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ORIGINAL RESEARCH

Parents' and Physicians' Perceptions of Children's Participation in Decision-making in Paediatric Oncology: A Quantitative Study

Michael Rost · Tenzin Wangmo · Felix Niggli · Karin Hartmann · Heinz Hengartner · Marc Ansari · Pierluigi Brazzola · Johannes Rischewski · Maja Beck-Popovic · Thomas Kühne · Bernice S. Elger

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Abstract The goal is to present how shared decision-making in paediatric oncology occurs from the viewpoints of parents and physicians. Eight Swiss Pediatric Oncology Group centres participated in this prospective study. The sample comprised a parent and physician of the minor patient (<18 years). Surveys were statistically analysed by comparing physicians' and parents' perspectives and by evaluating factors associated with children's actual involvement. Perspectives of ninety-one parents and twenty physicians were obtained for 151 children. Results indicate that for six aspects of information provision examined, parents' and physicians' perceptions differed. Moreover, parents felt that the children were more competent to understand diagnosis and prognosis, assessed the disease of the children as worse, and reported higher satisfaction with decision-

M. Rost (✉) · T. Wangmo · B. S. Elger
Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, 4056 Basel, Switzerland
e-mail: michael.rost@unibas.ch
T. Wangmo
e-mail: tenzin.wangmo@unibas.ch

B. S. Elger
e-mail: b.elger@unibas.ch

F. Niggli
Pediatric Oncology and Hematology, University of Zurich, Zurich, Switzerland
e-mail: felix.niggli@kispi.uzh.ch

K. Hartmann
Clinic for Children and Adolescents, Cantonal Hospital, Aarau, Switzerland
e-mail: karin.hartmann@luks.ch

H. Hengartner
Ostschweizer Kinderspital, Claudiusstrasse 6, 9006 St. Gallen, Switzerland
e-mail: heinz.hengartner@kispisg.ch

M. Ansari
Pediatric Oncology and Hematology Unit, Department of Pediatrics, Geneva University Hospital, Geneva, Switzerland
e-mail: marc.ansari@hcuge.ch

P. Brazzola
Ospedale Regionale di Bellinzona e Valli – Bellinzona, Pediatria, Via Ospedale, 6500 Bellinzona, Switzerland
e-mail: pierluigi.brazzola@eoc.ch

J. Rischewski
Pediatric Oncology and Hematology, Children's Hospital, Lucerne, Switzerland
e-mail: johannes.rischewski@luks.ch

M. Beck-Popovic
Pediatric Oncology and Hematology Unit, Department of Pediatrics, CHUV, Lausanne, Switzerland
e-mail: maja.beck-popovic@chuv.ch

T. Kühne
Pediatric Oncology and Hematology, University of Basel Children's Hospital, Basel, Switzerland
e-mail: thomas.kuehne@ukbb.ch

making on the part of the children. A patient's age and gender predicted involvement. Older children and girls were more likely to be involved. In the decision-making process, parents held a less active role than they actually wanted. Physicians should take measures to ensure that provided information is understood correctly. Furthermore, they should work towards creating awareness for systematic differences between parents and physicians with respect to the perception of the child, the disease, and shared decision-making.

Keywords Decision-making · Paediatric oncology · Children's participation

Introduction

Decision-Making in Paediatric Oncology

When children are diagnosed with cancer, families and physicians face the cumbersome task of making urgent and difficult treatment decisions. In the paediatric setting, decision-making process includes multiple steps and at least three parties: the physician/nurse, the patient, and the parents: each with their own opinions, needs, and expectations (Whitney 2008). They form a triadic constellation that must share the process and make a decision in the best interest of the child. Literature on shared decision-making emphasizes the following aspects: a) the involvement of at least two parties; b) sharing of information between the parties; c) consensus regarding the preferred treatment; and d) successfully achieving an agreement (Charles, Gafni, and Whelan 1997; Moumjid et al. 2007). Shared decision-making requires the involvement of all parties, with the child participating in a developmentally appropriate way (Craig et al. 2007). However, neither the participation of the child nor the ability of parties to carry out their preferred role is guaranteed. For instance, Mack concluded that more than one-third of the parents held a passive role and that they were unsatisfied with the information they received (Mack et al. 2011; Mack et al. 2006). Moreover, physicians often face several obstacles to communication such as time limitations and uncertainty about the patient's current or projected condition (Carnevale et al. 2012; Kilkelly and Donelly 2006). Finally, despite recommendations by international guidelines to involve children (American Academy of Pediatrics 2013; UN General Assembly 1989) several studies have noted that children's participation is still low and that they are often shielded from difficult or bad information (Pousset et al. 2010; Ruhe et al. 2014; Zhukovsky et al. 2009; Zwaanswijk et al. 2011).

