

‘The medicine is to get me better’: Findings on Pediatric Patients’

Responses to Play with Medical Equipment.

Dr Pam McGrath, Director, IPP-SHR & NHMRC Senior Research Fellow &

Ms Nicole Rawson- Huff

Contact: pam_mcgrath@bigpond.com

ABSTRACT

Children coping with a haematological malignancy have to deal with an extensive number of stressors including frequent hospitalization, repeated intrusive procedures, and the stress of treatment and side-effects from prolonged chemotherapy. This article presents findings from recent qualitative research that documents through an unstructured play-based interview, which incorporated the opportunity to play with medical equipment, the insights and understanding of pediatric haematology patients about their disease and its treatment. This information is compared to baseline information on similar play-based interviews with a control group of healthy pre-schoolers. Although limitations to the comparison are noted, the significantly different results highlights the important of play as a medium for providing insights as to the knowledge, and meaning both healthy and seriously ill children bring to their understanding of leukaemia and related disorders. In summary, the healthy cohort of children displayed very short-lived, naïve, uninformed, joyous encounters in playing with medical equipment, whilst the children with haematological malignancies demonstrated either intense and extended play or complete avoidance (aversion) accompanied by a detailed and quite sophisticated knowledge base and understanding of both the disease and its treatment.

Keywords: Haematology; Pediatrics; Play; Psycho-social Oncology.

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INTRODUCTION

In recent years there have been exciting developments in the area of outcomes for treatments for pediatric haematology. For example, in the 1950s, a child diagnosed with acute lymphoblastic leukaemia (ALL) would be expected to die in just over a year, whilst today sixty to eighty percent of all newly diagnosed children are cured (Pui 2000; Rubnitz & Pui 1997). In fact, ALL has provided a landmark in cancer therapy as the first disseminated and otherwise lethal malignancy to be curable in the majority of patients (Greaves 1993; Keene 1999; Nygaard & Moe 1989).

Unfortunately, however, this benefit is gained at the cost of long, invasive and very arduous treatment protocols, which are perceived as being as problematic as the actual disease (Adams 1992). For example, a standard protocol for ALL extends over two to three years, and involves intensive chemotherapy treatments of remission induction, consolidation, and maintenance (Souhami & Tobias 1995; Keene 1999). Children coping with a haematological malignancy have to deal with an extensive number of stressors including frequent hospitalization, repeated intrusive procedures, and the stress of treatment and side-effects from prolonged chemotherapy (Keene 1999; Henderson *et al.* 1992; Hockenberry-Eaton *et al.* 1995; Woodgate & McClement 1998).

It is now understood that an important factor in caring for such pediatric patients is the assessment of the child’s understanding of the stresses associated with the disease and its treatment during hospitalisation (Ziegler & Prior 1994). Such work is still in

its infancy. Recent authors have highlighted the dearth of information available on the topic and call for more research to deepen our understanding not only of the children's experience, but also the language the children use to express their distress (Woodgate & McClement 1998).

One medium through which a child's reaction to the stress of treatment can be partially understood is through play (Abbott 1990). Play, considered the natural work of children, provides the child with the opportunity to explore and experiment, to express and cope with feelings, and to learn to adjust to new experiences (Abbott 1990). Most theorists now agree that play is an expression of the child's understanding of his or her world (LeVieux-Anglin & Sawyer 1993).

This article presents findings from qualitative research that documents through an unstructured play-based interview, which incorporated the opportunity to play with medical equipment, the insights and understanding of pediatric haematology patients about their disease and its treatment. This information is compared to baseline information (McGrath & Huff 2001), on similar play-based interviews with a control group of healthy pre-schoolers. Although there are limitations to the comparison, the significantly different results highlights the important of play as a medium for providing insights as to the knowledge, and meaning both healthy and seriously ill children bring to their understanding of leukaemia and related disorders. In summary, the healthy cohort of children displayed very short-lived, naïve, uninformed, joyous encounters in playing with medical equipment, whilst the children with haematological malignancies demonstrated either intense and extended play or

complete avoidance (aversion) accompanied by a detailed and quite sophisticated knowledge base and understanding of both the disease and its treatment.

