

# Parent Perceptions of a Pretend Play Intervention for Their Children With Cancer

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## ABSTRACT

**Background:** Although the rate of survival in childhood cancer today is close to 85%, a cancer diagnosis can still turn the world upside down for both children and parents. Often, children in oncology care are frustrated about their inability to control events and activities around them. Therapeutic pretend play has been suggested as a means to encourage children to express and handle emotions in a safe environment.

**Purpose:** This study was developed to describe and explore parents' experiences of a pretend play intervention that consisted of six to eight play sessions with a play facilitator administered to their children undergoing cancer treatment.

**Methods:** A descriptive qualitative method was used, including individual interviews with 15 parents.

**Results:** Three main categories were developed, including (a) experiences of joining the project, (b) perceptions of the play intervention, and (c) reflections on effects and implications, with subcategories evolved for each category. The parents experienced that the play sessions helped improve their children's communication skills and made them more capable of participating in their care. They appreciated that the intervention focused on the child's well-being and saw it as a positive break in their child's cancer treatment. It also helped them better reflect on their own situation.

**Conclusions/Implications for Practice:** According to the parents' experiences, pretend play can be a helpful tool for improving children's participation in their cancer care that strengthens their autonomy, emotional repertoire, and communication skills. However, the results also highlighted that some of the children did not fully understand the information provided about this study, which weakened the validity of their consent to participate. Thus, more work is needed on developing age-appropriate information to obtain participation consent from children. In addition, more knowledge is needed regarding how to appropriately include children with cancer in research in an ethically acceptable way.

## KEY WORDS:

autonomy, intervention, parents' experiences, pediatric cancer care, pretend play.

can still turn the world upside down for both children and parents. Children in oncology care are often frustrated about their inability to control events and activities around them (Secinti et al., 2017; van Warmerdam et al., 2019).

Childhood cancer has been shown to negatively affect parents' well-being, and a high level of emotional distress has been reported among these parents compared with norms and controls. These parents have described a broad range of symptoms such as concentration and cognitive problems, loss of control, depression, anxiety, and posttraumatic stress (Hovén et al., 2017; Sultan et al., 2016; Wikman et al., 2018). They have also reported childhood-cancer-related restrictions in everyday life and leisure activities as well as negative impacts on employment, studies, and earnings (Hovén et al., 2017; Öhman et al., 2021).

Shared decision making as the highest level of patient participation presupposes the cognitive and emotional ability to make these decisions. In terms of participation capacity, young children are disadvantaged by traditional images of children (Coyne et al., 2014). According to the United Nations' Child Convention, children must be respected and treated as individuals with the right to express their opinions (UNICEF, 1989). Therefore, every child has the right to get information and develop communication skills to relate to the surrounding context in their own, unique way. In Swedish healthcare, informed consent from the concerned patient is prescribed in law and highlighted in ethical guidelines for clinical practice (Health and Medical Care Act, 2017). Although children cannot provide legally binding consent, staff are expected to strive to obtain at least assent from the child for treatments performed in pediatric care. In Sweden, legal guardians are authorized to consent on behalf of children for medical procedures as well as for participation in research.

The participation of young children in research studies is somewhat tricky in pediatric practice. Several randomized

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## Introduction

Each year, about 300 children in Sweden are diagnosed with cancer. Although survival rates have increased during the last decades to around 85% (Gustafsson et al., 2013), this diagnosis

studies point to the importance of good communication skills among clinicians (see, e.g., McCorkle et al., 2011). The children's participation in the triadic conversation between physicians, parents, and children is usually meager, and communication generally occurs primarily between the physician and the parents. Often, parents also answer for or interrupt their children. On the other hand, physicians tend to address children frequently using jokes or amusement, thereby hindering a factual, informative course of conversation. Thus, the supposed triad becomes a dyad that excludes and thus disadvantages the children (Coyne et al., 2014).

Therapeutic pretend play has been suggested as a means to encourage children to express feelings and opinions. The literature on improving children's participation and communication in care situations through pretend play sessions is scarce, but some essential works can be found. For example, Fehr and Russ (2016) have argued that pretend play can encourage children to express and handle emotions in a safe environment, increasing children's emotional repertoire and reducing anxiety. Likewise, Coyne et al. (2016) and Coyne and Gallagher (2011) have argued that pretend play can assist the child in developing a cognitive and emotional framework to handle a challenging situation. This play can function as a dynamic bridge between the child's thoughts and feelings and the surrounding world.

