PRESCHOOLERS MAKING SENSE OF PROGRESSIVE ILLNESS: 
A REGGIO EMILIA INSPIRED STUDY

by

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Abstract

This qualitative study, inspired by the underlying pedagogy of the preschools in Reggio Emilia, Italy, expands on current limited research on young children’s understanding of their siblings’ progressive life-limiting illness. Two well siblings three-to-five year-old participated in a learning group with three other preschool children in five two-hour sessions. Sessions were co-constructed from the children’s understanding and recorded using digital video and audiotape, still photographs and the running record format. All of the children’s representations were collected. These records of the children’s learning formed the data for this study. The data was analyzed via microgenetic analysis of the children’s movement through all quadrants of the Vygotsky Space. The quadrants of the Vygotsky space are formed by overlaying two dimensions of space: public – private and social – individual. The first dimension public-private space is characterized by the degree to which cognitive activities are visible and therefore available for observation. The second dimension social – individual, reflects the degree to which the students use their own knowledge or the knowledge obtained from the group. Movement through the quadrants is recursive and at any one time a child’s cognitive functioning may be characterized as existing in one of these quadrants (Gavelek & Raphael, 1996). Microgenetic analysis is associated with the work of Vygotsky and allows for the systematic analysis of children’s learning. Microgenetic analysis allows one to focus on the process of change by examining the records of the children’s learning (digital-video and audio taped recordings; running records; still photographs; children’s representations) through densely spaced time intervals. It allows one to see where the learning begins and how the individual difference in knowledge affect the learning of the group. The results are presented in the form of pedagogical documentation, which is a tool that has its origins in the schools of Reggio Emilia. The young, well siblings, generally considered to be at risk for numerous psychosocial issues, demonstrated a sophisticated understanding of illness concepts, processes and equipment not previously identified within current literature. These findings suggest that young children’s understanding revolves around the illness process and as such has implications around content when developing support programs for the young, well sibling.
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Glossary

**Behavioural Record**: A series of drawings, representations, conversations or photographs or an edited piece of videotape that enables understanding of children’s pre-existing knowledge or learning process. A behavioural record can also be used to elicit children’s reflections on past activities in order to obtain clarification of their thinking and to promote additional learning. It provides tangible evidence of learning.

**Co-construction**: Each team member is seen as both a learner and as a teacher. Co-construction involves developing a shared understanding of a topic or a problem under investigation. A shared understanding is obtained by paraphrasing, explaining, reflecting and summarizing. Shared understanding enables the team members to work together. For young children to co-construct knowledge they need the right environment and a partner who can act as a provocateur (Fraser, 2000).

**Contagion**: Is identified as something that has a complex causal chain and can be transmitted between individuals (such as a cold).

**Contamination**: Is identified as a harmless object being negatively affected by contact with another object (such as falling down and scraping one’s knee).

**Design**: Any activities that make a record of the children’s ideas, thoughts or plans which are used to guide their ideas in the construction of something else.

**Discourse**: More than just talking to the children. Discourse involves the need to understand each other’s words on a deeper level. It involves a need for the teacher and the child to “listen” to what each other has to say and then to reflect on it.

**Documentation**: Any activity that renders a performance record with sufficient detail to help others understand the behaviour record. Thus, a single drawing by a child would not be considered documentation, but an edited videotape of a child creating a drawing or a set of redrawn portions to plot the development of the final drawing would be considered documentation. Documentation refers to two subjects: process and content. “Content” is the material that records what the children are saying and doing and “process” involves the use of that material in order to reflect on the work in a very rigorous, methodical way.

**Microgenetic Analysis**: Microgenetic analysis is associated with the work of Vygotsky and allows for the systematic analysis of children’s learning. Microgenetic analysis allows one to focus on the process of change by examining the material (digital-video and audio taped recordings; running records; still photographs) through densely spaced time intervals. It allows one to see where the learning begins and how the individual differences in knowledge affect the learning of the group.

**Performance Record**: A performance record can be an individual or a group drawing, a three dimensional representation, a photograph, videotaped recording of a given activity, or a written observation of an individual or group discussion or behaviour.
Piagetian Clinical Interview: The clinical interview involves three components: observation; the introduction of special questions and problems by the adult and the child's responses to those questions or problems. It is used to elicit children's spontaneous thinking.

Progressive life limiting illness: Is described as an illness that is progressive in nature and includes diseases that may be of congenital or environmental origin. Many life limiting illnesses involve increasing disability over a protracted period of time and include progressive degenerative diseases for which there is no cure such as muscular dystrophy, cystic fibrosis and central nervous system dysfunctions; congenital malformations that are not consistent with life, and malignant diseases and organ failures.

Reggio Emilia Approach to Education: This approach, which has developed over the past 30 years in the town of Reggio Emilia in Northern Italy, fosters children's intellectual development through a systematic focus on symbolic representation.

Revisiting: Enables children to go back or look at and listen to previous learning experiences. Revisiting encourages reflection and acts a provocation to re-think about a previous learning experience.

Zone of Proximal Development: “The distance between the child’s actual development as determined by independent problem solving and the level of potential development as determined under adult guidance or in collaboration with more capable peers” (Vygotsky, 1978, p.86).
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Dedication

This study is dedicated to the memory of Jolene Braun and her brother Evan who inspired all the work that surrounds this study.
Chapter 1

Introduction

Over the past several years I have had the opportunity to work in a hospice with children who have a progressive life limiting illness, and with their families. Working with siblings who have a brother or a sister with a chronic or progressive illness has allowed first-hand observation of what it is like to grow up with a sibling who is ill. From these observations I have come to understand the difficulties the well siblings experience and the effect this experience has on their developmental trajectory. Investigation of their plight in the academic literature supported my personal observations and illustrated the need for research. Williams (1997) informs us that because most children with a progressive illness live at home the impact of their illness on their sibling can be considerable. Houtzager, Grootenhuis and Last (1999) completed a review of 20 years of literature on sibling adjustment to childhood cancer and identified only 55 papers on this subject. They point out that each paper clearly indicated a need for research. Although my experiences in the hospice were not limited to children with cancer, the majority of the research on sibling adjustment to chronic illness deals with childhood cancer and therefore this literature serves as the base that informs this investigation.

Murray (1998, 2000, 2001) describes the growing need to understand the long-term developmental effects on young children that have a sibling with a chronic or progressive illness, and expresses a need for psychosocial supports for them. He cites observations of adjustment difficulties that include such things as overly good behaviour, role reversal, temper tantrums, difficulties with making relationships with others and feelings of abandonment, jealousy and guilt, as evidence of need. My own observations
in hospice support his findings. I noticed that it was not uncommon for the young, well child to be frequently passed around from one relative to another as if he or she were baggage. This did not appear to be intentional, but seemed to occur simply because the parents were overwhelmed by their experience of caring for a chronically ill child. I observed the young, well child caring for their sibling, and also caring for their parents. For example, they would take their parents things that they know they would like. It was not uncommon for a four or five-year-old child to ask for assistance with making tea or taking cookies to their parents or in making a picture for them because “it will help mommy or daddy feel better.”

Frequently, the young, well child was observed pushing their sibling around in their wheelchair, and helping with personal tasks such as dressing, washing and going to the bathroom. The well child would often act as interpreter, passing on the ill child’s needs and requests. They talked to the ill child like an adult, giving them instructions for tasks they need to complete. They frequently checked on their ill sibling to ensure that they were fine. To do this they would leave the room they were in, go up or downstairs to the nursing floor, walk into their brother or sister’s room, look at them or ask them if they need something and then return to where they were before. The well child was observed to be extremely kind to their ill sibling, frequently touching and kissing them and bringing them special things they knew they would like. These observations are also supported in the literature. Chesler, Allswede and Barbarin (1991) conducted 21 interviews of siblings, all of which identified the need to help take care of the ill brother or sister. They reported immense concern for the ill child and provided examples of a
range of behaviours, which included companionship, nurturing and other important services. Chesler et al. provide the following examples:

I try and read stories and stuff. I get him what he likes. Like when he had his biopsy, he wanted vanilla malt, so I got it for him. Little things like that, when you feel sick, make you feel better. I also play with him and get his school work. (p.28)

I was more careful around him. I used to take him home from school when he’d get sick in class. (p.28)

From my own observations it appeared that as the ill child moved towards end of life, the well sibling’s behaviour became more disorganized. Not only did they exhibit a lack of attention while at the in-hospice school, but they also had difficulties with dressing themselves – for example wearing odd socks and shoes and clothes that did not match. Completing tasks became difficult and they often needed adult help or guidance. Play sessions became shorter than one would expect from same aged peers. Tears were frequently observed. Some young children actively demanded their parents’ attention by clinging to them and wanting them to play with them. One little girl stated, “I shall be glad when (sibling’s name) is dead, because you will be able to play with me.” It was not uncommon to observe the role reversal and the disorganized behaviour described above both on the same day.

It was because of these observations that I began to investigate the type of supports that may be available for the young, well child, only to find that there were almost none. As previously discussed, a review of the current literature supported my observations and my conclusions about the well child’s needs, but provided little
guidance for the type of supports these children might need in order to help traverse this very difficult time. At this time only two support programs for well siblings have been identified within the literature, both of which were for school-age children, and as such provide no guidance for working with really young children. One program was offered at a hospice in Florida and met on a monthly basis (Orloff, 1998) and the other program was run out of a hospital in New York (Adams-Greenly, Shininski-Maher, McGowan & Meyers, 1987). The program in New York was completed as part of a study and consisted of a series of workshops aimed at providing the well sibling with information about the illness together with psychosocial support. Both of the programs offered help only to children from eight years of age and onwards, and as such provided no guidance in developing a support program for young children.

Due to my observations in hospice, the lack of available research on sibling adaptation to chronic or progressive life limiting illness, and limited supports within the healthcare community, I considered developing a support program for these young children, but was concerned about the form it should take and whether there was a need. Research into this question clarified this (Phillips, 2000). Both the parents and health care professionals who participated in this research confirmed the need. Many of the parents described the difficulties they had in comprehending their child’s illness and stressed that this was one of the reasons that they were finding it difficult to talk to their young, well child. Others cited as problematic the endless questions that are impossible to answer. The healthcare professionals also brought up language as an area of difficulty when communicating with young children. They stated that adults are able to go to the oncologist and say “I want to know about . . .”, “Tell me about . . .” They demand
attention and require information and therefore they get the response they require. As noted earlier, young children have difficulty verbalizing their needs and therefore they do not get the information they seek. This makes it difficult for them to make sense of what is happening and they feel left out and neglected because they are not part of the experience. These feelings lead to adjustment difficulties such as anger, depression, feelings of guilt, and social isolation (Chesler et al., 1991; Murray, 1998, 2000, 2001). Murray (2000) stated, “Healthy siblings are the most emotionally disregarded and distressed of all family members when serious childhood illnesses affect the family” (p.40). Clearly, all this evidence demonstrates a real need for some kind of psychosocial support for these young children. However, due to the lack of research on available programs we clearly do not have any idea of the form it should take, or of what their knowledge base is of this most difficult experience. Therefore the focus of this study was to investigate the young child’s conceptual understanding of their sibling’s progressive, life-limiting illness, by creating a model of investigation better suited to determine young children’s understanding than current approaches.

Rationale for This Study

Knowing when to provide young children with information and how to determine their level of understanding when provided with information has been historically difficult for everyone, but knowing when and how to do this during life’s difficult times becomes critical. Historically, families have chosen to share information with their young children only when and if the children had to know. This tendency has grown out of society’s beliefs about children and childhood, which encourage families to consider their young children as too little to understand, or better off not knowing the true facts of the
situation. These beliefs have led to the marginalization of young children’s voices during life’s difficult times (Zaslow & Takanishi, 1993).

This marginalization of young children’s accounts of what is happening to them is also noted in much of the current literature that focuses on the needs of the young, well child. However, most research that investigates these young children does so from a paternalistic point of view, choosing to interview significant adults in their lives about their needs, wants and problems, rather than the children themselves (Gabarino et al., 1992). This tendency to ignore children’s accounts of what is happening to them stems from the beliefs about children and childhood already described, and the consequential difficulties adults have in communicating with young children.

The typical method used to understand children’s ideas, needs and wants involve the use of a question and answer format, rather than interpretations of their play or their representations. The question and answer format is an adult form of inquiry (Yule, 1993) which children find difficult due to their limited communicative competence. Communicative competence involves not only understanding the rules of language usage, but also the social and cultural rules which surround it (Gabarino, Stott & Faculty of the Erikson Institute, 1992). This tendency to bypass collecting descriptive data that actually reflect children’s voices can lead to a flawed understanding of what is happening in their lives and, consequently, ineffective interventions should they be needed (Zaslow & Takanishi, 1993).

Therefore, this investigation, by providing young children with an opportunity to demonstrate their understanding of their siblings’ illness in a developmentally appropriate manner, provided a forum for their voices, enabling them to ask some of the difficult
questions they had about what is happening to them and their family.

**Research Objectives**

The main objective of this study was to determine young children’s (3-6 years) conceptual understanding of their siblings’ progressive illness. Historically, the process of determining young children’s understanding has been to either use parents or other significant adults in children’s lives as informants, rather than the children themselves (Guite, Lobato, Kao, & Plante, 2004), or require that the children provide information based on the question and answer format (Garbarino et al., 1992). Most contemporary methods of investigating children’s understanding of illness concepts utilize some variation of Bibace and Walsh’s (1980) Concepts of Illness Protocol (Bibace & Walsh, 1980; Burbach & Peterson, 1986; Kalish, 1996a; Perrin & Gerrity, 1981; Perrin, Sayer & Willett, 1991; Potter & Roberts, 1984; Williams & Binnie, 2002). This protocol is in the form of a semi-structured interview, and utilizes a Piagetian framework to analyze obtained results in order to determine children’s developmental level of understanding. However, as already identified, this format of obtaining information is not suitable for young children because it uses the question and answer technique. Consequently, in order to meet the research objectives of this investigation, it was decided to use a new methodology that grew out of the ideas that are espoused by the educators in the preschools of Reggio Emilia, Italy.

The educators in the schools of Reggio Emilia believe in the rich, competent child - one who is capable of making sense of the world (G. Dahlberg, personal communication, July 2005). They see this child as buried in a system of relationships, which includes parents, teachers and other children. They describe the child as having
many languages and therefore understand that children have many ways of demonstrating what they know. Consequently, the educators provide complex learning environments that are rich with materials that enable children to use their many languages to demonstrate their knowledge. Documentation is a cornerstone of their practice as teachers because of their belief in its ability, through reflective practice, to make children’s learning visible. Documentation of the children’s learning includes photographs of their activities, transcriptions of their remarks, representations of their ideas and a reflective dialogue that is obtained through the re-examination and co-construction of learning experiences with the children and other teachers. Project work is thought to be an important part of the children’s learning experiences. The ideas for the projects come from the child; are thought to grow out of the child’s lived experiences, and may last from several days to many months. Documentation and project work, along with ideas within the relevant literature on siblings of children with a progressive life-limiting illness and children’s understanding of illness, informed the research objective. These research foundations are reviewed in the following chapter.
Chapter II

Review of the Related Literature

Effects of Progressive Illness on the Well Sibling

The diagnosis and treatment of children with a progressive, life-limiting illness has a devastating effect on all the members of a family. The parents’ initial shock and disbelief is replaced by a sense of loss for the child they thought they had, and fear of the unknown. Nieto (1997) defines this as anticipatory grief and states that it refers to “the emotional reaction that occurs before the expected loss” (p. 26). Family life is changed after the diagnosis and never returns to normal. Well siblings have been shown to be “at-risk” for a number of emotional and behavioral problems. Significant internalizing problems such as emotional and social withdrawal, anxiety, feelings of intense sadness and loss, guilt and shame, or externalizing problems such as noncompliance, anger and acting out have been reported in numerous studies (Adams-Greenly et al., 1987; Barrera, Chung, Greenberg & Fleming, 2002; Cairns, Clark, Lansky & Smith, 1979; Chesler et al., 1991; Fanos & Wiener, 1994; Houtzager, Grootenhuis, & Last, 1999; Murray, 1998, 2000, 2001; Shapiro & Brack, 1994). Houtzager et al. (1999) stress,

The experience of a life threatening disease poses a potential challenge to the balance within the family system. Diagnosis, treatment, possible remission and relapse, plus extensive side-effects of treatment, repeated hospitalizations and hospital visits represent disruptions for all family members. (p.302).

