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Exploring the communication experience in caring for children with cancer: An ethnographic multiple case study approach from Jordan

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Background: There has been little research in the Middle East regarding the experience of communicating with children with cancer from the perspectives of physicians, family carers and nurses. Preliminary findings from a systematic review of research, primarily of studies undertaken within Western cultural settings, about health care providers shows that they report being poorly prepared to communicate with children with cancer and their families, feel inadequately prepared to support families facing loss and lack confidence to deal with difficult questions and conflict. However, the Arab culture significantly differs in numerous ways from Western culture, for example, with regard to disclosing prognosis information to children.

Methods: This study employed an ethnographic collective qualitative case study approach. It was conducted in one oncology unit in a Jordanian hospital. Two data collection methods were employed: participant observation and semi-structured interviews.

Findings: Ten interviews have been collected to date: physicians (n=10), nurses (n=27), children aged 6–18 (n=8) and mothers (n=22). A total of 200 observational hours have been completed. The initial findings reveal that while a few parents completely hid the diagnosis of leukaemia from their children, others tried to relieve the situation by informing their children of their having different diagnoses, such as a blood infection. The term cancer, a taboo term in Arab culture, was avoided in the discussion of the disease by health care providers and parents to ameliorate the negative effect of this term. Generally, children were not involved in discussions related to their disease and most communications about their illness were with their parents and physicians. Although a few physicians and nurses agreed on the importance of involving children in the discussion regarding their prognosis and illness, they reported a lack of skills on the appropriate manner of providing children with sensitive information.

Conclusion: The lack of communication skills education with children with cancer is quite clear and requires specialised communication skills education for both health care providers and parents. Strategies are needed to involve children in the communication regarding their disease and their prognosis on the hospital level.