

Participation in pediatric oncology: views of child and adolescent patients

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Abstract

Objective: The aim of the present study is to explore patient's perspectives in pediatric oncology on participation in discussions and decision-making surrounding their cancer diagnosis.

Methods: Seventeen patients between 9 and 17 years of age receiving treatment at centers of the Swiss Pediatric Oncology Group were interviewed for this study. Their interview data was analyzed qualitatively to identify themes with regard to participation in medical communication and/or decision-making.

Results: Participants highlighted how their roles in health care discussions varied from direct participation to indirect involvement. Overall, there were fewer accounts of involvement in decision-making than in overall health care discussions. Challenges with regard to completely understanding the information provided and making decisions were identified. Participants also discussed situations when they were not involved in medical communication or decision-making. While they generally valued their participation, the preferred level of involvement oscillated between participants as well as within one and the same child across time.

Conclusions: The complex pattern of participation found in this study calls for a flexible model of involving children and adolescents in health care that accounts for the varying roles and preferences that they manifest. A patient may appreciate active involvement in some decisions while choosing to remain in the background for others.

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Participation of children¹ in their health care is considered an important value in the provision of medical treatment [1]. The International Society of Pediatric Oncology states that children should participate in decision-making in a developmentally appropriate way [2]. Their participation² can take many different forms such as receiving or providing information, contributing an opinion, or making a health care choice [3]. Children's participation is critical because it can reduce their anxiety and uncertainty about undergoing medical treatment and make them feel more active in their treatment and in control, as well as prepared for different medical procedures [1,4,5].

When studying decision-making in pediatric oncology, Coyne and colleagues found that children's role in this setting was limited [6]. They noted that while younger patients (7–11 years) were satisfied with this level of participation, adolescents expressed frustration with the loss of control

and lack of choice. With regard to involvement in discussions, participation of children was found to be difficult because parents could both facilitate and hinder direct exchange between physician and their child [7]. The limited involvement of children is evident from a Cochrane review assessing randomized controlled trials of shared-decision making interventions for cancer patients [8].

Although it is clear that the realization of meaningful patient participation is a challenge within the pediatric oncology setting, it is increasingly recognized that children's own views are important [9]. Yet, there is little evidence as to young patients' needs with regard to decision-making when they have cancer [10] and their perspectives towards participation in health care communication [4,11,12]. Because professional guidelines recommend their involvement it seems important to gather children's opinions and experiences associated with health care encounters. We aim to fill in this gap by presenting results from our Swiss-wide project that interviewed children and adolescents living with cancer concerning their participation in medical discussions and decision-making surrounding their cancer diagnosis.

¹The term 'children' is used to denominate any minor patients. When results pertain to a specific group (e.g. adolescents) this will be clearly differentiated.

²'Participation' and 'involvement' will be used interchangeably in this manuscript.

Methods

Data from participating children and adolescent is presented in this study, which is a sub-set of a larger mixed methods project whose aim was to investigate how decisions were made in pediatric oncology in Switzerland and the extent to which children were included. The quantitative part of the project surveyed pediatric oncologists and parents. The qualitative part was composed of face-to-face interviews with minor patients, their parents, and physicians. For the qualitative component, a total of 52 interviews were carried out representing 21 sets of cases (19 parents, 17 children, and 16 physicians who discussed these 21 cases). From a total of 21 families who wished to participate, four children refused participation because of disinterest in talking about this topic or not wanting to look back. In this paper, we only report recruitment and results for the 17 young people.

Participating patients were receiving cancer treatment in eight of the nine centers of the Swiss Pediatric Oncology Group (SPOG). Face-to-face interviews were conducted at the earliest three weeks after the initial diagnosis to give the family time to come to terms with the diagnosis. The sampling was purposive in nature. To ensure greatest sensitivity with regard to participant recruitment, the physicians at the SPOG centers selected families which they thought would be willing to participate and where no adverse factors were present (e.g. exceptional emotional burden). They first informed the families about the study and those who expressed their interest were then contacted by the research team. The exact number of families who were approached could not be established because this step was carried out informally by participating physicians.