Murray (2001) highlights that even though childhood cancer is one of the leading causes of death in childhood, many pediatric malignancies are now perceived as chronic illnesses, and as such, families need to learn to build the repeated hospitalizations into
their everyday life. This causes enormous stress on all the members of the family. Fanos and Wiener (1994) describe the loss of the daily routines for the healthy child as one of these stresses. They state that the daily routines for the healthy child or children no longer exist and that it is often difficult for them to attend school or have friends to their house to play. Sloper (2000) interviewed 92 siblings of children with cancer. One of the main themes expressed by these siblings was multiple losses - loss of routine, loss of their family, loss of time to spend with friends, loss of attention and loss of certainty and security for the future. Sloper provides a number of examples:

*Loss of routine:* “I don’t go out much because I stay in with Guy, because he’s got no-one to play with.” (Younger brother, age 9) (p.302)

*Loss of attention:* “In some ways I feel left out, but I suppose it is not important because I do not have an illness. I haven’t got any problems but John has got an illness. I don’t really mind . . . They do more things for John . . . Sometimes I feel unhappy.” (Older brother, age 10) (p.301)

*Loss of certainty:* “The fact that this sort of thing can happen to anyone, especially one of us . . . The slightest headache . . . I tend to be a hypochondriac. It makes you wonder. If I got a headache before it never crossed my mind that’s what it could be.” (Older sister, age 16) (p.302)

Difficulty with attention to task, feelings of jealousy, and worries about health are themes noted in the literature on the siblings of children with cancer. The well siblings frequently state that they find it difficult to concentrate at school because of concerns about their sibling’s illness, and worrying about their parents (Fanos & Wiener, 1994). They describe the appearance of feelings of jealousy as the ill child becomes showered
with gifts and attention from everyone. It is noted that it is not uncommon for the healthy child to pretend to be ill or to develop similar symptoms to those displayed by the ill child, in order to seek attention. Their own health becomes the focus of their attention, and they worry that they will get sick too (Murray, 1998). Murray describes one sibling’s feelings, “I began to feel hatred for my sister. I often thought if I got sick, maybe I too would receive presents and sympathy” (p. 217).

Healthy siblings are frequently described as being often overly good, not wanting to cause any problems for their parents (Adams-Greenly et al., 1987; Barrera, Chung, Greenberg & Fleming, 2002; Cairns et al., 1979; Chesler et al., 1991; Fanos & Wiener, 1994). Role reversal is noted to be common, especially when the healthy sibling is female. The healthy sibling takes on the parental role, acting as “caregiver” to both their parents and their ill sibling (Sloper, 2000).

Long term emotional, behavioural, physical and psychosocial problems were identified in the research and this was noted to be especially so with the youngest children (Adams-Greenly et al., 1987; Cairns et al., 1979; Chesler et al., 1991; Fanos & Wiener, 1994; Houtzager et al., 1999; Houtzager, Grootenhuis, Hoekstra-Weebers, Caron & Last, 2003; Murray, 1998, 2000, 2001; Shapiro & Brack, 1994). In a study of 75 adults who had lost a sibling during their childhood the following long-term effects were noted:

- Global sense of guilt;
- Guilt over their relationship with the sibling and the way in which they had handled the death;
- Survival guilt, with some discomfort when they reached the age at which the sibling had died;
• Global anxiety;
• Hypochondriacal concerns or fears of an early death for themselves;
• Fear of intimacy, related to going through the loss of another loved one;
• Excessive concern for others;
• Somatic expressions, including headaches, ulcers or identification illnesses that mirror the symptoms of their sibling’s illness;
• Sleeping difficulties, including severe and persistent nightmares (Fanos & Wiener, 1994, p.44).

These same long-term effects were noted by Cunningham, Betsa and Gross (1987) and Terzo (1999). Sahler et. al. (1994) estimated that 63% of siblings of children with cancer displayed coping difficulties. These included physical symptoms such as headaches and abdominal pain, and psychosocial issues such as poor school performance, school phobia, depression and severe separation anxiety. Terzo reported siblings indicating behavioural and physiological changes, which included mood swings, sadness, agitation, headaches, stomach aches, irritability, aggressiveness and attention seeking behaviours. Cunningham et al. concluded that children between the ages of three and six years were at the highest risk for adjustment difficulties.

Havermans and Eiser (1994) interviewed 21 healthy siblings and asked them to describe their worst experience during their sibling’s illness. These children disclosed that seeing their sick sibling was the worst experience for them. They expressed that they were not prepared for the changes in the appearance of their sibling and were most distressed when they saw them in pain. “We were told what to expect, but it was still a shock when we saw him attached to all those machines.” (Johnson, 2002, p.459) Sourkes
(1987) supports this position. She divulged that young children have great difficulty with
the visibility of the illness and the treatment process. She explains that an illness that
has a visible focus, such as an amputation, is easier for young children to understand
than, for example, leukaemia, which is effectively invisible until treatment protocol is
initiated. Sourkes reminds us that young children may not understand the word
“treatment” and not realise that it is the treatment that is helping their sibling become
well again. This is because the treatment in reality can often be extremely invasive and
painful, which is seen as negative rather than positive by the young, well sibling. Sourkes
also discusses the difficulties young children have with understanding that their sibling is
the same person, because of their sibling’s altered appearance. She states that they have
to “co-ordinate the concepts of constancy and change, sameness and difference. They
must learn that it is the same person who looks different or that despite constancy in
appearance, inner change is making their sibling ill” (p. 167). Young children’s
difficulties with the appearance/reality distinction have been noted by a number of
researchers (Flavell, Green, & Flavell, 1986; Garbarino et al., 1992) and it appears to be
one of the major obstacles that limits young children’s adaptation to their changing
circumstances within the family. Not only do they have difficulty understanding their
sibling’s illness and the changes that are occurring to them, but they also have difficulty
understanding why everyone around is lavishing so much attention on their ill brother or
sister.

Programmatic Support for the Well Sibling

Even though there is much discussion in the literature about the positive and
negative effects of having a sibling with a chronic or progressive life limiting illness,
little direction is provided about what would be appropriate supports for young children. Only two ongoing programs were identified for children who have a sibling with a progressive, life-limiting illness - the Sibling Support Project and the Sibling Center at the California Pacific Medical Center, San Francisco - and both are for individuals of school-age children and older.

The Sibling Support Project is an international support program for adults and children who have siblings with special healthcare needs, developmental disabilities and mental health care concerns. The Sibling Support Project offers regular workshops at a number of hospitals internationally. These are called Sibshops. Sibshops offer well siblings the opportunity to participate in a variety of games and activities with other children who have similar life experiences. The Sibling Support Project also hosts a list serve for siblings call Sibkids. This enables well siblings to connect with other well siblings across the web (Sibling Support Project, 2007).

The Sibling Center offers a program that utilizes a counselling format where an individual child meets with a counsellor to discuss their emotional needs and any communication difficulties they may be having with their families and it occurs over a series of four sessions. The first session involves an interview with the child and their parents to determine evaluation and treatment. In the second and third sessions the child attends alone and the focus is on communication difficulties, alleviation of stress and increasing coping skills. The fourth session is divided into two halves. The first half involves the child and therapist only, and the second half involves both the parents and the child together. In this second half of this final session the therapist reviews what has happened and discusses future plans. A follow up session occurs approximately six
months after the last session to determine the emotional needs of the child. At this time should it be determined that extra support is needed, a referral is made to another therapist (Fanos, Fahrner, Jelveh, King & Tejeda, 2005).

Additionally, there are also a number of ongoing support programs and camps for children who have a sibling or a parent with cancer, provided by the Canadian Cancer Society (2007), however they too are for school-age children. Like Sibshops, these support meetings and camps provide well siblings the opportunity to participate in a variety of games, and activities with other children who have similar life experiences.

**Support Programs Identified Within the Literature.**

Cunningham et al. (1987), Adams-Greenly et al. (1987) and Barrera et al. (2002) all created very similar support programs for siblings of children who had cancer. The age range of the children who participated in these studies was from 6 to 17 years old, which limits the ability to extrapolate the findings to younger children. Participants in all three programs were required to have siblings who had cancer and were in the treatment phase at the beginning of the support program. The time period of the Cunningham et al. study was one and a half hours per week over a five-week period; the Adams-Greenly et al. study was 18 months in duration with an initial meeting followed by meetings every six months, making four meetings in total; and the Barrera et al. study consisted of eight weekly sessions of two hours each. All the studies identified that they had contacted the participating families following the conclusion of the study to ascertain the effectiveness of the intervention. The time frame for contacting the families in each of the studies varied.

All the studies included a multidisciplinary team of healthcare professionals and
utilized a format that included educational and psychological concepts. In the
Cunningham et al. (1987) study, the first four sessions involved visits to various parts of
the hospital that were involved with cancer treatment. During these sessions the children
were prompted to ask questions about these areas and how the procedures that occurred
there related to their sibling’s treatment. The final session was a general discussion aimed
at finding out what the children had learned about their sibling’s illness and cancer
treatment in general, and whether there were any other questions they still wished to ask.
During each of these meetings the children’s parents met with two of the healthcare staff
and were able to ask their own questions about their child’s treatment and the sibling
support group.

Adams-Greenly et al. (1987) gave their support group for siblings a name. They
called it the Specially Important Brothers and Sisters group, or SIBS for short. On
entering the program all the children received a T-shirt with SIBS written across the
front. Each child was told that they were very special and encouraged to wear the T-shirt
to each session. During the first session the children were encouraged to draw pictures,
play games, talk with the staff and the other children, and experiment with the medical
equipment brought in for investigation, under the supervision of a nurse. The remaining
three sessions were divided into educational and support sessions. The educational
sessions provided the children with information about cancer and its treatment. The
facilitators tried actively to draw out the children’s own thoughts and demonstrated facts
by using slides or by writing on a chalkboard. The children were also taken on a tour of
the parts of the hospital that they may have experienced with their sibling. In the support
segment the children were allowed to play and talk with one another in order to develop
rapport so that they would feel more comfortable about sharing their feelings. During the discussion session the social worker focused on drawing out the children’s experiences and then finding constructive ways of dealing with those feelings.

Barrera et al. (2002) focused their sessions on predetermined themes that arose from the previous sessions. The first session focused around learning to work as a group and the creation of rules for participation and interaction. The second session provided medical information related to cancer and its treatment, and sessions three through six addressed psychosocial issues. Session seven addressed the children’s hopes and dreams and session eight was a wrap-up and graduation. Each session opened with a fun activity, followed by an activity that set the stage for the theme of the evening. This normally included the sharing of homework from the previous session in order to consolidate the learning from the previous session.

Although the Adams-Greenly et al. (1987) study provides more age-appropriate intervention strategies for young children than the either the Barrera et al. (2002) and the Cunningham et al. study, it was still targeted at school-age children, requiring the children to be able to understand and utilize the question and answer technique, as well as the ability to share feelings.

**Noted Positive Effects**

Positive effects on the well sibling’s ability to cope were noted in both the Adams-Greenly et al. (1987) and the Cunningham et al. (1987) studies in the one month follow up questionnaires. The parents in both groups identified an increase in the well sibling’s knowledge about the illness. The children seemed to be more comfortable in the hospital environment and more able to discuss their sibling’s illness with their parents.
Many of the adjustment difficulties noted prior to the study such as feelings of anger, guilt, and resentment seemed to have diminished. Barrera et al. (2002) also identified that following the end of the eight-week intervention the siblings reported a reduction in the symptoms of anxiety and depression, behaviour problems and fear related to cancer on self-report measures. However, the parent reports only identified improvement in cancer related knowledge. In discussing this discrepancy Barrera et al. suggest that parents may have difficulty in assessing their child’s anxiety and depression levels.

Whether the positive effects noted in all the studies continued is difficult to determine, as no follow-up studies were published. In fact, within the literature base on sibling adjustment to cancer, studies specifically addressing long-term follow-up of any kind are sadly lacking.

Within the current literature on siblings who have a brother or sister with cancer, positive adjustment was noted when the well sibling was provided with age-appropriate verbal explanations: had realistic expectations about what happens in a hospital: was able to look at pictures and experiment with specialized equipment: had open communication with their parents regarding their sibling’s illness; and was included in visits to the hospital. When one compares these noted positive effects with the content and direction of the support programs discussed above, it is evident that many items known to be linked to positive adjustment in the well siblings were included in those programs.

All of the programs provided the siblings with opportunities to visit the hospital, where they were allowed to explore the treatment rooms and ask questions about the medical equipment and procedures that occurred there. Adams-Greenly et al. (1987) provided examples of the type of questions young children ask, “Why do we have to
cover our hair?”, “What do you do with a person’s leg when you cut it off?” (p. 60). These questions demonstrate the thinking that is occurring in the minds of young children. Hergenrather and Rabinowitz (1991) provide support for these examples of young children’s questions by reminding us that young children focus more on explicit features of an illness than implicit ones. All programs provided opportunities for the siblings to verbalize their feelings about their sibling’s illness in constructive ways. The healthcare professionals in each program ensured that the children felt comfortable with each other, so that they would feel safe in sharing their feelings. Adams-Greenly et al. helped the children feel special and identify with others who had similar life circumstances by providing them all with the same T-shirt. This T-shirt would have helped them feel as if they were part of a group and allowed them to understand that they were not alone.

**Parent Involvement**

Even though within the literature bases on sibling adjustment to cancer and intervention with children, parent involvement was cited as important (Adams-Greenly et al., 1987; Cairns et al., 1979; Chesler et al., 1991; Dadds, Spence, Holland, Barrett & Laurens, 1997; Fanos & Wiener, 1994; Houtzager et al., 1999; Murray, 1998, 2000, 2001; Shapiro & Brack, 1994; Meisels & Shonkoff, 2000), only Cunningham et al. (1987) provided opportunities for the parents to meet to discuss their concerns while their well child was participating in the support program. Phillips (2000) concluded that parent participation in a support program was a key component. In this study the parents expressed a need to meet with other parents and to observe other children who were having similar life experiences to determine whether their children’s “behaviours” were
typical for young children experiencing difficult life circumstances. None of the studies provided opportunities for parents to observe other children who were experiencing similar life events.

_Adjustment Difficulties_

Unfortunately, for most siblings, the types of supports that have been described as providing positive outcomes are not available. Consequently, most children do not traverse their sibling’s illness without demonstrating moderate to severe adjustment difficulties (Houtzager, et al., 1999; Murray 1998, 2000, 2001). Birenbaum, Robinson, Phillips, Stewart and McCown (1989), using the Child Behavior Checklist (CBCL, Achenbach, 1983), interviewed parents and teachers who were working with a well sibling of an ill child, and noted significant adjustment problems on the Internalizing Behaviour Problems Sub-scale. The Internalizing Scale contains behaviours indicative of somatic complaints, depression, social withdrawal, obsession, anxiety, immaturity, obsessive compulsion and uncommunicativeness. All of these behaviours have been noted in the sibling literature and in the author’s own observations.

Sloper and While (1996) discuss risk factors in the adjustment of siblings of children with cancer and point out that although a significant number of siblings of children with cancer are at increased risk of maladjustment, others manage to traverse this period with increased social competence. They remind us that there is considerable variability in the well sibling’s response to their sibling’s illness and for these reasons further investigation is needed to increase the understanding of the factors that contribute to both positive and negative outcomes. Sloper and While stress that many of the studies that have investigated the effects of childhood cancer on the well sibling have tended to
look at the outcomes of the process or the degree of maladjustment, rather than looking at the factors that may have placed these children at risk, and how they may have interacted either positively or negatively. Although Sloper and While believe that much work needs to be done on identifying the determinants or modifiers of risk to these children, and suggest that research on risk and protective factors may provide guidance regarding sources that influence adaptation, this area will not be addressed in this investigation as the focus is to determine children’s conceptual understanding of the illness experience.

**Psychosocial Issues**

Although the focus of this study is the young child’s conceptual understanding of their sibling’s progressive, life-limiting illness, it is pertinent to include a discussion of the context in which learning takes place, because it will affect not only what young children know about their sibling’s illness but also how they acquire that knowledge. Consequently, a discussion of the psychosocial issues that surround the learning context is included.

From the literature it is apparent that many young, well siblings experience the most profound long-term psychosocial disturbances. Examples of sleep disturbances, heightened anxiety - especially when separated from a loved one, aggressiveness, fearfulness, feelings of isolation, difficulties with concentration and long term relationships, and impaired social interaction are found throughout the literature on the well sibling (Chesler et al., 1991; Cohen, Copeland, Jaworski & Pendergrass, 1994; Cunningham, Betsa & Gross, 1987; Havermans & Eiser, 1994). Sloper (2000) identifies one of the main themes in interviews with siblings as the losses they experience as the result of their brother or sister’s illness. They discuss loss of routine, loss of certainty and
security and loss of the companionship of the ill child. When one examines the literature for the origins of this behaviour, it becomes apparent that the well sibling’s parents are constantly unavailable, either physically or emotionally. Due to the needs of the ill child, there is often a lack of parental presence in the home, and often when the parents are physically present they are emotionally absent. This lack of physical or emotional presence often leaves the care of the well sibling to other members of the family such as the child’s grandparents, aunts and uncles, or friends of the family (Chesler et al. (1991); Cunningham et al. (1987); Havermans & Eiser (1994)). This rotation of caregivers, plus the physical and emotional absence of the child’s parents, causes young children to become very confused. This confusion is frequently demonstrated in the form of inappropriate behaviour.