Pretend play is a fantasy activity that includes thinking of "as if" and externalizing the child's imagination (Fehr & Russ, 2016). It includes a transformation of reality for the child. In this play, children can imagine that an object or situation is something else than it is. Hence, therapeutic pretend play may function as a secure place for the child to express feelings and emotions. Through play, children can show both positive and negative effects that may in turn broaden their emotional repertoire and reduce their anxiety in stressful situations. According to Fehr and Russ (2016), pretend play can have an adaptive function and contribute to the child's development of creativity, coping ability, and socioemotional competence. In addition, when it comes to reducing pain in children in hospital care, pretend play has been shown to help reduce anxiety and increase self-esteem (Knell & Dasari, 2016).

Children's participation in the decision-making process related to their care and treatment is an essential ethical aspect in pediatric care (Stålberg et al., 2016). Runesson et al. (2007) found that children are not always allowed to participate in their care decisions, although they may be capable of understanding and participating in them. On the basis of the results, the authors suggested that children should be seen as autonomous individuals by medical staff, who thus have a duty to facilitate the participation of young patients in the decision-making process.

Coyne and Harder (2011) found that children's participation in their care is complex, as both parents and staff tend to be overprotective. The ethical dilemma concerns the values of doing well and increasing beneficence on the one hand and respecting the autonomy of the child on the other. Therefore, concerned adults must balance their will to protect and do well

against their duty to include children in the decision-making process and to respect them as autonomous persons.

Knowledge about children's participation in their cancer care and about whether and how pretend play can contribute to their involvement and well-being remains very limited. Thus, this study was developed to describe and explore how parents experienced a play intervention for their children undergoing cancer treatment.

## Methods

This study is part of a larger project designed to investigate the effect of a pretend play intervention on children with cancer. An international group of researchers from the United States, Germany, and Sweden formed the Pretend Play Project. The overarching aim of the overall project was to explore pretend play as a resource and evaluate if such interventions increase participation, independence, and well-being during the treatment process for children with cancer.

### The Intervention

The play intervention has its derivation in cognitive behavioral play therapy, with underpinnings in cognitive, behavioral, and social theory (Knell, 1993, 1998). During the development of cognitive behavioral play therapy, components of existing therapies were included, including modeling, problem solving, and coping (Pearson, 2008). Play interventions have been developed and tested in a variety of settings, targeting different emotional and behavioral factors (He et al., 2015; Russ, 2014). The particular intervention used in this project was based on the experiences of Dr. Russ and colleagues at Case Western University in Cleveland, Ohio, in the United States (Fehr & Russ, 2016; Pearson, 2008).

The intervention consisted of six to eight 30-minute play sessions conducted with each child. All of the sessions were led by an experienced and well-trained play facilitator who had prior play-therapy experience. The sessions consisted of four-story stems, including (a) everyday experiences such as attending preschool or having a picnic, (b) an affect (positive or negative) theme such as having a birthday party or being happy or sad from losing a favorite toy, (c) a medical theme, and (d) a free-play activity chosen by the child. The plays were tailored after each child's desires and abilities, but the same set of toys was used by all of the children. The toys were not free of choice for the play facilitator but followed the study protocol based on earlier studies (Fehr & Russ, 2016). The sessions were videotaped for quality and safety purposes. After the intervention, parents of the children participants were asked to participate in a phone interview. The results of these interviews are presented in this article.

### Study Participants and Data Collection

Data were collected in 2018. Eighteen parents of children undergoing cancer treatment who had participated in the pretend play intervention were asked to participate in the qualitative

interviews. Although all of the 18 parents consented to the interview initially, three of the families withdrew their consent before starting the study. Thus, data were collected and analyzed from 15 families. The postintervention interviews with the parents were conducted during Fall 2017 and Spring 2018 by two of the authors. Each interview lasted for about 20 minutes. The parents could choose whether the mother or the father was interviewed. The parent participants consisted of 13 women and two men. The 15 child participants (nine boys and six girls) ranged in age between 4 and 8 years. The children were undergoing treatment for cancers including leukemia (acute lymphocytic leukemia and acute myeloid leukemia), Burkitt's lymphoma, neuroblastoma, medulloblastoma, and Ewing sarcoma.

A semistructured interview guide with open-ended questions covering the following areas was used:

- Experiences of information and the consent/assent process
- Perceived benefits and challenges with the play intervention
- Experienced effects of the play intervention
- Suggestions for future pretend play interventions

Follow-up questions were asked when further clarification was needed or when the parents introduced new topics. Interrater reliability was secured through the same play facilitator in all play sessions and by the same interview guide used by both interviewers.

