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Exploring the Potential of a Pretend Play Intervention in Young Patients With Leukemia

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ABSTRACT

Purpose: The aims of the study are 1) to gain knowledge of parents' and professionals' perceptions about cancer stricken children's resources, burdens, and ability to pretend play, and 2) to prepare the initiation of a pretend play intervention based on children's needs and included parents' and professionals' feedback.

Design and Methods: Qualitative design using semi-structured interviews with 13 parents of children diagnosed with leukemia and 15 professionals in the field of pediatric oncology. Themes were derived with content analysis via deductive and inductive coding.

Results: Analysis resulted in five topics. (1) Ability to play in the context of leukemia (2) ways of coping with leukemia (3) difficulty in transition to normality (4) parental quality of life and parents' needs (5) perceptions of the potential of pretend play.

Conclusion: Study results indicate the potential of pretend play interventions for young cancer patients and the need for additional professional support of parents.

Practice Implications: Pretend play is a tool children carry with them regardless of their circumstances. If we can enhance their ability to play, doing so should give them an advantage in creative problem solving and creative expression as they deal with a life threatening disease.

Introduction

Leukemia is the most common malignant cancer in childhood and adolescence (Pirard, 2009). Cancer diagnoses can be psychologically traumatizing for both the child and the entire family. This can lead to massive changes in family life and a degree of psychosocial burdens (Creswell, Wisk, Litzelman, Allchin, & Witt, 2014; Kazak et al., 2012; Warner et al., 2011). Patients are exposed to heavy disease burdens in terms of duration and intensity (Foresto et al., 2015). Stress is triggered when patients are not able to overcome challenges they face with the available coping resources at their disposal, which may lead to various physical and psychological adjustment problems. Therefore, professionals have been developing and are continuously optimizing the concepts and structures of psychosocial care for children, adolescents and their families in pediatric oncology (Schröder, Lilienthal, Schreiber-Gollwitzer, Griessmeier, & Leiss, 2013). Elements of play are already used to support young children's well-being because play is an important resource in childhood development (Artilheiro, Almeida, & Chacon, 2011; da Silva, Cabral, & Christoffel, 2010). Play might be the most appropriate medium for children to build relationships, understand cause and effect principles, learn to handle stressful experiences, and acquire social skills (Chaloner, 2001). Recent studies on the effects of play therapy in the context of hospitalization demonstrate a positive relationship between the use of play in the context of medical procedures and surgeries (Stewart, Algren, & Arnold, 1994; William Li & Lopez, 2007; William Li, Lopez, & Lee, 2007). Play is an appropriate method for ill children to express their feelings and to voice their experiences of disease-specific challenges (Shapiro, 1995; Webb, 1995). By providing an environment where ill children feel at ease to voice their experiences and concerns to their therapists, play therapy can support the learning of appropriate coping strategies.

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Because abstract thought is not yet developed in young children, play is their main form of expression (Bratton, Ray, Rhine, & Jones, 2005; Christian, Russ, & Short, 2011). Play is incorporated in pediatric medical & psychological contexts for its responsiveness to unique developmental needs (Bratton et al., 2005) and its reducing effects in pre/post-intervention anxiety and pain (Chari, Hirisave, & Appaji, 2013; Li, Chan, Wong, Kwok, & Lee, 2014; M. A. Moore & Russ, 2006; Tsai, Tsai, & Yen, 2013). It allows caregivers and professionals to observe children's feelings (Fiorelli & Russ, 2012). Despite a lack of a gold standard approach, humanistic-nondirective approaches that incorporate parental participation show promise (Bratton et al., 2005). The heart of humanistic play therapy is the belief that the relationship between child and therapist is the “cause for all healing change,” in which the therapist cultivates an open, encouraging environment that allows the child to express and progress with minimal limitations or direction (Bratton, Carnes-Holt, & Ceballos, 2011). Because recent research suggests that this style of play therapy is more beneficial than non-humanistic directive approaches (Bratton et al., 2011), the pretend play intervention was developed using a humanistic-nondirective approach.

The specific approach of pretend play requires children to use fantasy, make-believe and symbolism. Pretend play can influence many different areas of adaptive functioning, emotional regulation, and creativity. Interventions based on pretend play can be used to improve the experiences of young children during hospitalization, outpatient visits, treatment procedures, and negative perceptions produced in medical situations (Moore & Russ, 2006).

This paper reports the results of a German qualitative pilot study that investigated the potential of a pretend play intervention for young patients with leukemia from the perspectives of both parents and professionals in order to recognize and adequately consider opportunities and obstacles before the initiation of this new intervention. The German pilot study is being conducted as part of a multi-center study (Germany, Sweden and the United States of America).

Methods

Sample and Recruitment

Parents of young children with leukemia and professionals in the field of pediatric oncology were invited to participate in this pilot study. Because the original play intervention was designed for children between four and ten years, both families with older and younger children were included to see if the age range can be extended. The professionals were distinguished by their expertise in the field of pediatric oncology. Therefore, a convenience sample with fourteen professionals and thirty-nine families were asked to participate in this study. The staff of the psychosocial service team of the Department of Pediatric Hematology and Oncology of the University Medical Center Hamburg-Eppendorf identified eligible families. Inclusion criteria were 1) children diagnosed with leukemia within the last four years so that the treatment and the transition into everyday life can still be remembered well (except one patient diagnosed ten years ago who was nevertheless interviewed because he was transferred from a regional counseling center), 2) children's age at diagnosis between one and eleven years, 3) the ability to understand and speak German fluently, and 4) be classified as emotionally stable by the psychosocial service team. This study was reviewed and approved by the ethics committee of the Hamburg Medical Association.

