

## REVIEW ARTICLE

# An Overview of Children's Participation in Shared Decision-making in Healthcare Settings

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## ABSTRACT

Paediatric settings use shared decision-making, which is also known as the pinnacle of patient-centred care. Nevertheless, implementing shared decision-making is relatively challenging as it involves the triad constellation interaction (communication between parents, children and healthcare professionals). This article provided an overview of previous studies related to children's involvement levels in health care decisions and the perception of children, healthcare professionals, and parents of children's participation in shared decision-making. It was concluded that children were engaged minimally in decision-making and most children were involved in minor decisions instead of major decisions. Furthermore, there was a diverse participation pattern, which varied in the same child based on the circumstances.

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## INTRODUCTION

Over the past decades, there has been increased interest in the topic of decision-making in healthcare settings. The decision-making process in the healthcare setting is imperative as it constitutes a key component for improving the patient's health. Aligning with healthcare advancements, healthcare delivery has shifted from paternalistic decision-making (decision is solely based on the healthcare professional's choice) to shared decision-making (patient and healthcare professional decide together) (1,2). Shared decision-making can also be described as a joint and interactive process where healthcare professionals and patients participate in all phases of the decision-making process. Both healthcare professionals and patients simultaneously will share information, such as the patient's values, choices of treatment available, and the risks and benefits of these choices before they negotiate together a treatment to implement (3,4).

Shared decision-making has been broadly accepted and applied in adult settings as a part of patient-centred care (5). Following the success of shared decision-

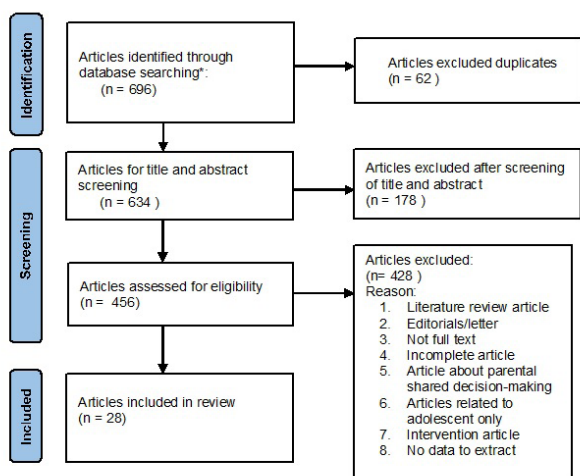
making in the adult setting, healthcare providers are currently attempting to implement it in all aspects of care and treatment in the paediatric setting (2). Nonetheless, shared decision-making in the paediatric setting differs from that in the adult setting. In healthcare situations involving children, shared decision-making was performed based on multiple steps and included triadic communication, which comprises at least three parties: the healthcare professionals, patients, and their caretakers or guardians (1,6,7). All involved will share information with each other and then expressed their treatment preferences. A treatment decision will be made when all the parties agreed with the choice they decided (8).

Shared decision-making in the paediatric setting can be challenging as all parties are required to decide together based on the best interests of the child and their family (7,9). To effectively promote adequate children's participation in shared decision-making, healthcare professionals specifically must have a thorough understanding of this collaborative process. In this paper, articles on shared decision-making in the paediatric healthcare setting regarding children's participation levels will be reviewed. Instead of focusing on parents' and healthcare professional's perspective, this paper will also review on the participation of children in shared decision-making from children perspective.

**METHODOLOGY**

Articles were searched in the Scopus, PubMed, Science Direct, ProQuest, and Google Scholar electronic databases. The keywords used were ‘participation’, ‘involvement’, ‘engagement’, ‘shared decision-making’, ‘decision making’, ‘healthcare’, ‘pediatric’, ‘child’, and ‘children’. The results of each category were combined using the Boolean terms ‘AND’ or ‘OR’ to refine the search findings. To provide the most recent and updated evidence and state of knowledge on shared decision-making among children in the paediatric setting, the search focused on research published between 2014 and 2021. Case reports, unpublished theses, clinical trials, academic conference proceedings, letters, editorials, and articles written in languages other than English and Malay were excluded.

Based on the article search results, 696 articles were found from the database. The articles were stored in reference setting (Mendeley software) to find out if there were duplications. 62 duplicate articles were removed, resulting in a remaining 634 articles. After reading the title and abstract, 178 articles were eliminated because of irrelevant title and abstract. The remaining 456 articles then were assessed for eligibility and total of 428 articles were eliminated because they did not meet the inclusion criteria. A total of 28 articles were included in this review. The flow of the selected article is presented in Figure 1.