## Analysis

The interviews were recorded and transcribed verbatim by the authors. Both an *a priori* approach using deductive coding (based on the specific areas that were predetermined by the uses of the semistructured interview guide) and an inductive approach (newly emerging fields that came up), as described by Elo and Kyngäs (2008), were used in this study. The coders read through the interviews several times to identify meaning units covering the research questions. Afterward, initial coding was done independently by each of the authors. The authors compared and discussed their coding before categorization was initiated. Quotations were sorted into categories, and the steps in the analysis process were repeated and compared with the transcribed text from the interviews to verify the content until complete consensus was achieved.

## Ethical Considerations

The study was approved by the regional ethics review board (Dnr 2015/011). The parents received information about the study both orally and in writing, and inclusion was made after informed consent. The information stated that participation was voluntary and could be interrupted at any time without giving any reason. All of the data were handled confidentially and in accordance with the EU General Data Protection Regulation. Reporting of the results was done in a way that secured the anonymity of participants.

## Results

The following categories were developed using content analysis, including (a) experiences of joining the project, (b) perceptions of the play interventions, and (c) reflections on effects and implications, with each covering several subcategories (see Figure 1).

In the following, categories and subcategories are illustrated using representative quotations from the transcribed text.

### Experiences of Joining the Project

The preparticipation part of this project was explored in this category, covering the thoughts and desires of the parents before the start of the intervention. The three subcategories included *motives to participate*; *information, assent, and consent*; and *expectations and worry*.

#### Motives to participate

The quotes in this category showed that the families had joined this project for altruistic reasons. The parents expressed an understanding that their children may not benefit directly from participating in the study but valued the importance of participating for others. The project's focus on doing something fun along with the child and on the children's psychological well-being while confined in an often grievous and monotonous situation was also stressed by the parents as an important motivation for participation.

*Well, we thought that we wanted to do what we could in order to improve the situation for other sick children. Give something back, so to say, as we can benefit from other research studies. So, you contribute with what you can. We also felt that our son could enjoy having quality time with another adult.* (Parent 12, mother of a 4-year-old son)

*I thought that it felt good to be part of a study where you focus on the child's mental health, not only on the medical condition. It felt like a welcome aspect, as they have not talked so much about that otherwise in the hospital during the treatment.* (Parent 3, mother of a 5-year-old daughter)

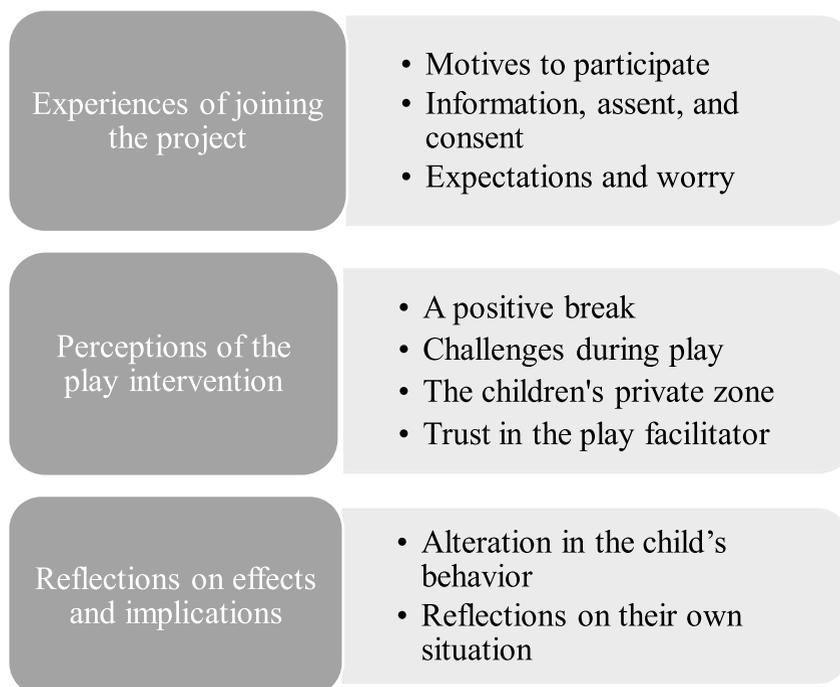
#### Information, assent, and consent

According to the parents, the information provided before the onset of the study was adequate, clear, and comprehensive. Moreover, they expressed that they valued that the information was provided both orally and in writing and that they were given the opportunity to ask further questions. In addition, the information that they could withdraw at any time during the study without providing a reason was appreciated. Thus, this process helped further solidify the parents' willingness to participate.