**Developing the Ability to Understand Others’ Emotions and Behaviours**

Throughout early childhood, children are developing the ability to interpret others’ emotions and expressions and increasing their understanding of how emotions are associated with other aspects of life and given behaviours, while also learning to manage their own behaviours with respect to the behaviour of others (Dunn, 2000; Watson, 2001). Bowlby (1965) and Karen (1998) both see the early attachment process as an important first step in learning how to understand others’ emotions and in facilitating healthy social and emotional development in young children. They identify the key point in the attachment process as the development of the emotional bond between the primary caregiver, which in most cases is the mother, and the child. Without a strong emotional bond between the primary caregiver and the child, the development of relationships with others becomes difficult. Bee (1992) goes further, however, indicating that this emotional
bond is built and maintained by a repertoire of behaviours, which requires the coordination of an internal working model and external observable behaviour. The internal concept and the external event must match, else the interaction becomes misleading and the child becomes confused and demonstrates this confusion with inappropriate behaviour. Therefore constancy of response is important to the emotional development of young children because once the child has developed a constant idea of what a given behaviour means, the child then uses this knowledge to interpret the emotional behaviours of others and also to manage their own behaviour. Donaldson (as cited in Astington, 1993) states that if someone does something that is not in accord with the interpretation the child has given to that particular action, the child disregards it. She goes on to state that children do not make sense of the words or actions in isolation, but they interpret situations, often without understanding the words that are involved in that situation. Consequently, for young children, actions speak louder than words (Ashington, 1993) and their behaviour becomes a manifestation of their understanding of any given situation.

Bowlby (1965) believed that long-term separation of a young child from his or her mother was extremely damaging to the child’s mental health and personality development. He stated, “When deprived of maternal care, a child’s development is almost always retarded, physically, intellectually, and socially – and . . . symptoms of physical and mental illness appear” (p.21). Bowlby stressed that all children under the age of seven are at risk and that frequently the physical and emotional disturbances that occur are life long. Current research (Steinhauer, 1999) also supports these findings. Steinhauer identifies that not only are there sensitive and critical periods in the
attachment process, but also that when young children are placed under chronic stress, physiological changes that are life long occur within their arousal system. These changes cause the child to become hypervigilant, which in turn increases hyperactivity and distractibility, and decreases attention span, leading to a reduction in cognitive capability. Children at risk also show more stress when adults are upset and are likely to try to intervene in order to try to change the situation. Bowlby stressed that maternal deprivation not only occurs when a child is deprived of his or her mother by abandonment or death, but can also occur when a child receives insufficient care or interaction, or if the child experiences a series of separations from their mother.

**Pathological Mourning**

Karen (1998) draws our attention to something called pathological mourning. He contrasts pathological mourning with healthy mourning, which he feels everyone suffers from when a loved one is lost. He states that in healthy mourning one goes first through a period of anger, followed by depression, and then reorganisation as one separates oneself from the loved one and begins to reach out to others to make new attachments. In pathological mourning the anger never abates. It continues to consume the individual, preventing him or her from moving on and making new relationships with others. Feelings of worthlessness, guilt and mistrust appear. Karen feels that this is what occurs in young children when they are deprived of their primary caregiver for prolonged periods of time. They find it increasingly difficult to make relationships with others, which in turn leads to developmental problems. Bowlby (1965) supports this and notes that these symptoms continue to appear throughout life as the individual faces other losses and separations.
Discussions by Bowlby (1965), Karen (1998) and Steinhauer (1999) on the abnormal behaviours that occur when the attachment process is interrupted are mirrored in the literature on the well sibling. Adams-Greenly et al. (1986), Cairns et al. (1979), Chesler et al. (1991), Fanos and Weiner (1994) and Shapiro and Brack (1994) all note behaviours in siblings of children with progressive, life limiting illness similar to those identified by Bowlby and Karen in their observations of children who have attachment problems. Lindsay and MacCarthy (1974) suggest that young children are placed at risk for attachment problems because early bonding may have been disrupted due to the parents’ constant preoccupation with the ill child. As young children have limited communicative abilities, it is possible for them to interpret this preoccupation with their sibling as parental rejection, and this belief would, therefore, form part of their understanding of their sibling’s illness.

Why is there a Lack of Information on the Well Sibling’s Experience?

Although it is glaringly obvious that there is a profound need for sibling support, the research is limited, with no data available on what is needed for the youngest of the children. Garbarino et al. (1992) make a number of suggestions for the reasons why researchers often find it very difficult to obtain accurate information from young children.

- Most of our knowledge about interviewing comes from what we know about adults and our own experiences of being interviewed. Interviewing has traditionally been an adult form of inquiry, which presumes that the individuals involved have linguistic and interactive competence. However, this is not the case with young children, who frequently have limited linguistic and interactive competence (the ability to not only
understand the language being used but also how that language is being used within a
given situation). Sourkes (1987) provides an interesting example to demonstrate a
young child's limited linguistic competence. As stated earlier young children often do
not understand the word “treatment” and frequently associate it with something that is
negative rather than positive due to their observations of the process.

- Historically, information about young children has been obtained from interviews
with the children’s parents or other significant adults in their lives, because they were
thought to be too young to understand or better off not knowing the true facts of the
situation. This point is supported by Chesler et al. (1991) who affirm that much of the
research on the well sibling is based on reports from parents and social workers rather
than from the children themselves. Havermans and Eiser (1994) point out that using
parents and significant others in children’s lives as informants, rather than the
children themselves, has actually served to limit the research in this area.

- Young children want to please; therefore they tend to provide the information they
think the adult wants to hear rather than what they actually know to be true. This is
especially true of the healthy sibling. Chesler et al. (1991) state that the well child is
often overly compliant, not wishing to cause their parents any more problems. In the
Chesler et al. study children were asked what they would tell other siblings in the
same position as themselves, and one of the things they stressed was the need to be
“good”.

- Children under the age of five years are still developing language skills and as such
there is often a discrepancy between receptive and expressive language development.
Therefore children may not have the verbal ability to demonstrate their knowledge or
may misunderstand what has been said to them. Garbarino et al. (1992) give an example of a four-year-old who is told that he needs a CAT scan. The doctor felt that the child understood what a CAT scan was, but when at home with his mother he told her that a CAT scan was a giant cat with big green eyes that could see right through him. The Canadian Cancer Society handbook (1992) cites an example of a little girl being concerned that her brother was going to be burned up when she heard that he was having radiation therapy.

- Young children are not familiar with the question and answer format and therefore may not realize that they are being asked to supply information. Conversations between the caregiver and child normally revolve around direction as a form of inquiry, rather than the solicitation of information. Consequently, when asked to provide information, young children tend to provide inappropriate answers.

- Young children have difficulty distinguishing appearance from reality. Campione (1986) discusses the difficulties young children have in understanding that objects can have multiple representations and that things are not always what they seem to be. Watson (1986) adds to this by explaining that in order for children to distinguish appearance from reality they must have developed dual-coding ability. Dual-coding ability enables one to hold two seemingly incompatible properties together like having cards and presents for your birthday and cards and presents when you are ill and to understand that one represents celebration and the other concern. Young children find this extremely difficult to do. They find it difficult to understand the dual nature of card and present giving and consequently become confused by the constant flood of cards and presents that their ill sibling is receiving. Due to this lack
of comprehension, feelings of jealousy and confusion increase in the young, well child. Many children reported feelings of anger and jealousy because of the attention that was lavished on their sibling (Adams-Greenly et al., 1987; Chesler et al., 1991).

- It is difficult for young children to consider visual or spatial perspectives that are different from their own. Flavell et al. (1986) suggest that perspective taking and the appearance/reality distinction are related. They suggest that in order for children to be able to take another person's perspective or to understand the difference between appearance and reality, children must develop a dual coding system, learned through pretend play. In pretend play children use objects and/or people to represent things that they are not. In Flavell et al.'s opinion, it is through this daily practice of pretending things are not what they seem to be that children develop dual coding ability. Once the dual coding ability is established it can then be transferred to the appearance/reality and perspective taking distinctions.

- Young children have poor memory strategies; therefore they are less able to direct their memories for the purposes of storage and retrieval. Garbarino et al. (1992) stress that most of their memories need to be cued. They note that often, in order to cue children's memories, adults or other children need to play an active role in structuring the situation by providing more explicit instructions and concrete retrieval cues.

- Children under six or seven tend to lack metacognitive strategies and consequently have difficulty focusing their memories in order to distinguish what they know from what they do not know. Therefore Garbarino et al. (1992) suggest that when attempting to elicit information from young children it is better to use cued recall rather than spontaneous recall.
• Sometimes the need to protect children is an indication of the adult’s own discomfort with the issue. When parents were asked about the need to provide their young children with information regarding their sibling’s illness, they all agreed that it was something that was very necessary but were unsure of what they should say (Phillips, 2000).

Children’s Conceptions of Illness

Research into children’s understanding of illness has changed over the past two decades (Williams & Binnie, 2002). A number of contemporary researchers have challenged the traditional view of children’s understanding of illness. This traditional view is grounded in Piagetian stage theory and concludes that young children (children under seven) do not have the cognitive capacity to reason about the causes of illness (Buchanan-Barrow, Barrett & Bati, 2004; Kalish, 1996a; Raman & Winer, 2002; Williams & Binnie, 2002). Within this traditional paradigm it is generally acknowledged that children’s conceptions of illness follow a developmental progression that reflects their increasing cognitive capacity, moving from circular, egocentric reasoning to abstract, logical thinking (James, 1995). Numerous studies have supported this notion by demonstrating that children’s conceptual understanding of illness developed through a predictable sequence of developmental stages that mirrored Piaget’s cognitive developmental theory (Bibace & Walsh, 1980; Burbach & Peterson, 1986; Perrin & Gerrity, 1981; Perrin, Sayer & Willett, 1991; Potter & Roberts, 1984) and as such, until recently, Piaget’s cognitive developmental theory has formed the theoretical base for most investigations into children’s conceptual understanding of illness.

Contemporary research into children’s understanding of illness has moved away
from this traditional Piagetian focus due to the growth in research that identifies young children as far more capable and competent than Piaget had once thought (Raman & Winer, 2002). These new theoretical underpinnings look at children’s knowledge as it relates to illness causation (contagion and contamination), generalisation of illness to biological and non-biological categories, imminent justice, and naïve versus sophisticated understanding of illness (Buchanan-Barrow, Barrett & Bati, 2004; Kalish, 1996a; Raman & Winer, 2002; Williams & Binnie, 2002). Kalish (as cited in Williams & Binnie, 2002) explains contagion as “a complex generic causal chain whereby transmission of contaminates occurs between people” and contamination as “an innocuous object being negatively affected through contact with another object” (p. 130). For the purposes of this study, when discussing children’s understanding of contagion and contamination these definitions will be used.

Understanding that there are two quite dichotomous areas of research that surround what is known about children’s conceptual understanding of illness, and that these two areas of research are used by clinicians to determine how healthcare education should be provided to children, it seems prudent to provide some deeper discussion on both the traditional and the contemporary ideas that surround this knowledge base, because these ideas are found in much of the literature on siblings’ understanding of and adjustment to progressive illness.

**Traditional Views on Children’s Conceptual Understanding of Illness.**

Findings in the traditional literature base demonstrate that children in Piaget’s preoperational period tend to focus on one aspect of illness at a time, and find it difficult to generalize their thinking from one experience to another. They seem unable to
distinguish physical symptoms of illness from cause, seeing illness in a more global, nonspecific way, and relying on external cues for information rather than internal symptoms (James, 1995). Young children interpret illness as caused by a concrete action and recovery as occurring by adhering to a set of rules. Beverly (as cited in Haight, Black & DiMatteo, 1985), in an investigation of children’s understanding of chronic illness, noted that 90% of the young children in the study believed that their illness was a result of their bad behaviour. Well siblings are frequently cited as feeling as if they had caused the illness (Adams-Greenly et al., 1987; Cohen et al., 1994; Fanos & Wiener, 1994; Shapiro & Brack, 1994). The siblings give examples of physically harming their brother or sister whilst playing, having inappropriate thoughts, or simply wishing ill of their sibling, as reasons for the illness.

During the concrete operational period, children develop the ability to describe illness via internal and external states because they are now more able to understand phenomena from multiple points of view, but this reasoning is still fixed in present, concrete situations. The concrete operational child is able to define illness through a set of multiple concrete symptoms, and to understand that illness can be avoided by avoiding a sick person. However they still feel that “all” children can get better by taking care of themselves and doing what the doctor says (Hergenrather & Rabinowitz, 1991). Redpath and Rogers (1984) stress that this is a misconception that needs to be addressed in any health care program for young children, because when the child realises that not every sick person gets well they many become concerned about their own mortality.

During Piaget’s formal operational period children become able to think about illness hypothetically, and to make generalizations from past illness experiences to fill in
the missing information in the present situation. Children now understand that illness is an internal state whose symptoms manifest themselves in an external way. Formal operational children are able to describe symptoms in an abstract way, and use language to articulate feelings of ill health and wellness. When asked to describe illness they provide terms like “lacking in energy”, “not feeling well” or “not feeling right”. They typically understand that there can be many causes of illness and that the body may respond in many different ways depending on the type or cause of the illness. The formal operational child is now aware that not everyone gets well and that to get well the body must be able to defeat the illness (Hergenrather & Rabinowitz, 1991).

Bibace and Walsh (as cited in Burbach & Peterson, 1986) derived a set of categories representing children’s developmental understanding of illness, based on the Piagetian categories described, and identified these categories as Prelogical Explanations, Concrete-Logical Explanations and Formal-Logical Explanations, corresponding to the Preoperational, Concrete Operational, and Formal Operational stages of development, respectively. Within each of Bibace and Walsh’s categories two subtypes of reasoning are identified that account for the progression of the child’s understanding of illness during that period. These are:

Prelogical Explanations (age range 2-6 years approximately)

- **Subtype 1: Phenomenism**
- **Subtype 2: Contagion**

Concrete-Logical Explanations (age range 7-10 years approximately)

- **Subtype 3: Contamination**
- **Subtype 4: Internalization**
Formal-Logical Explanations (age range 11 years and older)

- **Subtype 5: Physiological**
- **Subtype 6: Psychophysiological** (Bibace & Walsh, 1980)

Bibace and Walsh (1980) describe **Phenomenism** as the most developmentally immature explanation of illness. The cause of the illness is seen as an external concrete phenomenon, which may co-occur with the illness but is spatially and/or temporally removed. Children during this stage are unable to explain how events caused the illness. Bibace and Walsh provide the following example: “How do people get colds?” “From the sun.” “How does the sun give you a cold?” “It just does that’s all” (p. 914).

**Contagion** is described as the most common explanation for illness given by more cognitively mature children during the prelogical stage. Children see the cause of the illness as located in objects or people that may be in proximity to, but not touching, the child. The link between the cause and the illness is accounted for in magical terms. “‘How do people get colds?’ ‘From outside.’ ‘How do they get them from outside?’ ‘They just do that’s all’” (Bibace & Walsh, 1980, p. 914).

**Contamination** characterizes children’s explanation of illness during the early part of the concrete-logical stage. The child can now distinguish between the cause of the illness and the effect on their body. The cause is viewed as a person, object or some kind of external effect that has an aspect that is harmful to the child. The child becomes ill by touching the object or person or through engaging in a physically harmful action. “‘What is a cold?’ ‘It’s like in the wintertime.’ ‘How do people get them?’ ‘You’re outside without a hat and you start sneezing. Your head would get cold, the cold would touch it, and then it would go into your body’” (Bibace & Walsh, 1980, p. 914).
Bibace and Walsh (1980) stress that Internalization is the most common explanation for illness given by older or cognitively more mature children in the concrete-logical stage. The child now comprehends that the cause of the illness is located internally and understands that it may have been caused by an external person or object via the process of swallowing or inhaling.

‘What is a cold?’ ‘You sneeze a lot, you talk funny and your nose gets clogged up.’ ‘How do people get colds?’ ‘In the winter, they breathe air into their nose and it blocks the nose.’ ‘How does that cause a cold?’ ‘The bacteria gets in by breathing. Then the lungs get too soft and it goes in the nose.’ ‘How does it get better?’ ‘Hot fresh air, it gets in the nose and pushes the air back.’ (Bibace & Walsh, 1980, p. 914)

Physiologic characterizes children’s understanding of illness during the initial part of the formal-logical stage. During this stage, although children understand that the illness may have been triggered by some kind of external event, they describe illness as originating from the malfunctioning or nonfunctioning of an internal organ or process (Bibace & Walsh, 1980).