Intervention

The planned intervention will take place in individual sessions. The moderator and the child will tell different stories by playing with toys. The moderator will initiate a story saying e.g. “Let's tell a story about a girl that celebrates her birthday…”. The child will decide how the story will go on. The moderator will ask the child to express the feelings of the involved figures and develops options for action together with the child. Each session will include approximately 3–4 stories (one based on affect, one based on imagination, one based on medical play, and then finish the session with the child making up a story on their own). Parents will be in the same room if the child needs their presence. A detailed description of this pretend play intervention is shown in Table 3.

Data Collection

Individual, face-to-face interviews were conducted between May and July 2015. A summary of the pretend play approach for young children with cancer was sent to all participants before the interview. It included information about the aim, the duration, the frequency, and detailed information about its implementation by describing the topics of the stories, toys, etc. of the potential intervention. All participants were given written information about the aim of the study and a written informed consent form. Only participants who gave written informed consent were included. The thirty-minute semi-structured interviews with parents and professionals were digitally recorded and transcribed verbatim. The interviews for both parents and professionals were led by a trained interviewer and based on the same interview guidelines (Fig. 1), which have been predefined by the multi-professional Principle Investigators (PI) from Sweden, the United States of America and Germany. In addition, the German PI trained both interviewers, who were professionals in the field of health and family sciences, and regular supervision was available for both within the course of data collection.

Data Analysis

The transcripts were analyzed according to the qualitative content analysis method. Both an a priori approach, using deductive coding (based on predefined concepts of quality of life, coping, and psycho-oncology) as well as an inductive approach (newly emerging and supplementary concepts based on the interviews) were used to develop a code system in which all codes and categories were defined, described and illustrated with examples (Elo & Kyngas, 2008) (Fig. 2). Based on this final coding guideline all interviews were coded. To determine interrater reliability, the statistical measure Cohens Kappa κ was used. Six out of thirteen interviews with parents (46%) and seven out of fifteen interviews with professionals (47%) were coded by two independent raters. The number of matches of the coded text passages to certain categories of the coding guideline by the two raters was determined and from this, Cohens Kappa (Cohen, 1960) was calculated to evaluate interrater-reliability using:

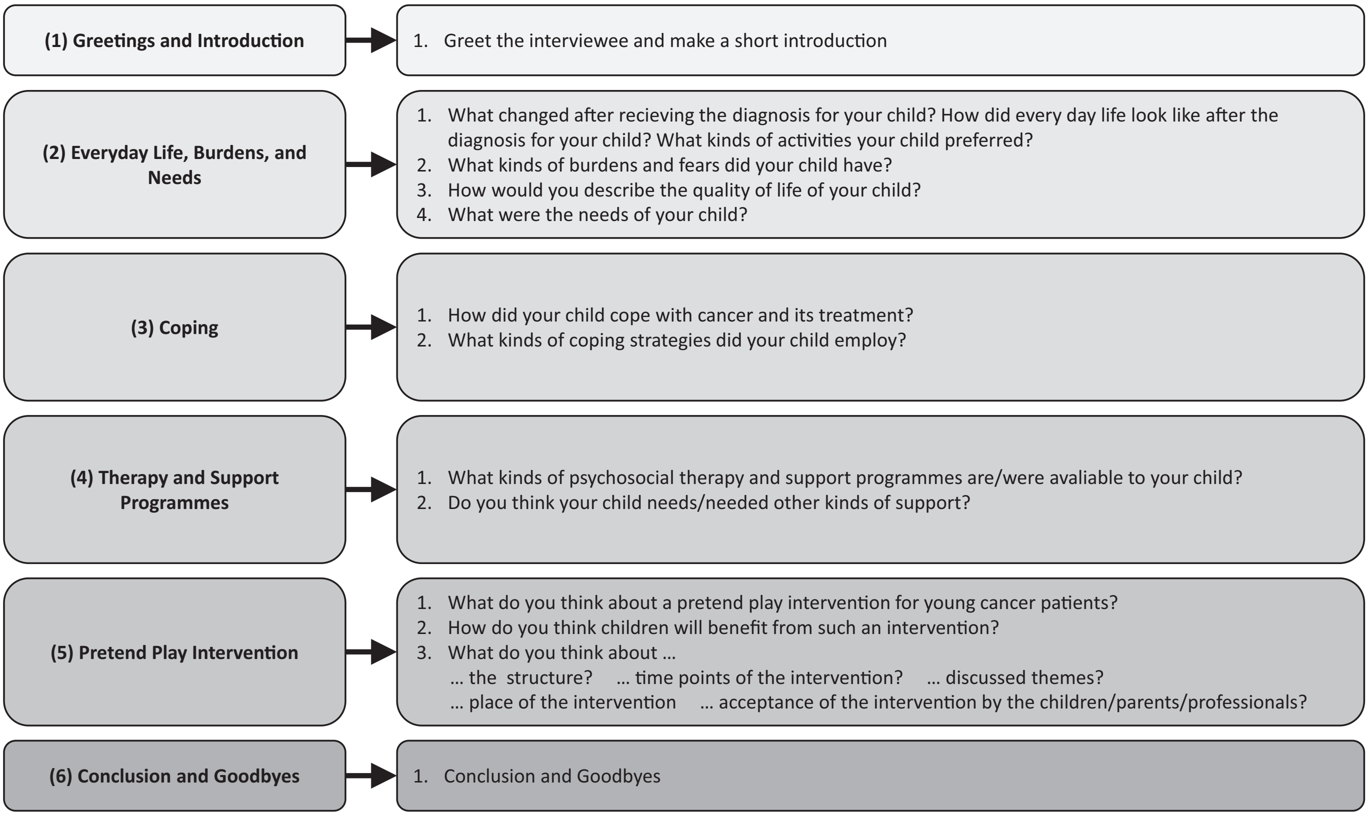
$$\text{Cohens Kappa } \kappa = \frac{\rho 0 - \rho c}{1 - \rho c}$$