**Figure 1: Flowchart for the literature review process selection of articles**

This review used thematic analysis for the synthesizing and analyzing part. After the selection procedure, all the articles were uploaded and stored in the data analysis software (Atlas-ti, version 9). The article’s methods and results section were read and coded using an open coding strategy in this qualitative data processing program. The code produced was then grouped into categories and themes. A discussion between team members was done to interpret the themes produced. At the same time,

an article matrix was created, where each study’s aim, methods, and results were listed, as in Table 1.

**RESULTS**

**Children’s experiences in shared decision-making**

Children’s participation in shared decision-making was diverse and ranged from no involvement to being the main decision-maker (1,6,8-33), as described in table 1. Children’s participation was categorised into ‘major’ and ‘minor’ decisions. Major decisions were similar to ‘serious’ decisions concerning treatment decisions while minor decisions referred to ‘having choices’ or ‘everyday’ decisions, which were usually associated with the timing and delivery of procedures (11).

In numerous studies, children were mainly involved in minor decisions (6,10,11,13,19). Ruhe and colleagues reported that children were involved in minor decisions, such as choosing whether they wanted to take medicine in tablet or liquid form or whether to undergo a procedure with or without analgesia (13). Furthermore, children were only consulted about minor decisions, such as in which arm and when a cannula should be inserted instead of whether or not an intravenous cannula should be inserted (10).

Both healthcare professionals and parents agreed that children may only be involved in minor decisions instead of major decisions, such as treatment-related decisions (11,13). This agreement might have been due to the child having a life-threatening illness, which might have resulted in the healthcare professional reasoning that the patient and their parents should not decide on the treatment as it was unavoidable and for the child’s benefit. Healthcare professionals agreed that involving children in major decisions was inappropriate. Yet, healthcare professionals also occasionally involved older children or children with chronic conditions in major decisions as they believed that the children understood their condition and were capable of making a related decision (10,13).

The children in the study by Ruhe and colleagues (13) exhibited different levels of participation in their healthcare decision-making where some were directly involved while others demonstrated lower participation levels. The authors stated that several participants participated in the discussion of their treatment not only by being present but also by being proactive and asking questions. Similar findings were reported in another study where children’s participation in perioperative care decisions was described. In that study, some children were able to make a decision while others did not want to participate and only wanted all procedures to be completed quickly (16).

Quaye (12) reported that children’s participation in decision-making encompass of dynamic involvement.

