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Young children's experiences of living an everyday life with cancer – A three year interview study

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ABSTRACT

Purpose: The young child's experiences of living with cancer are crucial to providing evidence based care. This study explores and describes experiences of everyday life of young children with cancer, over a three year period from diagnosis.

Method: This is a longitudinal, inductive interview study with young children with cancer, and their parents. Interviews from shortly after diagnosis, six and 12 months after diagnosis have been reanalysed. Interviews with the same children and their parents from 18 to 36 months after diagnosis have been analysed for the first time in the present paper. A longitudinal temporal analysis at category level for five synchronic data sets forms the basis for the results.

Results: The child living with cancer over a three year period is described as a child apart, striving to live an everyday life. This description is built on three categories: I want to be a child like any other, I need security and control and I feel lonely and left out. Young children with cancer actively strive to understand their illness, participate in care and live an ordinary everyday life- but with ongoing feelings of social isolation and loneliness.

Conclusions: Young children with cancer need access to and ongoing contact with peers and preschool. A structured follow-up throughout the cancer trajectory and not just during active treatment, is necessary. A child-centred philosophy of care would guide the child towards attainment of health and wellbeing.

1. Introduction

The present knowledge base on young children living with cancer is mainly informed by adult's views of children's experiences and lacks young children's own experiences, which they have a right to contribute and which are fundamental to caring for them. Without research in this area, approaches by care givers and health professionals lack children's informed opinions which could have significant influences on the type of care provided. There is a dearth of longitudinal studies with young children living with long-term illness, which this paper hopes to amend. Research with young children is not without methodological challenges, but accessing the young child's long term experiences of living an everyday life with the effects of cancer and its treatment could offer new possibilities for providing support, assistance and guidance, throughout the entire cancer trajectory.

2. Background

Children are the best sources of information about themselves (Eiser and Morse, 2001). The United Nations Convention on the Rights of the Child (UNCRC) asserts the right of every child to self-determination, dignity, respect, non-interference and to make informed decisions (UNCRC, 1989). This requires that health professionals take the responsibility to ensure that children are encouraged and enabled to give their views on issues that affect them in regard to health care. In reality, children's views have not been historically valued in medical care, and children in research, particularly young children under the age of six years, have been seen as a vulnerable group, difficult to access and unable to tell their story. Sick children have traditionally been seen as thinking and feeling as adult care givers say they do (Coyne, 2006). Despite the fact that parent' reports may not be consistent with children's own reports (Eiser and Morse, 2001), it is mainly parents' views on children's experiences that have been sought in published studies (Enskär et al., 2015). In order to ensure quality care, young children should be encouraged to give subjective assessments about their health when possible, and parent reports should be seen more as a complement to children's reports (Woodgate, 2000). Including young children in research generally requires both adult's perspective on the child and the

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child's own perspectives (Nilsson et al., 2015) such as in this study.

Cancer remains the most common cause of disease related childhood death in children over one year of age and although genetic factors are thought to play a part, the causes of childhood cancer are largely unknown (Gustafsson et al., 2013). The majority of the 300 or so children who receive a cancer diagnosis in Sweden per year survive their cancer. However, treatment is long, aggressive and causes adverse side effects (Gatta et al., 2009). Leukemia is the most common form of cancer found in young children, followed by brain and solid tumors (Gibson and Soanes, 2008). As survivorship increases, health care focus has shifted from survival and symptom management, to living an everyday life with the effects of illness and treatment, over a long period of time (Björk et al., 2006; Gustafsson et al., 2007; Woodgate and Degner, 2004).

Having childhood cancer involves many invasive and painful treatments and procedures, many with adverse side effects (Enskär et al., 1997; Hinds et al., 2004; Van Cleve et al., 2004). It also involves disruption of the children's everyday roles and routines (Björk et al., 2006; Hildenbrand et al., 2011). Creating good relationships with health care professionals (Björk et al., 2006; Enskär et al., 2015) and the comfort and support to parents (Björk et al., 2006; Björk et al., 2009) are described in the literature as vital components for the young child's health and functioning in everyday life. Over the first year after diagnosis, the young child actively strives for an ordinary everyday life by gaining control and making a normality of the illness and treatment (Stewart, 2003). However feelings of loneliness prevail and children report having difficulty with collaborative play and experience feelings of not fitting in with other children (Hildenbrand et al., 2011).

Living through the cancer trajectory has been described in the literature as an arduous journey after which life is never the same again (Woodgate and Degner, 2004; Woodgate, 2006). A current systematic literature review shows that distress appears to decline over time and well-being increases, but this can take a period of several years (Enskär et al., 2014). Labay et al. (2004) point out that cessation of cancer treatment is a period of crisis for family, as they adjust to the “new normal”. Returning to an ordinary life, without cancer, is not the same “normality” as before (Björk et al., 2009; Hildenbrand et al., 2011) but rather a process of reintegration. The need for information and support is still paramount, even after treatment is completed (Woodgate, 2006; Gibson et al., 2005). Parents are recognized as important in the child's cancer trajectory from the very beginning and information needs to be clear and relevant and repeated and updated at different time points, through the trajectory (Kästel et al., 2011; Gibson et al., 2005). However, it is mainly parents' views that have been sought in published studies (Enskär et al., 2015).

