

# Children's Experiences in Health Care Decisions: An Overview

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## ABSTRACT

This article attempts to provide an overview of issues related to children's participation in decisions relating to health care. It sets the discussion in the context of current debate about children's participation in health care decisions and explores the extent to which children want to participate in the decision. This article concludes that children mostly occupy a minimal role in communication and decisions regarding their care. The patterns of participation of children in communication and decisions are differing and fluctuate between the children and within the same child throughout their hospitalisation, depending on the participating child, their preferences, and requirements at a particular time.

**KEYWORDS:** Children, Participation, Decisions, Health Care

## INTRODUCTION

The past decade has seen a growing recognition of the importance of children's right and listening to and consulting with children, both at a national (1) and international level (2,3,4). The United Nations Convention on the Rights of the Child (2) states that the best interests of the child must be the primary consideration and that the child's views must be given due weight in accordance with the child's age and maturity. Until recently, however, attention on the child's right to be heard in the context of health care decisions is minimal, and participation of children in decisions relating to health care has been marginalised (5).

The term participation covers a broad continuum of involvement in decisions as it involves many different processes (6). As Alderson et al. (7) note, the concept of participation is open to a range of interpretations, ranging from having minimal information to having quite a full share in decision-making. In this article, however, the term participation does not simply mean just being present, but that children participate in the decisions if they are taking part or are being involved or consulted and have an influence on the decisions (6,8).

This article explores the participation of children and young people in health care decisions by considering the current state of participation in practice, drawing on a study conducted by the authors into realities of children's participation in health care decisions. It then evaluates the extent

to which children want to participate in decisions relating to health care.

## CHILDREN'S EXPERIENCES OF PARTICIPATION IN PRACTICE

The analysis of the literature reveals that research that seeks to determine the extent to which children are involved in actual decisions is remarkably small. The most common approach used to investigate the participation of children in the communication and decisions in health care is through the interview approach to a lesser extent observation is used as a method, either non-or semi-participant observation.

In studies where children have been interviewed, children were reported to have varying experiences of being consulted and involved in the decisions. For instance, Coyne et al. (3) used focus groups and individual interviews to investigate 7-18-year-old children's experiences of participation in consultations and decisions in three hospitals in Ireland. The study describes how children occupy a marginal position in consultations, without direct access to information about their healthcare, and with consultations being largely carried out between parents and healthcare professionals. Overall, the study shows that the children felt that their contributions were not given due weight and consideration. Some children preferred to receive information because it helped prepare them for what to expect and thus decreased their worries and provided reassurance. The authors argued that children are receiving information and having their views respected enhanced children's understanding and adaptation to the hospitalisation (3).

The same findings have also been reported in a study by Ruhe et al. (9) who interviewed 17 children aged 9-17 years with cancer in an oncological unit to explore children's experiences of participation in discussion and decisions surrounding time of diagnosis and treatment as well as opinions more broadly on their participation in health care. Using purposive sampling, the study employed face-to-face interviews with children and parents at three weeks after the initial diagnosis to give the family

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time to come to terms with the diagnosis. The key finding of the study was that children have little involvement in decisions. While the children in the study valued their participation, and their preferences for participation are vacillated across time, the authors claimed this as a complex pattern of participation. The main argument was that the children might appreciate involvement in some decisions while choosing to remain in the background for others.

This is in contrast with the findings of Sjoberg et al. (10) who explored the experiences of participation in decisions among 10 children aged between 8-11-years-old in relation to perioperative care in Sweden. The study found that the children were receiving information regarding the preparation of the operation, but, receiving a lack of information regarding the post-operative care. Thus, the children expressed that they wanted to have detailed information regarding both the preparation and postoperative care because they perceived the information to be important for their participation in their care and decisions. The children in this study expressed positive experiences of participation when they were listened to and had the opportunity to ask questions. The study demonstrated how healthcare professionals acted as facilitators for participation through their role in creating security for the child in uncomfortable situations and making the children feel comfortable and safe. The authors argued that a poor adaptation of the care environment to the children's needs, feeling uncomfortable while waiting and needs for distraction are examples of how the environment and the care in the operating theatre influence the children's experiences of participation. The study also highlighted that children's interaction with healthcare professionals, in terms of being listened to, and being involved is important for children's participation in the decisions.