Factors Hindering the Decision-Making Process

Forming a shared decision is not an easy process since all parties must overcome several difficulties. First, factors that inhibit parents include coping with the possible loss of their child and its consequences for the family (Kars et al. 2015). Parents must overcome intra-familial conflicts, may have unrealistic expectations regarding cure, and may deny that the cancer is terminal (Hilden et al. 2001). Parents' limited understanding of the medical information and low family educational level also impair their ability to adequately take part in the decision-making process (White et al. 2007).

Second, physicians perceive a series of ethical challenges in making treatment decisions. These include weighing what the consequences of their actions would be, questioning the role of parents, and uncertainty as to how the child's wishes should be considered (Carnevale et al. 2012). Physician's wishes to maintain some degree of hope may result in avoiding frank disclosure, thereby hindering decision-making. Furthermore, they face difficulties when asked "to provide uniquely tailored, culturally appropriate, holistic, comprehensive, coordinated, long-term care to all families" (Jones, Contro, and Koch 2014, 13; Mack and Joffe 2014; Mack et al. 2006). These concerns become more burdensome in light of the little formalized training that physicians receive in paediatric palliative care and in light of their reliance on learning through trial and error (Hilden et al. 2001; Jones, Contro, and Koch 2014; Zhukovsky et al. 2009).

Study Purpose

Available literature illustrates the need to shift the actual decision-making towards a process that empowers every involved person to occupy their preferred role. To know more about how shared decision-making in these situations occurs and how children are involved, more studies are needed. This research gap was addressed in this study carried out with physicians working in Swiss Pediatric Oncology Group (SPOG) centres and parents of children

suffering from cancer. Study participants were questioned about their attitudes towards the child's participation in the decision-making processes, their satisfaction with the process, and the actual involvement of the child. The study posed the following research questions: What are parents' and physicians' attitudes and orientation regarding inclusion of children in their cancer treatment decisions? What are their opinions on several aspects of shared decision-making and do they differ? Which factors determine children's actual involvement?

Methods

Study Design

Eight of the nine SPOG centres in Switzerland participated in this multicentre mixed methods project. The qualitative part of the project included interviews with children, their parents, and physicians. The results from the qualitative interviews have been reported elsewhere (Ruhe et al. 2015b; Ruhe et al. 2016; Wangmo et al. 2017; Wangmo et al. 2016). In addition, a quantitative collection of information using closed-ended surveys took place at the participating SPOG centres. In this quantitative part, children were not included. In this paper, we report the results of the quantitative surveys completed by parents and physicians. Distribution of the surveys began in November 2012 and was carried out until April 2015. Ethical approval was obtained from the responsible ethics committees for each SPOG centre. This inevitably meant that data could not be collected at all centres at the same time. The surveys were completed on a rolling basis according to when we received the ethics approval. The first centre began distributing the surveys and collecting them in November 2012 and the last one in June 2013. All centres ceased data collection in April 2015.

Study Population

Parents and treating physicians were included in the quantitative part of the project, if the respective child (a) was less than 18 years of age and (b) had a cancer diagnosis and received cancer treatment in one of the participating SPOG centres. The views of the paediatric patients were not gathered because we could not be sure that young children (less than twelve years) could understand and complete the study survey correctly. However, some variables captured children's views indirectly through the parents or the physicians evaluation of the child's view (e.g. "How satisfied was your child with decision-making?"; "Please evaluate your child's suffering due to the disease").

Data Collection

Before starting data collection, the research team visited the respective SPOG centres to introduce the study, its methodology, and study tool to the physicians, as well as to the data manager (where possible). The purpose of this visit was to explain the recruitment process so that data collection would be as uniform as possible within each centre and between different centres. Study materials with codes for physician and parent were labelled for each patient by the researchers and delivered to the participating centres. The data manager or the responsible contact person for the centre kept a note on which participant received which code. To ensure confidentiality, the researchers did not have access to participants' identifiable information.