**Table I: Summary of literature review**

Authors (year)	Objective	Design	Participants	Outcome measured
Barsky et al (2021)	To investigate physician attitudes towards involving children in decision-making surrounding lung transplantation	A quantitative and qualitative cross-sectional survey	- 20 Pediatric pulmonary physicians at Boston Children's Hospital in Boston	<ul style="list-style-type: none"> <li>- Majority of physicians thought decision-making regarding lung transplantation lies on parents regardless of age and maturity level</li> <li>- Concern regarding legal age – legal context makes healthcare professionals feel conflicted in encouraging children to make a decision</li> <li>- Age seems to influence healthcare professionals to involve children, while maturity has no effect</li> </ul>
Beck et al (2014)	To examine the treatment decision-making process for children hospitalized with newly diagnosed immune thrombocytopenia (ITP)	A qualitative study using a focus group	<ul style="list-style-type: none"> <li>- 7 children aged 10 to 18 years old</li> <li>- 17 parents</li> <li>- 10 healthcare professionals</li> </ul>	<ul style="list-style-type: none"> <li>- Children preferred to do a minor and manageable decision</li> <li>- Younger children perceived that their parents and healthcare professionals made a decision together, while Older children reported having a varying level of comfort during the shared decision-making process</li> <li>- Healthcare professionals' comfort level affects how they offer choices to children</li> </ul>
Bennett et al (2019)	To gain a better sense of treatment and decision-making preferences among patients with cleft lip and/or palate and their caregivers	A qualitative study using semi-structured interviews	<ul style="list-style-type: none"> <li>- 31 children at least 8 years old having cleft lip</li> <li>- 31 caregivers of children having cleft lip</li> </ul>	<ul style="list-style-type: none"> <li>- Most of the child state that they were not involved in decisions or that their parents regularly decide on their treatment</li> <li>- Only a few caregivers consider that the child's opinion mattered</li> <li>- Majority of child express that they want their opinion to be considered when making a surgical decision</li> </ul>
Feragen et al (2019)	to investigate children's experiences of multidisciplinary team consultations from the perspective of their parents.	A qualitative study using interviews	- 38 parents of children with a rare Craniofacial Anomaly	<ul style="list-style-type: none"> <li>- Some of the parents would be an advocator for their child during the consultation</li> <li>- Some parents preferred to discuss some issues without the presence of their children in order to protect them from upsetting information</li> <li>- Parents express the importance of healthcare professionals asking child's permission and involve them in making a treatment decision</li> </ul>
Carlsson, Nygren & Svedberg (2017)	To explore healthcare professionals' perceptions of what patient participation means in a paediatric care context.	A qualitative study using interview or open-ended questions in a survey	- 15 healthcare professionals who worked in paediatric care settings	<ul style="list-style-type: none"> <li>- Healthcare professionals express that children's participation is a prerequisite for care</li> <li>- Healthcare professionals agree that the degree of participation of children is varied</li> <li>- Healthcare professionals supported children in expressing their view</li> <li>- Children sometimes have no choice of refusing treatment</li> <li>- Children can only be involved in the minor decision</li> <li>- Major decisions sometimes were allowed for older children or children with chronic condition</li> </ul>
Coyne et al (2014)	To explored children's participation in shared decision-making (SDM) from multiple perspectives from one haematology/oncology unit in Ireland	A qualitative study using interview	<ul style="list-style-type: none"> <li>- 20 children aged 7 to 16 years old,</li> <li>- 22 parents</li> <li>- 40 healthcare professional</li> </ul>	<ul style="list-style-type: none"> <li>- The major decisions are mainly made by healthcare professionals and discussed about it with parents</li> <li>- Both healthcare professionals and parents agree that children are not suitable to be involved in a major decision.</li> <li>- Children trusted adults to make decisions for them.</li> <li>- Adolescent content adults decide for them. However, they preferred to be included in information sharing and decision-making process</li> <li>- Healthcare professionals and parents try to involve children in minor or small decision</li> </ul>

**Table I: Summary of literature review (continued)**

Authors (year)	Objective	Design	Participants	Outcome measured