A semi-structured interview guide was used that included questions surrounding time of diagnosis and treatment as well as opinions on their participation in health care (Table 1). These questions were adapted by the interviewer to meet pediatric participants' understanding (e.g. easier language was used with younger children). From the experiences of the researchers, interviews were

not so much influenced by the age of the participant but by his or her personality. While some patients were very open and shared a lot of information, others were more reluctant to go into detail. The study was approved by the Research Ethics Committees of all cantons³ in which the SPOGs were located.

For the project, only when parents agreed to be interviewed was their child approached for participation. Written informed consent (or assent in the case of children) was obtained from all participating adolescents (13–17 years) and children (9–12 years). In Switzerland, competent minors, most adolescents above the age of 14, must provide informed consent to research.

The interviews with the 17 participating children and adolescents were generally short and lasted between 15 and 40 min (with the exception of one interview that lasted 1.5 h). Interviews were conducted in German, French, Italian, and English. Thirteen interviews took place at hospitals; one at a Ronald McDonald House, and three at the family's home. Sixteen interviews were audio-taped and transcribed verbatim, which were checked for accuracy by a second person. For one interview, the recording device did not work, and extensive interview notes were written. During transcribing, a pseudonym was assigned to each participant to protect his or her identity. In light of the context where the study took place, we refrain from using the exact diagnosis and age of the participant to ensure anonymity.

Analysis of the interviews began with multiple readings of the transcript followed by initial line-by-line coding to gain familiarity with the data as well as to capture all possible codes and sub-codes. This minute initial analysis was supported by qualitative analysis software MAXQDA. From this analysis, several major themes were identified (e.g. diagnosis information, prognosis information, medical communication, decision-making, parents' role in communication, reasons for including/excluding children).

Children's participation in discussions and decision-making was chosen as a topic for this paper. Subsequently, the second level of analysis was directed towards this topic within all 17 transcripts [13]. A thematic map was generated followed by a final definition of themes. The analysis was carried out on transcripts in the original language of the interview, and quotes were later translated into English and checked by two authors fluent in those languages.

Results

Six girls and eleven boys between 9 and 17 years of age participated in this study (Table 2).⁴ The time since diagnosis ranged from three weeks to up to 2 years. The 17

Table 1. Examples of questions asked

Time of diagnosis

Can you tell me about the first time you heard about your illness?

Who told you about it?

What did you like or not like about this discussions?

Treatment options

What treatment options were you told about?

How were these options explained to you and by whom?

Do you have anything else that you would like to tell me about treatment choices?

Inclusion or exclusion of children

How did you feel about your involvement?

Would you like your parents or doctors to ask you more often or less often about what you prefer?

What is your opinion about children and their involvement in their health care in general?

³Canton is a denomination of the states of the Swiss confederation.

⁴The age of the participants was coded into three groups, and diagnosis was categorized according to ICC-3.

Table 2. Participant demographics

	ICCC-3 diagnosis*	Pseudonym	Age group**
I	Leukemias	Nora	II
		Jake	I
		Cristiano	II
		Liam	II
		Charlie	I
II	Lymphomas	Tom	II
		Vincent	III
		Ben	II
		Jeremy	II
III	CNS and miscellaneous intracranial and intraspinal neoplasms	Jessica	II
VIII	Malignant bone tumors	Hannah	II
		Angelina	III
IX	Soft tissue and other extraosseous sarcomas	Dillan	II
		Sam	I
		Alex	III
		Louise	II
XI	Other malignant epithelial neoplasms and malignant melanomas	Zoe	II

*International Classification of Childhood Cancer, Third Edition.

**Age group I (9–12 years), II (13–15 years), and III (16–17 years).

participants described their diagnosis history, their experiences with medical communication and decision-making, treatments that they had undergone, and opinions regarding their participation. The main topic of this paper, participation in health care, was explained by three themes: (a) participants' role in medical communication and decision-making, (b) the toll of participation, and (c) participants' thoughts and opinions about participation.

Participants' role in medical communication and decision-making

Participants reported both occasions when they were involved and not involved. Their role was defined as the position that they occupied when participating in medical communication and decision making. From these 17 interviews, this included (a) being present during the different occasions of medical communication, that is, diagnosis or treatment discussions, and any further medical discussions that took place during hospitalization or outpatient consultation; and (b) engaging in medical discussions or contributing to decision-making.