Treatment within the framework of a multi-disciplinary collaboration, long term follow-up for survivors and focus on quality of life for children undergoing treatment for cancer have been highlighted as areas requiring attention (Gustafsson et al., 2013). Considering the impact that experiences of illness in early childhood are likely to have on long term outcomes, children's experiences are vital to enhance children's health (Eiser et al., 2000). Health is related to the child's ability to perform the activities he/she wants to but also to the possibility to participate in an everyday life (Almqvist et al., 2006).

The few known studies in which preschool aged children (three-six years of age) themselves were asked about their experiences of living with cancer was described as a life with dramatic disruptions of everyday roles and routines and limited possibilities for relationships and activities (Gibson et al., 2010; Björk et al., 2006). Difficulties with collaborative play with other children were also reported (Hildenbrand et al., 2011). However, when children participate in different forms of activities it positively influences their health, learning and development (Larson, 2000; Larson and Verma, 1999). Barriers limiting the child's participation can be the physical and social environment as well as limited resources (Coster et al., 2013).

Several studies have been published on the young child's experiences of living an everyday life with a cancer diagnosis, but few, if any, have described the continuous adjustments children had to make to their lives due to the prolonged nature of childhood cancer. Therefore, the purpose of this longitudinal study was to explore and describe the young child's experiences of living an everyday life with cancer, over a three year period from diagnosis.

3. Method

3.1. Design

This is a longitudinal, inductive interview study with young children with cancer, and their parents, exploring the children's experiences of how cancer affects their everyday life, over a three-year period from diagnosis. Data from interviews shortly after diagnosis, six and twelve months after diagnosis have been reported previously ((Darcy et al., 2014b; Darcy et al., 2014a) and data from the 18 and 36 month interviews are reported for the first time in this paper.

3.2. Participants

Children being treated at a paediatric oncology center in the West of Sweden were consecutively included in the study. The inclusion criteria were that the child was between one and six years of age when receiving their first cancer diagnosis, being able to communicate in Swedish and agreed to participate. Thirteen children of mixed gender and diagnosis were included in the study during 2011, One child was lost to follow up after the first two data collections and twelve children remained in the study to the final data collection in September 2014. All types of cancer diagnoses were included. It was necessary to use several time-points to capture the continuous adjustments children had to make to their lives due to the prolonged nature of childhood cancer (Bearison, 1991; Docherty and Sandelowski, 1999). Data were gathered from children aged three years and older through interview at each data collection time-point. Six of the children were aged one and 2 years at inclusion in the study so data was gathered from parents only, prior to the child's third birthday. Interviews with these children were then included in the data collection when they reached the age of three (Table 1).

3.3. Data collection

The data collection procedure at diagnosis, six, and 12 months after diagnosis are described in Darcy et al. (2014a) and Darcy et al. (2014b). Data collected at 18 and 36 months after diagnosis was gathered from the same participants, in the same manner as the preceding interviews. The researcher contacted parents via telephone prior to the interviews at 18 and 36 months to gain their consent and arrange where to meet (Deatrick and Faux, 1991). It was explained to the child each time that there was no right or wrong answer as they were generally experts at trying to work out what answer they should give. It was also explained that they did not have to talk about things they did not want to. The researcher and child often talked and played for a short time at the beginning of the interview, as it is important to establish trust and build a rapport with the child before starting the interview (Deatrick and Faux, 1991; Kortesluoma et al., 2003). Parent interviews were also gathered at each meeting, as a complement to child data, as suggested by Irwin and Johnson (2005) and Deatrick and Faux (1991). As with previous interviews, parental contributions in this study are seen as a complement to, rather than a substitute for, the young child's contribution.

The interview questions, to both children and parents, consisted of semi-structured open-ended questions that focused on the child's experiences of their body and on activity, participation and support in everyday activities. Questions were similar at each interview and at each data collection time point: “Who you are and what you like to do?”

Table 1
Participants.

Data collection time-points after diagnosis	3–9Weeks (n = 13)	6 Months (n = 13)	12 Months (n = 12)	18 Months (n = 12)	3 Years (n = 12)
Age in years					
1	3	2	–	–	–
2	3	2	3	2	–
3	2	4	3	2	1
4	4	4	3	4	2
5	1	1	3	3	3
6	–	–	–	1	3
7	–	–	–	–	2
8	–	–	–	–	1
Gender of the child					
Female	9	9	8	8	8
Male	4	4	4	4	4
Diagnosis					
Leukaemia	9	9	9	9	9
Brain and solid tumours	4	4	3	3	3
Undergoing treatment					
On treatment	13	12	8	2	1
Off treatment	–	–	1	7	–
Follow-up to treatment	–	1	3	3	11
Place of interview					
Home	5	8	10	9	11
Hospital	8	5	2	3	1
Length of interview					
(median in minutes)	77	89	100	77	85
Child participated in the interview					
Yes	9	10	10	10	12
No	4	3	2	2	–
Parents participated in the interview					
Mother and Father	10	8	8	5	6
Mother only	3	5	4	6	5
Father only	–	–	–	1	1