THE RESEARCH

The material in this article has been gathered as an extension of the first stage of a longitudinal Australian study that looks at the psycho-social issues associated with the treatment of pediatric Acute Lymphoblastic Leukaemia (ALL) and associated haematological disorders. The Royal Children's Hospital Foundation and the Financial Markets Foundation for Children have jointly funded the study. The study, conducted in association with research clinicians from the Haematology and Oncology Unit of the Royal Children's Hospital (RCH), Brisbane, and the Mater Children's Hospital (MCH), Brisbane, is an exploration of the experience of treatment for pediatric ALL and related haematological disorders from the perspective of the child, their parents and well siblings.

Ethical consent to conduct the study was obtained from the CQUniversity Ethics Committee, and the RCH and MCH ethics committee. Written consent was obtained from the parent for their child's participation in the research.

Target Population

The research accrued consecutive patients, aged from birth to sixteen years, who have been diagnosed with ALL and related disorders enrolled at the Banksia Ward at the RCH and Ward 3 at the MCH. During the initial stage of treatment the parents and

siblings of these children were approached with regards to participation in the research. Of the initial thirteen families approached during the first year, only one declined giving a response rate of ninety-two percent (n=12; 92.3%).

Play Interviews

The interviews were conducted by a Child Life Specialist, trained at Johns Hopkins Hospital, who had many years of experience working with both healthy and hospitalized children.

A number of strategies were used to build rapport with the children including providing the opportunity for the children to draw and offering the children a range of toys to play with as they choose. During the free play session the children were provided with a set of toys which were developmentally appropriate for each age group, as well as variety of play medical equipment (bandaids, chemo glasses, swabs, IV bag and tubing, gloves, bandages, syringes, arm board, wipes, blood collection tube). For the older children cards and board games were also used. Free choice was important to monitor the level of interest the child displayed in the medical equipment over the other toys or activities. Throughout the interview the Child Life Specialists engaged the children in open-ended conversation, using questions to elaborate on the issues that the children raised. The sessions were audio-taped, and the time spent in medical play was recorded by the Child Life Specialist with an unobtrusive but identifiable sound during the play session.

Data Entry and Analysis

The interviews were transcribed verbatim. The language texts were imported into the QSR NUD*IST 4 computer program (Qualitative Solutions Research, for Microsoft Windows) and analysed thematically. All of the children's statements were coded. The codes were then thematically organised into major headings and sub-headings. The time spent in medical play was calculated. The findings associated with the children's statements about their diagnosis and treatment, and time in medical play are presented here.

Demographics

The findings report on the interactions with nine (n=9) of the children during the first point of contact (T1; Induction Remission). The children range in ages from three to ten years. With the exception of two four year olds, there was one child representing every age group in this bracket. All of the children came from two parent families, with the parents' ages ranging from thirty-one years to forty-six years. With the exception of one child, all of the children had siblings (three siblings n=2; two siblings n=3; one sibling n=3). With the exception of one child who had Lymphoma, all of the children had ALL, and four of these were high risk. Four of the families do not have children represented in this study because of the young age of the child (infant or toddler).

Comparison with Previous Pre-school Study

The contact with these child patients was similar to that of a previous project (McGrath & Huff, 2001) which involved open-ended interviews during a play and art session with a number of healthy pre-school children to assess their understanding of leukaemia and medical equipment. The results that have emerged from interviewing the child patients with exposure to similar equipment and art material during similar open-ended interviews are starkly different in comparison to the earlier study. Thus, the pre-school study will be used as a reference point but it will not be argued that the present findings can be directly comparable or that it is even possible to repeat the conditions of pre-school study with the seriously ill and hospitalised children.