However, it is likely that most of the children did not fully understand the meaning of participation. Important information provided to gain the assent of the children included that they would be playing with an adult and that they would be asked questions about their well-being. One parent described the assent process for her son as:

**Figure 1**

## Overview of Categories and Subcategories



No, I don't think he really understood what it meant. But he understood that he was going to play, that someone would come and visit and talk to him and play with him and so on. But the aim of the study...I don't think he understood that. But he took part and when they recorded the sessions—he enjoyed that! So, he was positive toward participation, although he didn't fully understand the aim. (Parent 9, mother of a 5-year-old son)

**Expectations and worry**

The parents expressed trust in both the researchers and the intervention. Many parents aired expectations and hope for something that would amuse their children and allow them time to simply be a child for a while or get away from thoughts of being ill. In addition, they expressed hoping the intervention would increase their children's sense of security in the hospital. Some of the interviewed parents worried that their children would have trouble cooperating during the intervention, as they regarded them as willful and sometimes headstrong.

*The expectations were that she should escape from thoughts of being so sick...that she would be allowed to be just an ordinary child, so to say. So, I suppose that was her expectation, that she should distance herself from the hospital and all that.* (Parent 14, mother of a 7-year-old daughter)

**Perceptions of the Play Intervention**

In this category, the parents elaborated their views on the play intervention itself. This category includes the four subcategories of *a positive break*, *challenges during play*, *the children's private zone*, and *trust in the play facilitator*.

**A positive break**

The children took part in many demanding situations in the hospital. Thus, play presented a welcome break. According to the parents, the children enjoyed the opportunities to play and to feel “normal” again. Many of the children did not see their friends as much as they did before turning ill. So, a playmate in the form of a play facilitator was most appreciated. In addition, the time the play facilitator spent with the child provided a well-needed break for the parents.

*This is of utmost importance in the case of cancer! The children are under such pressure because of their illness. So, this became something positive, something they could relate to. It could make the day for a child with cancer!* (Parent 11, mother of a 5-year-old son)

*Everything was so good! We could have gone on forever! And the play facilitator—so sweet and full of joy! He really longed for the meetings. So, everything was super! (...) And the design was really nice, too. A perfect mix of play and serious questions. So, it was a fantastic project and we're really glad that we participated.* (Parent 12, mother of a 4-year-old son)

**Challenges during play**

According to the parents, the ease of the play facilitator's task was highly affected by the current status of the children. The children did not always conform and could be cranky, according to the parents. In addition, some of the older children expressed during the early part of the intervention that the activities in the play sessions were a bit childish for them.

*One thing that was not so good, was that my daughter was not so easy-going in the beginning. So the facilitator had to use some tricks. And when she did that, it went better. And then, several times, my daughter didn't want to stop playing, but just wanted to go on and on (laughter).* (Parent 6, mother of a 5-year-old daughter)

Furthermore, some of the boys expressed a dislike for the dolls that were part of the play sessions and suggested the need to add some more “boyish” toys such as “action figures.”

*He was upset, because they always played with dolls. He didn't like that, and wanted to play with something more fun. But it was always the dolls! He thought they were boring and he stopped looking forward to the play facilitator's visits.* (Parent 5, mother of a 6-year-old son)

### **The children's private zone**

The parents expressed how the play sessions came to serve as a private space for their children. They trusted the children to be safe during their play and tolerated not knowing many details about the sessions. They described not only how they could be curious sometimes but also how they respected their child's integrity.

*Actually, she hasn't told us what they did during play, and we haven't asked, either. Only if they had fun and so on, and then she would say “yes”. (...) But she has never really told us, so I gather she wanted to keep it as her own thing. And we didn't ask, because we saw that she was always happy afterwards.* (Parent 14, mother of a 7-year-old daughter)

### **Trust in the play facilitator**

The parents accepted perceiving the play sessions as the children's private zone because they trusted the facilitator. They described the play facilitator as a person with appropriate knowledge and experience. The interviewed parents expressed the need for this role to be held by persons with a child-oriented personality, and they were grateful to have met someone who connected so well with their child.