The study team requested each physician at the participating centre to complete one survey for every patient he or she treated. This meant that the physicians completed multiple surveys; however, each was for a unique patient case. They were also asked to approach the parents for each patient for whom they filled out a survey. The treating physician thus informed the parents about the study and provided the parents the study information documents: informed consent, a survey, and refusal card. Based on their preference, the parents could either return the survey to the hospital in a sealed envelope or post it using the self-addressed stamped envelope provided. Since parents completed the survey within a short time span of a few weeks after they were approached by their child's treating physician, we expect that within one dyad perspective, the point along the child's disease trajectory (e.g. diagnosis, relapse) would not have differed greatly. By emphasizing that parents have the opportunity to refuse to participate and by handing over a refusal card, the study team ensured that no undue pressure was placed on parents, given their difficult situation.

Study Sample

A total of 229 surveys were completed and returned (138 by twenty treating physicians; ninety-one by parents) during the data collection period. These 229 responses represented 151 unique children cases. From the 151 children, dyad-perspective (of parent and physician) was captured for seventy-eight children. For seventy-three children, only one perspective was available: sixty from the treating physician and thirteen children from a parent. We cannot confidently estimate the number of patients who sought treatment at the participating SPOG centres during the study period as this data is not obtainable for the research team. However, twenty of the twenty-eight physicians at the participating SPOG centres participated in the study. Since 138 surveys were completed by the twenty physicians, we expect that 138 parents received a survey. From those parents who have received a survey, a completed survey was sent to the research team in 66 per cent of the cases. We received a total of eleven refusals from the parents.

Study Questionnaire

The study tool focused on the inclusion of children in the overall treatment decision-making. Several aspects and items of the detailed questionnaire were developed from the research team's knowledge in the field and input from collaborating physicians. The survey was designed to gather the following data: a) demographics information; b) the amount of information given to the parents and whether the patient was present at this time; c) the capacity of the patient to understand disease-related information; d) decision-making and satisfaction with decision-making within the triadic system of child, parent, and physician; and e) current and preferred role of parents within decision-making. Questions concerning roles in decision-making were adapted and revised from Mack and colleagues. The questionnaire consisted of items with categorical responses or Likert scales. It was pilot tested in August 2012 in one SPOG centre. A few adaptations were made that did not change the questionnaire's overall purpose.

Statistical Analyses

A research assistant entered all completed surveys into SPSS 22 and another checked for correctness of data entry. Statistical analyses were performed using SPSS 22 (SPSS Inc, Chicago, IL). For analyses described below, reported p values are two-sided and statistical significance level was set at $p < .05$.

To understand the general age at which children are considered capable of understanding different treatments and related consequences, physicians' evaluations of the age from which the majority of children were considered able to understand various information related to their illness and capable of making related decisions were assessed descriptively. To be able to determine this age, we first counted how many children at a given age were considered capable versus how many children of the same age were not. Second, we examined the age at which these frequencies shifted from "more children were deemed not capable" to "more children were deemed capable." This shift represented the "turning point" that we describe in this paper.

Moreover, we compared physicians' and parents' perspectives on the decision-making process, on children's characteristics, and on disease-related features. Using the seventy-eight dyad-perspective, a Wilcoxon signed-rank test was carried out to evaluate differences between physicians' and parents' responses to the following seven variables: suffering of the child, prognosis of child's cancer, capacity of the patient to understand disease-related information, past and expected treatment duration, satisfaction with decision-making, current and preferred role of parents in decision-making, and amount of information given to the parents. Additionally, using the parental perspective, we compared parents' current and preferred role in decision-making in order to evaluate whether they hold the role they wanted.

Finally, we evaluated factors associated with the actual involvement of the child in the shared decision-making process using generalized linear mixed model (GLMM). Categorical responses regarding the involved parties in decision-making (question: "who was involved in decision-making?") were dichotomized into "with child" and "without child." This binary variable was the dependent variable. Based on a priori theoretical considerations, four predictor variables were included: age of the child, gender of the child, cancer prognosis, and physician's professional experience as a paediatric oncologist. Since children receiving care from a particular physician and/or centre might have similar data, the analysis was adjusted for clustering within