Fay et al (2021)	To analyze the ways in which pediatric patients have agency in relation to their parents and palliative care professionals within the hospital setting,	A qualitative study using non-participant observation and interviews	- 13 cases underage patients with their families - 5 healthcare professionals in Palliative care Unit of the Pediatric Hospital	- Observations portray that parents with children very young or unable to communicate routinely relayed their children's feelings to healthcare professionals - Healthcare professionals reported that they considered the opinion of the child, however when it concerns crucial decisions, parental opinions were more significant
Gilljam et al (2019)	To explore the experiences and preferences for participation in healthcare situations among children with juvenile idiopathic arthritis (JIA) as a foundation for creating strategies to promote their participation in pediatric healthcare	A qualitative study using interview and focus group	- 20 children aged 8 to 17 years old with juvenile idiopathic arthritis	- Children stated that their feelings of fear and uncertainty influenced their participation in healthcare situation - feelings of uncertainty lead to stress and hinders their participation. - They added that they would feel stronger if their voice were taken seriously, were given information individually, and allowed to be involved during shared decision-making process. - Most children also claimed that they appreciate it if healthcare professionals told them the truth instead of 'sugar-coat' the information - Children feel assured when being consulted by the same healthcare professional.
Gutman et al (2018)	To describe the perspectives of children with chronic kidney disease (CKD) and their parents with regard to communication and decision making	A qualitative study using a focus group	- 34 Children aged 8 to 21 years old with CKD - 62 parents	- Most of the parents were overprotective and controlling not only decisions regarding treatment but also children's daily life - Children stated that they have no choice regarding their treatment, however, they want to make a decision regarding their lifestyle - Parents value that their children are involved in decision-making, however, they need to interfere if they disagree with the children's preferences
Harder, Söderbäck & Ranheim (2018)	To describe health care professionals' understanding of significant encounters with children and parents to uncover the meaning of participation.	A qualitative descriptive design using participant narrative	- 12 healthcare professional	- Healthcare professionals, parents, and children can participate either in mutuality (interacting with each other as a three-part unit and create a relationship) or alienation (all parties are participating but without encountering each other as a three-part unit and did not create a relationship) or movement between both
O'Connor et al (2021)	To described the decision-making experiences of children, parents and therapists in occupational therapy	A qualitative study using Semi-structured interviews	- 6 children aged 6 to 12 years old - 5 parents - 6 occupational therapists	- All children in the study express the importance of their voices being listened to and respected - All three parties agreed that children should be involved in decision-making as it might affect the children in positive ways - Children still want adults to be involved acknowledging adults are more knowledgeable than them
Kelly et al (2017)	To better understand how children and adolescents viewed their treatment decision making involvement.	A qualitative study using interview	- 20 children aged 9 to 17 years old	- Children portray variations in preferences ranging from wanting or not wanting to hear information and to be involved or not to be involved in treatment decision - Children were more concerned with the amount of information they obtained instead of making a treatment choice
Kerklaan et al (2022)	To describes clinician perspectives on shared decision making in CKD	A qualitative study using semi structured interview	- 15 clinicians from 18 hospital and 4 university research across 11 countries	- Healthcare professionals try to involve especially older children in decision-making - Healthcare professionals feel that both children and parents should be informed and educated about the long-term effects of treatment
Koller (2016)	To examines how children with chronic medical conditions view health care education and decision-making. To propose the application of universal design for learning (UDL) in pediatric settings	A qualitative study using semi structured interviews	- 26 children and adolescent aged 5 to 18 years old	- Participant express their interest to learn more about their condition - Most of the participants expressed being listened to and allowed to take part in their self-management and decision-making.