In this $\rho 0$ represents the relative observed agreement between raters, while pc represents the probability of agreement due to chance measured as a quotient of 1 and the total number of codes. Cohens Kappa $\kappa = 0.85$ for the interviews with parents, and $\kappa = 0.86$ for the interviews with professionals represents a good interrater-agreement (McHugh, 2012). Data were managed using the software MaxQDA 11 (GmbH, 2011).

Results

Sample

Fifteen professionals working in different areas of pediatric oncology at the University Medical Center Hamburg-Eppendorf (UKE) or at a regional psycho-oncology counseling center and thirteen parents of children diagnosed with leukemia (current age between three and



(1) Greetings and Introduction

1. Greet the interviewee and make a short introduction

(2) Everyday Life, Burdens, and Needs

1. What changed after recieving the diagnosis for your child? How did every day life look like after the diagnosis for your child? What kinds of activities your child preferred?
2. What kinds of burdens and fears did your child have?
3. How would you describe the quality of life of your child?
4. What were the needs of your child?

(3) Coping

1. How did your child cope with cancer and its treatment?
2. What kinds of coping strategies did your child employ?

(4) Therapy and Support Programmes

1. What kinds of psychosocial therapy and support programmes are/were avaliable to your child?
2. Do you think your child needs/needed other kinds of support?

(5) Pretend Play Intervention

1. What do you think about a pretend play intervention for young cancer patients?
2. How do you think children will benefit from such an intervention?
3. What do you think about …
   … the structure? … time points of the intervention? … discussed themes?
   … place of the intervention … acceptance of the intervention by the children/parents/professionals?

(6) Conclusion and Goodbyes

1. Conclusion and Goodbyes

Fig. 1. Interview questions for parents (questions for professionals were reworded accordingly).

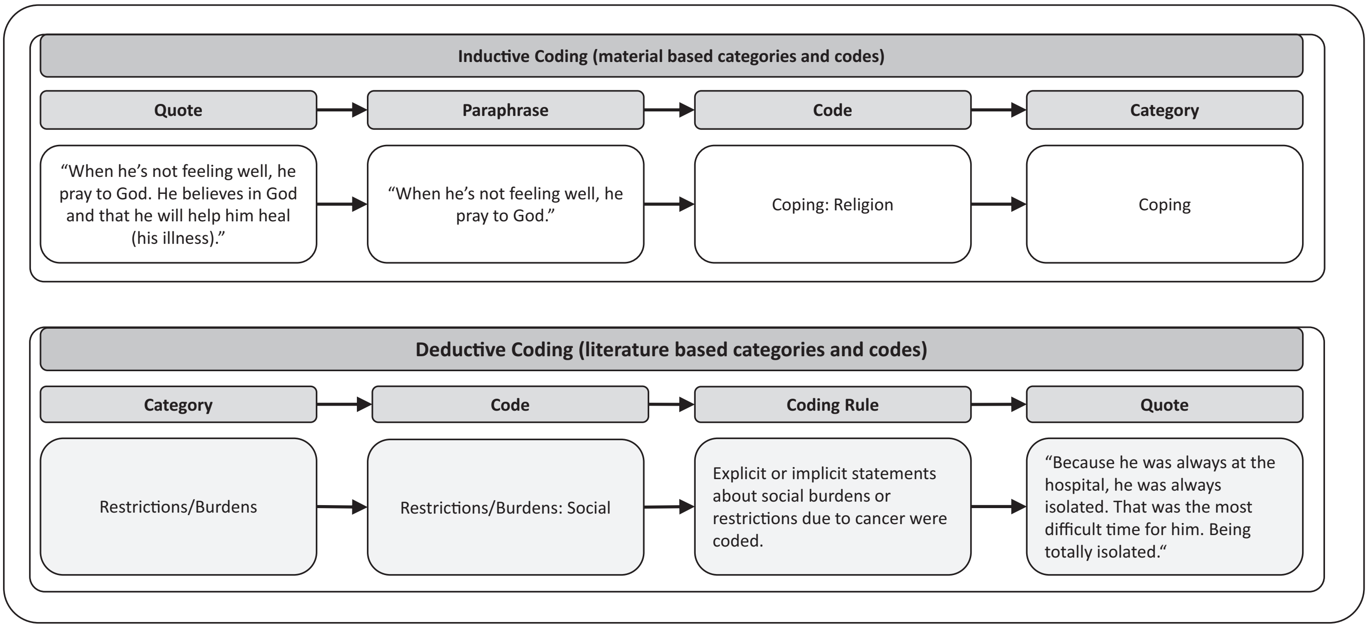
thirteen years; M = 8 years) who were being treated or have been treated at the UKE participated (Tables 1 and 2).

