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

BIANCA M. WIERING^{A, *}, JANNEKE NOORDMAN^A, KIEK TATES^B, MARIEKE ZWAANSWIJK^A, GLYN ELWYN^{C, D, E, F}, EVELINE S.J.M. DE BONT^G, AUKE BEISHUIZEN^H, PETER M. HOOGERBRUGGE^{I, J}, SANDRA VAN DULMEN^{A, K, L}

HIGHLIGHTS

- We audio-taped diagnostic consultations in pediatric oncology.
- We analyzed oncologists' assistance in shared decision-making (SDM).
- Decision-making appears to focus on non-treatment related decisions.
- Oncologists' assistance mostly concerned sharing information, instead of SDM.
- Research is needed to provide insight in how to increase oncologists' assistance.

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.

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] and [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-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], [17] and [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] and [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] and [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] and [26]. Observing the actual

decision-making process provides a more objective insight. Recorded consultations are a valuable tool for analyzing clinical interactions [10] and [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] and [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] and [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] and [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] and [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. Verbatim transcriptions of the consultations were used to determine the number and type of decisions parents and children were faced with. Decisions were only included if the oncologist explicitly mentioned that a decision needed to be made.

2.4. Statistical analysis

Descriptive statistics were used to describe whether and how oncologists involve children and parents in decision-making during diagnostic consultations. Partial correlations were performed to explore which factors were associated with SDM (total OPTION score). Factors investigated as possible correlates of the SDM process were: the child's age [22], whether trial participation was discussed, the consultation duration [30] and [31] and in which hospital the child was treated. Analyses were controlled for the child's presence during the consultation, the number of discussed decisions, and the number of appointments during which diagnostic information was communicated [40]. Additional analyses of variance were performed for any significant correlations. Data were analyzed using Stata 11 [41].

3. RESULTS

3.1. Response

Prior to the diagnostic consultation, 60 families gave initial oral consent. 13 families withdrew their consent after the consultation. From the 47 families who gave a written consent, four audio-recorded consultations could not be analyzed because of technical problems.

3.2. Sample characteristics

Of the 43 consultations, 27 consultations were conducted with the parents and the child simultaneously. Twelve consultations were held separately and four consultations with the parents only. The duration of the complete diagnostic

consultations was 59.5 min on average (range: 23–102 min; median: 59 min). Eighteen oncologists divided over three hospitals participated, with an average of 2.4 (range: 1–7) consultations each. In hospital one 18 consultations were recorded, in hospital two 15 consultations and in hospital three 10 consultations. Fifty-one percent of children ($n = 22$) was male. The mean age of the children was 11.9 years (range: 8–16). Most children suffered from Leukemia ($n = 21$) or Malignant lymphoma ($n = 15$) (Table 1).

[TABLE 1]

3.3. Decision-making during diagnostic consultations

During the diagnostic consultations 3.5 (SD = 2.0; range: 0–8) decisions were, on average, discussed. The most frequently discussed decisions were whether parents and children consented to be registered in the national database for child cancer patients (42%) and what children and parents preferred to do about hair loss (33%) (Table 1). Permission to start treatment was discussed in two consultations.

3.4. Involvement in decision-making

Oncologists scored on average 1.1 (range: 0.16–2.60) per item of the OPTION scale, indicating a minimal attempt to exhibit a behavioural competence. On a scale from 0 to 100, the mean total score on the OPTION scale was 27.5 (SD = 9.5) (Table 1). Oncologists showed several competences in every consultation. They appeared most skilled in giving the children and parents explicit opportunities to ask questions (average of 2.6). Least observed competences were indicating the need to review a decision (average of 0.56) and eliciting the patient's preferred level of involvement in decision-making (average of 0.16) (Table 2).