“‘What is a cold?’ ‘It’s when you get all stuffed up inside, your sinuses get filled up with mucus. Sometimes your lungs do too, and you get a cough.’ ‘How do people get colds?’ ‘They come from viruses I guess. Other people have viruses and it gets into your blood stream and it causes a cold.’”(Bibace & Walsh, 1980, p. 915)

Bibace and Walsh (1980) use the term Psychophysiologic to explain the most mature understanding of illness. In this stage children provide explanations of illness in
terms of a physiological process but also provide psychological attributes that involve thoughts or feelings that an individual can have about illness.

"What is a heart attack?" 'It is when your heart stops working right. Sometimes it is pumping too slow or too fast.' 'How do people get a heart attack?' 'It can come from being all nerve wrecked. You worry too much. The tension can affect your heart.'" (Bibace & Walsh, 1980, p. 915)

This sequence in developmental understanding of illness appears to be predictable and consistent across the literature base in this area (Bibace & Walsh, 1980; Burbach & Peterson, 1986; Perrin & Gerrity, 1981; Perrin, Sayer & Willett, 1991; Potter & Roberts, 1984).

Contemporary Views on Children’s Conceptual Understanding of Illness

Generally, throughout the traditionalist literature, children’s understanding of illness has been limited to observable features and a lack of understanding about cause and effect. However, recently, a number of studies based on different theoretical ideas and using different methodological approaches (scenarios, stories, puppets and open-ended questioning rather than forced-choice questioning) have contradicted these findings by demonstrating that young children do have some understanding of illness causation and do reason about the biological and non-biological causes of illness (Williams & Binnie, 2002), suggesting that children’s understanding of illness may be no more appearance based than that of adults (Kalish, 1996a).

Buchanan-Barrow et al. (2004), in an investigation of children’s generalization of illness to biological and non-biological categories used children’s naïve theory of biology as the theoretical framework for their study. This “theory” suggests that children’s
understanding of illness takes the form of content-specific knowledge, rather than
domain-independent knowledge and that young children are capable of forming and
using complex mental structures that function as explanatory systems. Carey (as cited in
Buchanan-Barrow et al., 2004) adds to our understanding about the development of these
complex mental structures that function as explanatory systems for children by relating it
to experience. She suggests that increased exposure to, and experience with, illness
increases children’s understanding which in turn causes structural change, enabling
earlier psychological theories of illness to evolve into biological ones. Buchanan-Barrow
et al. provide evidence from a number of researchers to support this position and explain
that many preschool children have clear theories about the way in which illness can be
transmitted. They stress that it should not come as a surprise that young children’s
understanding of illness is based on concepts of contagion or contamination because this
knowledge grows out of their personal experiences.

Kalish (1999) explains four models that surround children’s understanding of
illness that include both traditional and contemporary ideas. First, in the associate model,
illness is believed to occur without evidence of contact and therefore magical descriptions
of how the illness occurred are provided. Kalish provides Bibace and Walsh’s (1980)
descriptions of children’s understanding of illness and children’s understanding of
imminent justice (Kister & Patterson, 1980) as examples of this model. Second, in the
physical model, it is understood that physical contact is necessary for illness to occur, and
germs are frequently cited as the vehicle of transmission. Third, in the simple biological
model, it is understood that germs are living and as such have the ability to affect other
living organisms. Fourth, in the differentiated biological model of illness it is understood
that there are many different types and ranges of illness. Kalish references his own research in relationship to the three latter models, and goes on to argue for the model that he sees as best fitting young children’s understanding of illness. He states that young children, when questioned about illness appropriately, provide examples of an intermediate mechanism as the cause of illness. He therefore concludes that young children’s understanding of illness cannot possibly be in the form of a simple associative model as suggested in the past, but must be in the form of the physical model. Kalish relates children’s experience to depth of understanding. He says that children who have had extensive experience with illness may have developed a deeper and broader understanding than normal, healthy children.

Further, Kalish (1996a, 1996b, 1997, 1998, 1999) has demonstrated that children as young as three and four years of age, after being told a series of short stories and then asked to predict if illness would occur, were able to differentiate germs from other illness-causing agents such as poison. When asked to describe how they knew that someone was ill, preschoolers described two properties – feeling (fever) and action (taking medicine). These findings suggest that from a very young age children do understand that invisible entities can cause illness and that they are able to “reason about specific hidden mechanisms in the domain of biology” (Kalish, 1996b, p.99).

Kalish (1996b, 1999), as well as providing descriptions of four models of understanding about illness, argues that people of all ages hold a variety of different concepts as they relate to illness. He describes three kinds of knowledge concepts - nominal kinds, property clusters and natural kinds - which he states can be used to explain this variance in thinking. Kalish explains that nominal kinds are characterized by
a simple definition, for example children may say that someone is sick if they demonstrate a particular set of symptoms. He describes property clusters as "representations of correlated attributes. . . . [with] no definition but simply a set of features more or less associated with the concept" (p.1648). He describes these features as being associated with a prototype of some kind. For example a tummy ache may be associated with not feeling well, a pain in your tummy and then vomiting. An additional attribute that also may be associated with this prototype may be avoidance of food.

Natural kinds are described as different from property clusters due to the incorporation of ideas and causal connections between the features that can include beliefs of how and why certain features are related to one another. He describes these features as being theory based rather than similarity based and as such, they tend to be related to experience rather than simple observation.

When investigating children’s understanding of illness as it relates to knowledge, Kalish (1996a) found that a preschooler’s understanding of illness is not limited to symptoms or obvious features (nominal kinds) as previously described by other researchers, but does take into account the causes underlying observable features including the realization that not all illnesses are caused in the same way. Consequently, a preschooler’s understanding of illness falls within the knowledge concept of a property cluster. He goes on to argue that there may not be any general developmental progression in children’s understanding of illness causation as discussed within the traditional literature, and that it appears that children’s understanding of illness, like that of adults, falls within that of a property cluster in that both symptoms of the illness and the cause of the illness affect their judgment about causation. These findings have significant
implications when thinking about educating young children about illness (Buchanan-Barrow et al., 2004). Clearly it would seem that children, like adults, can benefit from receiving factual information about the causes of illness and would likely worry less if they knew that something was not contagious.

In recognizing this importance of providing children with accurate, factual information about illness that is developmentally appropriate, a number of researchers have worked to create a developmental profile of children’s conceptual understanding of illness. Unfortunately, although the sequence of children’s understanding of illness-related concepts appears to be consistent and predictable across the literature base in this area, there are some concerns with the results obtained for younger children due to how the knowledge base has been constructed. This therefore limits the ability to extrapolate this information into a support program for the young, well sibling. Further, much of the research involves questioning children’s understanding of about an illness, rather than determining what children understand about the illness information they are provided. Consequently, prior to determining the type of supports that these young children may need in order to provide answers to the questions they seek, it seems prudent to develop a clearer understanding of what young children know about their sibling’s illness specifically, rather than illness generally. Therefore, the following research questions direct this study:

- What is the nature of young children’s knowledge of their sibling’s progressive illness?
- How do young children (3-6 years) construct and represent their understanding of their sibling’s progressive illness?
• How does their knowledge develop as a result of participating in a learning group?

Rationale for the Approach Used to Investigate Children’s Understanding

Until recently, most research into children’s understanding of illness has used a Piagetian framework. However, rather than considering Piaget’s findings regarding how children’s thinking changes over time and then using this information to guide an exploration of children’s understanding, most researchers collected data and then compared their findings to the Piagetian stages of cognitive development to confirm or deny whether their results conformed to these stages. The investigative methodology used within this traditional framework primarily consisted of forced-choice questioning and semi-structured interviews, using the Piagetian Clinical Interview technique. The Piagetian Clinical Interview utilizes open-ended questions designed to elicit children’s understanding. From these responses the interviewer makes hypotheses about children’s thinking, which must be interpreted in relationship to the child’s other answers, motivation and beliefs (Ginsburg, 1997).

Most of the traditional papers on children’s conceptual understanding of illness used some form of Bibace and Walsh’s (1980) Concept of Illness Protocol with either open or closed forced-choice responses, even when using preschool children as part of their demographic. Bibace and Walsh’s Concept of Illness Protocol contains 12 sets of questions with each set probing the child’s understanding about a single notion regarding illness. A typical set of questions involves queries about the definition of an illness, rather than what children understand about the illness information they are being provided and involve questions such as, “How do children know when they have a cold?” and its
cause, "Why do people get colds?" (Bibace & Walsh, p.913). Other less focused variations include questions such as:

- "All children get sick once in a while. How do kids know when they are sick?"
- "Some kids get stomach aches when they are sick. How do kids get stomach aches?"
- "Sometimes when kids get sick they have to stay in hospital. What would be wrong with them that would make them have to stay in hospital?"
- "When children are sick, how can they get better again?"
- "Sometimes when kids get sick they have to take medicine. How does medicine work?" (Perrin & Gerrity, 1981, p. 842)

This question and answer technique is an adult form of enquiry (Gabarino et al., 1992) which presumes that the individual involved has linguistic interactive competence. This is an ability that young children are still developing. Consequently, when required to use the question and answer technique, children tend to provide inappropriate answers. When considering children’s linguistic competence, children under five are still developing language skills and the ability to understand when and how to use the questioning technique. ‘Wh’-questions (what, where, which, who and how) are classed as a complex grammatical form (Berk, 1991) because they require the integration of several pieces of information (Valian & Casey, 2003). Wh-questions do not appear in children’s language until stage seven (Weitzman, 1992), which is the final stage of language acquisition before children develop an adult-like language stream. Stage 7 of language development typically occurs between ages four and five. Even the acquisition of wh-questions follows a developmental pattern that should be considered when interviewing young children. “What”, “where”, “which” and “who” questions appear first because they
relate to concrete objects, people and places, whereas “when”, “how” and “why” appear later and are related to more difficult concepts (time, manner and causality) which often require children to make a decision and then string together complex sentences to provide an appropriate answer (Berk, 1991).

This ability to make a decision and then string together a complex sentence in order to provide an answer is a task that young children find difficult. However, when one reviews the questions in Bibace and Walsh’s (1980) Concept of Illness Protocol, it can be seen that many of the questions include “how” and “why” as they relate to “causality” (How do children know when they get a cold) and “manner” (Why do people get colds?). Understanding that young children find it difficult to provide information about their conceptual understanding of illness in this way has brought the findings of the traditionalists into question. Sigelman, Carpenter, Epstein, and Maddock (1993) and Siegal (1988) point out that, under pressure, children frequently give inconsistent responses to prolonged or repetitive questioning and will often provide adults with the answers they think are wanted rather than what they actually know. This can be extremely problematic with something as abstract as illness and therefore may underestimate children’s knowledge.

A further issue that clouds the findings in the traditionalist research relates to young children’s poor memory strategies. Young children are less able to direct their memories for the purposes of storage and retrieval; consequently recall needs to be cued. Adults or other children need to play an active role in structuring the situation to be recalled by providing more explicit retrieval cues (Gabarino et al., 1992). Although a number of researchers may have provided this structure as part of their interview strategy,
it was not made explicit in the literature reviewed. Interestingly, this is an issue that has been explicitly addressed by a number of contemporary researchers (Kalsih, 1996, 1996, 1997, 1998; Raman & Winer, 2002; Siegal, 1998; Sigelman, Carpenter, Epstein & Maddock, 1993; Williams & Binnie, 2002). When reviewing their investigations into children's understanding of illness it is evident that not only have they considered these memory difficulties, but they have also implemented data collection methods that are aimed at helping support children's recall. Their retrieval cues include such things as puppets, stories and simple scenarios and the opportunity to participate in structured peer discussion groups. However, these researchers still tended to focus on the more global aspects of the illness concept and children's understanding as it changes over time.

Because of the focus of this study – young children's understanding of their sibling's progressive illness – the interest of this investigation was in determining what these children know about a particular type of illness and its process and how they demonstrate this knowledge. Consequently, this investigation differed from many of the existing studies described, which addressed children's understanding of the more global aspects of illness and how this changes across time. Due to this difference in focus and because of the issues raised about the appropriateness of the methods used historically, there was a need to use a new methodology in this study. Accordingly, the methodology chosen grew out of the field of education, rather than psychology, and was based on the principles espoused by the preschools of Reggio Emilia.

**The Reggio Emilia Approach to Education**

The Reggio Emilia Approach to Education is an educational experience that has been constructed over a 40 year period by parents, children and teachers. The philosophy
underlying this approach is one that constructs an image of the child as a strong, capable individual who is able to determine his or her own understanding of the world. The educators from Reggio Emilia state, "All children have preparedness, potential, curiosity, and interest in engaging in social interaction . . . constructing their learning, and negotiating with everything the environment brings them" (Gandini, 1997, p.17). These educators see the child as a rich child, one who is intelligent, rather than poor and in need. The educators in the schools of Reggio Emilia see themselves as co-constructors of knowledge with the children. They understand learning to be a cooperative, communicative experience whereby children and adults, embedded within a system of relationships, co-construct knowledge (Dalberg, Moss & Pence, 1999; Malaguzzi, 1998; Rinaldi, 1993).

The educators within the schools of Reggio Emilia understand observation and pedagogical documentation (Dahlberg, et al., 1999) to be fundamental to the learning process and in developing an understanding of how children learn. Pedagogical documentation involves focusing on the child's learning processes and important content in that process, via the tools of observation and reflection. In pedagogical documentation content refers to the material which records what the children are saying, and the process involves using that material to reflect on the children's work in a very rigorous and methodical way (Dahlberg, et al, p.148). Therefore the knowledge building is process followed closely and shaped by documentation (Kocher, 2004). Pedagogical documentation can take many forms and often includes written observations, examples of children's work, photographs, and videotape. However it is important to understand that each of these observation tools has its own bias, potential and limitation. Dahlberg et al.
describe documentation as a dangerous exercise because it has the capacity to reveal the “character of knowledge construction and as such functions as an emancipatory practice” (p. 156). Pedagogical documentation serves three functions. It provides children with a visual memory trace, teachers with a tool for research, and parents with detailed happenings of the children's school experiences (Hewitt, 2001).

Rinaldi (2006) describes pedagogical documentation as a collection of documents that can be used for verifying the truth or confirming a thesis, and states that through the process of recall, re-examination and reconstruction of these documents the learning path becomes clear. Teachers and researchers, by recording what children say, can read or play back previous conversations of their experiences to help them (children and teachers) recall past learning or to expand their knowledge about a new one. Photographs and children's graphic representations can be used for the same purpose. Forman and Fyfe (1998) call this revisiting the experience and describe it as something more than just remembering. They state: “Revisiting is . . . a return to a place of significance for the purpose of establishing friendly relationships and establishing new relations . . . You look on the experience as an outsider. You no longer reside in the experience . . . The past is reconstructed from the present” (p. 248).

Malaguzzi (1998) describes children as being born with a hundred languages, a hundred ways of knowing, and therefore as having the ability to demonstrate their learning in many ways. Due to this belief the educators within the schools of Reggio Emilia encourage children to represent their understanding through “languages or modes of expression” (Edwards, Gandini & Forman, 1993, p.3), which include such things as drawing, painting, sculpture and drama. Dahlberg and Moss (2005) state that in order to
understand, as adults, these many languages or modes of expression used by children one should consider them metaphorically as one would understand a painting, a sculpture or a dramatic representation.

Children within the schools of Reggio Emilia are seen as researchers and so the teachers encourage in-depth studies of topics that are of interest to one or more children. During those studies the children are encouraged to explore, observe and listen to each other, hypothesize, represent, and revisit previously learned experiences in order to clarify their understanding.

Pedagogy of listening: Symbolic languages and the movement from hearing to listening. When considering the components of pedagogical documentation and their utility in helping young children explain their understanding of their sibling’s progressive, life-limiting illness, there are two other additional concepts that need consideration. These are symbolic languages and the movement from listening to hearing. Children’s representations such as drawings, paintings, sculpture, construction and drama are often called symbolic languages, but what does this mean? Forman and Fyfe (1998) clarify this by stating that language is more than a group of symbols. Language contains rules about how the symbols can be combined in order that all the participants using the language are able to comprehend the meaning. Consequently, when thinking about children’s symbolic languages, a single representation of any kind would not represent a language. However, a series of representations that are put together in such a way that they inform, is a language. Therefore when examining the representations of the well sibling to determine their understanding of their brother or sister’s illness, examples of communicative intent were sought.
Forman and Fyfe (1998) describe the movement from listening to hearing. They explain that listening implies that one has heard what the child or the group of children has said, whereas hearing connotes that one has tried to understand what is meant by the communication. It involves more than listening because it requires one to consider the context and other implied forms of the meaning in the children’s communication. Clark and Moss (2001) provide a framework to help us understand this concept of moving beyond listening to understanding the context and other implied forms of meaning in children’s communication. They describe the movement from listening to hearing as:

- multi-method because it recognises the different ‘voices’ or languages of children;
- participatory due to its treatment of children as experts and agents in their own lives;
- reflexive as it includes children, practitioners and parents in reflecting on their meanings, and addresses the question of interpretation;
- adaptable because it can be applied in a variety of early childhood environments;
- focused on children’s lived experiences because it can be used for a variety of purposes including looking at lives lived rather than knowledge gained . . . ;
- embedded into practice as it provides a framework for listening which has the potential to be used as an evaluative tool . . . (p.5).