**Table I: Summary of literature review (continued)**

Authors (year)	Objective	Design	Participants	Outcome measured
Lundberg et al (2021)	To explore how children, adolescents and young adults with Juvenile Idiopathic Arthritis (JIA) and parents of children with JIA view their participation and communication in healthcare encounters with healthcare professionals	A qualitative study using participatory workshop	<ul style="list-style-type: none"> <li>- 4 children and 2 young adult</li> <li>- 4 parents</li> <li>- Child and adolescent centre at a Swedish tertiary hospital</li> </ul>	<ul style="list-style-type: none"> <li>- Children felt alienated during the healthcare encounter if they felt disregarded or stressful</li> <li>- Parents reported that the child would feel disregarded when the healthcare professionals did not listen to and take the child's view seriously</li> <li>- Children express their desire to actively participate by speaking for themselves and exchange information as much as possible</li> <li>- Some of the children were reluctant to join the discussion as they could barely understand the conversation between adults</li> </ul>
MacDonald et al (2020)	To assess the level of decisional conflict and shared decision-making experienced by older children and their parents when considering elective adenotonsillectomies	A prospective cohort study - survey study using questionnaire	<ul style="list-style-type: none"> <li>- 53 children aged 9 to 16 years old who underwent consultation for surgery</li> <li>- Parents</li> <li>- 3 fellowship trained paediatric otolaryngologist</li> </ul>	<ul style="list-style-type: none"> <li>- No significance difference of parent's and children's decisional conflict scale with demographic factor or perioperative factor</li> <li>- No significance different of decisional conflict scale between children who chose to monitor symptom or undergoing surgery</li> <li>- Children shared decision-making score were lower than both parents and surgeon score -this indicates children feel excluded from shared decision-making process</li> <li>- Lack of participation of paediatric patients involved in considering elective procedure</li> </ul>
Melong, Meier & Hong (2019)	To explore how pediatric otolaryngologists involve older pediatric patients and their parents in SDM and which factors influence this process	A prospective cohort study using questionnaire and video recording coded with OPTION instrument	<ul style="list-style-type: none"> <li>- 81 families consist of Children between the ages of 6 to 16 years old who considered for elective surgery</li> <li>- 3 surgeons</li> </ul>	<ul style="list-style-type: none"> <li>- Shared decision-making was not generally observed during the consultation</li> <li>- Healthcare professionals provide patients and parents with information, but it is not decision-making related information</li> <li>- Patients and parents also did not share their preferences and values during the consultation</li> </ul>
Quaye et al (2019)	To explore and describe the child's active participation in daily healthcare practice at children's hospital units in Sweden.	A qualitative study using overt, non-participant observations	<ul style="list-style-type: none"> <li>- 34 children aged 2 to 17 years old</li> <li>- Parents</li> <li>- Healthcare professionals in three hospital in Sweden</li> </ul>	<ul style="list-style-type: none"> <li>- Children participations are varied</li> <li>- Children interact during decision-making through both verbal and nonverbal</li> <li>- Children's, parents' and healthcare professional's actions influenced children's active participation in decision-making processes</li> <li>- Presence of parents influences and gave limitation to healthcare professionals to involve children</li> </ul>
Rost et al (2017)	To present how shared decision-making in pediatric oncology occurs from the viewpoints of parents and physicians	A quantitative study using survey	<ul style="list-style-type: none"> <li>- 20 physicians</li> <li>- 91 parents</li> <li>- Eight Swiss Pediatric Oncology Group centers</li> </ul>	<ul style="list-style-type: none"> <li>- Children who were 9 years old and older reported understanding more on cancer causes and the prognosis</li> <li>- Parents evaluate children's capability to understand the disease process higher than healthcare professionals. Parents seen their children as capable</li> <li>- Older children and girls were more likely to be involved</li> <li>- Parents evaluate girl capacity higher than the boy</li> </ul>
Ruhe et al (2015)	To explore patient's perspectives in pediatric oncology on participation in discussions and decision-making surrounding their cancer diagnosis	A qualitative study using interview	<ul style="list-style-type: none"> <li>- 17 children aged 9 to 17 years</li> <li>- Centers of Swiss Pediatric Oncology Group</li> </ul>	<ul style="list-style-type: none"> <li>- This study found lack of involvement of children as only few were involved.</li> <li>- Levels of participation was varied; some involved while others showed lesser participation.</li> <li>- Children emphasized that they were involved in the minor decision</li> <li>- Children reported that they were involved in decision-making to some extent and were satisfied with their level of involvement.</li> <li>- As for their preferences, it is reported to be diverge as some wish to be consistently involved while some others were content with lesser participation.</li> <li>- Preferences of involvement also changing and fluctuate within one and the same patient. Some initially show lesser participation during early communication due to shock or overwhelmed. However, they changed their mind later and became more active</li> <li>- Children felt appreciated when they were able to choose their level of participation in shared decision-making</li> </ul>

