



## Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences



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### A B S T R A C T

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*Purpose of the research:* Despite decision-making featuring throughout the trajectory of cancer care, children's participation in decision-making remains an area much under-researched and complicated by conflicting opinions. This study explored children's participation in shared decision-making (SDM) from multiple perspectives from one haematology/oncology unit in Ireland.

*Methods and sample:* Qualitative research design was used to explore participants' experiences of children's decision-making. Interviews were conducted with children<sup>1</sup> aged 7–16 years ( $n = 20$ ), their parents ( $n = 22$ ) and healthcare professionals ( $n = 40$ ). Data were managed with the aid of NVivo (version 8).

*Key results:* Parents and children's roles in decision-making were significantly influenced by the seriousness of the illness. Cancer is a life-threatening illness and so the treatment 'had to be done'. Children were not involved in major decisions (treatment decisions) as refusal was not an option. They were generally involved in minor decisions (choices about care delivery) with the purpose of gaining their cooperation, making treatment more palatable, giving back a sense of control and building trusting relationships. These choices were termed 'small' decisions that would not compromise the child's welfare. Some adolescents were aware that choices were not 'real' decisions since they were not allowed to refuse and expressed feelings of frustration.

*Conclusions:* Healthcare professionals and parents controlled the process of SDM and the children's accounts revealed that they held a minimal role. Children appeared content that adults held responsibility for the major treatment decisions. However, they desired and valued receiving information, voicing their preferences and choosing how treatments were administered to them.

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### Introduction

Childhood cancer is relatively rare. The incidence rate for Ireland is approximately 112 cases per year (Stack et al., 2007). Cancer continues to be described as a life-threatening illness, one that causes considerable emotional and physical distress for children and their families (Hedstrom et al., 2003; Woodgate and Degner, 2002). Increasingly however, children are surviving cancer due to medical advances and better treatment protocols (Gatta et al.,

2003). Whatever the treatment protocol children usually undergo lengthy aggressive treatments that can include chemotherapy, radiation, surgery and possibly bone marrow transplants along with numerous medical examinations and procedures (Woodgate and Degner, 2003). Thus there are many aspects of cancer which make life difficult and ensure that life can never be 'normal' for the family of a child with a life-threatening illness (McCaffrey, 2006). All of these stressors and the unpredictable nature of cancer mean that children's cancer care is characterised by challenging decision-making (Whitney et al., 2006). Both parents and children usually face multiple issues that require decisions along the cancer journey to either recovery and survivorship or end of life care.

Current recommendations state that children should be supported and encouraged to participate in healthcare decisions (Spinetta et al., 2003). Studies tell us that children with cancer

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<sup>1</sup> The term 'children' is used to denote both children and adolescents and to avoid cumbersome repetition.

benefit from being involved in decision-making, and that this influences their general wellbeing (Spinetta et al., 2002). Having a voice in decisions enables children to develop a sense of themselves, instils confidence, enhances communication skills, improves the effectiveness of services and encourages their participation in our wider society as active health consumers (Cohen and Emanuel, 1998). Therefore, key documents emphasise the importance of children's participation in shared decision-making (SDM) at a level commensurate with their experience, age, and abilities (Boylan, 2004; Cavet and Sloper, 2005). Shared decision-making is defined as the ways in which children can contribute to the decision-making process, independent of who makes the final decision. Although there is strong support from policy makers for children's SDM, the evidence on children's participation in SDM is weak as this area of research is young and under-developed.

There is evidence to suggest that children should be involved in decisions that affect them when they are able to do so and that children would like to be active participants in their health care, or at least have the choice to participate (Hinds et al., 2001; Zwaanswijk et al., 2007). However, research with hospitalised children indicates that they can often encounter obstacles to participating in SDM (e.g. Coyne et al., 2006; Runeson et al., 2002). Lack of involvement can lead to increased fears and anxiety, feeling unprepared for procedures and reduced self-esteem (Coyne, 2006).

