

## ORIGINAL RESEARCH

# Family participation in childhood cancer care

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## Abstract

**Background:** Child cancer care is becoming increasingly successful, the treatment brought more success through intensified therapy, but this development has not been easy to achieve due to the pain and anxiety that the treatment often causes. It is not possible to eliminate the chaos the family experiences, but it can be reduced through a deepened understanding of the situation.

**Purpose:** The aim of the study is to highlight families views on participation in childhood cancer care.

**Method:** A qualitative design, appropriate to gain a holistic view, has been chosen. Eight families with children diagnosed with cancer, of various ages and gender and from various backgrounds, participated in five interviews each during the first year of the child's illness.

**Findings:** The families constitute a cornerstone in paediatric oncology care today, but the results indicate that all the various tasks and commitments for the families, sometimes entail too heavy a burden. They are in need of better support and clearer instructions to be able to cope with the situation including rules and measures concerning the child. Therefore, it is urgent to clarify who has the formal responsibility for medical consequences that might occur in connection with delegated responsibility. The study shows that there is a lack of pedagogical thought and a need to create a pedagogical model.

**Conclusion:** There is a need for guiding principles and education for the parents, which would contribute to their increased confidence.

## Key words

Childhood cancer care, Family participation, Decision making

## 1 Introduction

Child cancer care is becoming increasingly successful, and today 75% of all children diagnosed with cancer are cured; the treatment brought more success through intensified therapy. The survival for most diagnoses has improved continuously, but this development has not been easy to achieve due to the pain and anxiety that the treatment often causes<sup>[1]</sup>. Therefore, families report various degrees of psychological stress, as the treatment for children and its side effects are very trying<sup>[2]</sup>.

In this difficult and changed situation for children and their parents, it has been proven that the children felt safer and more confident and their level of stress was reduced when their parents took part in the care of their child and participated as

caregivers<sup>[3]</sup>. It was also shown that the children had less pain and slept better when their parents were present and took care of their child, after being adequately informed. Furthermore, it was described that a child's increased confidence in his/her parents was combined with a greater willingness to participate in the caring efforts, and thereby contributed to a sense of security in the child. Further on, this might have a positive impact on the child's pain experiences and reduce stress<sup>[4]</sup>.

As a result of research within the area there has been a change towards more family-centred care during recent decades<sup>[5]</sup>, which is also described as a changed view within paediatric care<sup>[6]</sup>. Family-centred care is based on the assertion that the family is the child's best adviser and source of support. Even if the situation and context change, the family remains unchangeable<sup>[5,7]</sup>. It has been proven that when the parents' needs are fulfilled, they are better equipped to cope with their child's illness<sup>[5]</sup>.

From a family-focused perspective is described how to inform and support the family through the crisis caused by the illness of their family member<sup>[8]</sup>. It is not possible to eliminate the chaos that the family experiences, but it can be reduced through a deepened understanding of the situation. This suggests a need to be better prepared to meet the family through understanding of human nature<sup>[9]</sup>.

Thus, there are many positive aspects that come to light concerning parental participation, but as the parents' contribution to the caring efforts changes and intensifies, it is important to re-evaluate the situation and consider what is reasonable. There is no consensus among specialized paediatric nurses concerning family-centred care, from the aspect of what it should entail and the extent to which parents are expected to participate<sup>[10]</sup>. There is lack of knowledge regarding parents' understanding of what helps or hinders them in their caring responsibilities for their child, or of what impact their caring position has<sup>[11]</sup>.

It is primarily understanding and a sensitive ear in the communication between nurses and parents that is needed to achieve family-focused care<sup>[5]</sup>. The importance of a sensitive ear is described as well as the need for clarity concerning parents' efforts in participation and their attitude in this respect. Demands that are not congruent with the parents' wishes or capacity might become problematic<sup>[12]</sup>. Parents were willing to participate in the care of their child, but preferred to decide themselves the extent of their involvement. They wanted the staff to be responsible for the clinical care, while they handled the basic care themselves<sup>[13]</sup>. The parents' needs to simply be parents now and then during the child's treatment and the importance of the staff to take this into consideration. The importance of a sensitive ear and understanding the parents' vulnerable situation is highlighted<sup>[14]</sup>.

