



Communication study

Sharing decisions during diagnostic consultations; an observational study in pediatric oncology



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ABSTRACT

Objective: Children and parents need to make important decisions in the period of being informed about the diagnosis of childhood cancer. Although parents' and children's involvement is legally required, it is unclear whether oncologists involve them. This study explored which decisions families face, how oncologists involve them in shared decision-making (SDM) and which factors are associated with this process.

Methods: Forty-three families with children, starting treatment for childhood cancer, were recruited from three Dutch academic pediatric oncology clinics. Diagnostic consultations were audio-taped and coded with the OPTION.

Results: On average, 3.5 decisions were discussed per consultation. Most frequently discussed decisions concerned registration in a patient database (42%) and how to deal with hair loss (33%). Oncologists' assistance in SDM focused on giving information and ensuring the parents' and the child's understanding. The hospital in which children were treated ($F(2,2) = 5.39, p = .01$) and discussing trial participation ($F(1,1) = 8.11, p = .01$) were associated with oncologists' assistance.

Conclusion: Decision-making during diagnostic consultations appears to focus on non-treatment related decisions. Oncologists' assistance mostly concerned sharing information, instead of SDM.

Practice implications: Additional research is needed to provide insight in how to increase oncologists' assistance, while taking into account children's and parents' preferences concerning SDM.

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1. Introduction

Being informed about the diagnosis of childhood cancer elicits negative feelings in children [1] and parents, such as stress,

disbelief [2] and a feeling of loss of control over one's life [3]. Within this stressful period, children and parents have to make important decisions that will affect their life and wellbeing. Although in most cases evidence-based treatment protocols are used which leave parents and children fairly choiceless, ethics and laws prescribe that parents and children have to give permission to start treatment [4,5] and have to decide on whether or not to take part in a trial contrasting standard care with a care protocol with research components [6]. To fully participate in the decision-

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making concerning trial participation, parents and children need to understand complex concepts such as randomization and risks at a time when understanding is hindered by strong emotions [7]. Apart from these treatment-related decisions, parents and children also need to make non-treatment related but still important decisions such as how to deal with hair loss [8] and potential infertility problems [9].

A widely endorsed form of decision-making that enables participation is shared decision-making (SDM) [10]. SDM requires that clinicians provide understandable information and subsequently involve patients in making a treatment decision with which both parties agree [11]. Although there is room for improvement [12], adults have played an active role in SDM in medical settings for some time. Yet, according to the UN Convention treaty of 1989 [13] and legislation of many western countries [5], children also have the right to be involved in their own treatment. Their contribution may range from complete involvement for children above the age of twelve [4], to receiving information and being involved according to their development level for younger children [14]. SDM in paediatric oncology is defined as “the ways in which children can contribute to the decision-making process, independent of who makes the final decision” [15].

Most parents and children want to be informed about treatment, collaborate with the oncologist [16–18] and particularly value age-appropriate information [19]. However, health professionals experience difficulties engaging children in medical discussions [20]. Besides, parents tend to shield children from information that could be upsetting by managing what the child is told, and when and how this information is provided [18,20]. Parents' preference is in some hospitals granted by organizing split appointments, in which parents are informed prior to their children [21]. Even though there is an increased demand for SDM and informed consent, children still seem to be passive spectators [22,23].

Research concerning children's participation in SDM in pediatric oncology is lacking [24]. Most research on SDM in oncology focuses on patients' post-visit evaluations of the decision-making process [25,26]. Observing the actual decision-making process provides a more objective insight. Recorded consultations are a valuable tool for analyzing clinical interactions [10,27]. Audio-observation studies revealed that oncologists involve their adult patients in SDM to a limited degree [28] and seem more likely to disclose information than to facilitate participation in decision-making [29]. Analyzing pediatric oncology visits may be especially important because of the family system dynamics [23] and children's passive role [22,23].

Moreover, it is important to understand which factors influence oncologists' assistance in SDM. The child's age may influence the level in which health professionals involve them in medical discussions [22] and children's involvement in SDM increases with the length of the consultation [30,31]. Patients' involvement may also vary between hospitals and may be more extensive when discussing difficult issues such as trial participation.

The present study investigates which decisions parents and children face during diagnostic pediatric oncology visits. In addition, we explore how oncologists involve children and parents in SDM during diagnostic visits and whether contextual factors influence this process.

2. Methods

2.1. Patients

Participants were recruited by consecutive inclusion from three Dutch academic pediatric oncology clinics between April 2006 and

August 2008. All children (aged 8–16) who started treatment for childhood cancer and their parents were invited by their oncologist to participate. A minimum age of eight was required as children above the age of seven have the cognitive- and reading-skills to understand disease-related questions [32] and are able to participate in communication about health-related topics [33,34], within paediatric oncology [35]. Insufficient mastery of the Dutch language, a lag in development, treatment for secondary tumours, and being in a palliative phase of care were exclusion criteria. Participants were not excluded or included based on their diagnosis.

2.2. Procedure

This study was part of a larger study on communication in pediatric oncology [18]. The study was approved by the institutional review boards of the participating medical centers (METC 2005–050, AMO 05/074, MEC-2005–280) according to Dutch privacy legislation and complied with the Helsinki Declaration. We defined the diagnostic consultation as the consultation or consultations during which the diagnosis is confirmed and treatment is discussed for the first time. Before the diagnostic consultation, eligible participants were informed about the study by their oncologist and were asked to participate. When oral consent was obtained, the consultation was audio-taped. A researcher was present to operate the recorder. After the consultation, families who had given initial oral consent received written information about the study and informed consent forms. Families could withdraw their consent at any time, without explanation or consequences. If consent was withdrawn, the audio-tape was erased.

2.3. Measures

The decision-making process was assessed by coding the audio-taped consultations with the OPTION. The OPTION has been shown to be reliable and valid [36] and has been used to investigate shared decision making in pediatric health care before [37,38]. OPTION measures the extent to which clinicians involve patients in decision-making by coding 12 behavioural competences (Table 2) on a five-point Likert scale ('0=no attempt has been made' – '4=the behaviour is observed and executed to a high standard'), ranging from 0 to 48 per consultation. Clinicians are judged on how well they inform patients about options and consequences, whether they make sure that patients have understood the information, that concerns, expectations and preferences are discussed and how well they guide patients through the decision making process. The total score is calculated by counting up the scores for all the items and is transformed to a 0–100 scale. A higher score indicates that an oncologist executed a higher level of competence. Split consultations were scored separately, after which the highest score on each item was used to calculate the total score for the combined diagnostic consultation. As it was usually not possible to distinguish between parent and child oriented assistance from the oncologist, all assistance by the oncologist was included in the OPTION score.

Coding was conducted with observer software [39] by two coders, according to the official OPTION protocol [36]. Observer allows coders to code communication while listening to the audio-tape. Verbatim transcriptions were used to ensure full understanding of what was being said on the audiotape. The inter-rater reliability (ICC) was calculated using SPSS (version 18, 2009). The ICC was calculated on a random 10% of the consultations observed by the main coder ($N=4$). Inter-rater reliability of the OPTION was 0.93, indicating a high inter-rater agreement.

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