"What do you do every day and with whom?" "Has your body changed?" "Who supports you/Do you have the help you need?" were asked and adapted to the interview as necessary and made developmentally appropriate, as suggested by previous research with young children (Irwin and Johnson, 2005; Spratling et al., 2012). Smiley faces from very happy to very sad, and dolls and puppets were used as a complement to help the child answer the questions. Similar methods had been successfully used previously (Aldiss et al., 2009; Almqvist et al., 2006; Gibson and Hopkins, 2005; Gibson and Twycross, 2007). Parent and child interviews were interwoven in each other, and parents answered the same basic questions, with focus on the child's everyday experiences. The majority of interviews took place in the child's home and lasted between 49 and 104 min. Child participation in the interviews varied but the child's participation in the interviews at 18 and 36 months was greater than previous interviews. All interviews were recorded and transcribed verbatim.

3.3.1. Data analysis

A cross sectional analysis of data sets from five time points was performed. Each data set comprised of interviews with children and/or their parents (Table 1). Synchronic data sets as a whole, for all participants, one data set per time point has been used throughout, rather than case studies (Henderson et al., 2012). A checking of the previous analyses on the first data set of interviews from shortly after diagnosis, the second data set from six months after diagnosis and the third data set 12 months after diagnosis was performed, with the aim of the present study in mind. Categories from the original analysis of the first, second and third data sets were in agreement with the present aim. The content of one of the categories from the second data set was given a new category title to fit in with the overall synergy presentation. The next step in the analysis involved the analysis of raw interview data from interviews 18 months after diagnosis and from 36 months after diagnosis. Qualitative content analysis with an inductive approach according to Elo and Kyngäs (2008) was performed on each of these two data sets separately. A sense of wholeness for the data was gained by initially reading the interviews a number of times before meaning units concerning the children's everyday life were highlighted and extracted. Each meaning units were received a code describing the content related to the study aim. Agreement on coding for each data set was reached through discussion with the papers' co-authors and with our research group. Codes were merged to form subcategories based on similarities and differences of content in the subcategories as proposed by Elo and Kyngäs (2008). Lastly, a merging of the five synchronic data sets was performed (Holland et al., 2006). This merging or synergy occurred at category level and resulted in main category findings over the five-time point period (Fig. 1). Thus, the present paper presents a longitudinal temporal analysis at category level for five data sets.

3.4. Ethical considerations

Ethical approval was given by the Regional Ethical Review Board, Linkoping, Sweden (dnr2010/343-31). This study was carried out in accordance with the Helsinki Declaration (World Medical Association, 2015) and the four ethical principles of Respect for Autonomy (the children had the right to make their own choices), Beneficence (the researcher acted with the best interest of the children in mind), Non-

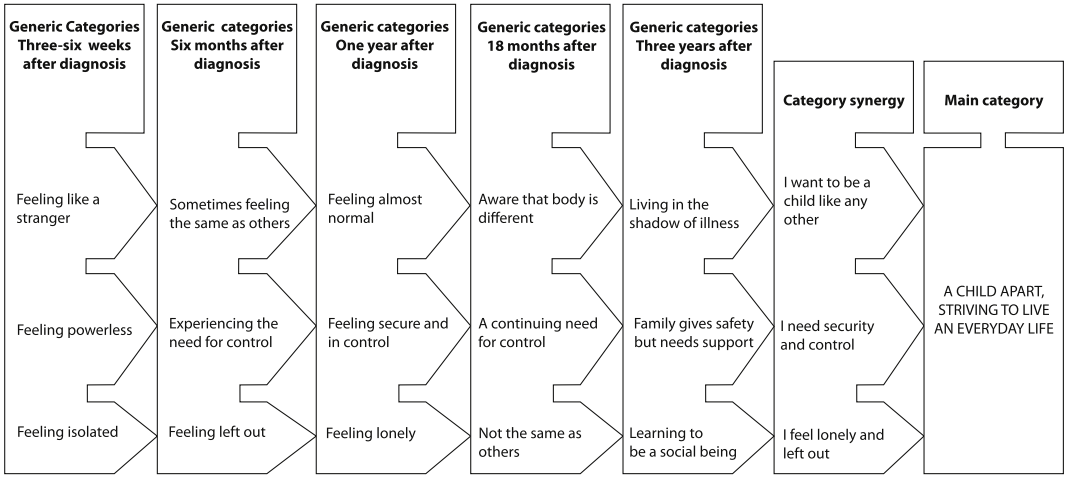

Fig. 1. A synergy of categories from _ve data sets describing young children's experiences of living with cancer over a three year period.

