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Understanding Parental Role in Children's Participation in Decision Making during Hospitalisation: An Ethnographic Study in Malaysia

(2023) *Malaysian Journal of Medical Sciences*, 30 (3), pp. 143-150.

DOI: 10.21315/mjms2023.30.3.13

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Abstract

Introduction: Despite a growing recognition internationally that children have a right to participate in matters that affect their lives, they are not always involved in decision-making processes concerning their health care. There is a lack of information on how parents influence children's participation in this decision making. This study explored the roles parents assume in processes regarding their children's participation in communication exchanges and decision making in a paediatric oncology unit in Malaysia. Methods: This study adopted a focused ethnography design within a constructivist research paradigm. Participant observations and semi-structured interviews were conducted with 21 parents, 21 children and 19 nurses in a paediatric oncology unit in Malaysia. All observation fieldnotes and interview recordings were transcribed verbatim. A focused ethnographic data analysis technique was performed to analyse the data. Results: Three themes emerged regarding parents' roles in the communication and decision-making processes involving their children: i) facilitators of communication; ii) communication brokers and iii) communication buffers. Conclusion: Parents controlled decision-making processes concerning their children, while children preferred and welcomed parents as consultants in the decision-making processes regarding their health care © 2023, Penerbit Universiti Sains Malaysia. All rights reserved.

Author Keywords

children; decision making; ethnography; parental role; participation

Index Keywords

adult, Article, child, child parent relation, data analysis, decision making, ethnography, female, health care, health care personnel, hospitalization, human, human experiment, male, medical education, parental consent, semi structured interview

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Publisher: Penerbit Universiti Sains Malaysia

ISSN: 1394195X

CODEN: MJMSA

Language of Original Document: English

Abbreviated Source Title: Malays. J. Med. Sci.

2-s2.0-85171524683

Document Type: Article

Publication Stage: Final

Source: Scopus

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