Presence during medical communication

The degree of involvement in medical communication varied with some patients being directly involved while others participated to a lesser extent. All participants described being informed about their cancer diagnosis, however, in different ways. Several participants revealed that this diagnosis disclosure happened during the initial communication that took place with the health care team. Consequently, they received this information at the same time as their parents. Those patients who found out about their cancer

diagnosis during this first medical communication were older than 13 years of age.

Tom (Age group II): Well, we were sitting together with the family, father, mother, mother's partner. (...) He [the physician] first talked with (...) [all of us] together, then [with] the parents, afterwards me.

Other participants reported learning about their cancer diagnosis and treatment protocol at a later time. For a few patients, their absence at the initial medical communication that took place with the parent(s) was because of their poor health status or they were recovering from emergency surgery. Hence they stated that they were informed later either by their parents and/or physicians. As Hannah (Age group II) recalled: 'I was in intensive care with lots of morphine (...) I cannot remember. But I was told in intensive care (...) My parents told me [about my diagnosis]'. Very differently, Jake (Age group I) reported overhearing when his parent and physician talked as follows:

I heard them talking about some kind of thing called leukemia? Then I asked my mother about it and she explained to me that I have a disease called leukemia (...).

Engaging in medical communications and decision-making

During the medical communications that occurred, several of the participants were not only present at these discussions and thus included, but they also became active by asking questions which ranged from inquiring about side effects to another treatment possibility. For example, Alex (Age group III) reported: 'When a new [round of] chemo started, I always asked: What are the side effects of this chemo?'

There were fewer accounts of involvement in decision-making. However, participants highlighted being involved in minor choices, such as indicating whether they preferred liquid drugs or tablets or undergoing a procedure with or without anesthesia. Jake (Age group I) stated: 'Well, the only option they gave me was if I wanted it [drug] as like, you know, the liquid they drink or as pills.'

Dillan (Age group II): But also after the surgery, I had a lot of opportunities to choose: how slow or fast I wanted to do something (...) [the choice] was getting up, exercise, physiotherapy (...) if I wanted something [a procedure] with or without anaesthesia.

In addition to these decisions, there were a few occasions when more than a minor decision must be taken such as choosing to enter a medical trial or fertility preservation. Under such circumstances participants reported making decisions together with parents and/or a physician.

Nora (Age group II): Well, my parents and I, we decided together [about trial participation]. My parents said that it was my decision. And yes, I did not want it (...) then we decided against it.

The toll of participation

All participants revealed being involved to some extent in their health care and most reported being satisfied with the level of their participation. Vincent (Age group III) stated: 'I think I have my place in the discussions, always.' While Hannah (Age group II) emphasized that she had access to the information she considered important: 'I found out everything that I wanted to know.' However, some participants stated that information was not at all times entirely comprehensible. A few identified obstacles in clearly understanding what they were told (e.g. medical terminology) and felt confused. For example, Jessica (Age group II) mentioned how she did not even understand her diagnosis, 'they [physicians] talked about my tumour, for example, it is called [medical term], in the beginning I did not understand (...) then they told me that this means tumour.' Jake (Age group I) beautifully epitomized the confusion that could be generated because of a lack of clarifications.

In the beginning, I wouldn't understand what it was (...) the only thing I've heard (...) is that I have bad white-blood cells (...), some people say it's [other diagnosis],⁵ others say some word called leukemia, and it's just all mixed up.

⁵When Jake started showing symptoms, he was initially given another diagnosis.

Related to information about diagnosis and treatment that participants deemed unclear, the second concern was the usefulness of the information. That is, information was not always given in a manner that would help anticipate what would happen later on.

Ben (Age group II): It was explained to me what side effects they [drugs] have. And then: Mouth ulcers! When I heard that I thought: Yes, ok. When I first had it, I thought: Wow! (...) That you will have boils in your mouth and that it *really* hurts and that you can barely eat anything, that was not explained to me but I would have liked that.