*There were so many new adults around her all the time, which was really tough for her. But then the facilitator came along and they built up immediate mutual trust. So, I think the play facilitator is extremely important.* (Parent 3, mother of a 5-year-old daughter)

## **Reflections on Effects and Implications**

The third category reports the parents' opinions regarding the intervention's impact and how participation affected them and their children. The two subcategories that emerged from this analysis included *alteration in the child's behavior* and *reflections on their own situation*.

### **Alteration in the child's behavior**

The parents contributed several reflections on their children's altered behavior after completing the play intervention. According to the parents, some children had really improved their play skills, especially the ability to play imaginary games on their own. Many of the children had also changed the ways

in which they connected and communicated at the hospital, as they had improved their ability to express their needs and desires. Some parents described that their children were much more independent after the pretend play intervention. For example, they were less afraid of invasive procedures and had become calmer and more open-minded in their contacts with the hospital staff.

*Yes, I think he has become much more able to express if he is afraid, for example if they are going to use a needle. I think he has improved in expressing his feelings. And we noticed that quite soon. After just a few play sessions, he started to express things in front of the nurses and so on. /---/ I think it was amazing that it happened so quickly! So, the intervention really changed him in many positive ways.* (Parent 12, mother of a 4-year-old son)

*My daughter has said herself that she finds it easier to talk to the staff at the hospital now after the play sessions. Before, we very much had to be her voice during the cancer treatment and she used to go into herself very much when she met the doctors and so on. But that has really changed now.* (Parent 3, mother of a 5-year-old daughter)

### **Reflections on their own situation**

The parents expressed how the practical arrangements of the intervention helped them and their children take part in the study.

*The fact that the researchers came to our house—that was the best! Because during that time he was quite fed up with the hospital, and going to the hospital was the last thing he wanted to do at the time. So, it was very convenient that they came to us for the play sessions.* (Parent 9, mother of a 5-year-old son)

*Well, it was really nice that the facilitator came to our home, and there were no problems if things got messed up and we needed to reschedule. So, it worked really well.* (Parent 13, mother of a 5-year-old son)

During the intervention, both parents and children were asked to fill in some questionnaires. In the interviews, the parents also reflected on this. They did not find the questionnaires problematic from either a practical or emotional perspective. Instead, they described how filling out the questionnaire had made them reflect on their own situation during their child's cancer treatment.

*We did the first questionnaire together, me and my husband. Afterwards, we felt exhausted. It was so much! And it became so obvious! Such as: “Has your child experienced pain?” Yes. “Can he do what he wants to do?” No. “Can he go to preschool?” No. So it became very clear to us: God, he's really, really sick! You know, we work quite hard to repress it. Not that it [the questionnaire] was anything bad, but it made us think. So, it was like an awakening for us, too.* (Parent 12, mother of a 4-year-old son)

## **Discussion**

The main finding of this qualitative study was that the parents perceived the pretend play intervention had improved their

children's ability to communicate, cope with their situation, and participate in their care. They also experienced the intervention as a positive break in their children's cancer treatment.

Concerning the information and consent process, we found that most of the participating families had joined the project for altruistic reasons. This result is in line with previous research on patients with cancer, showing that adult research participants are often aware that the results may not help them immediately but could support future patients (Godskesen et al., 2015). The findings of this study are impactful, as they indicate that the ethical reasoning used in studies on adults may be applied to research involving children.

The written and oral information on this project shared with the participants by the researchers was described as easy enough to understand for the parents, but they believed their children did not really understand it although the researchers in this study had done their best to make the information provided to the children age-appropriate. One explanation for this may be that the children focused largely on the intervention's provision of opportunities to play, which they really enjoyed, to the exclusion of other provided information. These results support the findings in other research that healthcare professionals experience difficulties in communicating research objectives, research concepts, and treatment alternatives to parents and children in clinical studies (Cousino et al., 2012, Weisleder, 2020).

Our results may also be discussed in light of the results of Runesson et al. (2007), who found that children were not always allowed to participate in their care decisions, although they might have been capable of doing so. In our case, although the children were informed and given the opportunity to participate in decision making, a valid level of assent was challenging to achieve. Hence, more work is necessary to develop information for research that is age appropriate for children as well as to acquire more knowledge on how to include children with cancer in research in a way that is ethically acceptable.

The parents described that they appreciated the intervention focused on the children's well-being and psychosocial situation. These aspects are lacking during their children's normal care, according to the parents, which points to the need for an increased focus on such aspects in pediatric care.