Maleficence (no harm should be done) and lastly Justice (fairness and equality among individual children), were included throughout the study (Beauchamp and Childress, 2013). Initial contact between the researcher and parents was taken by telephone and repeated before each data collection. The researcher informed the participants about the study, made sure that they understood the information about what the study entailed, that they could withdraw participation without consequences for their future care and received their consent (International Ethical Guidelines for Health-related Research Involving Humans, 2016). At each contact, the parents were reassured they could withdraw consent at any time without an explanation. Children received both written and verbal information initially and verbal information prior to each data collection. The text was written in an easily understandable language and pictures were added to enhance their understanding. The parents received more detailed written and verbal information. Both adults and children got time to ask questions to consider their participation before consenting. Both parents gave their informed consent for their own and the child's participation. Children themselves assented to participate in the study (Neill, 2005) as minor children are not legally capable of entering into a contract and therefore unable to give legal consent (Leikin, 1993). Steps were taken to ensure that the participants are not identifiable in the resulting material (International Ethical Guidelines for Health-related Research Involving Humans, 2016), thus promoting integrity and guaranteeing the participants confidentiality.

4. Results

The main category finding A CHILD APART, STRIVING TO LIVE AN EVERYDAY LIFE describes the child living with cancer over the three year trajectory as different than before, different than peers and actively striving to make sense of the world.

4.1. I want to be a child like any other

4.1.1. Feeling like a stranger

Shortly after diagnosis and start of treatment the child described feeling like a stranger in an everyday life that was described as utterly changed: *"Now I get help from my Mummy to do pretty much everything, (before) I did it all myself"* (four-year-old girl). The nasogastric tube (NG), central venous catheter (CVC) and intravenous drip stand became symbols of illness for the child: *"Tape on my cheek … nobody allowed touch"* (three-year-old-girl). Many hours were spent looking at old photographs and films of the child prior to start of treatment. The previously playful, social, mobile, competent child was suddenly replaced by a child who did not recognise themselves. Parents expressed a changed and unfamiliar role with a child who was changed by the illness: *"It's not really the same child, before she was normal … like any other child …. now we don't recognise her"* (Mother to two-year-old-girl). "*You all ask me why he is crying? I don't know, I have never had a child with cancer before"* (Father to a three-year-old boy).

4.1.2. Sometimes feeling the same

Six months after diagnosis children expressed awareness that they were different than their preschool peers but became aware that there were other children in hospital in similar situations to theirs. When they met other children with cancer they thought that they were scary*: "She had tubes and stuff and no hair, she looked sad"* (six-year-old boy). But over time playing with children with similar diagnosis they met in hospital helped them understand their own situation: *"When those two play you see how they start to relax … nobody staring at them and saying they are weird, no questions about tubes or that their hair is gone … it's just to play"* (Mother to a four-year-old girl). The friends children had with cancer also used each other in play to understand procedures they needed to work though. A Mother to a four-year old girl related that: *"They sat there in the play room with spatulas and torches and took turns to be the doctor and said "open wide, there's a good girl", and put the spatula gently in to the others mouth".*

4.1.3. Feeling almost normal

One year after diagnosis, children related experiences of feeling almost normal: "*Look at me, I'm almost like a real child again"* (five–year-old boy); *"Mummy, Mummy, it feels almost like I'm well, like I was before I got this illness"* (five-year-old girl). Parents meant that children were aware that the body was different but were adamant that they were not ill: *"He wants to be healthy now. We actually looked at all his cuddly toys last week and he wanted to take away the CVC and band aids on the toys*" (Mother to a five-year-old boy).

4.1.4. Aware that body is different

Eighteen months after diagnosis, the child expressed awareness and of bodily changes which meant that their body was different than others: *"I have thousands of scars now … one here, one here, one here, see? no one else in my class has these"* (seven-year-old girl. Children experienced themselves as the same as their peers but also different: "*They can cycle and I can't cycle - I`ve been sick you see*" (five-year-old girl). The child expressed feeling sad and having lower energy levels than their peers. They described differences between themselves and how they were before diagnosis and treatment and between themselves and other children: "*Before, I had a best friend, now we don't play anymore, I can't do anything"* (four-year-old girl). They also became aware of side effects of treatment: "*Next week I start cortisone treatment again, I'll be a real witch for a while*" (five year-old girl).

4.1.5. Living in the shadow of illness

At the final interview, three years after diagnosis, the child continued living in the shadow of illness: "*I'm going to school soon … Mum is going to the parent-teacher meeting with Dad, both of them, so that the school know I have a port here"* (six-year-old girl). The child was described by parents in terms of a child some any other but anyway not the same as children without a cancer experience: *"She has loads of scars and stuff now, but she, she doesn't see it as a problem really … only sometimes"* (Father to a five-year-old girl). The child now lived a life where cancer did not play a central role for them. However, they were aware that they had experiences of ill-health and hospitals: *"Sometimes I want to be sick again … I miss the nurses and I miss the presents"* (seven-year-old girl). Parents described a life of still living with the worry of cancer: "*Every fever, every bruise is cancer. Our worry affects her too*" (Father to a five-year-old girl).