Table 1 Descriptive statistics of children and study population

Children (n=151)[a]		Parents (n=91)		Physician (n=20)	
Age (M; *SD*)	8.05 (4.85)	Age (M; *SD*)	39.16 (7.23)	Age (M; *SD*)	43.56 (6.28)
Gender (male)	62%	Gender (male)	16%	Gender (male)	44%
Prognosis (M; *SD*)	1.63 (0.93)	Nr. children (M; *SD*)	2.22 (0.93)	Experience (<8 years)	50%
Suffering (M; *SD*)	2.49 (1.00)	Religious (yes)	54%	Religious (yes)	39%
Prev. Treatment (<6 months)	63%	Marital Status (married)	82%		
Exp. Treatment (<12 months)	31%	Relationship with the child (father)	16%		

Prev. Previous, *Exp.* Expected

[a] Information about children was obtained from physicians and parents. Due to minor discrepancies between parents and physician, we evaluated age and gender for the ninety-one cases from parents and the remainder from physicians. Prognosis, suffering, previous treatment, and expected treatment were evaluated by the physicians in all cases, except for thirteen cases for whom we did not have the physician survey. Prognosis was measured by a five-point Likert item ranging from 0 ("extremely good") to 4 ("very bad"); suffering from 0 ("a great deal") to 4 ("not at all").

physicians and SPOG centres. The GLMM analysis included the 138 cases that were completed by twenty physicians.

Results

Demographic Characteristics of the Sample

Of the children, 62 per cent were male. Parents were between eighteen and fifty-nine years old, and most of them were mothers (80 per cent; two missing values). Physicians were between thirty-five and fifty-eight years old, with a small majority (56 per cent) being female (two missing values). Other demographic information of patients, parents, and physicians is presented in Table 1.

According to the twelve categories (I–XII) of the International Classification of Childhood Cancer (ICCC), the most frequent diagnoses were as follows: leukaemia (ICCC-I; 49.7 per cent), central nervous system neoplasms (ICCC-III; 18.5 per cent), malignant bone tumours (ICCC-VIII, 7.9 per cent), and lymphomas and reticuloendothelial neoplasms (ICCC-II, 6.6 per cent). Two diagnoses were not represented in our sample: retinoblastoma (ICCC-V) and hepatic tumours (ICCC-VII). Compared to the Swiss Childhood Cancer Registry (SCCR), leukaemia was over-represented (49.7 per cent vs 33 per cent) and central nervous system neoplasms were comparable (18.5 per cent vs 19.6 per cent) (Swiss Childhood Cancer Registry 2016). Patients' ages were overall comparable to SCCR (in brackets): 0–4 years 34.8 per cent (36 per cent), 5–9 years 26.2 per cent (21.5 per cent), 10–14 years 27.5 per cent (22.7 per cent), and 15–20 years 11.4 per cent (19.8 per cent; note: SCCR includes adolescents up to twenty years of age).

Physicians' Evaluations of Children's Understanding and Capacity

With regards to understanding diagnosis, only one out of four children who were five years of age were deemed capable, three out of eight children who were six years of age were considered capable, and the same goes for seven out of thirteen children who were seven years old, and seven out of nine for children eight years old. Accordingly, the turning point was reached between six and seven years of age (Table 2). Therefore,

Table 2 Turning points[a] of children's competency evaluations by physicians (n=138)

Variable	Age (years)
Understanding diagnosis	6.5
Understanding prognosis	9.0
Understanding cancer cause	9.5
Understanding response to treatment	6.0
Making treatment decisions	11.5
Making decisions to be included in CT	11.5

CT Clinical trial

[a] From this age physicians considered the majority of children at a given age capable of understanding/decision-making

physicians judged understanding of response to treatment and understanding diagnosis to be easiest and thus deemed the majority of children older than six years to be capable of these two tasks. Understanding of cancer cause and prognosis was reported more positively for those children who were nine years and older. The capacity to make treatment-related decisions was evaluated as most challenging with the age limit for these choices being above eleven and a half years. Because of lower numbers we do not present the evaluations of the parents.

Factors Influencing Decision-Making Process

With regard to the *provision of information* the results highlight that for all six aspects of information provision (diagnosis, prognosis, treatment options, cancer cause, response to treatment, and clinical trial inclusion) parents' and physicians' perceptions differed significantly (Table 3). Compared to physicians, parents rated the amount of information that was given to them by the physicians as being less satisfactory.

