Deposited with the permission of the publisher - © Springer
Journal of Bioethical Inquiry. 2017;14(4):555-565.

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

Michael Rost, MSc, MA, Tenzin Wangmo, PhD, Felix Niggli, MD, Karin Hartmann, MD, MPH, Heinz Hengartner, MD, Marc Ansari, MD, Pierluigi Brazzola, MD, Johannes Rischewski, MD, Maja Beck-Popovic, MD, Thomas Kühne, MD, Bernice S. Elger, MD, MA

M. Rost, Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, 4056 Basel, SWITZERLAND, Michael.rost@unibas.ch

T. Wangmo, Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, 4056 Basel, SWITZERLAND, Tenzin.wangmo@unibas.ch

F. Niggli, Pediatric Oncology and Hematology, University of Zurich, Zurich, SWITZERLAND, Felix.Niggli@kispi.uzh.ch

K. Hartmann, Clinic for Children and Adolescents, Cantonal Hospital, Aarau, SWITZERLAND, karin.hartmann@luks.ch

H. Hengartner, Ostschweizer Kinderspital, Claudiusstrasse 6, 9006 St. Gallen, SWITZERLAND, heinz.hengartner@kispisg.ch

M. Ansari, Pediatric Oncology and Hematology Unit, Department of Pediatrics, Geneva University Hospital, Geneva, SWITZERLAND, Marc.Ansari@hcuge.ch

P. Brazzola, Ospedale Regionale di Bellinzona e Valli – Bellinzona, Pediatria, Via Ospedale, 6500 Bellinzona, SWITZERLAND, pierluigi.brazzola@eoc.ch

J. Rischewski, Pediatric Oncology and Hematology, Children's Hospital, Lucerne, SWITZERLAND, johannes.rischewski@luks.ch

M. Beck-Popovic, Pediatric Oncology and Hematology Unit, Department of Pediatrics, CHUV, Lausanne, SWITZERLAND, Maja.Beck-Popovic@chuv.ch

T. Kühne, Pediatric Oncology and Hematology, University of Basel Children's Hospital Basel, SWITZERLAND, thomas.kuehne@ukbb.ch

B.S. Elger, Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, 4056 Basel, SWITZERLAND, B.elger@unibas.ch

Abstract

Objective
The goal is to present how shared decision-making in pediatric oncology occurs from the viewpoints of parents and physicians.
Methods
Eight Swiss Pediatric Oncology Group centers 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.
Results
Perspectives of 91 parents and 20 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-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.
Conclusion
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; Pediatric oncology; children's participation

Introduction

Decision-making in Pediatric Oncology

When children are diagnosed with cancer, families and physicians face the cumbersome task of making urgent and difficult treatment decisions. In the pediatric 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 to carry out 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; United Nations 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 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 the coping with the possible loss of their child and its consequences for the family (Kars et al. 2015). Parents must overcome intra-familial conflicts, they 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 (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 little formalized training that physicians receive in pediatric 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 the 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) centers and parents of children suffering from cancer. Study participants were questioned about their attitudes towards 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-centers 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. 2016a; Wangmo et al. 2016b). In addition, a quantitative collection of information using closed-ended surveys took place at the participating SPOG-centers. 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-center. This inevitably meant that data could not be collected at all centers at the same time. The surveys were completed on a rolling basis of when we received the ethics approval. The first center began distributing the surveys and collecting them in November 2012 and the last one in June 2013. All centers 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-centers. The views of the pediatric patients were not gathered because we could not assure that young children (less than 12 years) 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-centers 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 center and between different centers. Study materials with codes for physician and parent were labelled for each patient by the researchers and delivered to the participating centers. The data manager or the responsible contact person for the center 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 center 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 20 treating physicians; 91 by 91 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 78 children. For 73 children only one perspective was available: 60 from the treating physician and 13 children from a parent. We cannot confidently estimate the number of patients who sought treatment

at the participating SPOG-centers during the study period as this data is not obtainable for the research team. However, 20 of the 28 physicians at the participating SPOG participated in the study. Since 138 surveys were completed by the 20 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 11 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 role in decision-making was adapted and revised from Mack and colleagues. The questionnaire consisted in items with categorical responses or Likert scales. It was pilot tested in August 2012 in one SPOG-center. 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 2-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, physician's evaluation 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 was 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 78 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, satisfactions 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 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 pediatric oncologist. Since children receiving care from a particular physician and/or center might have similar data, the analysis was adjusted for clustering within physicians and SPOG-centers. The GLMM analysis included the 138 cases that were completed by 20 physicians.