4.2. I need security and control

4.2.1. Feeling powerless

The child's entry into illness was characterised by trauma. The child required help with eating, going to the toilet, sleeping and moving around. Children were bothered by going to hospital and described difficulties in communication with health care services. A sense of control was experienced when health care professionals treated the child with respect: "*Tell me … ask ME if it's OK to lift up my t-shirt*" (four-year-old-boy).The suddenness of diagnosis and start of treatment led to feelings of being abused by the treatment and feeling powerless: *"She was bright red and sweating and you could see panic in her eyes and she didn't have any control over her own body and couldn't fight back"* (Mother to a two-year-old girl). The experience of parents as assisting staff to perform painful procedures left the child powerless and suffering: *"She screams help … mummy help me … and then we're standing on the other side helping the baddies … it feels very wrong, somewhere in all of this it's in our arms she needs to climb up in when she needs comfort and safety"* (Mother to a four-year-old girl*),* rather than protecting them: "*Those first few days after we had to hold her down (for procedures) she didn't want anything to do with us. We had to work hard to build up her trust again*" (Mother to a two-year-old girl). Allowing for the whole family to be

present in hospital gave the child a sense of security.

4.2.2. Experiencing the need for control

Six months after diagnosis, the child's ability to do things increased as energy levels and self-confidence increased. Health was expressed of terms of physical activity and independence in activities of daily living. They described themselves and hospital visits as almost normal. The child described experiences of fighting for control and actively striving to make a normal everyday life of the cancer experience: "*Put it on at home (anesthetic cream) … so that it won't hurt, put on the tape myself*" (four-year-old girl). Gaining knowledge and understanding of the illness and treatment through adequate information and through play helped the child gain control in everyday situations: "*I get good medicine in here (CVC) … to fight the bad guys in my blood"* (three-year-old girl). Deciding how and when procedures should be carried out, how much they wanted to be involved and at what pace it should happen, allowed the child to participate in their care and experience control: "*It's important how staff treat the child, how they approach him before they do anything, it makes a difference to how he takes it … if they just take that extra minute and just talk to him and maybe ask him if he wants to help*." (Father to a four-year-old boy). Gaining knowledge and understanding of the illness and treatment through adequate information and through play helped the child gain control: *"Have to take tests and stuff..because thats good … so that I'll get better and that … so that those mean cells won't … I don't want them in my body. Stupid cells! Get out*!" (four-year-old girl).

4.2.3. Feeling secure and in control

A year after diagnosis the child made a normality of the illness and treatment by incorporating hospital visits and procedures into everyday life: "*I'm not sick, I have leukemia*" (four-year-old girl). They now expressed experiencing security and control: *"So I said to the nurse, don't you touch me with your cold hands, warm them up first"* (four-year-old girl*)*. Learning to live with a changed body helped in the striving for normality and the central venous catheter and naso-gastric tubes in particular were expressed as part of themselves: *"No, no, that (NGtube) belongs to me and it's to stay right here"* (four-year-old girl). Going to hospital was mostly fun and relaxing, and birthdays and holidays such as Christmas or Midsummer were celebrated there: "*When it was my birthday, the nurses came in here in the morning and sang to me*" (four-year-old girl). Access to parents for comfort and security continued to be important but parents also became more proficient in giving cancer related care, which led to feelings of control for the child: *"Mummy is the only one on this ward who knows where the tape sits best– I want her to do it"* (five-year-old girl).

4.2.4. A continuing need for control

Eighteen months after diagnosis*,* a strong need for control over decision making was expressed by the child both when in contact with hospital services and in their everyday life: "*I decide which finger to stick and what number to count to. I get to press the button on the lift too – don't I Mummy*?" (three-year-old girl). It was with a sense of pride and determination they described how they liked treatment related procedures to be carried out and their own participation, as decided by them: "*I push my own medicines down this nose tube with this (syringe) … Mummy is allowed watch me"* (five-year-old girl.

The family, including parents and siblings are highlighted by parents as vital to the child's sense of safety and control throughout the diagnosis and treatment phase: *"When she needs to be admitted, she watches us like a hawk to make sure we are all there – little brother as well" (Mother to a four-year-old girl*). The need for structured psychosocial support was an area that came to the fore for parents at this time, rather than the present practice of being encouraged to contact services themselves when parents felt the need: "*They (psychologist and social worker) told us to ring if we needed to talk – when we need to talk we don't have the strength or perseverance to get hold of them*" (Mother to a five-year-old boy).

4.2.5. Family gives safety but need support

Three years after diagnosis, parents were more verbal in the interviews about the child's life than the children. The family continued to represent safety for the child according to parents but parents in particular expressed that they live with constant worry and express a need for continued support: *"More* support *to parents is needed so we can function better and give the child the* support *she needs"* (Mother to a four-year-old-girl). Many parents experienced difficulties with posttraumatic stress symptoms but that the family struggled to remain the child's place of safety. Difficulties with the child's access to, support from and communication with health care services were described: "*She is now too well for us to ring the oncology unit for advice, but according to primary health services, she is still a child with leukemia*" (Mother to a six-year-old-girl). They also expressed a worry of whom to turn to for information on starting school and concern about long term effects of treatment on the child.