The staff must thereby determine what is congruent with the parents' wishes and capacity from the parents' own perspective<sup>[10]</sup>. If the parents demonstrate a capacity for various tasks they could be at risk for experiencing the responsibility as too burdensome<sup>[15]</sup>.

It is obvious that many parents would like to participate in the care of their child, but stress concerning their different efforts might occur, especially if the information they receive is vague and defective. Parents are willing to share the responsibility for the care of their child but feel insecure, as the situation is very different when the child is treated at hospital<sup>[6]</sup>. The pressure of the parents' changed role might affect the participation and communication between parents and staff<sup>[5,10]</sup>.

Situations occur in which nurses experience being involved in a tug-of-war between parents' anxiety and wishes, versus physicians' plans and duties<sup>[16]</sup>.

## Aim

The aim of the study is to highlight families' experiences of participation in childhood cancer care.

## Questions at issue

How are the families being prepared for participation in various caring situations?

## 2 Methods

A qualitative method was appropriate for this study, and has been chosen to contribute to the understanding of the interaction between families and nursing staff. To fully comprehend why parents/siblings think and feel the way they do, it is necessary to have discussions with the families. Having their stories listened to and participating in interviews allowed the family members to express their experiences<sup>[17]</sup>. The study was conducted at a paediatric oncology ward, following up eight families, each with a child diagnosed with cancer, during the first year after diagnosis.

### Participants

The families were selected using a qualitative design, to achieve variety among several factors. This is important in order to create a realistic representation from the various experiences of parenting a child with a cancer diagnosis. Thereby was done a selection from certain criteria: the *family constitution*, the *child's age and sex*, the *child's diagnosis and prognosis* and the *socio-economic situation*. Eight families were chosen: five of Swedish background, one of Nordic background, one Asian family and one family with a father from southern Europe. The Asian family was represented by an older sister and brother to the patient, due to health aspects in the family. Educational background varied greatly, from highly educated to working class, as did the socio-economic situation. The children had been diagnosed with various types of leukaemia and solid tumours of different levels of severity, which might have had an impact on the families' experiences. There were five boys and three girls in the study, aged two months to 17 years.

### Setting

The study was conducted at a paediatric oncology ward accommodating 14 children. The treatment periods are short and characterized by high intensity, with some variety depending on diagnosis, after which the children are soon transferred to the outpatient ward. The medical staff is made up of registered nurses, registered nurses with specialist education in paediatric nursing, unregistered assistant nurses and physicians.

### Data collection

Informal meetings with the families were held several times during the first year, in order to get a sense of the interaction in the ward context. This approach facilitated the understanding of the families' views, as their situations and experiences tend to change greatly, especially during the first year after the cancer diagnosis. With the same purpose, talks and interviews were carried out on five occasions with both families and nursing staff (five interviews with eight families and an additional five with eight members of staff = 80 interviews) spread out over the first year of the child's illness (see Table 1). The interview questions were open-ended with a focus on the parents' stories, and were planned over time to follow the parents' progress from diagnosis to the end of the first year. The parents described their initial experiences from the introduction to the ward and meeting the staff, and the continuing communication and interaction.

**Table 1.** Participants in Each Interview

	Interview 1	Interview 2	Interview 3	Interview 4	Interview 5
<b>Family 1</b>	Mother	Father	Father	Mother	Father
<b>Family 2</b>	Mother + father	Mother	Mother	Father	Mother
<b>Family 3</b>	Mother	Father	Mother	Father	Mother
<b>Family 4</b>	Mother	Father	Mother	Father	Father
<b>Family 5</b>	Mother	Mother	Mother	Father	Mother
<b>Family 6</b>	Mother	Mother	Father	Mother	Mother
<b>Family 7</b>	Mother	Father	Father	Mother	Father
<b>Family 8</b>	Brother*	Mother	Sister*	Brother*	Sister*

\* Older sibling substituting for the parent in the family

## Data analysis

All the interviews were audio-taped and transcribed in their entirety and were held in the Swedish language. A content analysis was conducted, as described by Neumann<sup>[18]</sup>. The transcripts were read several times to get a sense of the whole picture. Dominating themes and subthemes were identified, and coding was done at the subtheme level. Discussions within the research team were held to reach consensus about the coding, and any discrepancies were resolved. One dominating theme emerged from the results of the data analysis, concerning *involvement, with subthemes, participation, responsibility and decision-making*. Translation of the completed paper was done by authorised English translators.