The limitations to the comparison include firstly, the ages of the children are different in both studies. Because of the small number of children diagnosed with a haematological disorder each year it would not be possible to replicate the numbers in any age group. However, it must be noted that the voices of the pre-schoolers in the second study are quite significant and hence increase the comparability. Secondly, the context and setting for the studies differ remarkably. It would not be possible to replicate the first study with the child patients. The first study was carried out with a group of healthy children, in a structured environment where their involvement in the play session was organised as a collective part of their day, and the expectation was that they need only focus on the designated play and art activity. Many of the child patients, however, were interviewed in the hospital where they were distracted by the distress of their condition, were unsure of the uninterrupted time that would be available, and were anxious about their treatment. In that setting the medical

treatment was the first priority. Some (n=3) who lived locally were interviewed at home which was more conducive to a play environment, although it was not a group setting and anxiety about treatment was pervasive. The children interviewed at the hospital had relocated for specialist treatment and hence were not able to be interviewed at home. Thirdly, unlike the pre-school group, a designated time could not be allocated to the child patients as the time available was determined by the demands of treatment or the hospital or home routine. It is a great privilege to include child patients in research and so in order to incorporate the voices of these children the research design was very flexible, rather than standardised, to be attentive to the child's needs.

Even with these limitations it is considered that the comparison between the findings from the two studies provides important insights and so forms the basis for the present discussion.

FINDINGS

Non-Medical Play

Unlike the healthy pre-schoolers who enthusiastically join in the activity, there was evidence of resistance from the child patients. One child was reluctant to join in and expressed a curiosity as to 'wondering why (the research assistant) was there'. Others asked the research assistant direct questions about her role such as 'Do you work in the Children's Hospital?' or 'But how come you have a (hospital) name tag?' or 'Are you a teacher?'

There was also more evidence of resistance to doing suggested activities. For example, when offered the opportunity to draw a picture one child (6 yrs) responded with 'Do I have to? I don't really want to'. Another responded, 'I can't draw' (9 yrs). For some the difficulty with drawing was physical, 'It's a bit tricky because of this here (points to Drip in hand)'.(8 yrs)

For those who did draw, the conversation during the drawing included discussions of colour, size of people, who will be included in the picture, what they will be wearing, and other subject matter for the picture (for example a horse), and choice of medium (for example markers or crayons).

There was laughter and questions about the toys, in particular the toys on the key chain. All of the children became involved in task oriented play such as reading books, playing card games, cutting and gluing, putting on stickers, stamps, making cards, and playing with finger puppets, blocks, puzzles or bricks. Much of the conversation was instructional (for example, how to use the glue) or informational (for example, discussions on dinosaurs).

All of the children demonstrated a curiosity about the tape recorder, asking direct questions about it such as 'Why do we need that?' or 'How do you know it is recording?' or 'Can I listen?' or 'How do you turn it off?'. The children experimented with turning it on and off and recording their voices, at times asking 'Can I have another listen?'

Medical Play

Unlike the healthy pre-schoolers who played joyously and for a very short time with the medical equipment, the child patients polarised into those who played for extended lengths of time and those who avoided medical play completely.

Some children obviously enjoyed the medical play, as can be seen by the following comments from a four year old, '(What is your favourite thing to do?) Play doctors (Play doctors?) Yep!', or 'I want to do this (Do you like to play with the medical equipment) Yeah!'.

The enthusiasm was reflected in the field notes of the Child Life Specialist, 'The child sees the box of medical equipment and immediately reaches for it to explore its contents. She is not exhibiting any signs of being tense. Just a strong sense of curiosity about the medical equipment, which leads to a forty minute medical play session' (4yr).

The realism and intensity of the play can be seen by the following list of action sequences from the transcripts of one child's play. This child (4 yrs) acting as the doctor pretended to do a blood test, put on the chemotherapy glasses, gave the doll a needle, pretended to take blood, bandaged the doll, gave the doll a drip wipe, applied sticky tape on the doll's arm, put in an IV and hang up the IV bag, gave another needle, pretended to cut the doll open to put the 'port-a-cath' in, applied sticky tape, then a bandage, pretends to flush the port, applies an alcohol wipe, pretends to draw blood with a syringe, and lastly, pretends to put blood in the sample container.