4.3. I feel lonely and left out

4.3.1. Feeling isolated

The child's entry into illness was characterised by isolation: "*I always played with my best friend before, now we never play"* (four-year-old girl). Shortly after diagnosis children described how they missed their preschool, teachers and friends *"I can't go (to preschool), I just have fever all the time" (three-year-old)*. They expressed a longing to return to their peers and hoped the ones at preschool thought about them as well: *"I wonder what they are doing at preschool – do you think they think about me?"* (five-year-old girl). Parents described how children wanted to look at preschool from the outside at evenings and weekends, when nobody else was there: "*He wanted me to lift him up to look through the window to see if his coat hook with his name over it was still there*" (Mother to a three-year-old boy). The child was where the parents were and life was spent mainly in the kitchen or sitting room and sleeping in their parent's room or bed. Play was important but according to parents it had changed to something children did individually or with adults rather than together with other children: *"The play department is fantastic, but its other children she needs really, not more adults"* (Mother to a four-year-old girl).

4.3.2. Feeling left out

Feelings of loneliness continued to prevail, six months after diagnosis. Children began to return to interacting with their peers more and more, something they had longed for. However, this interaction often resulted in *the child* feeling left out: *"She's often sad … she just couldn't manage to climb an stuff and got upset that the others could*" (Mother to four year old girl). In play with others the children described not quite fitting in: *"I wish I was well and could play again"* (four-year-old girl). The need to observe others interacting with each other was expressed, even if they could not participate themselves: "*She goes to the neighbor's house when she is feeling a bit down and needs company … she lies on their sofa and watches while the other children play*" (Mother to a four-year-old girl).

4.3.3. Feeling lonely

The children complained of feeling lonely and missing preschool, 18 months after diagnosis, when they were unable to attend. It was important for them that preschool personnel kept in touch: "*My teacher actually said she misses me*" (four-year-old girl). Despite a strong desire to take part in activities with other children, the children with cancer found that they did not quite fit in, when given the opportunity to be at school or preschool. Difficulties expressed included not feeling part of a peer group: "*They (teachers) say she has matured so much due to the illness … she's more advanced than the others in her group … it's hard for her*" (Father to a five-year-old girl). Difficulties were also expressed with the child's behavior such as with taking turns when playing with others: *"I'm the one who decides, and today don't want to play that game"* (four-

year-old girl).

4.3.4. Not the same as others

Eighteen months after diagnosis, the child post cancer treatment started to emerge with (re)-entry to preschool/school and other social activities. Children expressed a strong desire to play but experienced feeling different from other children: "*They play chasing but my legs get tired"* (Five-year-old girl). A different sort of play was described when difficulties with personal interactions with others and socially inappropriate behavior was seen as many of the children finished active treatment and began to interact more with peers and preschool personnel:*"She tries so hard, too hard, to be just like everyone else, you know? Not that girl who has cancer" (Father to a six-year-old girl)*. The difficulties described at this time related to the treatment's negative affect on everyday activities such as feeling left out of the peer group: *"(My friends) go to swimming classes … I want to swim too"* (five year-old-girl).

4.3.5. Learning to be a social being

Three years after diagnosis, most children lived their lives as social beings with focus on friends and school: *"I go to football after school … and I go swimming too*" (six-year-old boy). The ability to play with other children was a sign to them that they were like other children: "*I have a best friend now*" (six-year-old girl). Parents expressed the child's fear of losing play time which resulted in the child playing as intensively as possible when they had the opportunity: *"She never wants to stop the game, even when the others have had enough*" (Mother to a six –year-old-girl). Difficulties in emotional functioning, such as the child's socially in-appropriate behavior, were described by parents at this time: *"Starting school has been difficult, she's very social but you become aware that there are many, many social codes that she has missed out on"* (Father to a six-year-old girl). Continued contact with preschool services was very important for children who did not attend regularly: *"She was very, very sad to discover that they forgot to invite her to the pre-school summer party*" (Mother to a three-year-old girl).

5. Discussion

5.1. Methodological discussion

Throughout the study different steps were considered to enhance the studies trustworthiness (Lincoln and Guba, 2007). To strengthen credibility the researcher tried to build a rapport with the participants (Lincoln and Guba, 2007). This is a longitudinal study where the researcher met the participants at five time-points over a tree year period. One benefit with a longitudinal study is that the rapport between the researcher and the participant develops over time (Sterling and Peterson, 2005). Participation by some of the children aged three years and over was sporadic, particularly at the beginning of the cancer trajectory, as they were very ill. When the interviewer met the child for the first time a bag with toys and children books were brought to the child. The child remembered this and looked forward to the researcher coming again as they thought the bag was so fun. This contributed to rapport building with the researcher. A progression in the children's ability to answer questions was seen at sequential interviews, as they felt better, matured cognitively and developed their ability to express themselves. Thomson and Holland (2003) found that interviewing children in longitudinal studies had an impact on them and their answers. For example, they found that in their second interview the children knew what was going to happen and they were more forthcoming in their answers. In this study we could see the data collection most likely benefited from the younger children being interviewed several times, as they learned how to talk about what was in focus in the interview. Children with health difficulties grow up and mature quickly which may influence their understanding in spite of their age. Young children can have a limited communicative capacity in relation to healthy peers but be very competent in many other ways, related to their experiences of their disease (Kortesluoma et al., 2003). We experienced that interviews grew deeper and richer towards the end of the study. The researcher also became more skilled at meeting the child over time and children's responses can have been influenced as her interviewing skills became more honed. In fact, the interviews could be seen as an intervention both for the child and parent. Thomson and Holland (2003) described that interviewing children in a longitudinal study could help them to express and resolve emotions but also to clarity feelings and ideas and that they were involved in a process of change. They also found the interviews to be longer over time which is also something experienced in this study. It was impossible to separate parents from children and play from interviews, requiring the researcher to be flexible and follow the children's leads during the whole interview process. Parents were present during most child-led interviews, as the child wished. Parents sometimes prompted child responses such as "do you remember when you said …" The availability of parents made children secure and able to express their needs and experiences, in accordance with Bowlby (2008).