Themes Emerging From the Analyses

The analyses of parents and professionals interviews resulted in five main themes. Four of these themes were predefined a priori by the deductive code system, one theme - focusing on parent's needs - was added to the code system using the inductive approach. Furthermore, the additional sub-categories "religion" and "rebellion" were added to the code system as they were before not predefined coping strategies in the coping theme.

Theme One: Ability to Play in the Context of Leukemia

Both parents and professionals emphasized reduced opportunities to play in young oncology patients. This includes the restrictions and



Inductive Coding (material based categories and codes)

Quote → Paraphrase → Code → Category

"When he's not feeling well, he pray to God. He believes in God and that he will help him heal (his illness)." → "When he's not feeling well, he pray to God." → Coping: Religion → Coping

Deductive Coding (literature based categories and codes)

Category → Code → Coding Rule → Quote

Restrictions/Burdens → Restrictions/Burdens: Social → Explicit or implicit statements about social burdens or restrictions due to cancer were coded. → "Because he was always at the hospital, he was always isolated. That was the most difficult time for him. Being totally isolated."

Fig. 2. Coding guideline for both inductive and deductive coding.

Table 1
Characteristics of the participating professionals.

Characteristics of the professionals (n = 15)	n	(%)
Gender		
Male	4	(27)
Female	11	(73)
Professional background[a]		
Nurses	3	(20)
Physicians	2	(13)
Social education workers	3	(20)
Pedagogues	2	(13)
Music therapist	1	(7)
Psychologists	4	(27)

[a] Eight participants had an additional approbation as psychotherapists.

limitations caused by physical aspects of quality of life (QoL) like side effects, physical weakness and loss of concentration. Pain appears to be a limiting aspect of cancer on being able to play.

> "From the start of the treatment, the children have permanent pain."
> [(Mother of a 3-years-old boy at diagnosis)]

> "Then I always had to carry him up and down the stairs. When we went out, we had to use a stroller although he was five years old and could already walk."
> [(Mother of a 4-years-old boy at diagnosis)]

Maintaining social contact with friends was reported to be a frustrating endeavor for the children to undertake, simply because they did not have the energy or felt well enough to engage with their friend(s).

> "Bodily, he just wasn't fit enough anymore. When he had visitors, he often couldn't play with them because he wasn't healthy enough to keep up with his peers who are healthy."
> [(Mother of a 6-years-old boy at diagnosis)]

Both parents and professionals have also noticed a change in demeanor in the children that sets them apart from their healthy peers, in which they appear to have matured rapidly after being diagnosed with cancer and undergone treatment.

> "My child has grown up-he's started to think about things more deeply and decisively. The impulsive boy that I know is (to an extent) there sometimes, but in some situations, that boy is entirely gone."
> [(Mother of a 6-years-old boy at diagnosis)]

Games that children played while undergoing acute treatment were reported by parents to be mostly isolated, passive activities such as watching TV & movies, playing games on a tablet/smartphone, or reading (out) books. This lack of exposure to playing non-solitary games was viewed to be a possible disadvantage because the children do not learn how to interact with their peers or how to resolve conflicts.

Table 2
Characteristics of the children.

Children characteristics (n = 13)	n	(%)	M	Median	SD	Range
Gender						
Male	12	(92)				
Female	1	(8)				
Age						
Age at the interview (in months)			101	101	33	42–156
Age at the diagnosis (in months)			66	53	39	16–134
Diagnosis						
C-ALL	8	(62)				
T-ALL	3	(23)				
AML	2	(15)				
Diagnosis of Relapse	3	(23)				
SCT	4	(31)				
Respondent						
Mother	12	(92)				
Father	1	(8)				

Note. Abbreviations SCT (Stem Cell Transplant), HrQoL (Health-related Quality of Life), C-ALL (Common Acute Lymphoblastic Leukemia), T-ALL (T-Cell Acute Lymphoblastic Leukemia), AML (Acute Myeloid Leukemia).

Table 3
Description of a pretend play intervention for young cancer patients.