During the medical play the children could name all of the equipment. Examples

include;

- 'Drink cup like I have' (medicine cup) (3 yrs).
- 'Needles' (3 yrs).
- Glasses for putting in needles (chemotherapy glasses) (3yrs).
- 'That's a drip' (4yrs).

Children indicate that they are aware of the use for the equipment,

- Gives the doll a needle and puts bandaid on after the needle (3 yrs).
- Indicates that the medical name tag has to be put on by putting the loop through the holes because 'that's how it stays on' (3 yrs).
- Points to the IV tubing - 'the fluid goes through there and down there and through there' (3 yrs).
- 'And then you go like this. Yuck! (points to the blood vial). (What goes in there?) Wee" (3 yrs).
- 'and another glove (What are the gloves for?) giving needles' (4 yrs).
- (Before giving a doll a needle) we need a wipe on the arm' (4yrs).
- (Putting a bandage around a dolls arm) we need a board, a board, a board (then reaches for IV arm board) (4 yrs).
- 'Oh, you flush it (the port). Now we have to flush it. (What does it feel like when you flush it?) Cold' (4 yrs).
- 'I get needles in my arm and in the leg... because of the medicine' (4 yrs).
- 'I know how to open them (opens sealed bag with IV connectors in them)' (4 yrs).
- 'We need a little syringe (to take blood from a doll)' (4yrs).
- 'Oh, they put needles in there, they do (points to her port)' (4 yrs).
- '(referring to alcohol wipes) they hurt a little bit, don't they' (4yrs).

They not only spontaneously demonstrate appropriate actions with the equipment, but

also request direct and realistic involvement with the toy equipment, for example:

- pushes needles into objects (3yrs).
- puts on gloves (3 yrs).
- asks for bandaids to be put on - 'I need a bandaid, Where is a bandaid?' (3 yrs).
- Washes mouth out with mouth wash (3 yrs).
- 'Put it (arm board) on me'. (3 yrs).
- 'I need scissors to cut my bit off the bandage' (3 yrs).
- Wants plastic medical identification tag on (3 yrs).

When asked what the toys were for the common reply was 'Medicine'. A child on

seeing the medical equipment for play, states clearly, 'This is my hospital ones', and

point to the bag of medical equipment. The doll provided is assumed to be sick. When playing with needles, some children acted out giving the needle to the doll. Some indicated that they do not like needles and that it hurts, and they cry when they have the needle. There were protective actions towards the doll in relation to needles as can be seen by one child’s comment, 'Put the tape around there so the baby can't see it, so the baby can't see the needles'. Another child stated that children get needles 'because they are naughty' (3 yrs).

One pre-school patient (3 yrs) who engaged in protracted play with the medical equipment built a structure out of four needles, medical tape, name tag and medicine cup. The child who was interrupted was disappointed that she could not play with the medical equipment because she had to leave and asked if she can play with it next time. In the short time she had with the equipment she immediately wanted to 'put the doctor stuff on the doll'. The child was provided with the opportunity to play at a later time and at this point engaged in medical play for 45 minutes.

Participant Age	Time Spent in Medical Play
3 yrs	➤ 50 minutes
4 yrs	➤ 40 minutes
4 yrs	➤ nil
5 yrs	➤ nil
6 yrs	➤ nil
7 yrs	➤ nil
8 yrs	➤ (started to play and interrupted. Later 45 mins)
9 yrs	➤ Nil
10 yrs	➤ Nil

There were other children who had the exact opposite reaction and displayed signs of tension and a strong resistance to playing with the medical toys. An example of one child’s strong negative reaction to the display of medical equipment can be seen by

the notes from the research assistant which read, 'at the sight of the IV and medical equipment the child immediately starts pushing herself away from the medical equipment. She distances herself from it by about half a metre in a matter of seconds. When asked if she would like the equipment put away, the child answers a clear yes. The equipment was immediately put away' (4 yrs). Another, upon seeing the equipment demonstrates signs of tension (for example, clench fists, and tense high pitched voice and says 'I don't really want to' and pushes the bag with the equipment away from him with both hands (6 yrs). Another ignores the equipment and focuses on the hospital school's lap top (10 yrs). Some children noted that they do not like to talk about their treatment experience with statements such as, 'I don't want to talk about it' (6yrs).