Results

Demographic Characteristics of the Sample

62 per cent (93 of 151) of the children were male. Parents were between 18 to 59 years old and most of them were mothers (80 per cent, 71 of 89; two missing values). Physicians were between 35 to 58 years old with a small majority (56 per cent) being female (10 of 18; two missing values). Other demographic information of patients, parents, and physicians are presented in Table 1.

According to the 12 categories (I-XII) of International Classification of Childhood Cancer (ICCC), the most frequent diagnoses were as follows: leukemia (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 Swiss Childhood Cancer Registry (SCCR), leukemia was overrepresented (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' age were overall comparable to SCCR (in bracket): 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 20 years of age).

Physicians' Evaluations of Children's Understanding and Capacity

With regards to understanding diagnosis, only one out of four children who were 5 years of age was deemed capable, three out of eight children who were 6 years of age were considered capable, and the same goes for seven out of thirteen children who were 7 years old, and seven out of nine for children 8 years old. Accordingly, the turning point was reached between 6 and 7 years of age (Table 2). Therefore, physicians judged understanding of response to treatment and understanding diagnosis to be easiest and thus deemed the majority of children older than 6 years to be capable of these two tasks. Understanding of cancer cause and prognosis was reported more positively for those children who were 9 years and older. The capacity to make treatment related decisions was evaluated as most challenging with the age limit for these choices being above 11.5 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 physician 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 (47 of 74) reported that their current roles matched their preferred role; 8 per cent (6 of 74) reported a more active role, and 28 per cent (21 of 74) reported 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 what determines parents' less active role. This analysis did not reveal any predictors.

Characteristics of Children Involved in Decision-making

Only 44 (out of 137) children were involved in decision-making. They belonged to these age groups: 3 out of 50 children from 0-4 years, 6 out of 36 children from 5-9 years, 23 out of 38 children from 10-14 years, and 12 out of 13 from 15-17 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).

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 pediatric oncology, particularly Swiss pediatric oncology setting. The findings suggest appropriate and feasible ways to facilitate shared decision-making in pediatric oncology for all stakeholders. The study is unique as it highlights the dyad perspective on the same case.

Results from our dyad perspective first highlights 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 most parents want to be informed honestly and frequently, also 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. 2016b). For example, one study reported that the main reason for conflicts between physicians and parents was the latters' 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 treatment seemed to be a long-lasting process. This divergence in the perception of information received can 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 information that was not sufficiently tailored to the parents' need, by 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 mechanism 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 that the likelihood of children's involvement in decision-making increases with age. While Hinds concluded that children between 10 and 20 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. 2016a). 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 child's voices heard. However, this parental ability can be limited, for example, by their 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 pediatric 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 USA, our study found that only 64 per cent of the parents held their preferred, 28 per cent a less active, 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 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 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 pediatric oncology (Sung and Regier 2013). Thus barriers that hinder shared decision-making and individual level factors that affect such process 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 centers. One center that refused participation, but we do not believe that parents and physicians in that center 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 overrepresentation. Fourth, from the 151 children, only for 78 the dyad-perspective was captured. 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 of the point along the child's disease trajectory on the results. 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 from the part of 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 family's satisfaction with health care. Finally, our findings can be applied beyond pediatric oncology to the general aim of facilitating the optimal participation of parents and pediatric patients in shared decision-making.

References

American Academy of Pediatrics. 2000. Palliative care for children. *Pediatrics* 106(2 Pt 1): 351-357.

American Academy of Pediatrics. 2013. Pediatric Palliative Care and Hospice Care. Commitments, Guidelines, and Recommendations. *Pediatrics* 132(5): 966-972.

Association for Children's Palliative Care. 2009. A Guide to the Development of Children's Palliative Care Services. Bristol, UK.

Carnevale, F.A., C. Farrell, R. Cremer, et al. 2012. Struggling to do what is right for the child: pediatric life-support decisions among physicians and nurses in France and Quebec. *J Child Health Care* 16(2): 109-123.

Charles, C., A. Gafni, and T. Whelan. 1997. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 44(5): 681-692.

Craig, F., H. Abu-Saad Huijer, F. Benini, et al. 2007. IMPaCCT: standards of paediatric palliative care. *European Journal of Palliative Care* 14(3): 109-114.

de Vos, M.A., A. van der Heide, H. Maurice-Stam, et al. 2011. The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics* 127(4): e1004-1012.

Eder, M.L., A.D. Yamokoski, P.W. Wittmann, and E.D. Kodish. 2007. Improving informed consent: suggestions from parents of children with leukemia. *Pediatrics* 119(4): e849-859.

Gravel, K., F. Legare, and I.D. Graham. 2006. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 1: 16.

Hilden, J.M., E.J. Emanuel, D.L. Fairclough, et al. 2001. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 19(1): 205-212.