Rinaldi (2001) talks about a pedagogy of listening. She describes listening as a process that requires interpretation and stresses that it involves the listener in “making meaning in an interpretive process” (p.3). Rinaldi continues by stressing, “Listening is a basis for any learning relationship [and] through action and reflection, learning shapes the mind of the subject and, through representation and exchange, becomes knowledge and skill” (p.3).
Understanding children’s drawings. As children’s graphic representations are part of the data and therefore an important component in determining children’s understanding of their sibling’s illness in this study, it was important to develop a deeper understanding of drawing as a form of communication for young children. Within the schools of Reggio Emilia drawing is seen as another language for children and has been used as a tool by educators to enable children to investigate topics of interest, thereby allowing them to make their learning visible. In order for children to use drawing as a medium of expression the educators in the schools of Reggio Emila believe that children need to be supported to move beyond the exploration stage (Tarr, 2005). Tarr explains that the educators in these schools draw directly from Vygotskian theory, seeing knowledge as socially constructed through collaboration and the sharing of multiple perspectives. Consequently, “drawing is placed at the centre of a communicative process. Children become active interpreters of their work within the social context. The use of drawing becomes a two-way communication process” (Malaguzzi, as cited in Tarr, p.6). Tarr continues by explaining, “Drawing, in a social constructivist context can become a form of inquiry and a way of making thinking visible that serves as a means to open up a dialogic relationship with others and constructing meaning from this interaction” (p.6).

Malchiodi (1998) describes drawing as providing children with the potential to tell stories through the images they draw and what they say about the images themselves. The narrative quality of the children’s drawings offers opportunities to understand them from the children’s perspective. Malchiodi identifies a narrative as a story, a statement or a recounting of a past experience. Drawings as narratives provide children with an opportunity to express what they are feeling and also provide some distance between
themselves and the problem they are experiencing, allowing them to make the problem visible (Malchiodi). Malchiodi, like Forman and Fyfe (1998) in their discussions on documentation, states that when understanding children's narratives one or two drawings are not helpful. It is necessary to have a series. She states that each drawing contributes to the narrative by presenting a different aspect of what the child is thinking. Frequently new details appear as the series progresses, giving a more complete understanding of what the child knows. Malchiodi stresses the importance of having children talk about their drawing once it is finished, rather than asking questions about it. To encourage dialogue with children she suggests that it is better to say, "I see a person looking out of the window" (p.50) and wait for the child to add to the conversation, than saying "why" did you paint the person looking out of the window or "what" is the person looking out of the window "doing" or "seeing". She suggests that if you have a question it is better to wonder out loud, as if you were talking to yourself, rather than to ask direct questions, stating that most children will respond to this technique. Malchiodi also points out the importance of considering the context of children's drawing, stating that each drawing should be considered in context to the previous one and in context to the child's lived experiences. When children draw they tend to draw what they know and include only what is necessary for the graphic representation (Wales, 1990).

Helping children recall past experiences. One of the important components in pedagogical documentation is reinstating the context so that children can recall past experiences. In order to assist children with this complex process the educators within the schools of Reggio Emilia use a variety of techniques that have been shown to assist children with this task. These include using photographs of their experiences; discussing
artwork completed during previous sessions; using real materials in their play and constructions, and encouraging in depth conversations with their peers and the teachers. These various methods of encouraging and supporting recall of past experiences have been identified as helpful in the literature on interviewing preschool children.

Aschermann, Mantwill, and Kohnken (1991), Aschermann, Dannenberg, and Sachultz (1998), Larsson, Granhag and Spjut (2002) and Poole and Lindsey (1995) discuss this process of revisiting or reinstatement of the original context or environment as being important in helping children to recall past experiences. In their research they use a process called the cognitive interview (Geiselman et al., 1984). The cognitive interview uses two principles of memory - the multi-component view of a memory trace, and encoding-specificity. The multi-component view of a memory trace presumes that a memory is multi-faceted; consequently if one feature is not accessible by a particular probe, then another one might be successful. Encoding-specificity suggests that the most effective retrieval probe will be the one that reinstates the context where that memory trace was first created (Larsson et al., 2003).

The cognitive interview requires the interviewer to assist the child to recall a previous experience and then, via a series of open-ended questions or prompts, to help the child recall events they have experienced. Poole and Lindsey (1995) refer to these questions or prompts as the “tell”, “more”, “looked”, “heard” and “think” prompts and combine them in the following form:

- Tell me everything you can about . . .;
- Can you tell me more about . . .;
- Sometimes we can remember how things looked . . .;
• Tell me things you heard in . . . ;
• Think about what you told me . . . Is there anything else that you did not say? (Poole & Lindsey, 1995, pp.135-136)

Children interviewed using the cognitive interview technique were able to report more correct information than those just using spontaneous recall (Aschermann et al., 1991; Larsson et al., 2002).

This evidence lends support to the importance of using various types of documentation (e.g. photographs and artwork) and more able peers to access memory and thereby reinstate the context, helping children recall past experiences. A more able peer can be a child or an adult with greater knowledge or understanding, who forms a learning group of some kind with another child who is less able in some way. In the process of forming a learning group the interaction between these two individuals extends the learning beyond that which the child on their own could accomplish. The more able peer acts as an external mediator by extending the child’s memory and deliberately focusing the child’s attention, thereby enabling him or her to attend to, or focus on, objects, events or behaviours that may be difficult without this kind of support (Bodrova & Leong, 1996). From this interaction they create a collective body of knowledge that can then be used to extend the cognitive capacity and/or learning of either or both individuals. The types of questions that are typically asked in a cognitive interview and found to be helpful in eliciting information from young children are similar to the types of questions that are used in the process of collecting pedagogical documentation.

Ginsberg (1997), in his discussions of the Piagetian clinical interview, identifies the importance of using “flexible techniques” (p.40) when working with young children
in order to “understand how the child constructs their personal worlds, how they think, how their cognitive processes operate and how their mind functions” (p.28). Ginsberg reminds us of the importance of considering children’s responses in the context of those that have already been provided and in the context of their experience. Based on this evidence it was determined important to consider children’s responses within the context in which they were providing the information, which included conversations with peers and teachers, play actions and graphic representations, in order to determine their understanding of their sibling’s illness.

Vygotsky (as cited in Ginsberg, 1997) saw the clinical interview as useful for studying children’s understanding but considered it restrictive because of its ability to measure only what a child can do alone, rather than what a child can accomplish with a more skilled peer (Ginsberg, 1997). Consequently he saw a need to reshape the clinical interview to include more able peers. This change of focus from what the individual can do alone to what an individual can do with more able peers enables the use of flexible methods when investigating children’s understanding. Consequently, this study was framed so that data could be collected as the children participated as members of a small group.

Poole and Lindsey (1995) discuss methods of interviewing preschoolers and describe the limited information preschoolers provide in open-ended interviews as one of the challenges. Poole and Lindsey note that many researchers who acknowledge this difficulty have used props such as dolls and other types of models to try to elicit more information, only to find that props increase the likelihood of re-enactment and accuracy errors. To circumvent this problem in their study, they used visual feedback in the form
of talking feltboard heads and audio taped recordings of the children’s conversations as recall techniques, prior to prompts for more information. Following the playback of the audio taped recording the interviewer asks, “Think about what you told me, so you can decide if there is any more you can remember about . . . . Is there anything that you did not say on the tape that you can tell me now?” (p.136). Their results demonstrated that, when provided with visual and auditory prompts, preschoolers’ recall is substantially increased.

Aschermann et al. (1998) describe their decision to use photographs as retrieval cues in their research as stemming from the following issues:

- Understanding that young children rely more on external cues for recall.

- Knowing that reinstatement of cues from the actual event is especially helpful to preschoolers.

- Understanding that although using props such as dolls or models increases the amount of information obtained, it decreases the accuracy of information when compared to the use of a real item.

Aschermann et al. suggest that the reason that accuracy of recall goes down when preschoolers use props such as dolls or models is that the child has to understand the dual nature of the item, which includes an understanding of the object itself and as a representation of an object to be remembered. Preschoolers have great difficulty with this concept. Therefore Aschermann et al. felt that by using photographs the child would not have to understand the symbolic nature of the object before being able to use it as a recall tool. Their results demonstrated a significant difference in the amount and accuracy of information recalled when photographs were used.
Elischberger and Roebers (2001) also discuss the use of visual prompts for improving children's narratives of an observed event. They support Aschermann et al.'s findings but stress that there is a need to teach children how to use visual prompts such as photographs in order to increase the amount and accuracy of information obtained. They suggest showing the child the photograph and then using verbal prompts such as “tell me more”, “tell me what you heard” and “tell me what you saw” (p.161) as aids in increasing length and accuracy of reporting. Moran and Tegano (2005) discuss photography as a language of inquiry. They state, “Photography is a dynamic representational system that uses sign to produce and communicate meaning [and] . . . like words is both encoded and decoded with meaning” (p.3). Therefore, like language, photographs have to be decoded in order to be understood and as such are open to interpretation. This interpretation is affected by the context, personal knowledge of and about the context, and understanding of the origins of the story.

Based on this information it was determined important in this study to:

- Use real medical materials rather than toy props.
- Use photographs taken of the doctor’s office and Children’s Hospital to replicate the context as closely as possible in the dramatic area of the preschool.
- Provide the children with a disposable camera so that they could take photographs of their families and then discuss these photographs when they came together as a group.
- Take photographs of the children during the data collection sessions and then use these photographs to encourage children to have conversations about their
play experiences in subsequent sessions.

- To replace the books with stories of children going to the hospital or the doctors so that we could have conversations with the children about the experiences they were reading.

Asking children good questions. Garbarino et al. (1992) state that in order to understand what is necessary to elicit children’s understanding, adults need to comprehend how children see the world and how their understanding about it develops. They emphasise that by doing this, it is possible to learn children’s strengths and weaknesses and thereby understand the possibilities and limitations in obtaining accurate information from young children. Forman (1989) provides some guidance on how to access the child’s world through their thinking: “Helping children ask good questions is a matter of helping children think about their thinking” (p.21). Many adults find this task to be problematic. Forman, however, provides us with a number of key reasons why this occurs. He explains that ordinarily, when asked a question by a child, adults frequently respond with another question. This tells the child that their attempt to communicate has failed, and often results in the child walking away, rather than re-engaging in the conversation in order to clarify the question. Forman believes that the way to engage children in asking good questions is to encourage them to focus on their own ideas. To help children do this it is necessary for adults to do two things: 1) change their ideas of what a question should be (he suggests that a child’s reflection on a previous answer could be considered a question and he terms this type of question a rhetorical guess) and 2) become an expert in focusing on a specific aspect that has the potential to reveal gaps in the child’s understanding. To do this a teacher must move away from just focusing on
technical elements that the child might have difficulty with, like appropriate word usage or being able to use a pencil or paint brush correctly, to having a theory about the child’s theory. Forman believes that it is almost impossible to build a conversation with children about their ideas without trying to guess what their theories might involve.

Gabarino et al. (1992) make a number of suggestions as to how to ensure the accuracy of information gained from young children, and provide us with the following guidelines.

- Questions need to be designed and props need to be obtained in order to reconstruct the context that needs to be recalled;
- Children are more communicative in settings with which they are most familiar;
- Children respond best to a more conversational form of inquiry;
- Questions should provide guidance without making implicit or explicit suggestions;
- It is important for the adults to recognise the child’s zone of proximal development;
- The more information the adult knows about the child the more likely the adult is to understand what the child is saying.

Based on this information the decision was made to use a preschool environment as the context for the study and a teacher who was an early childhood educator and was familiar with using this way of working with children as part of her daily practice.

**Rationale for the Choice of Research Methodology**

In this study it was important to use methods that were reflective of and able to support the values and beliefs about children and their capabilities espoused by the schools of Reggio Emilia. Therefore an interpretive orientation and a qualitative case design was the methodology of choice. A Vygotskian socio-cultural framework was
chosen as part of the system of analysis due to the beliefs of the importance of the social context espoused by the schools of Reggio Emilia for making children’s current, transitional and future knowledge apparent through social interaction and reflection on both the content and the process. According to Vygotsky (1978), “Every function in the child’s cultural development occurs twice: first on a social level, and later, on the individual level; first between people (interpsychologically) and then inside the child (intrapsychologically)” (p. 57). He explains that this occurs through a series of transformations. Harre’s (1984) model of the Vygotsky Space (Figure 2.1) provides a visual description of this series of transformations and was used as part of the system of analysis to examine, microgenetically, the children’s process of presenting existing, transformational and newly emerging knowledge. As can be seen from the model the relationship is circular and recursive and movement forward occurs through the process of revisitation. It is the process of revisiting or reflecting on what self or others have done that pulls the child through multiple zones of proximal development as the learning occurs. Vygotsky (1978) identifies the zone of proximal development as “the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or collaboration with more capable peers” (p. 86).

The first dimension, public – private space, is characterized by the degree to which cognitive activities are visible and therefore available for observation. Public cognitive activity occurs in a group or instructional setting. In contrast, private cognitive activity can only be inferred from a given behaviour and consequently we are unaware of the processes used. The second dimension, the social – individual, reflects the degree to
which the students use their own knowledge or the knowledge obtained from the group. When the two dimensions are overlaid, as in the model, they form the four quadrants of the Vygotsky Space. At any one time a child’s cognitive functioning may be characterized as existing in one of these quadrants (Gavelek & Raphael, 1996).

![The Vygotsky Space Diagram]

**Figure 2.1. The Vygotsky Space**

Quadrants one and four consist of observable events demonstrated either by the individual or the group. Quadrants two and three consist of unobservable cognitive activities, through which the learner or the group progresses as strategies are developed.

Gavelek and Raphael (1996) propose that, through the course of learning, individuals or groups move recursively through the quadrants in a spiral-like fashion. Each time the child or the group revisits something they have already learned, new information is incorporated and they move to the next level of understanding. Harre (1984) identifies four processes that characterise the transition through each of the
quadrants – appropriation, transformation, publication and conventionalisation. In quadrants one and two we see the process of knowledge being taken in. This is described as appropriation; as can be seen from the diagram this takes place in public or in private space. As movement occurs through quadrants two and three, knowledge is transformed through the process of engagement. This transformation frequently occurs in the private domain and as such can only be inferred from a given behaviour or an example of the child’s work once it is made public. The process of publication occurs when the child’s meanings and strategies are made public or visible, thereby enabling others to respond. The final process, conventionalization, describes the process whereby an individual’s public thinking, which can include their actions as well as their ideas, is incorporated into the group or community discourse (Gavelek & Raphael, 1996).

Microgenetic analysis and microgenetic methods of investigation are associated with the work of Werner, Vygotsky and Luria (Catan, 1986), and are therefore suitable for identifying change within the social context. Vygotsky (as cited in Guerrero & Villamil, 2000) stressed the importance of minute analysis in understanding psychological processes. He stated:

Any psychological process, whether the development of thought or voluntary behaviour, is a process undergoing changes right before one’s eyes. The development in question can be limited to a few seconds, or even fractions of seconds . . . Under certain conditions it becomes possible to trace this development. (p.61)

Consequently, a microgenetic analysis of the children’s movement through the Vygotsky Space was performed as a means to determine children’s known, transformational and
new emerging knowledge.

A description of the participants, program, data collection methods and analysis is presented in the following chapter.
Chapter III

Methodology

Research Methodology

The choice of research methodology for a particular study depends on the question being asked and on an understanding of the philosophy that forms the foundation of the study. Therefore, when one considers the question under investigation in this study, *young children's conceptual understanding of their sibling's progressive life-limiting illness*, the philosophy that surrounds it, the *Reggio Emilia Approach to education*, and the research orientation needed to be interpretive.

An interpretive orientation to research falls under the umbrella of qualitative rather than quantitative research. Qualitative research is multimethod in focus and involves an interpretive, naturalistic approach to its subject matter. Qualitative research occurs in natural settings where researchers are trying to make sense of or interpret phenomena in terms of the meaning people bring to them (Denzin & Lincoln, as cited in Walmsley & Johnson, 2003), and is sometimes referred to as the insider's view (Merriam, 1998). In qualitative research the researcher is normally the primary person involved with data collection and analysis and can therefore be more responsive to the context, adapting techniques to suit the particular circumstances under investigation (Merriam, 1998).