The findings have been discussed among the research group, with pediatric oncology nurses as well as with parents to children with cancer. They all thought the findings were sensitive and plausible.

To strengthen dependability (Lincoln and Guba, 2007) the researcher discussed pre-understandings about the phenomenon that is studied in order to see the phenomenon from the child's perspective. Researchers with different backgrounds read the interviews and familiarized themselves with the data. Thereafter, discussions regarding the analysis took place and interpretations were compared and discussed within the research team. To strengthen the confirmability (Lincoln and Guba, 2007) the analysis process is described as clear as possible and quotations from different children and different data collection time points are described in the results. Lastly, to strengthen transferability (Lincoln and Guba, 2007) the context and the participants are described as clearly as we could. The transferability of the findings in this study may be limited to young children with cancer in Sweden, as the majority of young children attend preschool services. However, it is plausible to believe that findings would be similar if a similar group in a similar context were studied in the same way (Lincoln and Guba, 2007). The findings may also be applicable to other groups of young children with long term illness who experience limitations in everyday functioning.

5.2. Discussion of the findings

The overall results of this longitudinal study reveal three particular categories describing the progress of experiences of young children with cancer over the three year study period; I want to be a child like any other, I need security and control and I feel lonely and left out.

5.2.1. I want to be a child like any other

This study highlights children's experiences of unfamiliarity in their new role as a child with cancer. They describe themselves as feeling like a stranger in their bodies and in the situation. Parents describe children as unfamiliar to them. Awareness of bodily changes and these changes in relation to others came to the fore, while longing for a return to or acquirement of a new normality. The time from 18 months and onwards after diagnosis and start of treatment marked a new period of stability and self-recognition in the everyday lives of children finished with treatment. Many adjustments to everyday life ensue and the child returns to a more ordinary everyday life, without cancer. However, children continued to express difficulties in personal interaction with others due to inappropriate social skills. Difficulties with personal interaction with peers and others occur when treatment has finished and the child returns to an ordinary everyday life (Darcy et al., 2016). The child is described as different from the other children and has difficulty with the social rules, despite wanting to fit it. The lack of some social

skills for children returning to a life without cancer has received attention in the literature (Björk et al., 2009; Hildenbrand et al., 2011; Woodgate, 2006). The negative effects of cessation of treatment are well documented yet few effective interventions are described (Soanes et al., 2009). Completion of treatment is seen only as a partial recovery and symptoms occurring after completion of treatment are extremely stressful for families (Björk et al., 2009; Ringnér et al., 2011). Labay et al. (2004) point out that completion of cancer treatment is another period of crisis for family, as they adjust to the "new normal". Returning to an ordinary life, without cancer, is not the same "normality" as before (Björk et al., 2009; Hildenbrand et al., 2011) but rather a process of reintegration. The need for support is still paramount, even after treatment is completed (Gibson et al., 2005; Woodgate, 2006). A structured follow-up beyond treatment and not just during treatment could help with children's attainment of the goal of health and well-being in everyday life, as propagated by UNCRC (1989).

5.2.2. I need security and control

The results of the study show that young children with cancer need their parents as protectors. At diagnosis and start of treatment health care professionals need to re-evaluate the newly diagnosed child's care routines so as to shift focus from the illness to the child (Darcy et al., 2014a). The trauma described by children and parents was partially due to the suddenly changed caring role parents' play. Parents help constrain the child and take part in painful and unpleasant procedures and treatments. Both children and parents in this study strongly expressed the need to have parents as a refuge – a place of safety and comfort they can retreat to. Bowlby's Attachment Theory describes the need for the young child to have a secure base or safe haven to turn to where the child can feel protected at times of trauma and uncertainty (Björk et al., 2006; Bowlby, 2008). The role of assistant to health care professionals, assumed by many parents in caring for young children with cancer, has been previously challenged (Kästel et al., 2011). Strategies for collaboration and role definition for parents and health care professionals need to be reassessed. This parental role changes over time as child and parent become more knowledgeable and proficient in care, but role definition is necessary at the traumatic start of their arduous journey and throughout their cancer trajectory. Family remains the safe harbor for the children also three years after diagnosis when most children were finished with treatment and regular follow-up.