Third, participants noted that receiving information or making a decision was sometimes burdensome and even stressful. Angelina (Age group III) had to make a choice concerning fertility preservation. In this case, she felt pressured and torn between her own wishes and those of her parent and her physician. Additionally, she was only given until the next morning to make this important choice. She explained her burden as follows:

I had to make a decision whether I wanted to freeze my eggs or not. (...) The problem was that I had to say yes or no. My [parent] told me: 'But no, start the chemo because health is above everything, children, you can adopt'. And then there was the physician who said: 'Yes, listen, it is not good to push back the chemo' (...) I told myself, it is not me who made this decision, it was *them*! I was influenced by *them*! If it were me, I would have frozen my eggs.

Participants' thoughts and opinions about participation

Despite the challenges they encountered participants believed that involvement in their health care was a natural thing and they revealed a wish to gain information directly from the physician. Those who were for one reason or another not involved in certain discussions or choices varied in their opinions on these experiences from being happy about it to feeling neglected and excluded.

Involvement is natural for the affected person

Participants reported that it was important for them, as the affected patient, to know what was going to happen. Echoing this attitude, Cristiano (Age group II) stated, 'Then you know what you will have to face. (...) I found it good. I knew what I would have to go through and yes, which drugs I am taking that are treating me'. Similarly, Vincent (Age group III) found informing patients as the normal thing to do: 'I find it a bit normal [to inform patients] because it is me, the person who is, who, after all, suffers from the disease. (...) I find it normal. I have to be present.'

Wish to receive information from the right authority

Some participants emphasized the importance of talking directly to physicians. Reasons that were identified for this preference included that physicians are most familiar with medical information and could not only explain certain aspects of disease or treatment but also can provide more detailed information. Another reason was that if only parents talked to the physician, this allowed them to keep things and thus leave the child in doubt. It was noted that such situation of uncertainty and not knowing was not desirable.

Ben (Age group II): I found it really important [that the physician talked to me] because I do not want my parents to know something and then maybe not tell me because, because I may start crying or something.

Diverging and fluctuating preferences of participation

Participants reported preferring different levels of involvement. While some emphasized their wish to be always involved, others were fine with lesser participation. For example, for Zoe (Age group II) it was alright not to be present during a discussion: 'No, I think it was good. For the moment being, I found it kind of irrelevant whether I was present during the discussion or not. (...) [It is] rather boring because you are there for an hour and then the talking goes on and on.' Similarly, Sam (Age group I) preferred using his father as a 'messenger' between him and the health care professionals: 'I always said that I do not want to be present. Daddy should tell me afterwards (...) because Daddy can also explain it well.' On the other hand, not being involved resulted in feelings of being overlooked or excluded. Louise (Age group II) stated: 'What I do not like is when someone hides things. (...) It hurts to know that, one feels betrayed.'

Preferences with regard to participation also fluctuated within one and the same patient. While some participants initially felt too shocked or overwhelmed to become involved in medical discussions or decision-making, they later changed their mind and described becoming more active.

Jeremy (Age group II): In the beginning I did not care ... because I was so shocked. But then, after a while I realized that I have to know what I have and what is going on. And then I started to listen again.

Overall, participants reported valuing when they were able to choose their preferred level of involvement. Liam (Age group II) expressed the following: 'We always looked at it together and my parents always said: You don't have to be present. And I could say: Yes, I will not come.'

Discussion

Findings from this study not only confirm aspects that are already known about children's perspective on participation [6,14–17] but they also underscore the need to revisit the model of involvement in health care [18]. From the perspective of children involved in this study, participation in medical communication and decision-making in pediatric oncology is complex. Participants mentioned some obstacles that came out of their involvement or non-involvement in their care. These were confusion of information provided, sense of being overlooked, and pressure in making a decision. Despite these challenges children considered their involvement as important because they were the ones affected by the illness and treatment.

With regard to the complex pattern of participation identified, we highlight the need to revisit Hart's 'Ladder of Participation' [18, p 9]. Although this model was not built specific to health care, it has had considerable influence in the literature on children's participation in various domains [19]. Hart's ladder conceptualizes different levels of involvement ranging from 'assigned but informed' ^{p109}, which is visualized at the bottom to child-initiated, shared decision-making visualized at the top. Hart [20] and others [21] have cautioned against conceptualizing the 'rungs' of the ladder as necessary steps in participation development or thinking of higher levels as 'better' participation. However, the analogy of the ladder does not accurately reflect these cautions.