In qualitative research data are often in the form of observations, documents and photographs. Data are frequently processed immediately and the findings used to continue to build the study. Qualitative research is often undertaken because of the lack of theory or because existing theory fails to explain the phenomenon under investigation,
as in this study. Currently, the literature base on children’s understanding of illness identifies a need for research in this particular area. Research findings in a qualitative study are normally in the form of themes, categories, typologies and concepts. The final product is often richly descriptive, consisting of words and pictures rather than numbers and tables (Merriam, 1998).

Therefore when one considers the focus of this study and the decisions made about who the participants are, how the data will be collected and what will be collected to answer this question, along with the underlying philosophy, a qualitative case study was identified as the research design of choice.

**Design**

A qualitative case study design was considered to be optimal for this investigation because it can be used within an interpretive orientation and allows for the exploration of a single unit or a bounded system (two children and their interactions with the three other children who form part of this study but are not part of the case) through in-depth data collection that involves multiple sources of information (digital video and audio tape, transcriptions of children’s conversations, photographs, artwork and any other representations of children’s thinking and learning along with comments and reflections from the teachers involved in the data collection) over a period of time (five sessions) (Creswell, 1998).

Merriam (1998) describes a case study as something that can be fenced in. She states that a case study can involve a person, a program, a group, a community or a specific policy and describes it as “an intensive, holistic description and analysis of a single instance, phenomenon or social unit” (p.27). Merriam stresses that the decision to
use a case study design frequently stems from the need to interpret the data, rather than test a hypothesis, and reminds us that case studies are frequently used by healthcare professionals, because they can be used to collect quantitative as well as qualitative data. Merriam states, "Case study does not claim any particular method for data collection or data analysis. Any or all methods of gathering data, from testing to interviewing, can be used in a case study" (p. 28).

Yin (1994) differentiates between three different types of case study - exploratory, explanatory and descriptive. He explains that the choice of which one to use depends on the question being asked. If the research question is primarily concerned with "what" and "how" then one would use an exploratory case study. If the research question was primarily concerned with "how" and "why" then one would use an explanatory case study and if the research question was primarily concerned with "who" and "how" then one would tend to use a descriptive case study. When one considers these comments in respect to the questions that guide this study one can see that this investigation falls under the umbrella of an exploratory case study as the questions that guide this study involve "what" and "how".

Yin (1994) identifies five components that are important in a case study design. These are: the study’s questions, because they inform the design of the study; the propositions of the study, which direct attention to what should be examined (the children’s understanding); the unit of analysis (the two well siblings and their interactions with the three other children who form part of this study but are not part of the case); the logic linking the data to the propositions, and the criteria for interpreting the findings. These last two components deal with the analysis of the data by identifying how the data
are linked to the propositions of the study. The results from an interpretative, exploratory study may take the form of topologies, concepts or categories that are richly descriptive.

**Strengths and Limitations of a Qualitative Case Study Design**

Both the strengths and limitations of a qualitative case study research design surround the fact that the primary researcher is involved with data collection and analysis. This means personal bias can affect what is collected and what is attended to in order to inform the results. In order to address this issue in this study a research team was formed and observational data was collected by two other individuals and used to support the findings. Observational data was collected using digital-video and audio recordings that spanned the entire study, and also a running record format.

**Participants**

Five children participated in this study. They were located through the Clinical Nurse Specialist at Canuck Place and through the Preschool Teacher at the preschool where the study took place.

After ethical approval at both the University of British Columbia (UBC) and Canuck Place, the researcher was provided with access to all the children's files at Canuck Place. From a review of the files the researcher compiled a list of 20 children who met the demographic requirements of this study. Individual telephone calls were then placed to each family. Initially four children were selected to participate in the study, from three different families. They included two well siblings and a well sibling pair. Unfortunately the family with the sibling pair withdrew two weeks prior to the start of the study due to the changing healthcare needs of their child. Despite repeated calls to other families who were attending Canuck Place and had been identified as suitable to
participate, no replacement children could be found.

Consequently in order to form a group, there was a need to identify additional children who had experience with chronic illness. Three additional children were located, and included a singleton and a sibling pair. These children were identified through the participating preschool teacher and were considered to be suitable because both families had experienced either recent chronic illness or death within their immediate family and circle of friends. The four-year-old female singleton had close family members who had experienced repeated hospitalizations, neurological difficulties and oxygen dependency. The five-year-old, of the female sibling pair, had a friend at school that had recently died.

Therefore the participants who formed the group for this study were the two well siblings, Joshua who was five-years-old and Katie who was three-years-old; the singleton, Martha, who was four-years-old, and the sibling pair, Claire five-years-old and Emma three-years-old. Due to the recommendations within the literature on group size when working with young children (Gandini, 1997; Garbarino et al., 1992; Krechevsky, 2001; Rinaldi, 1993), it was thought important to include Emma as part of the group even though she did not have direct experience with progressive illness or death, in order to create a group size of five children.

Four of the participants were female, and one was male. Only two of the children, Joshua and Katie, had a sibling with a progressive illness. They both had brothers with a progressive life-limiting illness who were participating in the respite program at Canuck Place. This participation included overnight and weekend stays at the hospice and participation in a number of the hospices outside activities. The two participating families from Canuck Place did not know each other prior to the study.
Prior to taking part in the study, all of the participating families were asked to provide demographic information and any other information that was thought to be helpful in understanding the children's base medical knowledge. Both of the well siblings in this study had brothers with neurological disorders that involved seizure activity, oxygen dependency and gastrostomy feeding (G-tube). Both ill siblings had experienced repeated hospital visits for both emergency and routine procedures. The male, well sibling was the youngest child in the family and the female was the oldest. While other demographic information (e.g., parental background) was collected, it is not included as part of this study, because of the confidentiality agreement that was signed by the lead researcher in order to obtain ethical approval for this study at Canuck Place.

Each family received at least two home visits prior to participation in the study, with each visit lasting at least one hour in duration. Appropriate permissions were obtained prior to commencement of the data collection. Because of the importance of sharing the findings with the participating families in this project, each data set was shared with the parents the day following each data collection session. As the data were in the form of digital videotape, each evening the researcher transferred the digital recording to VCR format so that the parents could sit together in the following session and watch on television what had occurred in the previous data collection session. A registered counselling psychologist, who specialized in working with children and families that had difficult life experiences, facilitated each of the parent sessions. Although it was thought important to share the findings of this study with the parents, no data were collected on parents' responses because the focus of the study was the children's understanding.
Information was supplied to the parents at the beginning of the sessions outlining what is currently known about preschool children who have a sibling with a life-limiting illness (Appendix A). This information was in the form of a simple handout. Contact information for the participating counselling psychologist and a list of additional agencies that could provide support to the parents was also supplied.

Although the data set included the interactions of all five participating children as they built their knowledge about progressive illness collectively, only the conceptual themes and procedural understanding introduced or built upon by the well siblings' knowledge were analyzed and presented because of the focus of this study — young children's conceptual understanding of their sibling's progressive life-limiting illness. The decision not to use themes or procedural knowledge introduced by either Martha or Claire was due to the fact that their life experience with progressive illness was different and as such meant that they did not meet the criteria for this case study. The names of the participating children and the names of the ill siblings were changed to maintain their privacy and that of their families.

**Group Size**

The group size in this investigation was limited to five children with an age range of three to five years. The decision to limit the group size grew out of the work of Krechevsky (2001), Rinaldi (1993), Gandini (1997) and Garbarino et al. (1992), who all discussed the importance of attending to the size of the group when working on projects with young children, pointing out that it significantly influences how and what is learned. Krechevsky (2001) states that group sizes of two, three or four are particularly effective, especially when children are of a similar age. She stresses that by limiting the group size,
complex interactions are able to take place, thereby enabling children to listen to, collaborate, and negotiate with each other. Rinaldi (1993) supports this statement and adds:

After much consideration we have concluded that in order to maximize the cognitive learning processes, group size should be limited to five. Beyond this number, group dynamics become too complex, and the sheer number of interactors is too many to allow each child to evaluate and then transform his or her knowledge and identity through a constantly changing knowledge of others’ identities. (p.107)

Gandini (1997) and Garbarino et al. (1992) also identify that when young children work in small groups their attention is much greater and they have an increased ability to listen to each other’s questions and respond with interest and curiosity. Based on this evidence and understanding that the interaction between the children was a very important part of this study, the group size was limited to five children.

Site

The site where the data collection took place was a Parent Participation Preschool located within a large major city in Western Canada. This particular preschool had adopted the Reggio Emilia Approach to education as its underlying philosophy. Consequently, it had a very rich environment for children; full of a wide variety of materials that enable children to use what is referred to as graphic languages (Katz, 1998) to demonstrate their understanding.

Prior to the start of the data collection the researcher visited her doctor’s office and photographed the waiting area and examination room in order to replicate it as
closely as possible in the drama area of the preschool. This need for authenticity grew
from the literature on children's recall (Aschermann, Dannenberg, & Sachultz, 1998;
Aschermann, Mantwill, & Kohnken, 1991; Larsson, Granhag & Spjut, 2002; Poole &
Lindsey, 1995) that clearly describes the importance of replicating the context as
accurately as possible in order to obtain the best data from young children. Consequently,
the easiest way to ensure accuracy was to take photographs of the doctor's office and
then work from the photographs to acquire materials and then set up the environmental
context in which the play would occur. These photographs of the doctor's office were
later projected onto the wall of the dramatic area to provide an additional level of
complexity in the environment. The initial set-up in the drama area of the preschool
included a waiting area and an examination room, along with the types of materials and
instruments that would be found there. The additional materials included real medical
items; books on families, doctors and hospitals; real hospital garments such as doctors'
coats, scrubs, hair and shoe protectors and facemasks; and medical equipment. All
clothing was child sized. Additional changes were made to the play space and
photographs of Children's and Women's Hospital were added when the children
requested that the doctor's office be changed to a hospital. Because of the importance of
context and the need to utilize real materials to aid children's recall, the researcher
supplemented the existing materials at the Preschool with materials that were selected to
provoke the children's recall of their illness experiences.

Observation

The teacher who normally works in this preschool and a college professor assisted
in the data collection. Both of these individuals have extensive experience with the
Reggio Emilia Approach to education, having traveled to study in the schools of Reggio Emilia and through using this methodology as part of their daily practice. The college professor has written a number of articles and two textbooks on this approach, as well as facilitating many national and international symposia and seminars on this topic. The teacher worked with the children, while the college professor and I collected the data. The data were in the form of digital videotaped recordings of the children at work, audio recordings of their conversations, photographs, examples of their work and reflections on each session. At the end of each of session the findings from that day were reviewed and discussed in order to prepare for the subsequent session. Particular attention was paid to the children’s interests, their questions and the list of requested items they supplied to us at the end of each session.

The data were collected over a period of two weeks during five, two-hour sessions. The children attended the preschool on Friday and Saturday during the first week and Friday, Saturday and Sunday in the second week, in the afternoon. The frequency of the sessions was designed to enable the children to become more familiar with the environment and to develop deeper relationships with their peers than weekly attendance would have afforded.

Prior to the commencement of this study it was thought that there would be a need for the children to attend the preschool for at least two sessions prior to data collection, in order to provide time for them to become familiar with the environment and to allow for the collection of baseline data. However, because of the children’s life circumstances, this was not possible and data collection started immediately.
The children's interactions were recorded on digital videotape and their conversations were recorded on audio-tape throughout each session as they moved through the activities. The second researcher (the college professor) also collected handwritten observations and photographs of the children as they played, to augment the data and to provide another perspective to that of the lead researcher. Additional data included examples of the children's artwork and some three-dimensional structures that were made. Only the children participating in the project attended the preschool during the data collection sessions.

The Sessions

Planning the sessions. Prior to the initial session the teacher and the researchers met and created a teacher's web (a planning tool often used in early childhood curriculum planning to consider what children might know about a given situation) in order to become familiar with the varying situations that could occur, and the type of language these children might be hearing on a daily basis. At this session we discussed the children, their siblings, and their home situation extensively. As part of preparing for the data collection the researcher made two home visits to each of the participating families and spent several hours with the children and their families. This was important to develop a relationship with the children and their families and to help the children understand what they would be doing, prior to data collection. Based on the knowledge obtained from these visits it was possible to create a list of questions that the children might be interested in asking so that we could prepare for them.

Due to the importance of using photographs to aid recall (Aschermann et al., 1998), we decided to start the initial session by using the photographs that the children
had brought with them. Three weeks prior to the beginning of the study each of the children's families was provided with a single-use camera. Each camera had enough film for twenty pictures. The parents were requested that whenever possible the children should be allowed to take their own photographs of their family. This decision was made so that at the beginning of the first session the children would have ownership of their photographs, and therefore want to talk about the images they had taken. This provided an initial place to start talking about their families and to begin to build a relationship with the children.

**Overall pattern of the sessions.** Taken together, the overall pattern of the five sessions was that of an emerging project as identified in the Reggio Emilia Approach to education by Katz and Chard (1989) and Saltz (1997), where the project is defined as an activity that is jointly planned by the teacher and the children and is something that unfolds over time and has no defined direction. Each of the individual sessions had its own particular predictable structure. The children were greeted on arrival and their family members were allowed to stay in the playroom for a short while. After the first session, because it was understood that the children needed some gross motor time before they could participate in the play session, they were given approximately fifteen minutes at the beginning of each session to play in the gymnasium. Tricycles and large balls and hoops were put out for their use.

Prior to the start of each session the teacher would write the agenda of each session on a whiteboard. This whiteboard was placed in the small meeting area and introduced to the children at the beginning of the first session, after the getting to know you time. It was then used at the beginning of each of the subsequent sessions. On the
whiteboard was written the sequence of the day’s session. The sequence was identified with words and pictures to ensure that the children would know what each session would involve. We also used the whiteboard as the session proceeded to ask the children what was going to happen next. This provided a predictable sequence to the sessions.

Each session began with information sharing. The first session involved sharing of information about the children’s families, but all subsequent sessions involved sharing of information about their sibling’s illness, doctors, hospitals and surgery. During the sharing time photographs were used to help the children remember what they had done in the previous session. At the beginning of the first session the children’s photographs were placed in little individual baskets. The children were then asked to take out the photographs one by one to share them with the other children. The teacher used these photographs to find common life experiences between the children. This was thought to be a necessary part of building a relationship between them. At the end of this session a washing line was strung across the corner of the playroom where the meeting place had been. Each of the children’s photographs was pegged onto the washing line. These photographs stayed on this line for the remaining four sessions. For each subsequent session new photographs of the previous play session were placed in the same baskets that the children had used the first day. At the beginning of each session the new photographs were taken out of the baskets and discussed, to aid recall of what had happened in the previous session. Some of these photographs were then chosen and also placed on the washing line.

Following the sharing of information the children participated in two group activities, one unstructured and one structured, with a focus on something that had
occurred as part of the children’s discussions. In all five sessions we used playdough as
the medium in the unstructured activity. Playdough was chosen for this activity because
all children seem to like it and are familiar with its properties, and will often talk about all
kinds of things while they are engaged with this material. The properties of playdough
seem to have the ability to free children’s hands from their minds while keeping them
purposefully engaged. To ensure that the playdough did not provide any other
provocation than as a vehicle for keeping the children’s hands busy while freeing their
minds, we chose not add any colour or scent. The purpose of this activity was to
encourage the children to talk to each other and to share ideas, enabling the teacher to
focus on the children’s theories. The structured activity changed each session. In the first
session the children made a stick puppet of their brother or sister; in the second session
they used loose parts (recycled materials that can be used to represent anything the child
many be interested in depicting) in a group collage; in the third session the children used
clay and sculpting tools, and in the fourth and fifth sessions the children made a sign for
their hospital and generated a song in celebration of what they had done.

Following the sharing time and the two activities the children had snack. This
provided another relaxed sharing time to talk to the children and to find out more about
their families and their interests as they related to their siblings.

Snack was followed with a dramatic play session and a closing where we asked
the children what they wanted to know about next time, and what they would like to see
in the doctor’s office or the hospital. The children and the teacher made a list of these
requirements. Most of the sessions involved the children doing homework with their
parents for next time. The homework involved the questions they had about their
sibling's illness. The following session always started by asking the children if they had completed their homework, sharing this homework together and then reminding the children about the new items that we had included from the previous day's requests.

**Data Collection Procedures**

Data collection occurred continuously across all five sessions from the beginning of each session until its end. The data collected were in the form of digital video- and audio-taped recordings of the children's conversations and their play as they interacted with each other; digital photographs of their interactions, play and their representations; examples of their writing and their representations either graphic or three dimensional; running record observations and reflections from the research group as the digital video recordings and the children's representations were reviewed from each of the sessions.