[TABLE 2]

3.5. Factors associated with decision-making assistance

The OPTION score was correlated with the hospital in which the treatment took place ($r(41) = -.46, p < .05$), and with needing to discuss trial participation ($r(41) = .41, p < .05$). No other factors were associated with the OPTION score (Table 3). Additional analyses of variance showed significant differences in the OPTION score between the hospitals ($F(2,2) = 5.39, p = .01$), and significant differences in the OPTION score dependent on whether trial participation was discussed or not ($F(1,1) = 8.11, p = .01$). Hospital two and three scored lower than hospital one at most of the OPTION items. The biggest gap in scores between the hospitals concerned the items: "The clinician indicates the need to review the decision", and "The clinician assesses the patient's preferred approach to receiving information to assist decision making".

[TABLE 3]

4. DISCUSSION AND CONCLUSION

4.1. Discussion

This study is, to our knowledge, the first to investigate the role of pediatric oncologists in the decision-making process during diagnostic consultations for childhood cancer by means of audio-recorded real-life consultations. We first

investigated the number of decisions. The number of decisions (mean 3.5) that were discussed during diagnostic consultations is similar to that found in adult cancer consultations [42]. Contrary to consultations with adult patients, most decisions in pediatric oncology did not directly concern treatment, but focused on decisions such as how to deal with hair loss and consent for registration of medical data. The focus on non-treatment related decisions is in accordance with children's wish to be involved in 'small', non-life-threatening decisions[31]. In pediatric oncology the decision to start a particular treatment does not leave much room for deliberation, which may explain the finding that although treatment is discussed, treatment-related decisions are usually not discussed. Qualitative research concerning shared decision making in pediatric oncology suggests that healthcare professionals do not view starting treatment as a decision that parents or children need to make, but as something that just has to be done. Furthermore, both parents and healthcare professionals agreed that although children could be involved in 'small' decisions, they could not be involved in treatment-related decision making. Healthcare professionals even especially offered 'small' decisions as a way to involve children [30]. These views may influence what is discussed during the diagnostic consultation. Alternatively, the lack of treatment-related decision making may suggest a mutual agreement between oncologist and parents to maintain optimism and focus on the short term [43]. This may be an effective strategy to ensure children's participation, since they tend to focus on the short-term [44].

We found that in only two out of 43 consultations explicit permission to start treatment was asked. This is surprising since obtaining consent from parents and children (in case of children >12 years of age) is legally required before treatment can start [4]. An explanation for this finding may be that pediatric oncologists assume that parents want their child to survive and treatment is therefore unavoidable. Besides, survival rates for childhood cancer are relatively high [45], which reduces the necessity to discuss the pros and cons of treatment versus quality of life. Finally, although permission needs to be asked, refusing treatment may have legal consequences for the parents.

Each pediatric oncologist showed several competences in trying to involve children and parents, but only a minimal attempt was made per competence. The most frequently observed competences focused on giving children and parents the information they required by making sure that questions were asked and the information was understood. The competences concerning the actual decision-making (e.g. indicating the need to review the decision or eliciting the patient's preferred level of involvement in decision-making) were less often observed. The focus on informing patients is also observed in adult oncology [29], while eliciting the patient's preferred level of involvement in decision-making appears to be missing in many medical consultations [46]. However, since most children and parents prefer to become involved in decision-making [16], [17] and [18] and legislation requires participation of parents and children in decision-making concerning treatment [5] and [13], efforts should be made to increase oncologists' competence in this respect.

An important treatment-related decision that needs to be made concerns trial participation. Since parents and children need to understand complex research-related concepts at a time when understanding is hindered by emotions [7], oncologist's assistance may be crucial for full participation in SDM. Oncologists are

also legally required to obtain informed consent which requires understanding of the trial [47]. As OPTION includes competences such as informing patients of options and consequences, making sure that everything is understood and guiding the decision making process, we expected to find that needing to discuss such a complex decision combined with legal requirements would give oncologists ample opportunity to score well on the OPTION. We did indeed find that having to discuss trial participation was related to more assistance by the oncologist. Apparently if oncologists are legally required to discuss a difficult decision, they are able to step up and offer children and parents more assistance in SDM.