The various forms of involvement can also be viewed as degrees of participation that were dependent on several factors (e.g. emotional state) and of equal value to the minor patient. Each form of such participation can be beneficial for the child, and this should be seen as case dependent (please refer to Fig.1) [21]. Thus, over time and the course of illness, patients could move freely from lesser degrees of participation to more intense involvement and the other way around or maintain the same degree all the time. Such a modification broadens the conceptualization by emphasizing a shifting rather than

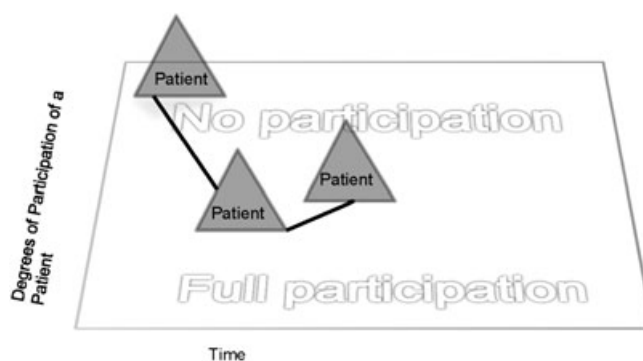


Figure 1. Degrees of patient participation in communication and decision-making over the course of illness

a linear illness experience [22–25].

Such degrees would allow children to occupy different roles based on their preference at that time avoiding the impression that they ‘climb down’ in their participation. We reemphasize that it is important to regularly assess children’s preferences concerning involvement. It is clear that such a model of participation requires high flexibility from adults involved in treatment and care. Finding from this study may also provide useful guidance in practice by prompting professionals to remain sensitive towards children’s changing preferences and regularly assess whether their degree of participation is still in line with their wishes. If not, professionals may take action to assist young patients and their families in adapting the level of involvement.

Further research

Future studies should focus on how professionals working in pediatric oncology can identify when children need help in making sense of information provided or with decision-making. Another useful area of investigation is identifying which professional group is best suited to facilitate decision-making when difficulties arise. Psycho-oncologists are in an excellent position for fulfilling this role because of their expertise in the area of communication and commitment to improving communication in the oncology setting [26]. Finally, research that provides concrete information for health care professionals as to how they should navigate such delicate issues in daily practice within their field is necessary.

Limitations

There often is an unspoken hierarchy between minors and adults [27], and some children who participated may not have been completely open to talk about negative experiences, despite an assurance of confidentiality. Second, our participants may have been those who are more articulate and confident than their peers. Third, because recruitment was done by treating pediatric oncologists, it is possible that they mainly approached families with whom they had a positive relationship resulting in higher patient satisfaction and more positive accounts of participation. Fourth, families who have more restrictive views on children’s involvement may be less likely to allow their child’s enrolment in such a study. Fifth, participants recruited for this study differed in age, time since diagnosis, and because of the small number of children who were interviewed, it was not possible to create age groups and interpret the data on participation in light of patients’ age

or experience with the illness. Last, it is not clear how important the topic of involvement in their health care is to participants themselves because this was an aim of the study and they were posed questions pointing towards this issue by the researchers. Because all participants provided not only their opinion on the topic but also cared to explain their experiences as well as preferences, it is reasonable to conclude that it was relevant to them. Despite the small purposive sample of participants, the findings of this study are significant as the present study is one of the very few that capture the views of this population.

Conclusion

Views of ill children are rarely sought in research concerning participation in their health care [4,11]. This study addresses this gap to an extent as it presents the perspectives surrounding participation in health care of 17 children and adolescents living with cancer. Based on our findings, we conclude that children and adolescents value their participation and that they do so in spite of the challenges it brings. However, at times patients may prefer to step back in participation and defer responsibility. Such desired non-involvement must be interpreted correctly. A flexible model that avoids a hierarchical perception of different forms of participation may be best suited to represent children’s involvement in discussions and decision-making in pediatric oncology.

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Disclosure of conflicts of interest

The authors declare that they have no conflict of interest.

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