Description of a pretend play intervention for young cancer patients
Purpose • To increase overall well-being/quality of life and adjustment • To decrease anxiety • To increase play skills, which could foster the use of new coping techniques • Intervention will be individually tailored to the needs and play ability of each child
Duration • 8 individual weekly sessions with a play facilitator • 20–40 min
Stories Approximately 3–4 stories per session (2 based on either affect or imagination, 1 based on medical play, and then finish the session with the child making up 1 story on their own) Imagination topics: going to school, visiting the zoo, cooking a meal, being superman/supergirl, traveling to the moon etc. Affect topics: losing a toy and feeling sad, hearing scary noises and being afraid, going on great vacation and feeling happy etc. Medical topics: getting a shot, having a port placed, having an appointment with the doctor, staying in the hospital overnight etc.
Set-up • Toys on the play table (a mix of medical play toys and non-medical play toys) • More toys can be added per session as needed
Toys • Human-like doll figures as well as accessories for doll figures • Animal figures • Legos, blocks, cars, balls • Medical play kit (includes stethoscopes, blood pressure, cuffs, needles, band aids, syringes, patient & doctor dolls)
General strategies • Model ideas and actions • Prompt • Follow the child's lead • Reinforce • Summarize • Don't be intrusive
Coping & problem solving techniques During some of the stories, the child may have difficulties with the topic or emotions being expressed. *Coping self-statements through the dolls.* *Problem-solving approach*: • Statement of the problem • Generation of possible solutions • Evaluate the solutions • Evaluate outcome *Reinforcement process*: • If it worked, strengthen the child in his/her ability to solve the problem. • If it did not work, compliment the child for his/her ideas and support the child to search for alternatives.

> "Because my child only played with adults during the treatment phase, it was hard for him to accept and learn that conflicts while playing with peers are totally normal and aren't a big problem."
> [(Mother of a 2-years-old girl at diagnosis)]

A mother described her son using play as a way to creatively and constructively deal with the diagnosis.

> "Playing was always an important activity for him. Even when he was just diagnosed with cancer, he had used his Legos to 'destroy' his cancer cells. In a way, playing was a way for him to process his illness."

[(Mother of a 3-years-old boy at diagnosis)]

Despite not being the primary mode of play, the children did engage in non-solitary games when their health condition permitted it.

Because of limited opportunities and restricted physical abilities to interact with their peers, parents and professionals highlighted the importance of social contacts within the family, such as siblings, who can provide peer social interaction.

> "I'm convinced he wouldn't have done as well as he did without his sister there….Sometimes he told his sister what to do with the dolls and cars when he felt too weak to play and just watched his sister playing for him."
>
> [(Mother of a 3-years-old boy at diagnosis)]

Theme Two: Ways of Coping With Leukemia

Parents and professionals focused on the various ways children coped with leukemia, its treatment and its consequences. The main coping strategies that were reported by parents included avoidance, acceptance, withdrawal and isolation, aggression, and rebellion. The parents described their children as being partly "apathetic, listless, and withdrawn" and emphasized distraction and repression by (mainly) digital media to be very frequent and important.

> "He went through very depressive phases and had moments where he was just unbelievably sad."
>
> [(Mother of a 6-years-old boy at diagnosis)]

> "Eventually he just let things happen to him-he didn't have a choice anyway."
>
> [(Mother of a 7-years-old boy at diagnosis)]

Additionally, parents talked about religion as an applied coping strategy which none of the professionals talked about.

> "He believes and prays. With God's help, we shaped our history."
>
> [(Mother of a 4-years-old boy at diagnosis)]

In other situations, parents described their children to show aggression such as screaming and stomping. They were "furious and irritated."

Professionals confirmed some of the same coping strategies that parents had reported, such as distraction and withdrawal and isolation.

> "Sometimes the children just needed to be distracted."
>
> [(Professional, E03)]

> "Older children were especially more likely to become withdrawn and listless sooner, as well as wanting to be left alone."
>
> [(Professional, E12)]

However, unlike the parents, professionals mentioned acceptance rarely, and aggression and rebellion were not reported at all. Contrary to the experiences of parents, the professionals observed seeing the children's search for social support and information, and have described these actions as important coping strategies.

> "The children talked to each other about their illness and dealt with challenges together."
>
> [(Professional, E05)]

> "The children wanted to understand their illness and wanted to learn a lot about it."
>
> [(Professional, E01)]

Theme Three: Difficulty in Transitioning to Normality

The transition from receiving intensive treatment to maintenance therapy (and therefore, living a more normal everyday life) has been described by parents to be difficult. Parents reported feeling overwhelmed because they find it hard to settle back into normality. This is because parents fear that their children's health will worsen again (or have a relapse), some may have difficulty looking at their children as being healthy and not as a severely sick child that requires help and treatment. At the same time, the parents would like to treat their children as they did before they became ill and establish a semblance of normality again. This inner conflict is difficult to resolve for many parents.

> "He had a special role for such a long time, and that [mentality] is difficult to just turn off."
>
> [(Mother of a 4-years-old boy at diagnosis)]

The parents describe a similar problem happening in their children. Although the illness greatly changed the children inwardly, outwardly they still looked the same as before they became ill.

> "When we went back to school, there was the problem that he appeared to be the boy from before the time he left a year ago…but he is not the same. Inwardly, he just isn't the same boy as before."
>
> [(Mother of a 8-years-old boy at diagnosis)]

The parents of very young patients reported that the illness had extremely delayed important developmental steps for their children - for example, interacting with their peers has become a big challenge.

> "During that difficult time, she couldn't play at all. Nevertheless, when she started to get better, she did not know how to play anymore. She longed for contact with other children, but did not know how she could get in contact with them. She didn't get to learn that."
>
> [(Mother of a 2-years-old girl at diagnosis)]

Because of these experiences, the parents have expressed interest in not only getting professional help and support for themselves, but also for their children.