Second, concerning *children's understanding of disease-related information*, results indicate that parents evaluated children's ability to understand diagnosis and prognosis higher than how it was evaluated by the physicians. Parents thus had a more capable image of their children (Table 3). Regarding the *characteristics of disease*, parents' and physicians' ratings of the suffering of a child as well as the expected treatment duration differed significantly. Parents assessed the disease of their child as worse (higher suffering, longer duration) than how physicians evaluated the disease. Finally, concerning *satisfaction with involvement in the decision-making process*, parents rated a child's satisfaction with the actual decision-making as higher than the physician (Table 3).

Parents' Preferred and Current Role in Decision-Making

Study results present that parents held a less active role than they actually wanted, $Z = -3.080$, $p = 0.002$. Of the parents who reported both their current and preferred role, 64 per cent reported that their current roles matched their preferred role; 8 per cent reported a more active role, and 28 per cent a less active role (Table 3). In order to further examine this difference in current and preferred roles, an exploratory GLMM analysis was performed addressing the question of what determines parents' less active role. This analysis did not reveal any predictors.

Characteristics of Children Involved in Decision-Making

Only forty-four (out of 137) children were involved in decision-making. They belonged to these age groups: three out of fifty children from zero to four years, six out of thity-six children from five to nine years, twenty-three out of thirty-eight children from ten to fourteen years, and twelve out of thirteen from fifteen to seventeen years. The findings from the GLMM reveal that a patient's age and gender significantly predicted whether the child was involved or not (Table 4). In particular, the older a child, the more likely was his or her involvement. Also, girls were more likely to be involved than boys. To illustrate, an additional year in age resulted in higher odds of being involved by a factor of 1.7; for a girl instead of a boy, the odds increase by a factor of 3.7. An exploratory independent samples t-test ($t(76) = 2.079$, $p = .041$, $d = .048$) revealed that parents evaluated girls' capacity (M = 1.95, SD = 1.58) to make treatment decisions higher than boys' capacity (M = 2.75, SD = 1.43).

The dependent variable in this analysis is the involvement of the child so that 0 = no and 1 = yes. Results were adjusted for physician and centre clustering

Discussion

By providing findings on children's actual involvement in decision-making, on parents' and physicians' evaluations of children's capacity to understand disease-related information and make treatment-related decisions, and on parents' roles in shared decision-making, this study presents new data contributing to the limited literature to date in shared decision-making in paediatric oncology, particularly in the Swiss paediatric oncology setting. The findings suggest appropriate and feasible ways to facilitate shared decision-making in paediatric oncology for all stakeholders. The study is unique as it highlights the dyad perspective on the same case.

Results from our dyad perspective first highlight that in comparison to physicians, parents rated the amount of information (on diagnosis, prognosis etc.) that they received as less satisfactory. Since studies have shown that

Table 3 Wilcoxon signed-rank test comparing physicians' and parents' perceptions on elements related to decision-making (dyad-perspective n=78)

Variable	PH=PA	PH>PA	PA>PH	z	p
1. Provision of information					
Information Diagnosis[a] (n=62)	48	13	1	-3.116[b]	.008[c]
Information Prognosis[b] (n=63)	39	20	4	.3.563[c]	.000[d]
Information Treat. Options[b] (n=62)	43	16	3	-3.065[c]	.006[d]
Information Cancer Cause[b] (n=62)	27	22	13	-2.178[c]	.029[d]
Information Response to Treat.[b] (n=62)	44	16	2	-2.840[c]	.010[d]
Information Inclusion CT[b] (n=56)	41	14	1	-3.231[c]	.005[d]
2. Children's understanding of disease related information					
Understanding Diagnosis[d] (n=67)	27	13	27	-2.202[e]	.028[d]
Understanding Prognosis[e] (n=63)	29	11	23	-2.497[f]	.026[d]
3. Children's competency to make treatment related decisions					
Competency Treatment Decisions[e] (n=66)	33	15	18	-.553[f]	.580[d]
Competency CT Decisions[e] (n=64)	31	15	18	-1.295[f]	.390[d]
4. Characteristics of disease					
Prognosis[f] (n=61)	20	21	20	-.162[f]	.872[d]
Suffering of the Child[g] (n=62)	27	10	25	-2.830[f]	.010[d]
Expected Treat. Duration[h] (n=67)	45	5	17	-2.802[c]	.015[d]
5. Satisfaction of involved parties					
Satisfaction Child[i] (n=33)	12	6	15	-2.538[f]	.011
Satisfaction Parent[j] (n=62)	23	15	24	-1.711[f]	.087
Satisfaction Physician[j] (59)	34	9	16	-1.224[f]	.221
6. Shared decision-making					
Shared Decision-making[e] (n=65)	16	20	29	-1.239[c]	.215
Preferred Role of Parents[j] (n=65)	29	22	14	-1.171[f]	.242