**Table I: Summary of literature review (continued)**

Authors (year)	Objective	Design	Participants	Outcome measured
Ruhe et al (2016)	to explore how patient participation was put into practice in a pediatric oncology setting	A qualitative study using semi-structured interviews	<ul style="list-style-type: none"> <li>- 17 children</li> <li>- 19 parents</li> <li>- 16 pediatric oncologists</li> <li>- Eight centers of the Swiss Pediatric Oncology Group</li> </ul>	<ul style="list-style-type: none"> <li>- There are several cases where all parties involved in medical consultation. Children received information simultaneously with their parents</li> <li>- While in some occasions, healthcare professionals discussed first with the adult before either oncologist or their parents conveyed it to the children</li> <li>- Healthcare professionals have involved children in expressing their preferences that do not affect the treatment</li> </ul>
Sahlberg, Karlsson & Darcy (2020)	To investigate children's experiences and paediatric nurses' experiences of caring in accordance with the UNCRC.	A qualitative study using interviews	<ul style="list-style-type: none"> <li>- 10 children aged 4 to 7 years old</li> <li>- 13 nurses at a paediatric clinic in western Sweden</li> </ul>	<ul style="list-style-type: none"> <li>- Children who felt secure and well informed would actively participate in their care</li> <li>- The nurse thought parents is the advocate for children in communication; especially when the children were scared</li> <li>- Some procedures at certain time and occasion need to be done and not really consider children's input. However, nurses try to give children an opportunity to involve in smaller decision</li> </ul>
Schalkers et al (2016)	To investigate healthcare professionals' perspectives on child participation in paediatric hospital care and their opinions on improving participation practices	A Qualitative descriptive design using semi-structured interviews	<ul style="list-style-type: none"> <li>- 32 Healthcare professionals from 10 paediatric wards in the Netherlands</li> </ul>	<ul style="list-style-type: none"> <li>- Healthcare professionals mostly actively engage with children by listening to them and supporting them in expressing their views</li> <li>- Healthcare professionals also provide an alternative and allow children to decide on how their treatment will be carried out</li> <li>- Older children and chronically ill patients were more involved in decision-making</li> </ul>
Sjöberg et al (2015)	To describe the experiences of participation in perioperative care of 8 to 11 years old children	A qualitative study using narrative interview	<ul style="list-style-type: none"> <li>- 10 children aged 8 to 11 years old receiving perioperative care in Sweden</li> <li>- 4 surgical clinics at a Swedish district hospital</li> </ul>	<ul style="list-style-type: none"> <li>- Children expressed that the information they received is crucial and may influenced their style of participation in healthcare situations.</li> <li>- Hence, they want to have more information regarding both preparation and postoperative care.</li> <li>- Children claimed that they were listened to and allowed to ask a question. They also described that they were allowed to decide about small matters which they perceived as important to them</li> <li>- Needs of information children deem to know and level of participation is based on the children's individual characteristic such as age, attitude and previous experiences</li> </ul>
Teleman et al (2021)	To explore barriers to participation in pediatric rehabilitation services, according to children and young people with disabilities, parents to children with disabilities, and professionals	A qualitative study using interview and focus group	<ul style="list-style-type: none"> <li>- 20 children aged 6 to 17 years old with disabilities,</li> <li>- 8 young people with disabilities,</li> <li>- 17 parents</li> <li>- 9 healthcare professionals</li> </ul>	<ul style="list-style-type: none"> <li>- Parents did not consider participations of children to be important</li> <li>- Children express that adults did not share information or not allow them to express their opinion</li> <li>- Healthcare professionals also thought of parents as a barrier in decision sharing as they often want to discuss without the presence of the child or speaking on behalf of the child</li> <li>- Children believe parents have a low level of trust in their capability to participate even though they think they are capable</li> <li>- Most of the children did not participate in the discussion, and some of them think it is unnecessary to participate as they trust adults to make the best decision for them</li> </ul>
Vigilante et al (2015)	To describe the quantity and quality of child communication during outpatient subspecialty encounters	A qualitative study using analysis of videotape (naturalistic observation)	<ul style="list-style-type: none"> <li>- 155 children aged 5 to 17 years old</li> <li>- 20 healthcare professionals</li> <li>- 155 caregivers</li> <li>- Subspecialty clinic</li> </ul>	<ul style="list-style-type: none"> <li>- Children's utterances covered of 15% of all utterances during the encounters</li> <li>- A small level of participation with parents controlling the overall children discourse space during the encounter</li> <li>- Children who attended the session with both parents were quieter compared to those who attended the session with only one parent</li> <li>- Children engage passively responded to adult utterance</li> <li>- Children learn over time by watching their parents' actions and how they communicate with healthcare professionals. they were adapting to shared decision-making based on what they see</li> </ul>

**Table I: Summary of literature review (continued)**

Authors (year)	Objective	Design	Participants	Outcome measured
Vinblad et al (2019)	To explore the experiences of children and young people with disabilities concerning increasing their participation in the pediatric rehabilitation services.	A qualitative study using interviews	<ul style="list-style-type: none"> <li>- 20 children aged 6 to 17 years</li> <li>- 8 young people aged 19 to 30 years with disabilities at pediatric rehabilitation services</li> </ul>	<ul style="list-style-type: none"> <li>- Children and young adults defined the participation, which resulted in the categories of feeling involved, feeling independent, and working in partnership</li> <li>- Both children and young people express their desire to be listened to and involved in decision-making related to their care.</li> <li>- Both children and young adult appreciate the good support from an adult, and some of them want to entrust adult to decide on their behalf</li> </ul>
Wiering et al (2016)	To explored which decisions families face, how oncologists involve them in shared decision-making (SDM) and which factors are associated with this process	A qualitative study. Diagnostic consultations were audio-taped and coded with the OPTION	<ul style="list-style-type: none"> <li>- 43 families with children starting treatment for childhood cancer at three Dutch academic pediatric oncology clinics.</li> </ul>	<ul style="list-style-type: none"> <li>- Only a few oncologists asked permission from parents and children to start treatment</li> <li>- Only minimal attempts were made by oncologists to involve children and parents even though they had the competence to do so</li> <li>- Children wished to participate in minor decision</li> <li>- Discussions mainly focused on non-treatment related decision</li> </ul>

Some children were active and asked questions, others were passive and only observed the healthcare provider's actions, and some protested and resisted the care given. Apart from verbal communication, children also used nonverbal cues. For example, children indicated acceptance by nodding and indicated refusal by crying, shaking their head from side to side, and withdrawing their hands, legs, or body away from the healthcare professional. These observations demonstrated that participation varied for each child and children behaved differently based on their personalities.