The primary researcher captured the children's experiences on digital videotape using a Sony Digital Video Camera Recorder model number DCR TRV39, and the college professor collected photographs using a Cannon Power Shot S10 digital camera and observations of the children utilizing the running record format. Running records are narrative descriptions of a particular sequence of events in a chronological order. They are typically used in early childhood settings when observing children and can cross time periods of minutes, hours, days or even weeks. The running record has the ability to paint a complete picture of the context and the child or children's behaviour within that context, so that reader can visualize the situation. Running records include an indication of the time the child was engaged with a particular activity (Wylie, 1999). The still photographs were taken to augment the observations that were recorded using the running record format. No running record data was collected while the still photographs were
The children’s conversations throughout each session were collected on audi-tape. Two nEXXTECH wedge boundary omni-directional microphones, model number 3303022 were used to ensure that that the children’s conversations were collected as clearly and as accurately as possible. One microphone was connected to the digital video camera and the other was attached to the audio tape recorder. Any drawings, sculpture or written notes created by the children during the sessions were retained for analysis. Photographs were taken of playdough and in-process graphic representations.

These tools of observation (digital-video and audio recording, photographs and running records of the children at work and play) were used as part of the data collection procedures because they are fundamental to the process of pedagogical documentation (Dahlberg et al., 1999), which was used as part of the system of analysis within this study.

Data Analysis

Preliminary data analysis was started immediately because we were using the data collected from the children daily to determine the direction of each of the subsequent sessions. At the end of each session the digital videotape and the children’s drawings and sculptures were reviewed; the written observations were shared; and much discussion occurred about the direction of the following session, before planning for the next session. A log was kept of these reflections. Planning for the subsequent sessions included thinking about the focus of our questions and the photographs that would be used to help the children recall the previous session. The subsequent session always started with a check-in to ensure that the children supported the initial analysis.
Following the end of the study the audio-tapes were transcribed and the observations, both written and digitally collected, were sorted and analysed to determine categories of understanding. After reviewing the data as a whole it was apparent the children's understanding fell into two major areas - sophisticated understanding of medical equipment and procedures, and major differences in the level of understanding than would be expected from the published literature. Consequently, the data from each session were examined for evidence of these two major areas and then sorted once again into subcategories under each major area. Each subcategory was then re-sorted, re-examined and coded for the children's level of understanding as they moved throughout all four quadrants of the Vygosky Space. This process was tracked by utilizing microgenetic analysis. From this analysis it was possible to determine the well sibling's current, transitional and new knowledge and how this knowledge changed or grew as a result of participating as a member of the group. This analysis of the children's movement through the Vygosky Space was holistic in that the digital videotape, audio-tape, photographs and the children's representations were examined as a whole for each subcategory. This analysis allowed for the well sibling's current, transitional and new knowledge to become apparent, and as such provided the data to begin to answer the questions that are the focus of this study.

The interrelationship between the philosophy of the study and the choice of methodology and analysis is illustrated in figure 3.1.

The results of the analysis were compared to what is currently known about children's understanding of illness within the traditional and contemporary literature. The findings are discussed in the following chapter.
Figure 3.1 Relationship between the Reggio Emilia philosophy, a Qualitative, Case Study design, and the Vygotskyian Social-Cultural Framework
Chapter IV

Results and Interpretive Discussion: Documenting the Co-Construction of Understanding

Data Format and Presentation

Because the research was completed using principles inspired by the Reggio Emilia Approach the results are presented in the form of pedagogical documentation. Pedagogical documentation refers to “two related subjects: a process and an important content in that process” (Dahlberg, Moss & Pence, 1999, p. 147). Content refers to any material which records what the children are saying or doing, and includes such things as photographs, digital video, audio recordings, drawings and handwritten notes of what was said and done. This material makes the children’s work concrete and visible to others. The process involves use of this material in an interpretive way through reflection independently, with other teachers and researchers, and with the children themselves. Pedagogical documentation functions as a tool to open up dialogues with dominant discourses and to construct counter discourses through which new, alternative understandings can be created (Dahlberg, Moss & Pence). Therefore, because pedagogical documentation has been used extensively within this study the results are presented using a reflective, interpretive style, demonstrating the two interrelated subjects of process and content in determining the understanding inherent in the work.

Where transcripts of the sessions are included, the transcript number (1-5) represents the session number.

Choice of Method of Analysis

In order to answer the questions that form the foundation of this study it was
important to use a system of analysis that has a tradition of being used within a socio-cultural framework, and would allow for systematic analysis of the children’s movement through the four quadrants of the Vygotsky Space. Microgenetic analysis is associated with the work of Vygotsky (Catan, 1986) and has the ability to provide an accurate picture of how children build their knowledge across time, providing the much-needed detail necessary to obtain an accurate picture of children’s initial understanding and their learning processes (McKeough & Sanderson, 1996).

Microgenetic analysis allows one to focus on the granular process of change by examining the material through densely-spaced time intervals. It assists in understanding how learning takes place. It allows one to determine at what point understanding begins and how individual differences in knowledge and learning affect the learning of the group (Siegler, 1996), which in this study relates to the two well siblings’ interrelationship with the rest of the group, and how this affects their learning. Microgenetic methodology enables the researcher to trace these minute changes in development, as the methodology has grown out of an interest in understanding the developmental process of learning from its beginnings (genesis) through a series of approximations to the original stimulus to its conclusion (Catan, 1986; McKeough & Sanderson, 1996). Microgenetic methods, therefore, enable the determination of the learning process from its beginning to its conclusion and, as such, make it an excellent tool to use in the process of answering the questions that form the foundation of this study.

The ability to observe the learning process in action requires the use of three key properties that define the microgenetic approach:
1. Observations span the entire time period from the beginning to the end.
2. The high density of observations enables the determination of both qualitative and quantitative change in the learning process.

3. The observed behaviour is intensively analyzed, with the goal being to infer from the data how the learning or the change took place (Siegler, 1995; Siegler & Chen, 1998; Siegler & Crowley, 1991).

These methods, combined with the trial-by-trial analysis of strategies used or developed by the children, provide the fine-grained data that are necessary to understand the learning that has occurred (Siegler, 1995) because together “they leave a trace of the rapidly shifting thinking that often characterizes cognitive growth” (Siegler & Chen, 1998, p.2).

Historically, when analyzing data on children’s learning processes, researchers have taken snapshots (e.g. before and after the learning has taken place) and from them determined that learning had occurred (Siegler, 1995.) However, although this methodology demonstrates that learning has taken place, it does not demonstrate how exactly the learning occurred, whether the learning occurred gradually, whether there was a sudden discovery or even what influences may have facilitated this learning (for example, other group members or life experiences) (Siegler, 1996). Therefore, this way of analyzing the data is not suitable for determining children’s understanding of their sibling’s progressive illness, because it is unlikely to yield data sufficiently rich enough to investigate the nature of their understanding.

Microgenetic analysis enables the distinction to be made between distal and proximal influences on learning. Distal influences are those experiences and/or knowledge that one brings to the learning situation. Proximal influences are those that
occur within the learning group and include such things as hypotheses that are formed, new strategies and skills that are applied, and changing and developing new ideas of how things work. The ability of this method of analysis to demonstrate these distinctions makes it an excellent tool for tracking the children’s movement through all four quadrants of the Vygotsky Space as they make their current, transitional and future knowledge apparent, through social interaction and reflection on both the content and the process.

Consequently, in this case study two levels of analysis occurred. The first level involved looking for specific themes of understanding. These themes were then clustered together into two major areas of analysis - major differences in conceptual understanding between the observations and what would be expected according to the published literature, and sophisticated understanding of medical procedures and equipment. Following this, a secondary level of analysis occurred using microgenetic methodologies. A microgenetic analysis was performed on all of the data that were clustered under each of these two overarching themes, as the children moved through all four quadrants of the Vygotsky Space. This analysis enabled the determination of their initial understanding of their sibling’s illness within the two major areas of interest and how they represent this understanding. It also enabled the tracking of the nature of the changes that occurred over each of the five sessions. It was expected that the children would come to the initial session with a base knowledge of their sibling’s illness and that this knowledge would change over the sessions because they were part of the group. This expectation was supported in the data. The changes in the children’s understanding were tracked from their beginnings to their final form via the representational tools used in the sessions.
Discussion of the Analysis

As already described, the analysis of the data fulfilled two purposes. The first was to determine the children’s knowledge about their sibling’s illness. This information was used to develop the program in which the children were participating. The second purpose was to answer the questions that form the foundation of the study. Due to the reflective process of analysing this data, the results and the subsequent discussion sections were discussed using a personal tone. The personal pronouns “I” and “we” were used at various times to reflect the two different types of analysis that occurred in this study. The personal pronoun “we” is used to discuss the analysis that occurred collectively by the research team in order to build the investigation with the children, and “I” is used when discussing the analysis that occurred alone.

In order to reduce the possibility of manipulating children’s ideas in this investigation we used a process called negotiated learning (Forman & Fyfe, 1998). Negotiated learning has its roots in reflective practice, which sees knowledge as socially constructed slowly over time by people coming together, sharing ideas and effectively being each other’s student. By taking a reflective stance towards each other’s ideas a deeper understanding of the subject develops. This methodology holds that “knowledge is never verifiable through listening or observation alone, but rather it gains clarity through a negotiated analysis” (Forman & Fyfe, 1998, p. 239).

Negotiated learning begins with close observation and documentation. In negotiated learning the ideas flow from the children and are made visible through their play, their conversations and their representations. The teacher’s role is to observe carefully, noting topics of play or conversations that seem important to the children. This
allows the investigation to grow out of the children’s interests, rather than the interests of
the teacher, or in this case the researcher. This type of investigation cannot be planned for
but it can be planned through the analysis of documentation, provocation and preparing
the environment (Oken-Wright, 2004).

In this investigation the research team tried to allow the themes or topics that
occurred over the five sessions to grow out of the children’s needs and interests.
Consequently, after each data collection session we collectively analysed the digital
videotapes, photographs and the children’s representations, looking for major themes or
questions. We wrote these themes and questions down and then discussed them in depth.
From these themes and questions we planned learning encounters that would enable the
children to continue to investigate their questions; provide opportunities for them to
revisit and reflect on earlier ideas, and then to build on or reconstruct their ideas through
play, representations and conversations with the other children and the teacher. The major
themes and questions that the well siblings identified as important to them are as
presented in table 4.1.

Table 4.1
Major Themes and Questions Identified by the Well Siblings

<table>
<thead>
<tr>
<th>Themes</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>How people die?</td>
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<tr>
<td></td>
<td>What it means to be dead.</td>
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<tr>
<td></td>
<td>Who dies!</td>
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<td></td>
<td>What happens when you die –</td>
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<td></td>
<td>spiritually and physiologically.</td>
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<tr>
<td>Hospitals: emergency hospital procedures;</td>
<td>What is surgery?</td>
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<tr>
<td>routine hospital procedures; difference</td>
<td>What happens in surgery?</td>
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<tr>
<td>between the care needed in doctor’s office</td>
<td></td>
</tr>
<tr>
<td>and the care needed in a hospital.</td>
<td></td>
</tr>
<tr>
<td>G-tubes: location on the body; being</td>
<td>What is a G-tube?</td>
</tr>
<tr>
<td>Fed through a G-tube.</td>
<td>How does a G-tube work? The difference between a G-tube &quot;hose&quot; and an oxygen &quot;hose&quot;.</td>
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<tr>
<td>----------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>X-rays: how to take them; why you needed to take them; type of camera used; the parts of the body that could be seen on an x-ray, and how to read them.</td>
<td></td>
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<tr>
<td>Importance of writing notes.</td>
<td></td>
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<tr>
<td>Specialized hospital appointments.</td>
<td></td>
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<tr>
<td>Doctor speciality: brain doctors, bone doctors, tummy doctors and doctors who just take notes.</td>
<td>What is a surgeon? What is a tummy doctor called?</td>
</tr>
<tr>
<td>Germ theory: dressing disposal</td>
<td></td>
</tr>
<tr>
<td>Germ protection procedures: hand washing; protective garments, and dressing disposal</td>
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</tr>
<tr>
<td>The need to take medication: how medication can be administered; why you need to take medication, and what will happen if you do not take prescribed medication.</td>
<td></td>
</tr>
<tr>
<td>Use of peripheral intravenous drip: mobility of the apparatus; understanding of the types of fluids inserted into the saline bag, and why a peripheral intravenous drip is needed.</td>
<td></td>
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<tr>
<td>Diagnostic procedures.</td>
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<tr>
<td>Wheel chairs: how they are used and why they are used.</td>
<td>Why is it that some people cannot walk?</td>
</tr>
<tr>
<td>Brains: where they are located in the body; how they work, and what they can do.</td>
<td></td>
</tr>
<tr>
<td>Oxygen: people die without oxygen; how supplementary oxygen is &quot;squeezed or pumped&quot; into the body; where/how you inhale supplementary oxygen, and the length of tubing needed to deliver supplementary oxygen</td>
<td>Why do some people need to use oxygen? What do the dials on an oxygen tank mean? Who uses oxygen? What happens if someone steps accidentally on an air &quot;hose&quot;? Types of oxygen—liquid or gas</td>
</tr>
<tr>
<td>Dressings: types.</td>
<td></td>
</tr>
<tr>
<td>Contamination and Contagion: identification of the difference.</td>
<td></td>
</tr>
<tr>
<td>Internal sources of illness: hearts stopping beating; blood pressure falling, and brains not doing well.</td>
<td></td>
</tr>
</tbody>
</table>
Body parts.

| Medical equipment: stethoscope; blood pressure cuff; syringe; x-ray machine; peripheral intravenous drip. |

These themes and questions that were evident throughout the five sessions and collectively identified by the research team were re-analysed at the end of the study. This was completed by performing a microgenetic analysis of the children’s learning process via examination of the content (the digital video tapes, transcriptions of what the children were saying, running records, still photographs and examples of the children’s work) through each of the quadrants in the Vygosky Space. In this process particular interest was paid to the knowledge the children brought to the learning group, how this knowledge was represented and how their knowledge changed or transformed by being part of the learning group.

**Sophisticated Understanding of Medical Equipment and Procedures**

Throughout the five data collection sessions the well siblings demonstrated a very sophisticated understanding of medical equipment and procedures, particularly Joshua who was the eldest of the two. From the analysis of the play observed it would seem that this knowledge had grown from the constant visits to the hospital, and the need to build the repeated hospitalisations of their siblings into their daily lives. As we analysed the data it was evident that these children had experienced repeated emergency visits as well as visits for ongoing medical examinations and procedures with their siblings. The children were able to replicate these three different reasons for a visit accurately in their play, and to provide explanations for certain types of procedures and medical equipment during work time and sharing time. The following play episodes demonstrate the
children’s understanding of a hospital, the procedures and processes that occur in it, as well as their understanding of particular equipment. As part of the analysis I investigated the children’s understanding of a hospital and of the procedures and processes that occur there, prior to the analysis of their understanding of particular medical equipment. However, in the play episodes that surround the initial investigation of hospital play, evidence of children’s understanding of certain types of medical equipment occurs. This evidence is addressed more specifically in later sections.

*Hospital and emergency play.* Even though a great deal of care was taken to ensure the authenticity of the play space as a doctor’s office, when the children entered the drama area their initial reaction was to engage in hospital play, rapidly followed by emergency play. The first play episode described below occurred within the first few minutes of entering the drama area. It describes the well siblings understanding of initial hospital procedures. In this first episode it can be seen that the children have taken the photographs of the doctor’s office that were projected onto the wall off the overhead, and replaced the projected image with a doll. From this point the overhead becomes an x-ray machine, and remains an x-ray machine for four data collection sessions.

*Hospital play.* In this opening play scenario Claire takes the role of the doctor, asking the nurse, Martha, to report on the baby’s health status.
Claire: I am doing the notes on the baby ok! Is the baby fine?
Martha: The baby is doing great!
Teacher: Joshua can you go down there and look at the baby and see what the x-rays look like?
Joshua: Broken bone! Broken bone!
Teacher: Is there any broken bones?

Joshua: I'll see! I'll see!
Martha: We just have to move this light.
Joshua: Looks fine!
Teacher: There's no broken bones?
Joshua: No!
Martha: We had better do something!
Teacher: What kind of something? Is the baby going to be ok?
Martha: We need this (brings a syringe). I am pumping some more air in her!
Teacher: You're pumping some more air in her!

Martha: Just squeeze air in!
Teacher: Just squeeze air in with what?
Martha: With this!
Teacher: I think you're an oxygen expert! I think you had better go and show her how oxygen works
Joshua: I am hurrying.
Joshua: Lifts the syringe – Is this oxygen?
Martha: That's the oxygen breathing thing!
Teacher: Did you get the oxygen in ok!
Joshua: The baby is going to be just fine!
Emergency play appears.