Despite the apparent benefits of children's involvement, doubts exist about the appropriateness of sharing illness related information and decisions with children (Young et al., 2003). Children's participation in SDM is complex because of issues such as: adults' concerns about children's competence to participate, a desire to protect children from distressing information and the burden of decision-making and the child's position in the three way relationship. Parents instinctively try to protect their children from information which may worry or upset their sick child (Zwaanswijk et al., 2007). As a result, children are not always acknowledged as active participants in decisions regarding their medical treatment (Tates et al., 2002b). However some children may wish to take a passive role and may prefer their parents and/or health professionals to make the decisions depending on the situation. Balancing children's right to participate in SDM and their need and right for protection can be at its most extreme in a healthcare situation. Although children's preferences for involvement in SDM may vary, it is important that children's rights to participation are supported and respected by adults.

There is growing agreement that children's participation in SDM is a difficult area comprising several ideas that may be taken to mean different things in healthcare. It remains an area under-researched and complicated by conflicting opinions (Gabe et al., 2004; Young et al., 2006). There is a great deal of research on parents' role as proxy decision-makers for children as opposed to obtaining the child's own views and experiences (Dixon-Woods et al., 2002; Hinds et al., 2000). There is a growing body of studies into children's participation in end-of-life and clinical research decisions (Hinds et al., 2005; Joffe et al., 2006; Snethen et al., 2006) but remarkably few studies into children's participation in cancer treatment decision-making. Treatment decisions include both medical (e.g. cancer therapy) and nursing procedures (e.g. catheter insertions, IV infusions, lumbar punctures, bone marrow aspirations, biopsies, scans, and venepunctures). There is a lack of information on how parents, children and health professionals work together in relation to the SDM process. It is unclear to what extent children's participation is supported and promoted in practice and the influence of parents and healthcare professionals. Hence this study sought to:

1. Explore with children with cancer, their parents, and healthcare professionals' experiences of children's participation in SDM.
2. Describe the levels of children's participation in the SDM process from the perspectives of all participants.
3. Identify confounding and facilitating factors that influence children's participation in SDM.

## Methods

### *Sample and study design*

A qualitative design was used to obtain participants' experiences from their own perspective (Speziale and Carpenter, 2007). The study was conducted in a paediatric haematology-oncology inpatient unit and day care unit in a children's hospital in Ireland. The inpatient unit had 19 beds and the day unit had 13 beds. There was a policy of family centred care in place, but no policy on information-sharing nor participation in decision-making. Parents and children were invited to participate if they met the following inclusion criteria: child receiving cancer treatment more than 6 weeks since diagnosis, aged 7 years upwards and not receiving palliative care. Members of the multidisciplinary team were purposefully sampled to obtain a rich and diverse sample of healthcare professionals.

### *Data collection*

Data were collected through audio-recorded individual interviews that were structured around six topic areas (Box 1). The open-ended interviewing technique was used to allow flexibility with the questions, and to follow participants' own story. Interviews took place during the child's hospitalisation to facilitate easy recall of concrete events. Each participant chose the time and place of the interviews, thereby minimising any interference with medical or nursing care. Interview durations varied from approximately 30–60 min and were conducted in quiet, private areas. Participatory techniques were incorporated to aid interviews with children. They were a jelly bean game and decision and people cards representing a child, parent and staff. In response to some questions, children could place jellybeans into four jars labelled 'none', 'a little', 'some,' and 'a lot' according to their response. Visual depictions of decisions were used to explore what type of decisions children were involved in and their preferences around who should make what decisions.

### *Ethical considerations*

Ethical approval was granted by both the University Faculty Ethics Committee and the Hospital Ethics Committee. In general, interviews with parents and children were conducted seven or more days after they had consented so that they had adequate time to reflect on their decision to participate. The average number of days between first contact with a family who agreed to take part and data collection was 14 days. Cancer is a life threatening serious disease and children often have to undergo protocols with distressing side effects (e.g. pain, fatigue, nausea, vomiting), therefore the children were approached with great care and sensitivity (McIlfatrick et al., 2006). Consent was seen as an on-going process throughout and children were provided with a 'red card', which they could use to stop the interview at anytime. Interviews were held when the child was ready and at a time which did not conflict with planned treatment schedules. Children were generally interviewed alone but some parents chose to be present and this was in accord with their child's wishes.

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