Professionals emphasize that there are strong support resources for both the children and their families during acute treatment, but the presence of these services during maintenance therapy depends on the amount of resources available and can be very limited. Professional follow-up care is established, but the parental demand is not sufficiently covered by existing systems.

> "During long-term therapy, children usually don't receive any more psychosocial therapy."
>
> [(Professional, E10)]

Theme Four: Parental Quality of Life and Parents' Needs

Despite the focus of the interview guidelines with its predefined concepts on the experiences and feelings of children, the inductive approach resulted in a new category which contained specific findings on the parents own enormous burdens. The parents emphasized that the demands and burdens that are brought by the disease have an impact on the entire family.

> "In the first weeks [after being diagnosed], every little thing could make us on edge."
>
> [(Mother of a 3-years old boy at diagnosis)]

> "He had two helpless parents. Therefore, in this kind of situation, parents are also facing a mountain. You can try to hope that things will be fine, but you cannot do much other than that. You're simply struck speechless."
>
> [(Mother of a 7-years-old boy at diagnosis)]

The parents' or family's life were reported to change abruptly. New short-, medium- and long-term planning and quick adaptions to sudden, new situations were reported. Because of this, parents experienced feeling helpless.

> "At first, it felt like the world was ending. (…) Therefore, I couldn't deal with it anymore. I had quite a lot of problems, so I felt pretty alone then."
>
> [(Mother of a 1-years-old boy at diagnosis)]

They described existential fears about their children's life, which they tried to forget. Specifically, parents would try not to show their fears in the presence of their children. Nevertheless, feeling fearful was expressed to be a permanent occurrence in their daily lives.

> "We only ever felt scared." (Mother of a 2-years-old boy)."I was scared that I would make my child scared too."
>
> [(Mother of a 6-years-old boy at diagnosis)]

Additionally, they were afraid of possible long-term consequences and relapses:

> "I would have given up everything so that this sword of Damocles would no long hang over us anymore."
>
> [(Mother of a 7-years-old-boy at diagnosis)]

However, parents also negated experiences of fear about their children's deaths by avoiding these kinds of topics with their children.

Some of the interviewed parents, whose children were already in the maintenance therapy or had already finished it, expressed retrospectively great fears and worries during the transition to maintenance therapy and everyday life.

> "At home, without the constant presence and the regular contact with physicians and nurses, I had quite some problems, I felt pretty left alone."
>
> [(Mother of a 7-years-old boy at diagnosis)]

> "I would have been good to have opportunities for an intensive exchange for the parents. It would have been so important if there is someone who has the time to do it professionally, who can then help the parent with his worries."
>
> [(Mother of a 10-years-old-boy at diagnosis)]

Theme Five: Perceptions of the Potential of Pretend Play Intervention

Both parents and professionals appreciated the idea of a pretend play intervention for young children with cancer. They emphasized that creative fantasy play (under professional supervision) can improve well-being and coping skills. Opportunities to develop new coping skills and ways of dealing with restrictions and limitations were highlighted.

Both parents and professionals believed that a planned intervention creates a secure framework where the child can express his or her emotions and feelings, which would be beneficial for children who do not talk to their parents. Professionals suggested testing this kind of intervention during acute treatment because it is during this time that children need the most support. However, they mentioned that support from psychosocial staff is still ongoing during acute treatment. Therefore, the period of maintenance therapy might be a better time to support children in dealing with experiences and to prepare and support them for reintegration into normal life. Parents' opinions about the best point of time to introduce the intervention were also diverse. However, they did emphasize that the children's willingness to take part, health status, and individual needs should be considered. Parents' expectations and preferences were again diverse when it came to the question of where this intervention should take place - at home, in the clinic, in ambulatory care, or in a neutral environment.

Parental involvement in this intervention was considered critical from the parents' point of view. The parents expressed the need to be informed about the content and topic, and information about the progress of the play intervention. Parents wanted to be sure that the child's interests and his or her current personal constitution are taken into account.

> "I would be very upfront with the psychologist and would ask him to avoid talking about big topics like how dangerous the illness is and about death."
>
> [(Mother of an 8-years-old boy at diagnosis)]

Parents and professionals emphasized the importance of the play moderator establishing a trustful relationship with not only the child, but also with the parents. Furthermore, they expressed that the children should be in good physical and mental condition so that they can play freely. In terms of what kind of setting the pretend play should be conducted in, some parents preferred a group setting because of the lack of contact with other children and the isolation they described above.

> "Maybe it should be done with other children who are facing the same things so that they can talk to each other about it."
>
> [(Mother of a 9-years-old-boy at diagnosis)]

> "I think he would have liked to do it in a group so that he could see other children…as a group intervention."
>
> [(Mother of a 4-years-old boy at diagnosis)]

However, other parents emphasized that one-to-one interaction with a professional should be adjusted for each patient and his or her family. With regard to structure and content, the professionals recommended increasing the session's period from twenty to thirty-minutes to thirty to forty-minutes and the number of four stories of each session to be reduced to two to three stories. They also suggested that the children themselves should choose the themes of the stories and that the play facilitator should let the children play as freely as possible. Additionally, questions that pertain to the current situation of the child (e.g. situations or experiences that the child is stressed by) could be included in the play sessions.