## Ethical aspects

Children with cancer and their families are extremely vulnerable, and it is of great importance to consider basic ethical principles such as the autonomy principal and the importance of volition, which were carefully considered in this study. The regional ethical committee at the Karolinska Institute, Dnr 04-1041/4, approved this study.

## 3 Findings

The aim of the study was to highlight aspects of involvement in paediatric oncology. Two meeting parties are involved – the families and the medical staff – and the findings are analysed from these parties separately. The statements from the families have been analysed qualitatively in this script, and quotations judged to be particularly illuminating were chosen. One of the dominating themes that appeared in the analysis of the families' statements concerned *involvement*.

### Involvement – to participate and gradually assume responsibility

Concerning *involvement*, patterns, supported by the families' statements, became visible and mainly concern *participation, responsibility and decision-making*:

**Participation** in basic tasks like feeding the child and handling his/her hygiene, but also in more complex matters like administering medication, tube feeding and injections.

**Responsibility** for basic tasks is important, as is a great part of the personal care and maintaining control over medications, like making sure the child gets his/her medicine at the proper times and monitoring the general condition of the child.

The families often mention lack of experience and understanding when describing their involvement in *decision-making*. The exception to this is when the decision-making becomes more complicated and there is no single path to take. In this situation, the parents became more actively involved in the decision-making.

The quotations below are cited with family number (fam ) and interview number (int ).

### Participation

Participating meant many different things to the families. Taking care of practical issues could be a way to avoid anxiety; a way to create confidence and provide comfort. It could also be of help in coping with the everyday routines at the ward in contrast to life at home, and in maintaining some normality.

“It is a kind of security to control the situation.” “It is important to be involved from the start, to be able to understand the medication part.” (mother fam 4 int 3)

The families did not want to be seen as a resource but it was natural for them to take over the basic tasks, which could entail a balancing act. They seemed to count on that the feeding of their child being their responsibility. As they knew all about their child's habits and wishes, it often helped to decide when and how the food was to be provided. When the families called themselves personal assistants, this was with a touch of disappointment and a sense of things being out of order.

“Otherwise he will not be fed.” “You could call me a personal assistant.” (father fam 3 int 2)

The situation was experienced differently concerning medical-technical procedures, and was not quite as obvious. When this happened, the families suddenly felt they were under a great deal of pressure, which caused some to oppose performing certain tasks. There was a resistance to causing their child pain and discomfort. Sometimes they initially hesitated, and later could not explain what had made them overcome their reluctance and become comfortable with the responsibility. From a long-term perspective the families did not actually have the choice to avoid certain tasks, as they had to solve the situation for their child’s best and the rest of the family. On one hand it might have been psychologically positive for them to handle the situation on their own, when their child was struggling. On the other hand, it is important to understand the energy it takes to be “mean mum or dad”. The families often described being forced into and having to cope with complicated situations, because it was necessary, but that it seemed a high price to pay. There was a distinct opinion among the families that it could not be a matter of course for them to shoulder certain responsibilities.

“We can’t choose medication. Sometimes it is scary, but we get used to it.” “It felt necessary to participate, but it has been tough.” (mother fam 2 int 3)

Obviously it was not quite clear what they as close relatives were expected to do, which might result in insecurity and indistinct expectations regarding their role. Sometimes there was a vagueness that the families associated with the staff being under stress. The initial information is vast when it comes to not only medical information but also basic information about routines, controls and other caring issues. The medical information was mainly provided by the physicians regarding treatment, prognosis, side effects and other things. Some medical information was provided by the nurses, concerning other aspects of the treatment, controls and measurements. The assistant nurses are the ones who carry out the controls and measurements, which sometimes results in a lack of information due to shared responsibility among different groups on the staff. At times less experienced assistant nurses were uncertain about whether to inform the families about specific details, which contributed to confusion for them.