Hinds, P.S., D. Drew, L.L. Oakes, et al. 2005. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol* 23(36): 9146-9154.

Hinds, P.S., L. Oakes, W. Furman, et al. 2001. End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nurs* 24(2): 122-134; quiz 135-126.

Jones, B.L., N. Contro, and K.D. Koch. 2014. The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring. *Pediatrics* 133 Suppl 1: S8-15.

Kars, M.C., M.H. Grypdonck, L.C. de Bock, and J.J. van Delden. 2015. The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase. *Health Psychol* 34(4): 446-452.

Kilkelly, U., and M. Donelly. 2006. The Child's Right to be heard in the Healthcare Setting: Perspectives of children, parents and health professionals. in *The National Children's Strategy*. Dublin, Ireland: Office of the Minister for Children.

Mack, J.W., and S. Joffe. 2014. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics* 133 Suppl 1: S24-30.

Mack, J.W., J. Wolfe, E.F. Cook, et al. 2011. Parents' roles in decision making for children with cancer in the first year of cancer treatment. *J Clin Oncol* 29(15): 2085-2090.

Mack, J.W., J. Wolfe, H.E. Grier, P.D. Cleary, and J.C. Weeks. 2006. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol* 24(33): 5265-5270.

Moumjid, N., A. Gafni, A. Bremond, and M.O. Carrere. 2007. Shared decision making in the medical encounter: are we all talking about the same thing? *Med Decis Making* 27(5): 539-546.

National Hospice and Palliative Care Organization. 2009. Standards of Practice for Pediatric Palliative Care and Hopsice. Alexandria, VA.

October, T.W., K.R. Fisher, C. Feudtner, and P.S. Hinds. 2014. The parent perspective: "being a good parent" when making critical decisions in the PICU. *Pediatr Crit Care Med* 15(4): 291-298.

Pousset, G., J. Bilsen, J. Cohen, et al. 2010. Medical end-of-life decisions in children in Flanders, Belgium: a population-based postmortem survey. *Arch Pediatr Adolesc Med* 164(6): 547-553.

Ruhe, K., D.O. Bădărău, B.S. Elger, and T. Wangmo. 2014. End-of-life decision making in pediatrics: literature review on children's and adolescents' participation. *American Journal of Bioethics Empirical Bioethics* 5(2): 44-54.

Ruhe, K., T. Wangmo, B.S. Elger, and D.O. Bădărău. 2015a. Decision-making capacity of children and adolescents : suggestions for advancing the concept's implementation in pediatric healthcare. *Eur J Pediatr* 174: 775-782.

Ruhe, K.M., D.O. Badarau, P. Brazzola, et al. 2015b. Participation in pediatric oncology: views of child and adolescent patients. *Psychooncology* 25(9): 1036-1042.

Ruhe, K.M., T. Wangmo, E. De Clercq, et al. 2016. Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology. *Eur J Pediatr* 175(9): 1147-1155.

Sung, L., and D.A. Regier. 2013. Decision making in pediatric oncology: evaluation and incorporation of patient and parent preferences. *Pediatr Blood Cancer* 60(4): 558-563.

Swiss Childhood Cancer Registry. 2016. Annual Report 2014/2015. Bern, Switzerland: Swiss Childhood Cancer Registry.

United Nations. 1989. Convention on the Rights of the Child.

Wangmo, T., C. De Clercq, K.M. Ruhe, et al. 2016a. Better to know than to imagine: Including children in their health care. *American Journal of Bioethics Empirical Bioethics* 10.

Wangmo, T., K.M. Ruhe, D.O. Badarau, et al. 2016b. Parents' and patients' experiences with paediatric oncology care in Switzerland--satisfaction and some hurdles. *Swiss Med Wkly* 146: w14309.

White, D.B., C.H. Braddock, S. Bereknyei, and J.R. Curtis. 2007. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med* 167(5): 461-467.

Whitney, S.N. 2008. Whose decision is it? The microstructure of medical decision making. *Z Evid Fortbild Qual Gesundhwes* 102(7): 423-425.

World Health Organization. 1998. Cancer pain relief and palliative care in children. Geneva, Switzerland: WHO.

Zhukovsky, D.S., C.E. Herzog, G. Kaur, J.L. Palmer, and E. Bruera. 2009. The impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions in pediatric patients with cancer. *Journal of Palliative Medicine* 12(4): 343-349.

Zwaanswijk, M., K. Tates, S. van Dulmen, et al. 2011. Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences. *Psychooncology* 20(3): 269-277.

Zwaanswijk, M., K. Tates, S. van Dulmen, et al. 2007. Young patients', parents', and survivors' communication preferences in paediatric oncology: results of online focus groups. *BMC Pediatr* 7: 35.