This study highlights the fact that young children with cancer need to be included in their care, and that their participation and engagement in care changes over time. Children in the study started moving forward after the initial trauma and actively strived for an ordinary everyday life. Health care professionals have a major role to play in the process by giving and updating information, making children participatory in their care and assuring access to both parents and peers (Darcy et al., 2014b). This process of "getting used to it" (Björk et al., 2009; Stewart, 2003) and "keeping the spirit alive" (Woodgate and Degner, 2004) is highly influenced by health care professionals. The degree to which children with cancer can understand and make sense of their experiences of being ill might determine how well they adjust to the demands of cancer and its treatment (Bearison, 1991). To be engaged in one's own care and not just being present encourages children's involvement in life situations (Imms et al., 2017). A child-centered approach to caring requires knowledge of the specific child in the specific situation as well as their life condition and development (Coyne et al., 2016; Söderbäck et al., 2011).

Lack of access to and support from health care services are reported by parents. Psychosocial support should be strategically planned as part of a structured follow up to standard care. The current care strategy of families themselves making contact with psychosocial services as needed, beyond the treatment period, needs to be reassessed. Planned and structured psychosocial support beyond the initial trauma and treatment period could help the child and family through social crisis points along the transition. Experiences of psychosocial issues are a main research focus in Swedish paediatric oncology (Enskär et al., 2014, 2015). However, clinical implications from studies are diffuse suggesting that there is an urgent need to transform research results into clinical practice. The results of this study, which show the need young children have for proactive psychosocial support add weight to Enskär et al.'s argument for urgent implementation of research results in this area (Enskär et al., 2014, 2015).

5.2.3. I feel lonely and left out

That young children with cancer need contact with preschool and peers was a major result of the study A strong sense of loneliness and feeling isolated was a category that persisted throughout the study. At entry into illness children described missing preschool and their peers and the importance of being remembered while they were not present. The children revealed a goal of getting back to preschool. The attainment of health and well-being requires keeping meaningful relationships and contexts (Dahlberg and Segesten, 2010). Young children miss their everyday life while ill with cancer and have reported feeling left out (Hedström et al., 2003). Previous literature has shown that ongoing contact with preschool and opportunities to meet peers is vital for the child's strive to make the illness and treatment part of everyday life (Björk et al., 2006; Stewart, 2003). Previous studies have highlighted the need for informing preschool about the child's illness (af Sandeberg et al., 2010; Enskär and von Essen, 2008) and Swedish outreach nurses do this shortly after diagnosis and if requested by the family at (re)entry to preschool or school. However increased awareness in addition to this is necessary. Preschool awareness of the isolation felt when unable to attend, and the loneliness expressed when able to attend, could influence present preschool practices. It's not just about the child presence at preschool but encouraging child involvement in this important life situation (Imms et al., 2017). Practices could become more child-centered to allow for flexibility with attendance, increased opportunities for outside play and keeping in contact with and remembering the child, particularly at special events such as the child's birthday, Christmas celebrations or end of term activities. Participation restrictions can be addressed by addressing environmental barriers (Imms et al., 2017).

Our study clearly shows the need for young children to mix with peers – in Sweden this mainly occurs within preschool services. The Swedish National Education Agency (2018) states that children with cancer have the same right to education as healthy children and efforts should be made to ensure this. Preschool falls under the same law but there are no clear guidelines for the preschool child's contact with or attendance at preschool. Af Sandeberg et al. (2010) have shown the social benefits of school attendance or contact with school for older children with cancer. Those children who attended school felt better, experienced a higher quality of life and increased sense of independence (af Sandeberg et al., 2010). There is every reason to believe that younger children would enjoy the same benefits regarding preschool. Starting, or starting back to school or preschool can be difficult for all children and not just those with a long term illness. Integrating in to school environment and re-establishing peer relationships has been described as a difficult process (Labay et al., 2004). Professional care givers need to be aware of the importance of, and plan for, ongoing contact with school services, also beyond the treatment period.

6. Conclusions

The study's longitudinal design gave insight to previously unacknowledged experiences beyond the treatment phase. Insight was gained on young children's suffering shortly after diagnosis that has not previously been highlighted in the literature. Young children with cancer actively strive to understand their illness, participate in care and live an ordinary everyday life- but with ongoing feelings of social isolation and loneliness. As the post treatment child emerges and starts to reintegrate to a normal life, new challenges are revealed, related to

personal interactions with peers and support from health care services that are not always in phase with care needs. The results from this study reveal emerging issues that need to be addressed as young children learn to live an everyday life with cancer and the effects of treatment. It adds unique knowledge to current information on the young child's everyday life through their cancer trajectory.

6.1. Clinical implications

The findings from this study can deepen health care professional's present understanding of the everyday life of young children with cancer. Interdisciplinary collaboration between professional caregivers, health care and preschool services, with the child's needs in focus, is necessary. Clear guidelines to ensure young children with cancer have functioning social lives such as those available for school aged children, are required. Care practices and support strategies that aid health and functioning in everyday life, need to be developed, both during and beyond the treatment period. Psychosocial support needs to be planned for by health care professionals and not left to parents to plan or ask for. An information pathway is required, beyond treatment, to ensure access to health care services for families. Young children should be acknowledged as valuable contributors in their care process.

Conflicts of interest

We wish to notify that there's no financial/personal interest or belief that could affect our objectivity and potential conflicts do not or don't exist.

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