Although oncologists may be able to assist more if that is required of them, there is still room for improvement as oncologist usually only show minimal assistance. Several contextual factors were considered that might be associated with oncologists' assistance in SDM. We found that only the hospital in which the children were treated was associated with the extent to which oncologists assisted in SDM. However, none of the hospitals followed an official protocol concerning SDM, apart from the general legislation regarding informed consent. The association may be due to differences in hospital cultures or could be explained by oncologists scoring significantly above or below average and thereby influencing the hospital OPTION score. The number of consultations per oncologists was too low to detect an influence of one oncologist.

Another contextual factor, the child's age, was not significantly related to the extent to which oncologists assisted in SDM. This is remarkable, since previous research in primary care showed that older children were more encouraged to participate in the decision-making process than younger children [22]. An alternative explanation for this discrepancy might be that the previous studies included younger children (from the age of 4–12), whereas the present study included children aged 8–16. The developmental gap between the children participating in the previous studies may be bigger than in this study, which may increase the influence of age on the extent to which doctors communicate with the children. Another possibility is that oncologists adapt the number and kind of decisions that are discussed to the child's age, instead of adapting their assistance in SDM to the child's age.

Another noteworthy factor was the duration of the consultation. Although previous research found that children's involvement in SDM increased with the duration of the consultation [30] and [31], the present study did not find any relation between the duration of the consultation and the oncologists' assistance in decision making.

However, the increased involvement in previous research may be unrelated to oncologist's assistance. The positive influence of the available time can also be explained by the fact that children are granted more time to absorb the provided information and to build relationships with the healthcare professionals [31].

The present findings should be regarded with some caution because of study limitations. First, the results may be influenced by the relatively small study sample. This may have had consequences for the detection of significant relationships and for how well the sample reflects pediatric oncology patients. Second, a researcher was present during the recording of the consultations. This may have influenced the communicative behaviours of oncologists, patients and their family. Third, as the consultations needed to be recorded, oncologists were informed of our wish to investigate communication during the consultation. Although the oncologists were not aware that their assistance in the decision making process would be investigated,

knowing that their communication would be investigated may have influenced their overall communication. As OPTION measures several fairly general communication competences such as making room for questions and concerns, and making sure that the information is understood, an improvement in overall communication could have influenced the OPTION score. Fourth, it was not possible to show separate results for the consultations with or without the presence of the child, because the two parts of a split consultation are not comparable to a complete consultation where the parents and the child or only the parents are present. Therefore, we included split consultations as a separate complete consultation. Although there seems to be no difference between the different kinds of consultations concerning the OPTION score, it may have resulted in a slightly more positive view on oncologists' assistance. Fifth, although no associations between the different kinds of consultations and the OPTION score were found, further research is needed to provide more insight into the effects of the different consultations on oncologists' assistance in SDM and especially on the roles of parents and children in SDM. Sixth, no distinctions were made between parent or child oriented assistance from the oncologist. The recordings were audio-taped, which made determining for whom the assistance was meant difficult, especially since earlier research concluded that parents often reply to health provider cues that were meant for the child [22]. Seventh, although assistance in SDM may be more important for some decisions than others and SDM may be limited by protocols or other restrictions, OPTION does not take these factors into account. Finally, although in most consultations several decisions were discussed, treatment-related decisions were rare. This may have implications for the usefulness of OPTION as a measure for the quality of the communication.

An important strength of the present study is that it gives a unique insight into the daily communication processes of pediatric oncologists by analyzing real-life consultations. This enabled us to establish what kinds of decisions are made when children and parents are confronted with the diagnosis of pediatric cancer. Furthermore, it provides insight into the ways in which pediatric oncologists try to engage children and parents in SDM.

4.2. Conclusion

Decision-making during diagnostic consultations appears to focus on non-treatment related decisions. Oncologists' assistance mostly concerned sharing information, instead of SDM. Additional research is needed to provide insight in how to increase oncologists' assistance, while taking into account children's and parents' preferences concerning SDM.