“It is difficult to see what we are supposed to do; sometimes it is not obvious because the staff is under pressure”. (mother fam 1 int 1)

## **Responsibility**

To a certain extent, the responsibility they were entrusted with was accepted, and sometimes made them feel even more involved. On the other hand, they also described vagueness about assuming responsibility. There was a discrepancy in explaining various matters between the different groups on the staff, which resulted in insecurity for the families. The amount of responsibility was fully accepted by some, but especially single parents were considered to carry a giant burden. A frequent tendency was to look beyond their own situation and be understanding about both the staff’s working speed and other families’ experiences. It was as if their own experience felt less heavy when they watched other families.

“At first, the responsibility made me feel empowered, I helped, and I was in control.” (mother fam 5 int 2)

“I understand that some parents can’t manage and I respect that”. (father fam 6 int 3)

It was expressed that the responsibility was huge, sometimes surprisingly huge, which was unexpected in relation to the experience of having a child struck by cancer. This particular experience means an extraordinary pressure in itself. The movement between instability and being exposed to great responsibility created astonishment and questions, and even shock, among the families. Situations were described in which their knowledge and understanding was lacking, but they were still expected to assume responsibility.

“It is not a problem anymore to go home with the responsibility but it was brave to let us go home at the start and take on full responsibility”. (mother fam 7 int 4)

“We were surprised by the responsibility. My dear - to take on full responsibility without knowing what it means”. (mother fam 6 int 2)

### **Decision-making**

Concerning decision-making, the physicians were considered to own the main responsibility for the medical decisions, and the families drew a sense of confidence from this. The physicians described the situation and possible treatment alternatives, allowing them to become involved in the decisions and gave the opportunity to argue. As the families stated, they were never in a position to question the suggestions for treatment, presented by the physicians, due to their own lack of medical knowledge. Thus they seemed satisfied with approving of the physicians’ proposals about their child’s treatment. Sometimes a physician revealed that this would have been his choice for his own child, which meant great confidence.

“They are doctors and not bus drivers.” (father fam 1 int 2)

Another situation sometimes occurred, in which the families had a sense of their fate being in the hands of the physicians. Allusions were made to problems understanding and keeping up, and a fear that the physicians would take over the decision-making and proceed too quickly. This situation might occur when the parents were still in shock, not functioning at their normal capacity.

“If we had not been determined, they might have just done their thing.” (father fam 2 int 4)

“We were in shock and not quite capable to cope with the situation.” (mother fam 3 int 3)

Decisions were sometimes very difficult to make even for the physicians, and the families fully accepted that, but felt that they occasionally became more involved in the decisions. When there was no possibility to make a best choice of treatment, it was of great importance that the families were informed about that and had a realistic view of the difficulties. Occasionally, the families were satisfied to be able to have an influence on the decisions, but still adapted to the proposals from the physicians. It seemed to be a necessity for them to lean on the physicians’ medical experience and knowledge.

“Before, they made the decisions and we just went along with them, but now it is in our son’s hands.” (fam 8 int 2)

“The doctors encouraged us to decide and it was ok, but we just felt the same (as they did).” (mother fam 2 int 2)

### **Aspects of participation over time**

The change over time was described differently by the families. At times they experienced that their strength returned and that the situation thereby became less vague, helping them manage to meet greater demands. Occasionally a certain phenomenon appeared, described as overwhelming fatigue that extended and took over. This was not parallel to the child’s recovery but was instead caused by other aspects, and seemed to appear when the child’s status had stabilized and the families had the opportunity to relax.