Medical Knowledge

Diagnosis

Unlike the healthy pre-schools, the child patients all demonstrated knowledge of leukaemia and related disorders, as can be seen by comments such as,

- '(Talking whilst drawing) The purple guy is the bad stuff (Is it! Oh, where is the purple stuff?) It is in the bone. Yeah. (And the medicine gets rid of that?) Yeah, it goes, boom, boom, boom. And the yellow one kills the purple one (And then you get better?) Yeah' (4 yrs).
- '(So what is making you sick?) Leukaemia' (4 yrs).
- 'For my lymphoma. (What is a Lymphoma?) Well.... It's a cancer... It is in me and it makes me sick...It is in the bone' (5 yrs).
- 'Leukaemia...Like four types of it. I've got one that's like the best. It's better than the others. It's ALL, Acute Lymphoblastic Leukaemia....Well, its like you got cancer cells called lymphoblasts. They're white cells that are after -after they changed bad' (6 yrs).
- 'In your blood there's, um, not very good stuff that can kill you maybe (Oh really, and what is it called?) Leukaemia'. (7yrs)
- 'Well it's a cancer' (8 yrs).
- 'I knew I had some sort of blood disease... Yeah, my pediatrician said, um, you've got a blood disease' (10 yrs).

Side Effect of Treatment

The children displayed a sophisticated knowledge of the reasons for administering the drugs and their side effects.

The purpose of the medicine was clearly explained,

- '(You get better) from the medicine' (4 yrs).
- '(What does the medicine do?) Fixes it all up... and kills all those bad ones ...inside your body' (4 yrs).
- 'If I don't take it I'll be very, very sick' (7 yrs).
- '(The medicine) is to get me better' (8yrs).

The children were also aware of the reason for and use of tests,

- 'We don't have any signs of any lymphoblasts since the last stage of chemo'(6 yrs).

They made sophisticated statements about the reasons for medical interventions,

- 'She (the doll) has got to have a port in there because she doesn't like it (the needle) in there (the foot)' (4 yrs).
- '(Blood transfusions) it has jumping beans in it' (4 yrs).
- 'Oh, after I get the blood, I feel good after I had it' (5 yrs).
- 'I had a chest infection and stayed in for twelve nights. We eventually got one day release after that' (6yrs).
- 'This is the Emla cream. Um, well I'm gonna get needled up today'. (6yrs)
- 'The medicine makes my poo softer (Do you have problems going to the toilet?) Yeah' (7 yrs).
- 'If you don't take the milk and that mouthwash you can get ulcers and you have to come back here' (8 yrs).
- 'I have the Emla cream on ... Which is like magic cream. It takes some of the sting away. But it still, but it is scary and it still hurts a little bit, but it takes most of the sting away' (8 yrs).
- 'I am going to put this food back. I am not hungry. That's another thing with this chemo, it's making me not want to eat. Yeah, I was on prednisone. And that made me eat. But on this one I just don't eat' (9 yrs).
- 'That ones for me (hospital bracelets), my name, and that's for (drug). I'm not allergic to (drug) but I get a umm, reaction. It makes me go red, and it itches. They can give it to me but they have to be careful' (9 yrs).
- 'A blood clot. You don't know what a blood clot is? Well it can go to your heart and go to your brain and be very, very, very, very, bad. So if you have blood clots they can give me heparin. That thins my blood down' (9 yrs).