4.3. Practice implications

The results of this study have several implications for pediatric oncology practice and research. Although oncologists already show several competences in assisting children and parents in participating in SDM, there is room for improvement. The finding that oncologists, parents and children rarely discuss treatment-related decisions may be a consequence of clearly prescribed treatments which leave little room for discussion, or may suggest that oncologists and parents mutually agree to maintain an optimistic attitude towards recovery and focus on the short term. Although this latter strategy may correspond with the wishes of most children [23], research suggests that some children want to be involved in the discussion of

treatment-related decisions [31]. It is therefore important to identify parents' and children's preferences concerning decision-making. Furthermore, the finding that oncologists seldom assist children and their parents in becoming involved in decision making indicates that further research, investigating how to increase the role of the oncologist in assisting child patients' and parental involvement in decision making during the diagnostic consultation for childhood cancer, may be very important for promoting SDM. According to Coyne et al. [24] there are currently no high quality interventions to promote participation in SDM for children with cancer. A suggestion for increasing oncologists' assistance therefore may be found in adult health care, as research concerning physician-patient interaction suggests that SDM communication training for doctors might help increase adult patients' involvement [43]. Similar interventions may be beneficial for SDM in paediatric cancer care.

ORIGINALITY STATEMENT

The manuscript contains original material and is not available elsewhere

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

FINANCIAL DISCLOSURE

The authors have no financial relationships relevant to this article to disclose.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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TABLES

Table 1
Characteristics of the children (N=43) and consultations.

Patient characteristics		N
Age (in years) ^a	11.9	Range 8–16 years
Male gender	22	51%
Diagnosis:		
Leukaemia	21	49%
Malignant lymphoma	15	35%
Bone tumour	4	9%
Soft tissue sarcoma	2	5%
Kidney tumour	1	2%
Characteristics of the consultation		
Duration (in min) ^a	59	Range 23–102 min
Present during the consultation:		
Child and parents	27	63%
Parents first, then child and parents together	12	28%
Parents only	4	9%
Total OPTION score ^a	27.5	Range 13–54
Number of discussed decisions ^a	3.5	Range 0–8
Most frequently discussed decisions:		
Registration in national pediatric oncology database	18	42%
How to deal with hair loss during treatment	14	33%
Trial participation	10	23%
Use of residual tissue samples for research purposes	10	23%
Options for dealing with possible infertility	9	21%

^a Reported are means and range.

Table 2
Pediatric oncologists' assistance in involving children and parents in decision-making.

OPTION item The clinician . . .	Number of consultations in which the competence is demonstrated (n= 43)	Percentage of visits that includes the competence (%)	Extent to which the competence is executed (range 0–172) ^a	Mean score per consultation
.. offers the patient explicit opportunities to ask questions during the decision-making process	43	100	112	2.60
.. checks that the patient understood the information	43	100	85	1.98
.. lists 'options', which can include the choice of 'no action'	32	74	55	1.28
.. draws attention to an identified problem as one that requires a decision-making process	32	74	55	1.28
.. states that there is more than one way to deal with the identified problem	31	72	45	1.05
.. explains the pros and cons of options to the patient	31	72	44	1.02
.. explores the patient's concerns about how the problems are to be managed.	30	70	38	.88
.. explores the patient's expectations about how the problems are to be managed	27	63	40	.93
.. indicates the need for a decision-making stage	21	49	39	.91
.. assesses the patient's preferred approach to receiving information to assist decision-making.	18	42	23	.53
.. indicates the need to review the decision	15	35	24	.56
.. elicits the patient's preferred level of involvement in decision-making	5	12	7	.16

^a The sum of the scores (range 0–4 per consultation) given to a single item of the OPTION over 43 consultations (range 0–172 for 43 consultations).

Table 3
Factors associated with the extent to which oncologists assist in shared decision making (n=43 consultations): results of partial correlations.

	OPTION
Discussion about participating in trials	.41*
Persons present during consultation	-.07
Number of discussed decisions	.28
Duration of the consultation (min)	.14
Number of appointments	.11
Hospital where treatment took place	-.45*
Child's age	.06

* $p < .05$.