Discussion

As part of a cross-cultural cooperation, the aim of this German pilot study was to gain knowledge of parents' and professionals' perceptions about children's resources, burdens, and ability to pretend play. The results of this project are intended to be used to prepare the initiation of a pretend play intervention, which will be applied in Germany, Sweden and the United States.

In Theme One (Ability to Play in the Context of Leukemia) we summarized statements of parents and professionals, which described a reduced ability to play of (young) children with leukemia. Physical restrictions resulted in less desire for active play and less social contacts. Especially the peer contact was reported to be reduced, on the one hand due to the risk of infection, on the other hand because of limited physical fitness. According to the estimation of parents and professionals, the above mentioned social isolation may in turn lead to a delayed development of social skills - particularly in interacting with peers and solving conflicts with peers in play situations. These feelings of isolation are reinforced by the pause in attendance in kindergarten and school and the interruption of almost all social contacts with friends, which can lead to "experiences of fear related to the social self" (Carlsson, Kihlgren, & Soelie, 2008). Parents reported difficulties in reintegrating in kindergartens or in schools and problems in finding common themes and topics with peers. Despite having vastly mentally matured, reintegration in school and kindergarten sometimes is difficult because of the children's delay of physical maturation (because of treatment and its side effects). Here, the pretend play intervention can be specifically used to support the transition to everyday life and to accompany it professionally. Still, according to both parents and professionals the children matured more quickly and started thinking about things earlier than their peers due to the treatment and the consequences of leukemia.

Fatigue, pain and listlessness, nausea, and vomiting are some common symptoms during the treatment that negatively affect the young patients' ability to play (Hedén, Poder, von Essen, & Ljungman, 2013).

These physical effects of the cancer diagnosis and its treatment also lead to psychological stress in the form of anxiety about further pain, fear of a medical intervention or general feelings of sorrow (Carlsson et al., 2008; Hedén et al., 2013). Arising from these experiences of physical pain and strain are also fears of unknown situations, relapses, and death (Carlsson et al., 2008).

In the second theme (Ways of Coping with Leukemia) parents and professionals described different coping strategies used by young children with leukemia. Avoidance, withdrawal and isolation were reported by nearly all participants. Social withdrawal was reported to be present in children having a chronic disease more frequently than in healthy peers (Boekaerts & Roder, 1999). Avoidance is also a common coping strategy in the context of chronically ill children (Dellenmark-Blom et al., 2016).

In addition, parents – but only few professionals - observed acceptance of the situation as well as aggression and rebellion by their children. Professionals, on the other hand, mentioned the search for social support and information to be important coping strategies to deal with the disease and its treatment. We divided the mentioned coping strategies according to the three categories (1) active coping, (2) internal coping and (3) problem avoiding behavior of Seiffge-Krenke (1984). Withdrawal, defined as problem avoidance, was described as a predominant coping strategy as well as avoidance itself and isolation. Internal coping, defined as "working on the inner attitude to a problem", was also described. But only acceptance fits in this category of internal coping. This finding is in line with a study, that identified seven different ways of coping for children with leukemia aged 7 to 14 years (Han, Liu, & Xiao, 2017), but of this seven only acceptance described internal coping. Faith in God as "active coping," defined as problem-oriented rational actions, was barely mentioned. Active interactions with other patients and the active search of information were described in older children. Therefore, the age of the children seems to play an important role when it comes to their search for information/support. Still, this study included older patients (patients aged 7 to 14 years) then our sample (aged 2–11 years) (Han et al., 2017). The search for information falls also into the category of active coping as well as aggression and rebellion. Overall, very few internal coping strategies were reported. The pretend play intervention can support the extension of internal strategies. The concept of the intervention includes a focus on coping and could help the children to develop alternative ways of dealing with an unpleasant situation. It is important that young patients are given the opportunities to expand their repertoire of coping strategies (both internal and active) to be able to develop a strong sense of emotional strength and security. It is again important to consider the age of the children. Children and adolescents differ from adults in dealing with longer hospital stays (Saile & Schmidt, 1990) but even within child- and adulthood, there is a great variance that needs to be acknowledged. Play therapy and this specific pretend play intervention provides a professional platform for these young patients to improve and develop their coping and problem solving techniques. In the perception of both parents and professionals young patients with leukemia are more open to talk about their feeling, especially when it comes to fears and sorrows, when the parents are not present.

The transition to normality after the acute treatment was discussed in Theme Three (Difficulty in Transitioning to Normality). This transition was described to be challenging for both parents and children, especially regarding the onset of maintenance therapy. According to Wong (1991) the transition includes the process of reduction the child's feelings of being different and ill by restructuring daily living according to normal expectations of a healthy child of similar developmental age. Parents reported to having to find a balance between the desire to protect their child and the desire to treat their child as they did before the diagnosis. Findings from Solan et al. (2015) confirm the parental uncertainty about their own worries and report about general worry and medically indicated worry. The participating parents also talked about their own fear to be too overprotective. There is also a challenge for the young patients. While they have received considerable attention from everyone, now they have to get used to be "just" a child. Some children find it harder to deal with this lesser attention or to be bored. In the pretend play intervention this topic can be reenacted with dolls and figures.