The children used many negative words to describe treatment such as 'yucky', or 'it hurts'. One child summed up his experience with treatment in three statements: 'bad luck', 'you can't stay at home all the time', and 'you have to have a lot of treatment'. Another spoke of the future off treatment, 'When I am much better I won't be bald, I'll have hair' (7 yrs).

Procedures and/or Protocol

The children also had a sophisticated knowledge of procedures and protocols,

- 'They put you to sleep with this gas... You just fall asleep in like ten seconds. Then they just do the chemo. Then after that I wake up' (6yrs).
- 'Blood, platelets. Platelets just go here. Salty water and blood, that's all... (When do you get them?) When your blood and that is low' (7 yrs).
- '(Get the medicine sleep) for getting a bone marrow test. And that is getting a needle in the back. And getting a bit of bone taken out' (7 yrs).
- 'She put the mask on me and it kinda like just goes over your nose like that. And the big machine here, with the big long things and all the buttons on it. And the big long tube which goes onto the thing to put all the gas in there' (7 yrs).
- '(Talking about the surgery for the portacath) (whispers) I think you have to get cut open a little. They sew it back up' (8 yrs).
- 'It is a cannula... It gets in the medicine'(8 yrs).
- 'The needle it under an anaesthetic. But they have always needled it when I've had a lumbar puncture' (9 yrs).
- 'I had L-Aspariginase. That one goes through the muscle'.(10 yrs)
- '(When first came down) I never knew I was going to be here for two years' (10 yrs).

Port-a-cath

The port-a-cath was a particularly important technology that most of the children mentioned and demonstrated that they understood its purpose,

- 'I've already got my port in- in here- (points to chest) Yeah, inside me... it's under my skin' (4 yrs).
- 'I've got my port in now... The needles in the hand hurt (So you like the port?) Yeah!' (4 yrs).
- 'Yeah, well that 's what the things and drugs, everything goes through' (7 yrs).
- 'And this big plastic bag goes (pause) and whenever you want the water to go down, it goes down here. And it goes all the way down, all the way down to here.

And that's where you get it. I'll show you (picks up the bag and demonstrates) (7 yrs).

- 'When I get the port-a-cath in I won't (get the needles in my arm). That helps me to have the needles because they put the needles into the port-a-cath' (8 yrs).
- 'Well it's a little round thing about that big. And its got a piece of metal, its metal or it can be plastic. And I think I've got a metal one. But its got rubber in the middle and what they do is put the needle in there. And that's like an IV thing. And they don't put it in my hand any more. They put it in my port-a-cath' (9 yrs).

Six of the children actively displayed their port-a-cath or drew attention to other physical evidence of medical intervention. Examples include:

- 'Look at what I had on there. All the blood went in there (points to a mark on his arm where he received an IV for platelet transfusion). The blood is gone now'.(3 yrs)
- 'I have had lots of blood tests (and points to the arm)'(3 yrs).
- 'I got a Mr Bump (pulls up shirt and points to port-a-cath)' (5 yrs).
- When asked what is a port-a-cath, pulls up shirt and points to it (6 yrs).
- 'It has a little tap on it (pulls up shirt and shows tap which is connect to her IV)' (7 yrs).

The children are able to critically assess the medical interventions. For example the children made comments about the preferability of a port-a-cath compared to having intravenous needles and the different locations of needles,

- 'It (port-a-cath) is better than the bandage thing (drip) because I had big problems with the bandage one with putting my shirt on' (5 yrs).
- 'It feels a little bit uncomfortable. But when you get used to it, it's all right' (7 yrs).
- 'When I didn't have my port, I had to have needles in my hand' (7yrs).
- 'The needles go in my leg. Well the ones I had in the first block hurt. Because the first ones were intramuscular' (10 yrs).

Coping strategies

Some of the children described their strategies for coping with the medical procedures,

- 'Sometimes I get a needle and I don't even scream very much' (4yrs).
- 'It feels a bit uncomfortable. But when you get used to it it's all right' (7 yrs).
- '(Handling the nausea) I keep myself amused. If I'm feeling yucky and I keep doing something. I love long stitch. It keeps my mind off it'(8 yrs).
- 'I don't cry when I have needles because I count..It doesn't hurt as much. I count and stuff. Count and read' (8 yrs).