Harder, Söderbäck & Ranheim confirmed the differing levels of children's participation (17). In that study, the healthcare professionals, parents, and children participated either in mutuality (interacting with each other as a three-part unit and creating a relationship) or alienation (all parties participated but without encountering each other as a three-part unit and did not create a relationship) or movement between both. In alienation, some parties were either alienated by others or alienated themselves from the unit. The authors argued that participation was dynamic and varied within a situation or between different situations involving the same people where participation changed from mutuality to alienation and vice versa based on the situation. The alienation and mutuality movement occurred due to each person's actions in a situation.

Similar findings were reported in an ethnographic study conducted in Malaysia (35), which highlighted the fact that individual children were not permanently active and passive participants. Rather, their role fluctuated throughout the hospitalisation journey. Importantly, those children were more likely to become active participants in communication when nurses interacted directly with them, listened to them, and provided them opportunities to ask questions in either their parents' presence or absence. Equally, a child was likely to be a passive participant when nurses directly interacted

with their parents and did not communicate directly with the child. The fluctuations of a child's role were highly dependent on their preferences, such as how and when they wanted to be included in communication and decision-making. Furthermore, children's roles in decisions were varied and dependent on context. A child's participation in one situation does not consistently reflect their participatory role in other situations.

Some children demonstrated minimal or no participation in shared decision-making. In a qualitative study, Vigilante (18) demonstrated that children were involved in communication but only played a minimal role and reacted passively to adults' statements. Parents and healthcare professionals were the main decision-makers (6,11) and most children relied on those adults to make decisions (11). In that study, the children were involved in shared decision-making but with limited roles.

Minimal participation was recorded in a qualitative study in which the level of shared decision-making among children and their parents when considering elective surgery was assessed (9). Although children participated in shared decision-making, their shared decision-making scores were lower compared to that of their parents and surgeons. That study concluded that children were involved in considering their elective surgery, but the participation levels were nevertheless lacking. The lower shared decision-making score demonstrated that children could have felt excluded from the decision-making process. Bennett (22) reported that children were not involved in decision-making and that their parents and healthcare professionals routinely made decisions on their behalf. Some children reported that their parents had offered them a choice but that they did not understand the treatment option given. The author concluded that the lack of children's participation in decision-making was mainly due to the children lacking understanding of their condition and the associated treatment (22).

In summary, children often participated minimally in decision-making. Essentially, all children could participate based on the situation. In most of the included studies, children participated at varying levels in shared decision-making. The participation levels also depended on whether the healthcare provider supported the children's involvement. Hence, the healthcare professional should be aware of the children's and parents' conditions to facilitate the participation of all parties in decision-making.

### **Children's preferences for participation in shared decision-making**

Children's participation in medical communication and shared decision-making in the paediatric setting is complex (13). Children may face challenges, such as confusion regarding the information provided, the sense of being disregarded, and pressure in making decisions, which affect their involvement in care (13). Thus, children's views regarding participation are crucial (12). Among the reviewed articles, a few reported children's preferences in shared decision-making (13) where the children wished to be involved and obtain information directly from their healthcare provider. For example, Ruhe reported that children in the oncology setting stated that they wanted to obtain information directly from their physicians as they were the most familiar with medical information and could provide more detailed information if the children felt they needed to know more (13). The authors also reported that most children expressed their preference to be involved in shared decision-making as they were affected by the illness and treatment (13). Some children stated that they wanted to be constantly involved while others preferred to be involved only occasionally. The children also stated that they would feel valued if they were able to choose their favoured participation level. Equally, the children in Sjöberg's study stated that the information they received was important and may have influenced their participation style in healthcare situations (16). Hence, the children desired more information on both preparation and postoperative care.

Children have varied decision-making preferences regarding their healthcare. Bennett and colleagues reported that children believed that their opinions were relevant to surgery decision-making even when their parents made the decision (22). Most children in that study reported that they wished to at least participate in decision-making and some even wished to make the final decision. The authors highlighted that some children perceived that their opinion was more important than that of their parents. Nevertheless, not all the children in that study shared the same opinion as a few children were uncomfortable with decision-making.

