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Lay Summary

Attitudes and motives concerning end-of-life decisions: Competency and autonomy of children and adolescents in paediatric oncology

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1. Background

Traditionally children have been excluded from the decision making process, however the medical setting is increasingly recognizing children's participation rights in choices concerning their health. Little knowledge is available on what children's participation in decision making exactly entails as it can range from being informed about medical treatments to being the main decision maker (Alderson 2007). Implementation of the child's participation remains difficult due to the absence of adequate tools to assess their capacity (Ruhe et al., 2015). Within the pediatric context decision-making is a complex process since it involves three parties: the child, his/her parents and the treating physician (Gabe, 2004).

There is evidence that children and adolescents with cancer between 10 and 20 years are capable to participate in decision-making (Hinds, 2005) and that doing so makes them feel appreciated, less anxious and distressed (Runeson, 2002; Moore & Kirk 2010). For some children being involved in certain decisions might be too demanding and scare them off (Coyne 2008). As a result, adults need to carefully decide between allowing children to take part in decision-making and burdening them with complex decisions (Harrison et al. 1997). Also adults' tendency to protect children from distress may result in exclusion of the pediatric patient. Parents may have unrealistic expectations regarding prognosis and cure and have difficulties facing the possible loss of their child (Kars, 2015). Physicians might also find it challenging to bring bad news and avoid frank disclosure (Mack, 2006). These communication challenges are exacerbated by the lack of training and education that physicians receive in pediatric palliative care and by the resulting lack of confidence in providing such care (Peng et al. 2016).

Palliative care for children is an important sub-speciality within the overall healthcare setting. It focuses not only on pain and symptom management, but also on the social, psychological and spiritual well-being of patients and their families. Although the concurrent administration of curative and palliative care is recommended, timely referral to pediatric palliative care services remains problematic (Keele, 2013). Furthermore, our insight in children's involvement and perspective in palliative care decisions remains limited.

2. Goals of the project

This study was designed to understand the end-of-life situation in the Swiss pediatric oncology context and how and by whom decisions regarding the integration of palliative care were made. It sought to (a) investigate the possibility of including children or adolescents living with cancer in EOL decision making processes; (b) examine associated motives and attitudes toward such decisions; and (c) examine EOL decisions in the course of disease progression and over time in order to be able to draw recommendations for pediatric palliative care guidelines.

3. Methods

The study followed a mixed-method design combining quantitative and qualitative methodology. The quantitative part was aimed at gathering general data on decision making in pediatric oncology in Switzerland employing surveys for parents and physicians as well as a retrospective analysis of medical records of deceased children. The qualitative part closely examined attitudes and motives regarding decision making and involvement of minor patients in this setting employing one-to-one interviews (with patients, physicians and parents) as well as focus groups with healthcare professionals. The study was conducted in 8 of the 9 centers of the Swiss Pediatric Oncology Group (SPOG): Aarau, Basel, Bellinzona, Geneva, Lausanne, Luzern, St. Gallen, and Zurich.

The quantitative part of the study was carried out using a survey with parents of children diagnosed with cancer and treating oncologists. The prospective survey study aimed to include all the parents of children who were receiving treatment for cancer in Switzerland and their corresponding oncologist. The 4-page questionnaire was distributed among parents and oncologists with matching questions to investigate the perspective of both participant groups on the same case. Questions asked included a) demographics information; b) the amount of information given to the parents and whether the patient was present at this time; c) the competencies 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) actual and preferred role of parents within decision-making.

Since few children in our sample (7 out of 21) were considered palliative, sufficient data on the topic of EOL decision making was missing. Hence a follow-up study was designed to retrospectively understand the EOL situation in pediatric oncology and to examine how and by whom palliative care decisions were made. For this purpose, a retrospective study was conducted of medical records of all pediatric oncology patients (younger than 18 years at the time of diagnosis) who died between 2008 and 2014. These medical records were carefully examined by four researchers. The following aspects from the medical records were extracted: a) demographics, b) diagnosis and relapse(s), c) treatments received, d) decision-making in the course of treatment, and e) death of the child.