Other research projects

Some of the children even spoke clearly about their understanding of research and their awareness that they were enrolled in studies, for example, 'Heparin thins my blood down. Yeah, so I'm in this study. They're got twenty kids and they give some of them heparin'(9 yrs).

Response to Picture 1 (Girl with IV drip)

When the situation allowed, that is there was time and the child seemed interested, some of the child patients were shown the same stimulus pictures as the healthy pre-school children. Unlike the healthy controls, even the pre-school child patients gave sophisticated answers,

- '(What has he got?) A drip'... 'I had some in here (points to port in chest and top of hand). Um, she's got a drip'... 'Like right here (points to his port)' (3 yrs).
- 'It's a robot (in excited voice). (Where do you get a robot?) I had some in here (points to chest with top of hand). A drip' (4yrs).
- 'She's go a drip, she's got a drip in... Yeah, a port-a-cath kind of thing'... 'Because it helps her get needles' (8 yrs).

The children also expressed feelings about their direct experience with the objects represented in the pictures. For example, in talking about the IV in the chest one child stated, '... And I got my port in now' (3 yrs). In relation to the IV in the hand, children made statements such as 'It hurts' (3 yrs).

Response to Picture 2 (Boy near an IV drip)

There was a similar reaction to the second picture,

- 'A drip'... 'He is sick at the doctors' (3 yrs).
- 'I don't know' (8yrs).

Response to Picture 3 (Child having gas mask for general anaesthetic)

Similar to the healthy pre-schoolers the third picture was perceived as indistinct and confused with a mother and baby,

- 'Um, baby got dummy... And it has a drip. It has a drip' (3 yrs).
- 'The mum feeding the baby, giving the baby a dummy' (3yrs).

When asked about the emotions of the child in the picture on four year old replied, ‘(Do you think they are happy, sad or mad?) Sad’ (4 yrs).

DISCUSSION

In many respects the findings from the interviews with the child patients were in direct contrast with the earlier findings with the healthy pre-schoolers. Whereas the healthy pre-schoolers had a very short-lived, naïve and joyous curiosity about the medical equipment, the child patients either played intensely for extended sessions or avoided the medical play completely. Whilst the healthy pre-schoolers had very little understanding of the use of the medical equipment, the child patients demonstrated a very sophisticated knowledge of the equipment and its use. Unlike the healthy pre-schoolers who resorted to imaginative constructs to help them explain the purpose of the medical equipment, the child patients used appropriate terminology and provided scientifically based thinking in their understanding of their diseases and treatments.

The child patients could name the equipment appropriately, were aware of its use and were able to mimic the health professionals through direct and realistic use of the equipment. The discussions about the equipment were accompanied by direct emotional descriptions of what it felt like to be involved with such equipment. Only one of the children (3 yrs) made reference to an emotional reason for being given needles (because ‘naughty’), but it is well documented that children of this age group

can view hospitalization and treatment as punishment (Ziegler & Prior 1994). In relation to their explanations about their diseases, even the young pre-school child patients provided sophisticated insights. This understanding extended to their knowledge of the treatment and its side effects, procedures and protocols, and the rationale for the use of different medical technologies.

As documented elsewhere, intrusiveness was a concern for the child patients as distinct from their healthy counterparts (Ritchie *et al.* 1984). Treatment was described in negative terms: there was not the joyous enthusiasm of healthy pre-schoolers.

Whereas the healthy pre-schooler enthusiastically participated in the play-based interview, the child patients exercised a worldly caution. Perhaps because such patients are used to dealing with a wide range of adults in the medical environment setting they were more questions about the researcher's role and the appropriateness of her involvement in the hospital setting. Direct information seeking as a coping behaviour has been documented elsewhere as a characteristic of a pre-schoolers response to hospitalisation (Abbott 1990).