CT Clinical trial, *Treat* Treatment, *PH=PA* Physicians and parents rated equally, *PH>PA* Physicians rated higher than parents, *PA>PH* Parents rated higher than physicians

[a] five-point Likert item ranging from "full information" to "no information"

[b] based on positive ranks

[c] since the overall-hypothesis was tested through multiple comparisons and to control for the increased likelihood of a type I error, p-values were adjusted applying Bonferroni-Holm correction

[d] five-point Likert item ranging from "absolutely agree" to "strongly disagree"

[e] based on negative ranks

[f] five-point Likert-item ranging from "excellent" to "very bad"

[g] five-point Likert-item ranging from "severe" to "no suffering"

[h] four-point Likert-item: "less than one year", "between one and two years", "between two and four years", "more than four years"

[i] five-point Likert-item ranging from "very satisfied" to "not satisfied"

[j] seven-point Likert-item ranging from "I prefer to make the decision with no input from the physician" to "I prefer that the physician makes the decision with no input from me"

most parents want to be informed honestly and frequently with respect to poor prognosis, this deficit in communication is likely to reduce parental satisfaction with decision-making (Mack and Joffe 2014; Mack et al. 2006; October et al. 2014; Wangmo et al. 2016). For example, one study reported that the main reason for conflicts between physicians and parents was the latter's overly optimistic assessment of their child's prognosis (de Vos et al. 2011). In addition, parents perceived the fate of their children (i.e. treatment duration, suffering) as worse than how physicians perceived it. They thus felt that their children were suffering more and that the

Table 4 GLMM of involvement of the child in decision-making (n=137)

	B	SE	t	P	Odds Ratio	95% CI for Odds Ratio	
						Lower	Upper
Intercept	-4.406	1.531	-2.878	.005			
Age of Patient	.498	.058	8.569	.000	1.646	1.467	1.846
Female gender of Patient	1.296	.610	2.129	.035	3.656	1.096	12.193
Physician's Experience	-.602	.415	-1.450	.166	.548	.228	1.317
Prognosis of Disease	-.301	.243	-1.235	.219	.740	.457	1.198

treatment seemed to be a long-lasting process. This divergence in the perception of information received could be because physicians avoided full disclosure to maintain hope. Although hope is a strong emotional motive, it may not produce the desired outcome in light of the value placed by the family on proper and adequate information in such situations (Hinds et al. 2001; Jones, Contro, and Koch 2014; Mack et al. 2006). On the contrary, full disclosure of prognosis is not only recommended by international guidelines (Association for Children's Palliative Care 2009) but can promote parental hope and peace of mind (Mack and Joffe 2014). Other explanations for this difference are that information was not sufficiently tailored to the parents' need, due to ineffective consent documents as well as difficulties associated with understanding complex information in a stressful situation with limited time (Eder et al. 2007). There is thus a need to assess whether information provided is actually understood by the family (White et al. 2007) and a need for mechanisms to ensure clear communication between the healthcare providers and the family (Ruhe et al. 2015a).

Second, parents held a more positive view of children's capacities as they rated the child's capacity to understand diagnosis and prognosis information higher than the physicians. This could be because they deemed their children more capable, perceived inclusion as being helpful, or were simply hopeful. Parent's more positive view raises the question whether physicians underestimate children's capacities or parents overestimate their children's abilities or whether the view of parents and physicians depend on factors not related to the child (e.g. the time when information was received, educational level of the parent, gender). Exploring the reasons behind parental and professional assessment of child's capacity is a fruitful area of investigation that is lagging presently (Ruhe et al. 2015a).

