

How Do Parents Interact with Information Related to Their Child's Cancer: A Qualitative Study

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ABSTRACT

Parents of children with cancer grapple with a great deal of information in the process of caregiving for their children. Providing parents with relevant information related to the care of their child is an essential form of supportive care. Past literature has focused on their information needs but lacks a clear explanation of how parents obtain and use the information in this context. This paper aims to propose a preliminary information behaviour model that explains how parents of children with cancer interact with information related to caregiving for their child. The model was derived from findings of a qualitative study involving 14 paediatric cancer parents and 8 healthcare providers. The parents had children aged between 2 ½ years to 15 years who were receiving treatment from two urban paediatric oncology centres. The study was conducted using a constructivist grounded theory approach. In-depth interviews were conducted with study participants based on semi-structured topic guides related to their information needs and experiences related to these information needs. Codes specific to parents' information behaviour were identified and categorised into meaningful themes. The inductive and abductive inference was used to generate the connection between these themes to form an information behaviour model. Three major themes formed a cyclical process. "Active information gathering" referred to active searching or gathering of information by parents. Paediatric cancer parents seek information from various sources but needed guidance to evaluate their credibility, trustworthiness, and applicability. "Obtaining information" referred to both active and passive receipt of information. These were affected by parents' readiness for information and the manner of information transfer. Cognitive and affective factors influenced their ability to understand and internalise the information received to form meaningful knowledge. Thus, healthcare providers need to be mindful of the way information is being given to the parents. "Acting on information" referred to the actions after obtaining the information. Besides informing their treatment decision-making, the information obtained may generate the need for further information gathering or be shared with the community of parents. In conclusion, this information behaviour model encapsulates how paediatric cancer parents interact with information related to the care of their child. It is a preliminary model which adds contextual clarity to previous health information behaviour models and is specific to parental caregiving for children with cancer. Based on the proposed model, healthcare providers should assess parents' readiness for information and select appropriate communication strategies. Providing guidance for information gathering may facilitate parents to obtain accurate and relevant information. The domains in the model can be mapped to the Theoretical Domains Framework to inform the design of future interventions and research.

Keywords: information behaviour, children, cancer, Malaysia, qualitative