The parents were weakened by the process, and it took a great deal of energy to learn about a great number of medicines. It was obvious that their amount of energy was more significantly reduced if there were mistakes concerning the care or setbacks. In connection with the fatigue, streaks of depression sometimes appeared and the families had a feeling of being left on their own. They felt abandoned, and there was occasionally a lack of time after the initial part of the treatment, causing them to ask for support. The following was expressed by a mother:

“There has to be room for being knocked down.” (father fam 3 int 4)

Entering the process and being able to cope with situations and measures was experienced as more difficult by some of the infants' families, and as even more difficult by the single parents. An infant cannot be verbally communicated with like an older child can, and many situations became more complicated to handle due to this. When the language was missing, it turned out to be a difficult task to explain the cause of various steps and motivate the child. It thereby took more energy and power to carry out various medical procedures with a small child, including administering pills orally. Furthermore, it was experienced as extra pressure if the parent was alone at home with the responsibility. A mother said:

“When you are not at the hospital you are scared to death every day. It is a constant struggle, a fear that will last a long time.” (mother fam 1 int 4)

The teenagers' families described other difficulties, like standing on the sidelines, observing the child's fight and tiredness, quite different aspects and problems than with the smaller children. There was usually no need for a physical struggle to carry out various procedures with the teenager, but sometimes thoughts about the future and fears occurred, and were more difficult to handle. In some situations there are patterns and unwritten rules about how to act, which made it more complicated for the teenagers to show fear and sadness, although there sometimes was a need for that.

It was a turning point, and very obvious, when a person on the staff showed empathy for the family and felt sorry for them, which helped them cope with the demands and handle various steps further on. There was a feeling of growing into the demands, and that convincing arguments helped in coping with various questions – a basic sense of confidence was instilled. The responsibility seemed to grow and was expressed as follows:

“I did not think of the responsibility, but the fact that it was necessary.” (mother fam 4 int 1)

The changeover to handling more and more tasks was obvious. It became a matter of course, and the families accepted performing even uncomfortable actions, despite their feelings of insecurity. But there was a very sharp distinction concerning painful and unpleasant procedures. As long as they were to deal with harmless matters, it was possible to accept taking over.

The change also included a possibility for the families to regain control and move forward, to enter a more peaceful phase. Gradually, they were encouraged to make decisions and assessments by themselves, which was parallel to the process of understanding. The aspect of time meant an increased need to tell and share their story.

The families were involved as caregivers in basic procedures, but also as a part of more complex medical tasks. It could be a positive experience to participate, to regain control. It could also be a negative experience if the demands were too heavy. At times there was an absolute reluctance to take care of medical issues, and the families were hesitant and very surprised about the responsibility they were given.

On the contrary, the families sometimes had a feeling of being more involved, through their participation, when the amount of responsibility was adjusted to their capacity. Even if they did not play an actual part in the decision-making, they had a sense of being part of the process and felt a satisfaction in the decisions made by the physicians. The most difficult situation for the families appeared when there were no easy and obvious treatment options and they were invited to join in the decision-making process.

Changes over time in mood and attitudes varied among the infants' families, the teenagers' families and the single parents. Overall, the families were weakened by the process and sometimes an overwhelming fatigue occurred that was not at all parallel to the child's recovery.

## Methodological considerations

The qualitative approach, described by Pilhammar Andersson<sup>[19]</sup>, has been used as a strategy for getting close to families of children struck by cancer, as a way to monitor their involvement and participation. The caring context is well known to

the author; therefore no extra time has been requested to form an understanding of the activities around the child. On the contrary, it was very important to discern what the families' true experiences were, compared to the author's preunderstanding. To be able to understand the truth in the families' experiences from participation, this preunderstanding has been used very consciously. The participation and performance of various procedures were not always possible to observe in a concrete way, because most of this took place at home. This could be considered one of the weaknesses of the study.

The concepts of "family" and "parents" have been used irregularly in different parts of the study as the family was represented both by parents and siblings. In the background and the discussions, both concepts occur not quite consistently, but with the same implication.

The prolonged period of data collection has contributed to a view on the change within the families, from the initial difficult period involving information about the diagnosis to a gradual adjustment to the caring context. The recurrent meetings with the families have also meant that a saturation in the data material occurred gradually, whereby themes returned and information was repeated. The selection of the families has responded well to the purpose and presents a spread of important factors concerning the diagnosis, the prognosis and the age of the child. The chosen families were also representative of the spread from education and socio-economic aspects.

A very positive aspect of getting closer to the families and following their efforts throughout the treatment was that the discussions and interviews seemed important. The main purpose was to collect data, but one of the positive side effects was the possibility to communicate with and listen to the families. The results indicate a lack of time for the staff in this respect.