Third, as expected our study findings point out that the likelihood of children's involvement in decision-making increases with age. While Hinds concluded that children between ten and twenty years of age are capable of participating in end-of-life decisions, in our sample only 69 per cent of this age group were involved, even though decisions considered in our study were not of this type and could be seen as being less cumbersome (Hinds et al. 2005). The qualitative findings from this project reveal that children and adolescents valued being involved in their treatment decisions (Ruhe et al. 2015b; Wangmo et al. 2017). Therefore, stronger involvement of children in light of their increasing age is recommendable for two reasons: age is highly correlated with the development of a child and involving children is internationally recommended (American Academy of Pediatrics 2000; Association for Children's Palliative Care 2009; Craig et al. 2007). Furthermore, guidelines highlight that children's level of understanding is often underestimated and that adolescents are aware of failed treatments (National Hospice and Palliative Care Organization 2009; World Health Organization 1998). Besides guidelines' recommendations and physicians' facilitation of children's involvement in decision-making, parents have the responsibility to make their children's voices heard. However, this parental ability can be limited, for example, by the burden of coping with their child's disease (Kars et al. 2015) and exclusion of children from medical discussions because they wish to protect their child (Zwaanswijk et al. 2007). Related to inclusion of a paediatric patient, an interesting finding of our study is that girls were more likely to be involved even when there was neither age nor prognosis

difference between boys and girls. An explanation from our exploratory analysis is that participating parents considered girls more capable of making treatment decisions than boys. Future research should carefully examine this finding.

Finally, similar to results from a study carried out in the United States, our study found that only 64 per cent of the parents held their preferred role, with 28 per cent holding a less active role and 8 per cent a more active role (Mack et al. 2011). It should be noted that there was no difference between parents' and physicians' evaluation of the parents' preferred role in decision-making. That means that participating physicians in our sample perceived the parental preferences correctly but the realization of preferred roles was hindered. This is concerning since a study pointed out that holding a less active role was associated with lower evaluation of communication quality (Mack et al. 2011). One reason for parents' less active roles could be that physicians were critical of the parental roles, namely parents holding too much decisional authority, and therefore restricted parents' participation (Carnevale et al. 2012). In the face of their child's disease, parents often want to gather further expert opinions (Eder et al. 2007), and it could be that parents did not receive enough time to make a decision in light of the time constraints in clinical practice (Gravel, Legare, and Graham 2006). It is important to take parental preferences into account and to conduct research on decision-making because this can influence practice in paediatric oncology (Sung and Regier 2013). Thus, barriers that hinder shared decision-making and individual-level factors that affect such processes need further evaluation to close this gap between perceived and current parental roles.

Limitations

The limitations of this study include the different time range during which data was collected in the eight participating centres. One centre refused participation, but we do not believe that parents and physicians in that centre would have provided a significantly different response. Second, physicians carried out survey dissemination to the families. We can neither ascertain the number of families to whom the study was explained and study materials distributed nor the number of families who refused to participate. The response rate calculated in the methods section is limited to the number of surveys completed by the physicians which composed our known denominator. Third, 80 per cent of the participating parents were mothers. Since mothers are more likely to carry out the main responsibility for their child during these situations, it is a legitimate over-representation. Fourth, from the 151 children, the dyad-perspective was captured for only 78. Correspondingly, for 48 per cent of the children, only one perspective was available, and thus comparative analysis could not be performed for all children cases. However, the number of dyad-perspectives is sufficient to derive statements about differences between physicians and parents. Finally, as our aim was to gather information about children who had cancer, we did not differentiate their disease trajectory. Therefore, this information was not gathered in our survey, and there could be an effect on the results of the child's point along the disease trajectory. Given that participating parent and the physician completed their surveys on the same child (dyad-perspective) within a few weeks, it is not very likely that the point along the disease trajectory differed significantly within a dyad.

Conclusion

Our study provides both valuable insights into the decision-making of physicians and parents, and information to improve the decision-making process. It reveals the need for healthcare providers to ensure that information provision is clear and correctly understood by the family. They should not take for granted that the information they relate to the family is perceived the way it is intended. That a girl patient is more likely to be involved in decision-making than a boy patient of the same age cautions both physician and parents to evaluate their perception of a child's capacity so that a capable male child is not denied participation. Additionally, our results note that physicians fail to ensure the preferred role of the parents. Measures to ensure that parents are enabled to enact their preferred roles in decision-making will be valuable to ensure good communication and the family's satisfaction with healthcare. Finally, our findings can be applied beyond paediatric oncology to the general aim of facilitating the optimal participation of parents and paediatric patients in shared decision-making.

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