Stressed by the seriousness of their condition, the invasiveness of treatment, and the demands of the hospital environment, the child patients did not demonstrate the initial naive joy of being involved in creative activities as the healthy pre-schoolers. The difficulty of creating the space for play in a hospital or medical environment is documented elsewhere (LeVieux-Anglin & Sawyer 1993). It is known that the hospital can leave the child "playless" and the sick child's reaction may be to withdraw into the self (LeVieux-Anglin & Sawyer 1993). Preliminary relationship

building was very important to establish rapport with the sick children. Once involved, however, much of the discussion and laughter during the activities paralleled that of their healthy counterpart. Indeed, therapeutic play is now known to be a valid means of reducing stressful responses to hospitalised children with serious illness (Zahr 1998).

CONCLUSION

Thus, it can be seen that there are important differences in how children who have been exposed to a serious medical drama and their healthy counterparts will approach medical play. The findings indicate that very different psychological and informational processes are influencing the behaviour of both groups during their exposure to play. It is hoped these insights will be helpful to others working in the important area of understanding the child's psycho-social adaptation to serious illness.

REFERENCES:

Abbott, K. (1990) Therapeutic use of play in the psychological preparation of preschool children undergoing cardiac surgery. *Issues in Comprehensive Pediatric Nursing*, **13**,265-277.

Adams, D. (1992) *Parents of children with cancer speak out: Problems, needs and sources of help*, Published Report, Candlelighters Childhood Cancer Foundation Canada, Toronto, Ontario, Canada.

Greaves, M. (1993) Stem cell origins of Leukaemia and curability. *British Journal of Cancer*, 67, 413-423.

Henderson, J., Goldacre, M., Fairweather, J. & Marcovitch, H. (1992) Conditions accounting for substantial time spent in hospital in children aged 1-14. *Archives of Disease in Childhood*, 67, 83-86.

Hockenberry-Eaton, M., Dilorio, M., Kemp, V. (1995) The relationship of illness longevity and relapse with self-perception, cancer stressors, anxiety, and coping strategies in children with cancer. *Journal of Pediatric Oncology Nursing*, 12, 71-79.

Keene, N. (1999) *Childhood Leukemia*. O'Reilly, Cambridge.

LeVieux-Anglin, L. & Sawyer, E. (1993) Incorporating play interventions into nursing care. *Pediatric Nursing*, 19, 5, 459-463.

McGrath, P. & Huff, N. (2001) 'What is it?': Findings on preschoolers' responses to play with medical equipment. *Child: Care, Health and Development*, 27, 1-12.

- Nygaard, R. & Moe, P. (1989) Outcome after cessation of therapy in childhood Leukaemia. a population-based Nordic study of 986 patients. *Acta Paediatrica Scandinavica*, Suppl 354, 1-24.
- Pui, C. (2000) Acute Lymphoblastic Leukaemia in children. *Current Opinion in Oncology*, 12,3-12.
- Ritchie, J., Caty, S. & Ellerton, M. (1984) Concerns of acutely ill, chronically ill, and healthy preschool children. *Research in Nursing and Health*, 7,265-274.
- Rubnitz, J. & Pui, C. (1997) Recent advances in the biology and treatment of childhood Acute Lymphoblastic Leukaemia. *Current Opinion in Haematology*, 4,233-241.
- Souhami, R. & Tobias, J. (1995) *Cancer and Its Management*, 2nd Edition, Blackwell Science, Cambridge, Massachusetts.
- Woodgate, R. & McClement, S. (1998) Symptom distress in children with cancer: The need to adopt a meaning-centered approach. *Journal of Pediatric Oncology Nursing*, 15, 1, 3-12.
- Zahr, L. (1998) Therapeutic play for hospitalized preschoolers in Lebanon. *Pediatric Nursing*, 23, 5, 449-454.
- Ziegler, D & Prior, M. (1994) Preparation for surgery and adjustment to hospitalization. *Nursing Clinics of North America*, 29, 655-669.