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EXPLORING THE EXPERIENCE OF COMMUNICATION IN THE CARE OF CHILDREN WITH PALLIATIVE CARE NEEDS: THE PERSPECTIVES OF FAMILY CARERS, PHYSICIANS AND NURSES IN JORDAN

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Background: Despite having limited access to specialist palliative care, countries can successfully satisfy palliative care needs by ensuring all health professionals are properly trained and educated in their respective roles. To ensure that adequate care is provided for children with palliative needs in all healthcare settings, adequate training and support for care professionals is essential, even in cases where minimal specialist services are offered. Effective communication is a fundamental element in ensuring the quality of care provided to children with palliative care needs and has a considerable effect on the well-being of children as well as their relatives and care professionals. Nonetheless, 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. They often lack the confidence to communicate properly with parents or to deal with difficult questions or issues of conflict. Whilst this seems to echo studies previously conducted across a range of countries worldwide, research shows that countries with an Arab culture face slightly different issues in terms of disclosing serious prognoses to families. The current study is the first to examine communication between children, parents, and health professionals, in the care of children with non-malignant life-threatening and life-limiting illnesses in Jordan, and in particular the cultural and spiritual context that affects this communication.

Purpose and objectives: The purpose of the current study is 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. In this paper, the findings concerning mothers' experiences will be presented.

BIOGRAPHY

Maha Atout completed her PhD from the University of Nottingham in 2017. She works as an assistant professor at the Philadelphia University of Jordan. She has experience in working with children with life-threatening and life-limiting illnesses led to her interest in understanding communication between children with life-threatening conditions and their parents and health-care professionals. Her PhD work is focused on investigating communication in the care of children with palliative care needs from the perspectives of Jordanian mothers, physicians, and nurses. She has published several papers in this field. She is also interested in investigating parental experiences of decision making at the end of life for children with life-threatening and life-limiting conditions. Currently, she is investigating children's awareness of death, a subject that is largely neglected in the literature. During her training in the University of Nottingham, she gained solid foundation in qualitative and mixed method research. She had presented in several international conferences and became increasingly productive in disseminating the findings of her research.

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