The intervention aimed to increase the participation, independence, and well-being of the children during the treatment process. According to the parents, these goals were also achieved by the intervention. They described how their children had improved their play skills and changed their ways of connecting and communicating with hospital personnel. Furthermore, many of the participating children had improved their ability to express their needs and desires, both at home and the hospital. This supports previous research results that showed pretend play to have an adaptive function and to contribute to the development of creativity, coping ability, and socioemotional competence in children (Fehr & Russ, 2016; Frygner-Holm et al., 2019; Witt et al., 2019).

An ethical challenge in the project related to the fact that the participants were vulnerable, as they belonged to families under stress from their child's cancer treatment (Hovén et al., 2017; Sultan et al., 2016; Wikman et al., 2018). However, the results indicated that participation in the project could help the parents reflect on their own situation. In addition, according to the parents, the children felt that answering the questionnaires was a positive experience, as it allowed them to talk about their situation and feel listened to. The positive effects of participation in research, particularly that involving sensitive issues, have been reported (Butler et al., 2018).

Overall, the participating parents were content with their pretend play intervention experience. The intervention offered a positive break for their sick children and was tailored to each child's needs and practical situation, which was appreciated. An important aspect that was highlighted in the interviews was how much the parents trusted the facilitator. This points to the importance of having an experienced person as play facilitator and of being able to handle all of the reactions that can occur in the children. In this study, the facilitator was a trained preschool teacher with previous experience engaging in therapeutic play with children in hospital settings, which bolstered the parents' trust in her competence.

Some negative aspects of the play sessions were also mentioned in the interviews. The main complaints related to the toys used in the intervention. Some parents described them as being too childish and also as more appropriate for girls than boys. As mentioned above, the toys were not chosen for this intervention by the play facilitator but rather replicated the study protocol developed by Fehr and Russ (2016). Therefore, further research on pretend play interventions is needed to address issues such as whether the same positive results can be achieved using different sets of toys.

Our results indicate pretend play to be an effective tool for improving children's participation in their cancer care. Used more broadly, it may help resolve the dilemmas identified by Coyne and Harder (2011), who found that children's participation in their care is complex, as both parents and staff tend to be overprotective to do good for the child. Thus, offering pretend play sessions for children in cancer care may be a way to increase children's participation in the decision-making process and improve their possibility to make autonomous decisions about their care in cooperation with their parents. Thereby, the ethical goal of respecting individuals in healthcare, irrespective of age, may be better realized.

## Strengths and Limitations

This qualitative study was conducted in Sweden on a relatively small sample. Thus, the evidence relates only to the qualitative responses of the study participants. However, the results are in line with previous quantitative data on pretend play interventions (Frygner-Holm et al., 2019; Witt et al., 2019), which strengthens the validity of our results. The authors consider the results to be transferrable to similar contexts such as pediatric cancer care in countries with healthcare systems similar to

Sweden. Furthermore, the results of an upcoming German paper are expected to lend additional credence to our findings. In this study, the parent participants were mostly women (13 women vs. two men). However, the potential impact of gender differences could not be evaluated because of the small number of total participants and the small percentage of men.

## Conclusions

The results indicate that pretend play is a helpful tool for improving children's participation in cancer care that strengthens their autonomy, emotional repertoire, and communication skills. The parents appreciated that the pretend play intervention focused on the child's well-being and that the play intervention could be adapted to individual family needs. They also expressed that the play sessions had helped improve their children's communication skills and made them more capable of participating in their care. However, the results also showed that the children did not always understand the information provided about the study, which made their assent to participation relatively weak. Hence, more work is needed to develop information for research studies that is age appropriate for the target participants (including children) and to improve knowledge on how to include children with cancer in research in an ethically acceptable way.

## Acknowledgments

We are grateful to the play facilitator, to the parents who participated in the interviews, and to the children who participated in the intervention. Funding for the study was provided by the Swedish Childhood Cancer Fund (Grant Number PR2013-0123).

## Author Contributions

Study conception and design: ATH, SFH, SW, JHQ

Data collection: ATH, SFH

Data analysis and interpretation: ATH, SFH

Drafting of the article: ATH, SFH

Critical revision of the article: SW, JHQ

Received: May 5, 2021; Accepted: October 26, 2021.

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The authors declare no conflicts of interest.

Cite this article as:

Höglund, A. T., Witt, S., Quitmann, J. H., & Frygner-Holm, S. (2023). Parent perceptions of a pretend play intervention for their children with cancer. *The Journal of Nursing Research*, 31(1), Article e253. <https://doi.org/10.1097/jnr.0000000000000532>

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