The aim of this study was to highlight family participation in childhood cancer care. The study was conducted for a period of one year, after the time of the child's diagnosis. Meetings with the families on five occasions during this year provided an extraordinary opportunity to experience their individual adjustment to the situation, and monitor their development. Therefore, the qualitative approach seems to be appropriate for capturing the magnitude of this particular life situation<sup>[19]</sup>.

## 4 Discussion

The findings in the present study offer an important perspective on the family situation concerning involvement. Becoming involved mainly concerns *participation*, *responsibility* and *decision-making*.

Taking on and accepting a great variety of tasks was not always agreed on by the families, and occasionally they refused to participate in medical technical procedures. Moreover, they would not accept being seen as a resource, but were still willing to handle all the basic procedures concerning feeding their child and handling hygienic tasks. It occurred that the families could otherwise have doubts as to whether or not their child would be fed. This is also noted by Newton (2000), who describes that the extent to which parents would want to participate is quite individual and it is therefore the nurses' responsibility to determine and respect parents' preferences in this aspect<sup>[10]</sup>.

According to Blower and Morgan (2000), nurses and parents had different expectations on parental participation in various caring actions for the sick child. It is thus necessary that nurses create a unique relationship with every parent and work out a care plan that includes the parents' as well as the child's needs<sup>[20]</sup>.

It can mean a great deal of pressure for parents to take over technically advanced procedures<sup>[21]</sup>, according to Leavitt *et al.* (1999), which is congruent with the results in the current study. There were situations in which the families hesitated to handle troublesome tasks, but sometimes their reluctance was overcome. Situations also occurred with total resistance from the families and they refused to participate. Still, it was not always possible to describe how they, against their convictions, ended up doing something they had initially considered impossible. The resistance emerged from an



unwillingness to take over painful and uncomfortable tasks and to harm their child. There was a strong comprehension among the families that medical procedures ought to be managed by the medical staff.

It is easy to understand the anxiety of the families, listening to the chaos they experienced before the child's first leave from the ward, with sometimes a lot of medication to handle. They had to understand the effect of the medication as well as how and when to administer it and, in the end, successfully give it to the child. Various techniques had to be learnt by the families, such as giving a subcutaneous injection or inserting a tube for feeding, which demands thought and an adequate pedagogical structure. The problem is that this structure does not always exist, according to the families.

It is necessary to educate the families in specific procedures, adjusted to their capacity and level, although circumstances might not be optimal. From a socio-cultural perspective, there is no precise definition of how learning is achieved, and not necessarily connected to technique or teaching methods. It is important to visualize our learning ability as part of a greater and more general process, concerning the reshaping of knowledge in society <sup>[22]</sup>. A great part of basic knowledge is obtained in the interaction between people in various contexts and, furthermore, learning is a result of human activity <sup>[22]</sup>. The socio-cultural perspective is actualized in the learning situations for the families, concerning important aspects of the interaction between the nurses and the families, meaning a different view.

The nurses and families, including the child, are related to each other in this specific caring context. The communication within this group, including listening, sensitive ears and confirmation, is vital for the amount of learning that is achieved, and it is thereby relevant to discuss the socio-cultural perspective in this respect. This view could possibly justify what the families are exposed to and expected to do, in relation to the gap in medical education level between the staff and the families.

Parental involvement in treatment decisions that appear in connection with clinical situations involve complex physician-parent dynamics. The complexity and impressive volume of information which is a prerequisite for parental involvement make parents feel dependant rather than autonomous <sup>[23]</sup>. This highlights the importance of the sociocultural context in understanding the practice of treatment decisions for critically ill children.

In this respect there is a connection to power, which should not be an issue of importance in health care, but it is, and is often expressed by competence and knowledge. Having competence and knowledge makes it easier to clarify what one does not understand and to ask professionals to use understandable language. A person with obvious competence and knowledge is probably capable of negotiating when decisions have to be made <sup>[24]</sup>. This corresponds to the findings in the current study and strengthens the aspect of how the families get involved in the process and the need for a pedagogical structure.

