A Mixed Method Systematic Review of the Experience of Communication in the Care of Children with Palliative Care Needs

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Abstract: Background: A mixed method systematic review was undertaken in order to explore issues related to the experiences of health care providers and parents in the care of children with palliative care needs. The aims of this systematic review were to identify existing evidence about the experiences of communication in the care of children with palliative care needs, to appraise the research conducted in this area and to identify gaps in the literature in order to recommend for future related studies. Method: A mixed method systematic review of research on the experience of communication in the care of children with palliative care needs, conducted with parents and health professionals was undertaken. The electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched for the period of 2000-2016. Inclusion was limited to studies of communication experience in the care of children with palliative care needs. Result: Thirty-eight studies were found. The studies were conducted in a variety of countries: Uganda, Jordan, USA, UK, Taiwan, Turkey, Ireland, Poland, Brazil, Australia, Switzerland, Sweden, Netherland, Lebanon, Spain, Greece, and China. The current review shows that parents tend to protect their children when they are discussing their illnesses with them, particularly where they have a life-threatening or life-limiting condition. The approach of parents towards the discussion of sensitive issues concerning death with their children is significantly affected by the cultural background of the families. Conservative cultures encourage collusion behaviours which tend to keep children unaware of the incurable nature of the disease. The major communication challenges reported by health professionals are facing difficulties in judging how much information should be given to parents, responding to difficult questions, conflicts with families and inadequate skills to support grieving families. Conclusion: It is probably significant for the future studies to consider the change of parent-child communication experience over time in order to understand how the parents could change their interaction styles with their children according to the different stages of their children's disease. Moreover, further studies are required to investigate the experience of communication of parents of children with non-malignant life-threatening and life-limiting illnesses.

Keywords: children with life-threatening or life-limiting illnesses, end of life, experience of communication, healthcare care providers, paediatric palliative care

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