The children in another study expressed their perception of shared decision-making as a negative emotion (6). The children reported that their perceptions of

the decision-making process were influenced by their anxiety, fear, and confusion. The children were dependent on healthcare professionals and parents for decision-making as they felt overwhelmed, uncertain, and worried about making the wrong choice. Despite the aforementioned feelings, the children nevertheless wanted to be involved in making manageable decisions, such as where an intravenous line should be inserted. Similarly, older children in that study stated that they preferred that their physician explain their condition directly instead of their parents (13).

Some children noted that their fear and uncertainty influenced their participation in healthcare situations (21). Most children stated that they felt uncertain during the health encounter as they did not know what to expect and how to act. The uncertainty led to stress and hindered their participation. The children added that they would feel stronger if they were respected, given information individually, and allowed to be involved during shared decision-making. The children valued being treated with respect as an individual instead of being disregarded due to their age. The children preferred healthcare professionals to be friendlier and talk about personal topics, such as sports, pets, or travel, as they felt calm and secure when healthcare professionals built a personal friendship with them. Most children also stated that they appreciated it when healthcare professionals were truthful instead of indirect. The findings can help healthcare professionals better understand children's feelings and plan their reactions accordingly.

Some children preferred not to participate in shared decision-making and preferred their parents and healthcare professionals to decide on their behalf, specifically relating to treatment decisions (6, 11). Specifically, younger children asserted that they did not want to be responsible for making a major decision while older children admitted to being contented that adult made the major decisions although they nevertheless wanted to be included during the information-sharing and decision-making processes. Overall, younger children were content for their parents and doctors to make decisions together whereas older children reported varying comfort levels when involved in decision-making (13).

To summarise, children had varied preferences for participating in shared decision-making regarding their healthcare, which depended on the child's condition at a particular time. Some children preferred to be involved in the shared decision-making while others were happy to be excluded and preferred their parents and healthcare professionals to decide on their behalf.

### **Parents' and healthcare professionals' views on children's participation in shared decision-making**

Healthcare professionals and parents played an important role in children's participation in shared



decision-making as they could either facilitate or obstruct a child's participation (8,12,19,34). Children's involvement in decision-making could be improved by knowing the related facilitators and barriers from the healthcare professionals' and parents' perspectives (1). Thus, understanding healthcare professionals' and parents' views on children's participation in shared decision-making is crucial.

Healthcare professionals perceived children's participation as a prerequisite for care in the paediatric setting (10) and that it was necessary to engage with children for them to cooperate with procedures and treatment (15). Thus, the healthcare professionals supported children's participation by presenting opportunities for involvement, providing treatment-related information, and presenting options (15). Although the healthcare professionals agreed that children should participate in healthcare decisions, they noted that involving children in medical decision-making was complex as the decisions affected the child's health and wellbeing (15). Furthermore, the healthcare professionals indicated that, as part of their work, they listened to children and involved them in their care (10, 15). Thus, the healthcare professionals considered children's views based on the child's age, medical condition, and type of decision made. Nonetheless, some healthcare professionals were concerned that the concept was unclear and that their healthcare organisations did not state related policies (10).

In other studies, most healthcare professionals considered that treatment was 'in the best interests of the child' and children were occasionally unable to refuse treatment (10, 11, 13). Therefore, the healthcare professionals believed that neither the parents nor the child could make real decisions such as treatment decision as cancer is a life-threatening illness (11). Hence, most parents and children were obliged to accede to the healthcare professional's decision and non-adherence was not an alternative. The parents involved in that study agreed that they had no choice but to follow the healthcare professionals' advice. The parents agreed with healthcare professionals that children could not be involved in major decisions as cancer is life-threatening. Hence, children could not refuse the treatment as it was necessary.

## CONCLUSION

Children's participation levels in shared decision-making were not consistent and varied with the situation. In most studies, the children typically wished to be consulted and included in decision-making regarding their treatment. Nonetheless, the adults ignored the children's right to participate and typically did not present the children with the opportunity to participate. Moreover, decision-making preferences appeared to fluctuate in single patients. It is important

to view participation in shared decision-making from the child's perspective so that healthcare professionals and parents will be more understanding of the child's desires. Parents and healthcare professionals can react based on the child's views to facilitate participation in shared decision-making. Healthcare professionals may require further training to better assess a child's capacity and establish an appropriate discussion based on each child's needs.

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