hope to be an essential part of life, and they found it very difficult to handle suffering without any glimmer of it. This study finds that using negative terms has extremely adverse effects on the parents' emotions. Hence, although the mothers asked the doctors to be as honest as they could, they still wanted the physicians to provide them with a positive message by communicating this information in a sensitive manner including hope.

Keywords : health professionals, children, communication, hope, information, mothers, palliative care

Conference Title : ICPPC 2017 : International Conference on Pediatric Palliative Care

Conference Location : Osaka, Japan

Conference Dates : October 09-10, 2017