Theme Four (Parental Quality of Life and Parent's Needs) was added as a result of the inductive approach of defining categories. Although this pilot study focused on young patients and their needs, parental burden and needs were ever present. Parents expressed demands and burden – not only during the phase of diagnosis and acute treatment but also in the phase of maintenance therapy and reintegration into everyday life, that require additional psychosocial support. This was demonstrated in another study of parents of pediatric oncology patients in which more than 90% of the parents reported a strong desire for further professional support. This desire appears to grow stronger in correlation to how stressed they perceive their children to be (Hürter, 1990). The transition from acute treatment to maintenance therapy is perceived as a burden because children and parents receive less support during this period and because of the chance of relapse during maintenance therapy.

Recent research has also shown that mothers of children undergoing maintenance therapy suffer from insomnia (Matthews, Neu, Cook, & King, 2014; Neu, Matthews, & King, 2014), anxiety, depression, and stress (Neu, Matthews, King, Cook, & Laudenslager, 2014) compared to mothers of healthy children. This can lead to a sense of insecurity and passivity among the parents. Helplessness and excessive demands on the parents are possible consequences of this phenomenon. Parents report that their children suffer from permanent pain with the onset of acute therapy. From a medical point of view, painful and pain-free periods alternate. Therefore, this perception of permanent pain is important for understanding the parental burden. These findings suggest that the parents' focus is on the child's limitations, which highlights their hard-to-bear feeling of helplessness. Subsequently, parents needs and burden should be integrated in the pretend play intervention, for example as an additional module.

In Theme Five (Perceptions of the Potential of Pretend Play Intervention) the attitudes of parents and professionals towards a pretend play intervention are summarized. Both parents and professionals mentioned that young patients with leukemia could benefit from the pretend play intervention. The children could obtain professional support to deal with the diagnosis, treatment and many negative experiences like pain, fear and isolation that come with cancer. As children use play to express their fears, worries, and to show their emotions, a pretend play intervention can be a child-oriented option to support young patients (M. A. Moore & Russ, 2006), especially if supported by both parents and professionals. Pretend play interventions with healthy preschool children were found to increase the subjective well-being and coping (Fiorelli & Russ, 2012). Furthermore, the emotional expression in a play therapy intervention is accompanied by strengthening the adaptive mechanisms of coping with the disease (Moore & Russ, 2008). For our adapted intervention for young patients with leukemia, we expect positive affects for the quality of life as well as an increase of variety of coping strategies. Additionally, the pretend play intervention could reduce parental feelings of helplessness and inactivity by the fact that their child receives professional support.

Implications for Practice

Findings also suggest that young patients with leukemia use predominantly avoiding and active coping strategies. However, the active coping strategies mainly include aggression and rebellion. Internal coping strategies are barely reported. A routine care that includes methods to strengthen and expand the repertoire of coping strategies may help the young patients to improve their disease management.

Despite the high level of satisfaction with the care in the clinical setting, the care gap reported by the parents in the transition from acute treatment to maintenance therapy and re-integration into everyday life should be supported professionally. In addition to the needs of the children, professionals can also recognize and address parental fears and worries.

Limitations

The pilot study employed standardized interview guidelines and interrater-reliability. However, interviews with parents were conducted in various ways (face-to face and via telephone) and the risk of bias due to the differences in child age, the duration of the treatment and the time span since diagnoses are study weaknesses. Even the one patient, who was transferred from a regional counseling center and had been diagnosed 10 years ago still experienced the same themes. Other possible study limitations are the unbalanced ratio between male and female children included in the sample, as well as the disproportion between the ratio of mothers and fathers who participated in the study and the missing sociodemographic information of parents and professionals.

Although, this pilot study includes a few number of participants, our results are considered scientifically viable and pretend play seems to be a promising opportunity to support children, especially young ones. Overall, there were varying individual needs. Nevertheless, both the parents and the professionals expressed appreciation of a pretend play intervention that considers these individual needs. In addition, the results highlighted that an intervention would relieve the parents of their helplessness. Therefore, a pretend play intervention study using a predefined setting with a trusted play facilitator and thus for children and parents a safe framework that considers individual needs of families will be investigated in a cross-cultural pilot study in Sweden, the United States and Germany to evaluate the feasibility of such an intervention. The needs expressed by the parents for their own support will be considered in a further step.

Conflict of Interest

The authors report no conflict of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

CRediT authorship contribution statement

Stefanie Witt: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - Review and Editing, Project administration. **Gabriele Escherich:** Resources, Writing - Review and Editing. **Stefan Rutkowski:** Resources, Writing - Review and Editing. **Gerhard Kappelhoff:** Resources, Writing - Review and Editing. **Sara Frygner-Holm:** Conceptualization, Methodology, Writing - Review and Editing, Project administration. **Sandra Russ:** Conceptualization, Methodology, Writing - Review and Editing, Project administration. **Monika Bullinger:** Conceptualization, Methodology. **Julia Quitmann:** Conceptualization, Methodology, Resources, Writing - original draft, Writing - Review and Editing, Project administration.

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