The qualitative sample for this project consisted of parents, oncologists, and children and adolescents with cancer aged between 9 and 17 years of age. One-to-one, semi-structured, individual interviews were conducted to explore the time surrounding diagnosis and treatment as well as attitudes and motives regarding children's involvement in healthcare decision making.

Additionally, one round of focus groups was conducted. Building on the data obtained from the retrospective review of medical records, a focus group interview guide was developed. The goals of the focus group discussions were to (a) explore what stakeholders understand with palliative care; (b) present case patterns and discuss when, why and how care changes from curative to only palliative, how patients/families participate in these discussions, and (c) whether and how the change from curative to palliative care as well as the palliative care phase as such are structured, if no protocols are in place. Discussions focused on how decisions on symptom management and supportive care are and/or should be provided.

4. Results

Inclusion of children in decision making processes

In line with pediatric guidelines, parents and physicians recognized the importance of participation, but emphasized that children should never take the sole responsibility in the decision making process as long as curative treatment is possible. This was because of possible unwise decisions, and fear that this process would scare them off. It is only with the shift from curative to palliative care that the child's perspective was considered to be more prevalent when making decisions (Wangmo & De Clercq et al, 2016, AJOB).

Parents and physicians valued children's participation, but they did not refer explicitly to notions such as autonomy or self-determination. Children's participation was considered important because they have not only the right but especially the *need* to be informed about their illness, treatments, and side-effects. This need was closely related to ethical issues of trust and truth. Inclusion was considered to be a sign of respect for the child. Underlying this respect was the belief that as the affected persons, children already know that something is wrong. An important instrumental reason to include children was the conviction that informing them about their illness and its procedures could translate into compliance with treatment matters (Wangmo & De Clercq et al, 2016, AJOB).

Factors influencing children's role in decision-making processes

An important aspect influencing children's ability to participate in their healthcare is the provision of information regarding illness and treatment. In paediatric oncology, this is often done using story books. A qualitative analysis of books and written materials in German and English (Ruhe, Elger, and Wangmo, 2015; Cancer Nursing) revealed that children can obtain useful information from these resources, such as information on: diagnosis, treatment procedures, emotions associated with the illness experience, and coping strategies.

Also contextual influences influence children's ability to participate in the decision making process. Parents and physicians have an important role and responsibility in the development and exercise of children's decision making capacities (Ruhe et al. 2016, Journal of Bioethical Inquiry). At the same time, it remains difficult to assess children's capacity to make EOL decisions due to the lack of adequate tools to assess their capacity and the blurriness of the concept of capacity itself (Ruhe et al, 2014; European Journal of Pediatrics). Finally, our study shows that a patient's age and gender significantly predict involvement, with older children and girls being more likely to be involved in treatment related decisions (Rost et al., accepted, Journal of Bioethical Inquiry).

Children's opinions are missing

An initial systematic literature review revealed that the perspectives of children and adolescents were only rarely sought in studies on EOL decision making. From a total of 57 articles on EOL decision making, 75% included the view of parents and/or healthcare professionals while only 25% reported on minor patients' views. Examples of children's participation in this context included: receiving information, planning care details, or being consulted before or after an EOL decision was made (Ruhe et al, 2014, AJOB Empirical Bioethics).

We sought to gather the opinions of children on EOL decision-making by conducting qualitative interviews with pediatric patients, their parents and physicians. Children and adolescents in this study identified several roles with regard to communication and decision making (Ruhe et al, 2015, Psychooncology). Some children were directly involved in diagnosis communication and received information on their cancer and treatment together with their parents. Other participants were informed later by their parents and/or oncologists. Children and adolescents reported participating in decision making. This concerned mostly decisions surrounding smaller aspects of their care (e.g., whether to take medication in liquid form or as a pill). From time to time, children were involved in more essential decisions (e.g., fertility preservation, change to high-risk treatment). Additionally, they identified occasions when they were not involved.

While children generally valued their involvement and found it important to be informed, they also identified challenges associated with participation. These concerned the clarity and quality of information provided to them as well as difficulties when making decisions (e.g., balancing other people's wishes against their own). Participating children differed in their preferred level of involvement and while non-participation was preferred by some, it caused feelings of exclusion in others. Some children valued not being involved in the beginning while becoming active later on (Ruhe et al, 2015, Psychooncology).