The legal aspect of performing various technical procedures is not clarified or described in any document in Sweden, concerning delegation. The families in the current study were astonished by the responsibility they had been entrusted with. Therefore it is important to sort out the expectations and limitations that exist. The question is what the families are actually expected to do and whether they are prepared to do it. Is there enough patience, time and economy to let them grow and gradually enter the situation, waiting until they are confident and prepared? A mother recommended members of the staff to clarify, that the parents were to be future members of the team and pointed out the vagueness of this particular role <sup>[25]</sup>. This is congruent with the findings in the current study, where the families felt insecure and uncomfortable with the aspects of "what" and "how".

It is described as a challenge to find the right level of involvement for families and that blurring boundaries within the relationship between nurses and families can have serious consequences <sup>[26]</sup>. Still, involving parents as partners is a recognition of the fact that they are experts too, and that by learning from each other, the quality of the care might be improved <sup>[26]</sup>.

To compare, SIOP (the International Society of Paediatric Oncology) describes “therapeutic alliance” as respect and support for parents in their participation and cooperation with the medical staff. This alliance occurs when both parties work together with a mutual purpose and available resources towards a mutual object, defeating the cancer. This includes reducing the medical and psychosocial side effects and a mobilization of all available strength in the members of this alliance <sup>[28]</sup>.

When the parents are listened to in the decision-making, they are more likely to experience themselves as members of the team. In a caring context the parents are needed for many reasons, for both their own and their child’s best. The results, however, point out the importance of and the difficulty in individualizing and adjusting the expectations to every individual parent <sup>[24]</sup>.

In the decision-making, the families were confident with the physicians’ decisions. They became involved in the process without a feeling of being excluded. This seems to agree with other studies describing parents’ preferences for a cooperative role in decision-making <sup>[29]</sup>. Both parents and children were often involved in the decision-making process, but did not make the decisions on their own. Moreover, it was difficult to oppose the decisions and very few of the decisions taken were re-decided <sup>[24]</sup>. The results of the present study point out the families’ absolute conviction that the decisions ought to be in the hands of the physicians.

The whole situation of a devastated family life, the threat of death, the feeling of emergency and the intense effort on treatment effects had a main impact on the limited choices available. Thereby the medical staff was entrusted with the decisions <sup>[30]</sup>. Parents want to be a part of the decision-making process but not to actually make the decisions <sup>[24]</sup>.

This is why a difficult situation occurs when a child does not respond to treatment and the prognosis is bad. By this time there are no easy choices, which places increasing pressure on the families. Inviting them to participate in the decision-making process in this position, possibly for the first time during the treatment, entails enormous psychological pressure. The families are neither educationally nor emotionally prepared to make these decisions.

Many parents want no part of decisions that could, if the intervention fails, result in the death of their child; they want the clinician to make the choice and bear the responsibility. There is no conflict between family authority and the active role in decision making that clinicians sometimes take, as a result of their knowledge and experience. The distinction between decisional priority and authority is the key to understanding that this process can be highly ethical <sup>[31]</sup>.

The feeling of insecurity regarding important decisions about treatment might result in psychological distress such as anxiety, cognitive disturbances or a feeling of helplessness in parents <sup>[32]</sup>. Parents also emphasize the need to simply be parents under certain circumstances and occasions during their child’s treatment process. This is a particular need for the medical staff to pay attention to <sup>[14]</sup>.

Aspects of cultural differences occur, concerning obstacles in transcultural meetings that might result in consequences like unequal care. Considering cultural identity, education, attention and empathy is necessary to be able to meet expectations from parents, even at times of organizational limitations in the time schedule <sup>[33]</sup>.

## 5 Conclusion

Family participation and involvement is a reality today and the family constitutes a cornerstone in paediatric oncology care. The results though indicate that all the various tasks and commitments sometimes entail too heavy a burden. Having parental responsibility added to a responsibility for the basic care and, moreover, several specific medical-technical measures, signals a huge workload and a need for change and improvement. Families are in need of better support and clearer instructions to be able to cope with the complex situation. It is also important to respect the families’ needs

concerning support in decision-making. The current study reflects on the demand to clarify, who has the formal responsibility for medical consequences that might occur in connection with delegated responsibility to the families. The conclusion is that there is a need for guiding principles and education for the families, which would contribute to their increased confidence.

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