

GENERAL PEDIATRICS, ADOLESCENT MEDICINE AND NEONATOLOGY CONGRESS

December 12 - 13, 2018 | Abu Dhabi, UAE

Maha Atout, Curr Pediatr Res 2018, Volume 22 | DOI: 10.4066/0971-9032-C3-009

CHANGING PRIORITIES IN THE CARE OF CHILDREN WITH CANCER: THE EXPERIENCE OF JORDANIAN PARENTS

Maha Atout

Philadelphia University, Jordan

Background: When a child has a terminal illness, parents reach a stage of acceptance of their forthcoming bereavement, refocusing their efforts on providing the best end-of-life (EOL) care that is possible. This comes when all treatment options have been explored, and there is no cure found for the illness. Cancer is the most common illness that requires EOL care in Western countries, with life-prolonging treatments explored. It is more and more becoming the norm in Western countries for EOL care to take place out of hospitals and in the patients' homes which is in response to the wishes of the patients and their families, as well as the medical professionals involved in their care. However, the Arab culture significantly differs in numerous ways from Western culture. There have been no prior studies in Palestine on different issue related to parenting for children with cancer, but is something that requires attention.

Purpose: The purpose of the current study is to explore the experience of parenting among parents who care for children with cancer.

Methods: A Phenomenological hermeneutic approach was conducted informed by the philosophy of Martin Heidegger. The study was conducted in one oncology unit a Jordanian hospital. Parents of children aged (6-18) years old or with all types of cancer were considered eligible. A purposeful sampling strategy was adopted to recruit the participants. Maximum variation sampling will be employed. Data was collected using semi-structured interviews.

Findings: Thirty-two interviews were collected involving mothers (n=29), fathers (n=3). The parents changed their focus during the care of their children from an initial emphasis on normalising their children's lives, to relieving their physical and psychological discomfort. This change of focus accompanied changes in the parents' understanding of their children's disease over time. They became more realistic regarding the future of their children, and therefore attempted to make their lives as enjoyable and comfortable as possible. Moreover, they evaluated any activity their children performed according to how much it affected their levels of comfort. When these activities resulted in further physical or psychological effort, the parents prioritised the comfort of their children over the benefits of the activities.

Conclusion: The parents' experiences should be taken into consideration when the medical teams establish the children's treatment plans. Additionally, the continuous education and specialised training for professionals, which

provides staff with specialised communication skills and emotional support for children and parents are imperative in improving the clinical practice in the healthcare settings with limited access to specialist palliative care.

BIOGRAPHY

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

Maha.atout@hotmail.com