In observational studies, the existing literature on children's participation in the decisions strongly suggests that children have limited and differing levels of participation in the decisions about their care. For instance, in Sweden, Runeson et al. (11) conducted an observational study with 24 children (aged 5 months to 18 years), and 21 parents and nurses to observe the interaction between parents, children and nurses in relation to consultations and decisions during hospitalization. Key findings from the study were that children had limited involvement in decisions, parents did not always support their children's participation in difficult situations, and healthcare professionals frequently informed children without eliciting their views or presenting alternatives. Another important point is that there are different levels of participation were observed<sup>11</sup>. The findings of the study found that level 5 applies to situations where the member of staff acts in accordance with the child's wishes, and this is reported as occurring in 48 of 137 situations. It is to be noted that these decisions mainly occurred during daily activities such as how they would like to eat and drink, and whether their parents should be present during the procedure. Conversely, 43 out of 68 situations were judged as belonging to level 3 (A communicates with B but does not care about B's answer; B's opinions, wishes and valuations do not influence the actions of A), and 4 (A cares about what B says but acts only partially in accordance with B's opinions, wishes and valuations).

The children's participation was considered as meaningful participation, which is defined by the authors as situations where the children receive information, take part in decisions, and sometimes compromises were made, and appropriate alternatives were suggested (11). Whereas the remaining 21 situations classified as level 1 and 2, which was not considered as meaningful participation because the normal conversation between the children and staff did not even take place. Using the same data, further exploration on how decisions were made, and reported that children and parents made few decisions themselves and even if one or more persons protested the decision made, decisions were seldom reconsidered (12). Overall, these studies concluded that children are not always given the opportunity to be involved in decisions regarding their care to a desirable level, which could be influenced by the wide age range of the participants.

The differing levels of the participation of children were confirmed by Lambert et al. (13) ethnographic study with 49 children, ranging in ages from 6 - 16 years with a variety of medical and surgical conditions in a children's hospital in the Republic of Ireland, to explore the nature of communication for children in the hospital. The research involved various modes of data collection, including observation, interviews, and participatory activities (including draw and write techniques and a child-friendly 'stick a star' quiz), and documentary evidence. Like the previous studies, it found that the children occupied varying degrees of participation in the communication process. The key finding of the study was that children did not exclusively occupy any one position in the communication process; rather they move in constant motion, back and forth, along the continuum between the two extreme poles of 'being overshadowed' and 'being at the forefront'. This suggests that the same child could occupy both positions throughout their hospitalisation, where the child may occupy the background, and at other times he/she may occupy the forefront of the communication process.

Further analysis of this ethnographic study reported that healthcare professionals positioned children as either 'passive bystander' or 'active participants' in the communication process (14). These two positions signified the extent of children's inclusion or exclusion in the communication process and the degree to which children's communication needs were met or not. The study suggests that children remained marginal in the communication process as passive bystanders when health professionals did not communicate directly with them, but rather directed any interaction to the child's parents. This often resulted in the healthcare professional and parent conversing about the child in his/her presence, with the child eavesdropping in the background. Conversely, children became active participants in the communication process, when healthcare professionals interacted directly with them (either in the presence or absence of their parents), listened to them and gave them an opportunity to ask questions (14). The study also highlights that the children's preferences resulted in oscillating between a passive bystander and active participant position within the communication process, and this depended on their needs at any given point in time.

This was echoed with the finding of a study which used a participatory-based approach with 38 children with cancer (aged 4 - 19 years) from three Principal Cancer Treatment centres in the United Kingdom (15). Some findings confirmed previously reported issues, such as young children's inability to voice their preferences, and the importance of familiar environments and parental support for all ages. New findings of the study suggested children worry about the permanence of symptoms, and older children are unhappy about their parents leading communications with health professionals. The study also suggests children's preferences for communication and information is not static; they change over the course of their illness. Age of the child has identified as an important factor to determine children's communication role either in the background or forefront position because they associated the age and movement of children with gaining autonomy (15). Nevertheless, it could be argued that to be in the forefront or background depends on children's dominant perspectives of their ability surrounding their illness, as well as those of others. The main argument is that the participation of children in decisions may not purely be influenced by the age of the child; it could be due to other child-related factors such as children's understanding, emotional state, personality, illness state, and children's preferences, which have been reported in other studies (3,9,11,13,16,17,18,19). In addition, the movement of children in the forefront or background could also be explained by the social-cultural aspect that children learn through their interaction and communication with others. The more activities and interactions that children participate in, the greater will be their understanding, which results in greater participation (20). As such, children with greater understandings are mostly likely to move into the forefront rather than stay in the background.