A secondary analysis of a subpart of our qualitative data, aimed to explore how children, parents and physicians make sense of progressive childhood cancer. We found that the possibility that the child could die was either ignored or only briefly contemplated by adults. Children almost never directly addressed the topic of death. Our findings raise important questions about how the social discourse on dying is framed in terms of choice, autonomy and individuality (De Clercq et al., 2017, European Journal of Cancer Care).

EOL decisions in the course of disease progression

At diagnosis, physicians' role was dominant as they identified the appropriate protocol for the particular cancer and advised starting the treatment. Most participants perceived these decisions as a "choiceless choice" which was not the result of physician constraint or pre-exclusion of other similarly good options, but the consequence of a constraining context (Badarau et al, 2017, AJOB). Parents, in fact, expressed their trust in the physicians' expertise. For decisions that affect quality-of-life but not treatment outcome, the family's role became more prominent. In the case of relapse or terminal illness, when therapy failed, decisions had to be made regarding experimental treatment and palliation. These decisions required not only the consultation of different specialists, but an increased involvement of the family as well. For patients with progressive cancer, in fact, there is no best option as the medical judgement of the available treatment options is unclear. For this reason the decisional priority was mostly shared between families and physicians and in some cases it lay fully with parents and patients (Badarau et al, 2017, AJOB) .

5. Significance of the results for science and practice

The results of the present study are important because they show that children and adolescents diagnosed with cancer in Switzerland vary in how much they want to be involved and this may also change across time. Parents, physicians, and others caring for these young patients should thus check whether the level of involvement is in line with children's preferences or whether they wish to participate more or less. This is a challenging task not only because of the considerable differences among children, but also because of the changing preferences of one and the same child. For instance, a patient for example may wish not to be involved at diagnosis, but may want to become more active later onwards.

The findings highlight the need for specific guidelines on how participation of children and adolescents can be achieved in everyday paediatric oncology practice in Switzerland. Physicians and other healthcare professionals need further education and training to develop and implement strategies to promote the participation of children and adolescents in discussions and decision



making. Moreover, our results indicate that parents' and physicians' perspectives on the information provision differed systematically (Rost et al., accepted, *Journal of Bioethical Inquiry*). Parents rated the information received from the physicians as less sufficient. Therefore, physicians need to make sure that parents understand everything correctly. Moreover, parents' assessed the disease of their child as being worse (higher suffering, longer duration) than physicians, and rated their children's capacity to understand the diagnosis and prognosis higher than physicians did. Apart from these systematic differences, parents often hold a less active role in decision-making than they actually wanted. Consequently, physicians need to work towards enabling parents to hold their preferred roles in the decision making process.

Findings of a quantitative study of the Bonus part (Rost, Wangmo et al., in-preparation) underscore the need for a raised awareness among clinicians of the treatment burden for leukemia patients. The burden of treatment for this diagnostic group might be underestimated given the comparably good prognosis for leukemia patients. Health care professionals need to be aware of the characteristics of leukemia treatment, like for example its highly disruptive effects on families' daily lives due to the high number of hospital visits. Another manuscript using the data from the bonus part (medical records) underscores that due to the overall good prognosis for leukemia, pediatric palliative care begins at a very late stage for this diagnostic group when compared to patients with other types of cancer (Acheson, et al., in-preparation). An increased awareness about the high burden treatment for leukemia, may be an incentive for healthcare providers to integrate palliative care alongside curative treatment at an earlier time.

The literature review on studies discussing palliative care guidelines indicates that a critical assessment of both research guidelines and medical practice is required in order to promote timely implementation of pediatric palliative care (De Clercq et al, 2017, *Palliative and Supportive Care*). A second review (Rost et al., under review) focused on the language used in palliative guidelines and in particular on the four core domains of pediatric palliative care, namely physical, psychological, social and spiritual care. This analysis highlighted that these care domains lack conceptual clarity. Since a consistent use of terminology is a prerequisite for quality pediatric palliative care, a shared understanding and unambiguous use of terms have to be envisaged both within academia and within the clinical setting.

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