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## Participation in communication and decisions with regards to nursing care: The role of children

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### Abstract

**Objective:** The study was to examine the role of children in communication and decisions regarding their nursing care in a paediatric oncology ward in Malaysia.

**Methods:** The principles of focused ethnography underpinned the study design. Fieldwork took place over six months in one 32-bedded paediatric oncology ward. Twenty-one children, ranging in ages from 7 to 12 years diagnosed with leukaemia, their parents and 19 nurses participated. Data collection consisted of participant observation and semi-structured interview.

**Results:** Hospitalized children employed different roles of passive or active participants during the communication and decisions about their nursing care. Importantly, children are more likely to become active participants in the communication process when nurses interact directly with them, listening to them and giving them opportunities to ask questions in either the presence or absence of their parents. Equally, children are likely to be more passive participants when nurses do not communicate directly with them, choosing instead to directly interact with the child's parents. This study highlighted that the role of children as active and passive participants is not permanently engaged by individual children, rather their role fluctuates throughout the hospitalization journey. The fluctuations of a child's role are highly dependent on their preferences: how and when they want to be included in the communication and decisions process. Children's roles in communication and decisions are also varied and dependent on their particular contexts. A child's participation in one situation does not consistently reflect their participation with their role in other situations. The ways in which the children participate were oscillated throughout their hospitalization.

**Conclusions:** This study provides empirical insight into children's experiences of triadic (child-nurse-parent) interaction during the decisions about their nursing care in paediatric oncological setting. A key recommendation calls for the development of assessment strategies to determine the 'ideal' position children would like to occupy, at any given point in time, throughout their hospitalization. (C) 2019 Published by Elsevier Espana, S.L.U.

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