#### **DO CHILDREN WANT TO PARTICIPATE IN DECISIONS?**

The existing literature on children's participation strongly suggests that children have a commonality of preferences for participation in decisions concerning them. For instance, research involving children from similar age groups (8-12 years) in various settings, such as outpatient clinic<sup>21</sup>, paediatric medical and surgical wards (22, 23), and perioperative care<sup>10</sup> shows that children want to have more information and want to be able to participate in their care and decisions concerning their care.

Similar findings were reported in research that used an observation approach. A qualitative study by Bjork et al. (24) in Sweden, used non-participant observation over 10 months, to describe the needs of 12 children under the age of seven by observing their behaviour, body language and verbal expression, and found that children expressed their needs for participation in care and treatment. The wish of the children in this study (24) to participate in care and treatment was consistent with an ethnographic study by Lambert et al. (13), reported the children wanted to participate in the communication process, the study noted that there are times when children choose to be less involved, for example, in the situation of one child who was in pain.

Comparable findings were reported in research where children were being interviewed, for instance, Coyne (25) interviewed 11 children from four paediatric wards in two hospitals in England.

The study found that children expressed the need for consultation and information so that they could understand their illness, to be involved in their care, and to prepare themselves for the procedures. This finding was consistent with a qualitative study conducted in Ireland of 51 children between the ages of 5 and 14 years, which shows that children want and need to be involved in consultations and decisions around their healthcare and to be respected as having opinions about their care and treatment (26). Similar findings were also reported in a study that used a phenomenological approach, where 10 children aged between 13 and 16 years in a paediatric ward in a District General Hospital in the South West of England were interviewed (27). The children in this study stressed the importance of being able to make choices and to be involved in making decisions that would have an impact on their health (27).

Studies also suggest that children prefer their parents to be present during care provision and that the parent's presence helped them to express other needs. For instance, a study identified the need to have the parent close by as the most prominent finding of the study, and that the presence of the parents is necessary for the children to express their other needs (24). The children expressed that they wanted to have physical and emotional contact with their parents, to be comforted, to have the parent as a facilitator, and to use the parent as a secure base (24). Consistent with these findings, research (27) reported that some children needed their parents to be with them and that the parents' presence enabled children to give their expression. Correspondingly, a qualitative study (28), who interviewed 23 children aged between 6 and 11 years (9 boys and 14 girls), who had been admitted to a paediatric day care department for a planned procedure, reported that the children in this study preferred support from their parents or the healthcare professionals during the decisions.

In addition, studies on children's participation suggest that children have different preferences for participation in the consultation and decisions concerning them. For instance, a qualitative study in Ireland (29) of 55 children, aged between seven and 18 years, reported that many children wanted to make 'small' decisions related to everyday care such as in relation to their diet and medications. Some children would prefer to leave the serious decisions (i.e. surgery) to parents and health professionals because they perceived the healthcare professionals and their parents as the experts who know best. Only a few children wanted to make those decisions, while others preferred such decisions to be shared (29). Consistently, another study (30) involved a similar age group of children with cancer and survivors (aged 8 - 17 years), and it reported that, while most children preferred decisions about treatment to be a collaboration between patients, parents, and healthcare professionals, few children in their study wanted to be involved in less important decisions regarding their care. In relation to children's communication preferences, the participants of the study valued honesty, reassurance and support from healthcare providers, sufficient time for communication, and the continuity of healthcare providers. The participants also expressed the need to be informed fully and to be allowed to ask questions (30).

## CONCLUSION

The review has revealed that children's participation in decisions in healthcare settings are varied. Children are not always given the opportunity to participate in decisions regarding their care, with discussions mostly carried out with their parents. As a result, children mostly occupy a minimal role in communication and decisions regarding their care. The patterns of participation of children in communication and decisions are differing and fluctuate between the children and within the same child throughout their hospitalisation, depending on the participating child, their preferences, and requirements at a particular time. Despite their limited involvement in decisions, children wish to be involved in discussions about their care; however, their preferences differ from one another. Few children wanted to make their own decisions in relation to their care, some preferred their parent or healthcare professionals to make decisions for them on their behalf, and others preferred to work together with their parent or healthcare professional during the decisions. The consistencies of children's preferences for participation were identified in that most children preferred their parent to be present to enable them to express their views.

## RELEVANCE TO CLINICAL PRACTICE

In summary, although children are not always given the opportunity to participate in decisions regarding their care, with discussions mostly carried out with their parents, yet, children want and need to be heard by healthcare professionals and to be provided with age appropriate information in order to help them to cope with the consultation and treatment processes. Therefore, future research in this area would help to raise awareness of this aspect of children's nursing and encourage healthcare professionals to consider their everyday practice so that children's participation becomes visible in clinical practice.

## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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