Transcript 1: Lines 1412-1454

Martha: I need this (takes the stethoscope). I need to listen to the baby’s heart!
Martha: It's not pumping the baby's heart is not pumping — it's not!
Teacher: What will happen?
Martha: She will die!
Teacher: What shall we do?
Joshua: (Rushes and says) We need this! (Holding the blood pressure cuff) We had better put this round.
Teacher: What is that? How can it help?
Joshua: Its just going to be — its just going to check something!
Teacher: Ok!
Joshua: Ok I will put this around. (Places the blood pressure cuff around the baby’s arm and pumps.)
Martha: (Using the stethoscope listens to the baby’s heart.) It's pumping! It's pumping!
Martha: We are gonna hafta hurry.

Joshua: I am gonna do some notes.
Teacher: Martha, ask him what the notes say so that you know what you have to do!

Martha: (Using the telephone) Hello! Can you help please? Can you come and help us? You have to help us because one of the babies are dying! Her heart’s stop pumping! Bye!
This movement from hospital play to emergency play occurred within the first few minutes of the children playing in the drama area, during the first data collection session. The pace of the play suddenly changed from the gentle pace of taking a case history to the frantic pace of an emergency situation. The children developed a sense of urgency in their conversations and their movements in and around the play situation. Knowledge of emergency procedures was very evident. The children acted out falling blood pressure, failing heart rate and the need to take copious quantities of notes so that when they called other doctors to "come and help" they could explain what had happened. Four out of the five children were involved in this play scenario and they all worked together as one cohesive unit, even though they were requesting items that needed to be located and then brought in to the play situation. None of their roles overlapped and it was evident from their play (behaviour and dialogue) that there was an understanding that all their roles were important. The key players in this scenario were Joshua and Martha.

Even though the physical context in which this emergency play was occurring represented that of a doctor's office, the children played as if they were in a hospital. This intense level of emergency play continued throughout this dramatic play session with the additional themes of operations and death arising.

Transcript 1: Lines 1478-1486

Teacher: How can you tell that she is not feeling good?
Martha: Because she is having an operation.
Teacher: Operation! What is she having an operation on?
Joshua: This is bad.
Martha: Her stomach!
Teacher: Oh! Oh!
Joshua: And she is also having an operation on her knee!
Teacher: Her knee?
Martha: Is this a real bone Amy?
Teacher: No!
Martha: I need to fix this!
Martha: Hi! It's me! Dr. Martha and we have to go and fix the baby for now bye!
Joshua: And she is going to die if we do not do it quick!

When reviewing all four transcripts for additional examples of hospital and emergency play it was interesting to see how the play changed in the subsequent sessions from emergency play to that of medical examinations and procedures that would occur after someone had been admitted to or referred to the hospital. Within the play episodes and during work and sharing time there was evidence that the children had a rudimentary understanding of doctor speciality. In the following play episode, the children move from discussing doctor's speciality to performing a medical examination where the “brain doctor”, who “works on bones and brains” performs an examination.

Transcript 2: Lines 833-854

Teacher: Do you remember which doctors you were yesterday? You each had a different role. Do you remember what doctors you were?

Martha: Yeah, I was a back doctor, yeah, yeah, yeah!
Teacher: What kind of doctor were you?
Joshua: A brain doctor.
Teacher: You were a brain doctor. And what about you Emma, what kind of doctor were you?
Emma: I was a belly button doctor!
Joshua: I check the brain and bones
Teacher: How are you gonna check my brain?
Joshua: (Points to the bed). . . on there!
Teacher: I'm a little busy right now I am having my brain checked.
Joshua: and your bones checked . . . stay there I will be right back.
Teacher: Do you need a nurse?
Joshua: No.
Teacher: Can I sit up while I wait for you?

Joshua: (Leaves to put on foot covers and then picks up the notes) I'm afraid you will not be able to sit up for a couple of days.

Teacher: How come? What is my diagnosis?
Joshua: 'cause I need to check the bones and the brain. I'm afraid the bones don't look that good.
Teacher: Why don't they look that good?
Joshua: 'Cause of the needle and the bones and I need to check your brain.
Teacher: You’ll check my brain? I hope my brain is doing better than my bones.
Joshua: Your brain is fine.
Teacher: Did you check my whole brain?
Joshua: (Nods yes!) Can you point to the part of my brain that is not doing so well?
Joshua: Actually none of the parts are mmm! All of the parts are fine.
Teacher: Oh Yay! Can I go now?
Joshua: You have to stay here.

Teacher: Here?
Teacher: Katie can you bring me a wheel chair so that I can go for a walk and I do not have to stay in the hospital? I need some fresh air.
Joshua: Yeah! Because, because if she doesn’t go in the hospital she will have to stay in the hospital . . . and if she does not have air then she will have to stay even more days.
Teacher: If I don’t have air . . . but remember if I don’t have air you can put an oxygen tube in me and then I would have air. So am I that bad that I need oxygen?
Joshua: Bad, but you need two glasses of medicine everyday.
Teacher: Two glasses or two shots?
Joshua: Two shots of medicine every day.

Teacher: Where does the medicine go on my body? How do you administer medicine?
Joshua: It is going in your mouth.
Teacher: Yuck! That tastes awful!
Joshua: I am sorry that is the only medicine that we have!

Teacher: Is it! I need a glass of water I will be right back.
Joshua: You are supposed to have. You are supposed to have . . .
(Teacher leaves the bed and goes to get some water. Joshua approaches)
Joshua: I’m afraid you still need to be in bed.
Teacher: Ok! I’m supposed to be in the hospital. Katie will you visit me because I will be lonely in the hospital.
Joshua: You will not be lonely because I will be there.
Teacher: You’ll be there? Do doctors stay with patients all of the time?
Joshua: I will be there sometimes.
Teacher: Sometimes. Katie will you come and keep me company?
Joshua: You have to drink something.
Teacher: Ok! What do I need to drink?
Joshua: You have to drink chocolate so that you will get better.
Teacher: Ok! So I have to drink it just to get better?
Joshua: Sometimes you have to drink things you do not like.
Teacher: Do you have any tricks for how I should drink this without it coming up again?
Joshua: Do you like apple juice?
Teacher: I love apple juice.

This play episode demonstrates the depth of Joshua’s understanding of medical procedures that occur in hospital, after admission. He leaves the patient to prepare for the examination. He puts on protective bootees, collects the notes on his findings and then shares these findings with his patient, clearly providing a rationale for the need to stay in hospital along with the possible duration, and appropriate medication to remediate the situation, including dosage amounts. In this play episode he even demonstrates that he understands the need for psychosocial support. When the patients demonstrates reluctance to take the medication because it “tastes awful” he asks if they like apple juice.

At the end of session two we asked the children what they needed in the home corner for the next time. We felt that it was important to do this because we wanted the children to demonstrate their understanding of the illness process and we felt that by providing the children an opportunity to identify their own needs they would be more likely to demonstrate what they knew. The Teacher wrote their ideas down as they shared them to demonstrate that we thought the children’s ideas were important, and also to remember their requests for next time.
Teacher: So for next day when you guys come next weekend, is there something that you’d like me to bring?
Joshua: Yes!
Emma: Yes!
Teacher: What can I add to the house corner that would make you happy?
Claire: Everything in a hospital, to make it look like a real hospital.
Teacher: Make it look like a real hospital?
Katie: And flowers.
Teacher: And flowers. Flowers are really important for a real hospital, aren’t they?
Joshua: There has to be more beds!
Teacher: More beds, okay.
Teacher: More beds. And what did you say Katie? You said more flowers?
Teacher: And Martha, what do you think is missing in the hospital?
Martha: A picture.
Teacher: Oh pictures. And what kind of pictures?
Martha: Some pictures.
Teacher: Like pictures on the wall or –?
Martha: Wall.
Teacher: And Claire, what do you think is missing in our hospital?
Martha: Um, pictures.
Teacher: I’ve got that down. Look at it, I wrote your words right there. P-i-c-t-u-r-e.
Emma: Excuse me, could you please write me –?
Katie: And doctors.
Teacher: We need doctors. So we need more, oh okay, what kind of doctors?
Katie: All doctors.
Teacher: All doctors. Alright! And what about you Claire?
Claire: Um, pictures.

As per the children’s request we reset the home corner to be more a like a real hospital for the third and fourth sessions. We added more beds and created a ward-like atmosphere, with a nursing station at the entrance to the ward area and two examination rooms.
One room was set up with the overhead, which the children had previously used as an x-ray machine. We added the light table to this area because we wanted to see if the children would demonstrate knowledge of how to read the x-rays as well as take x-rays, as they had done in the previous two sessions. We decided to use a light table in this area because it is very similar in concept and usage to the light screens that are commonly found in hospitals and used to read x-rays.

The other room was set up as an examination room. In this room we provided hand-sanitizing products, paper towels and latex gloves, a peripheral intravenous drip with a hanging pole, a child-size wheelchair, an oxygen tank with cannula and line, and an examination area. We were curious to see how the children would respond to the change in space and what they would demonstrate in their play.

Prior to opening the doors into the hospital area we asked the children to think about what happens in a hospital. We asked them to identify who were going to be the patients and who were going to be the doctors. We asked them if the hospital should have a name – they decided that it should and called it “Children’s Hospital”. They proudly made a sign for it and then made up a song in celebration as they hung it over the entranceway.

**Children:** Let there always be doctors! May there always be nurses! May there always be mommies! May there always be love!

The children sang this song at the opening and the closing of the hospital each session.
The children's play in the hospital over sessions three and four was much more organised and less frantic. Their interest focused on medical examinations and procedures. The children rotated the role of doctor and patient. The patients would lie in their beds and the doctors would do their "rounds". It was visible that the children had an understanding that the doctor had notes when they talked to their patients. Patients were taken into one or other of the examination rooms for medical examinations and procedures.

Movement around the hospital occurred in the wheel chair and the medical procedures involved giving a medical examination and providing a diagnosis; casting broken bones; giving intravenous and oral medication; reviewing x-rays, and cleansing an eye. Katie spent a great deal of her time demonstrating her knowledge of a G-tube and the peripheral intravenous drip. Ideas around length of stay in hospital emerged. The following visual essays demonstrate the well sibling's understanding of hospital procedures.
Intravenous medication.

Transcript 3: Lines 1718-1788

Teacher: Ok! Nurse Katie is going to help me out here. Tell nurse Katie where you want us to go!

Joshua: Right there! Go that way!

(Joshua takes the end of the peripheral intravenous fluid line and places it on the Teacher's hand.)

Teacher: Does it go in my hand like that?

Joshua: No! I will get you a band-aid. I have got a band-aid.

Teacher: Promise it won't hurt!

Joshua: It won't hurt.

Teacher: You had better put it on me if it won't hurt.

Joshua: I will put it on!

Teacher: I am really scared!

Joshua: It won't hurt a bit.

Teacher: Oh! It won't hurt a bit. Oh! You're going to put it over here. Oh! Is that where you are going to put it? That will reinforce it.

Joshua: What does reinforce mean?

Teacher: Well doesn't hurt that much! Is there medicine going into my body right now? (The teacher asks this question as Joshua is inspecting the intravenous line, checking and adjusting the flow.)

Joshua: Yes!

(Joshua turns the fluid bag to look at it, presses the bag with his hands to check what is inside and then adjusts the flow rate.)

Teacher: What does that do?

Joshua: It makes it go more.

Teacher: Do I need more?

Joshua: I need to check your temperature. Right now it's high.

Teacher: I think I need to go back to my room right now!

Joshua: This is your room! But before
you go on your bed you have to have one x-ray.

Teacher: How can I have an x-ray with this stuck in my hand?
Joshua: I get it out. (Joshua pulls out the peripheral intravenous line.)
Teacher: Are you going to take it out? Ow! I think I need a band-aid. (Turns to Katie) I like your idea that band-aids make you feel better, so could I have a band-aid?
Martha: Amy what is this?
Joshua: It's a different kind of band-aid, only that kind does not stick (describing a dressing).
Martha: Katie how do you open this?
Katie: You need to cut it.
Teacher: Oh! That is a good idea.

Taking and reading an x-ray.

Transcript 3: Lines 1791-1800

Joshua: (Takes the Teacher over to the light table in the wheel chair.)
Teacher: What are you x-raying?
Joshua: I just need to check your bones!
Teacher: Ok!

Joshua: Your foot is fine, your head is fine and your tummy is fine.
Teacher: Oh! Head, foot, tummy (Points to the x-rays).
Joshua: Now you have to go on the bed.
Giving medication.

Transcript 3: Lines 1835-1875

*Joshua:* You have to take some medicine right now.
*Teacher:* I don’t want to!
*Joshua:* You have to do what the doctors and nurses tell you usually.
*Teacher:* I don’t want to!
*Joshua:* If you do not do what the doctor tells you then you will not get better.
*Teacher:* I don’t want to.
*Joshua:* But you have to drink what that doctors and nurses tell you to drink
*Teacher:* I don’t want to. What if I do not want to get better?
*Joshua:* Then you will be sick until you die.
*Teacher:* Then I had better take the medicine then?
*Joshua:* Yes and drink what the nurses and doctors tell you to drink.
*Teacher:* As soon as we have done my examination you will be able to go for a walk. Is my examination over yet guys?
*Joshua:* It will take a bit of a while yet.

This series of photo essays demonstrates not only a deep understanding of a hospital as a location, but also of the processes and the procedures that occur in it. In session four when Joshua enters the hospital ward for the first time that day, it is evident from his behaviour that he understands the doctor-patient relationship. He goes into the ward, remembers that he needs his notes, returns to the receptionist’s desk and collects the clipboard, and then returns to the patient’s bedside and begins to discuss the case.

Katie and Joshua worked closely together when administering the peripheral intravenous drip. It is visible that they both have a clear understanding of the procedure that needs to occur and they follow it exactly. The peripheral intravenous line is attached to the back of the Teacher's hand. They tell her that it will not hurt and Joshua has a band-aid prepared to attach the line to the back of the Teacher’s hand and Katie applies
the gauze afterwards as protection. After pretending to insert the line into the back of the Teacher’s hand, Joshua very carefully monitors the flow, and when questioned explains what he is doing and why he is doing it. Joshua informs the Teacher that it is medication, not water, in the intravenous drip, demonstrating that he understands medication can be given both intravenously and orally.

The general pattern of behaviour demonstrated by the siblings in these two sessions provided evidence that they understood a number of highly complex hospital procedures. First, rounds occurred, followed by the patients being taken to the examination rooms where various procedures were performed. Frequently, groups of children worked together on these procedures, demonstrating that they understood that numerous individuals are often involved. The nurse’s role, played by Katie, was frequently portrayed in a gentle, supporting manner. Once the procedures were completed the patients were then returned to their bed in the ward and visiting occurred. The children demonstrated an emerging sense of time associated with the various procedures.

In the play episode where Joshua tells the Teacher that she must take medication the Teacher asks, “Is my examination over yet guys?” and Joshua replies, “It will take a bit of a while yet”. The children’s ideas around visitation involved playing games on the bed, rather than bringing gifts and sitting talking.

When analysing the data above with relation to traditional Piagetian thinking, there is no evidence of the children focusing on just one aspect of the illness process, which according to the work of Piaget and others one would expect in this particular age group. From the well sibling’s behaviour it is apparent that the children realise illness to be a complex medical process which involves a visit to the hospital and a variety of
medical procedures, and may involve emergency procedures.

According to the traditionalists, young children interpret illness as caused by a concrete action and recovery as occurring by adhering to a set of rules. From the analysis of the data there was some evidence to support this understanding in Joshua’s rationale around the need to take medication:

**Joshua:** But you have to drink what that doctors and nurses tell you to drink.
**Teacher:** I don’t want to. What if I do not want to get better?
**Joshua:** Then you will be sick until you die!
**Teacher:** Then I had better take the medicine then?
**Joshua:** Yes and drink what the nurses and doctors tell you to drink!

However it is clear from other conversations discussed later, that he did not think that you could always get well from adhering to a set of rules.

From the sibling’s behaviour involving the peripheral intravenous drip and Joshua’s ability to review x-rays, it is clear that the children have an understanding of illness as an internal state, whose symptoms manifest themselves in an external way. However, there is evidence that some confusion still exists when certain procedures result in a positive outcome, for example “*Your foot is fine! Your head is fine and your tummy is fine*.” In reality this type of diagnosis would normally result in the patient leaving the hospital without the need for treatment. However in the sibling’s play the need to go to bed and take medication is still prescribed. From the analysis of all the sessions it is not clear whether this discrepancy is due to confusion, misinformation or following of a protocol they have observed with their siblings many times. On reflection, the choice of words, “*Your foot is fine! Your head is fine and your tummy is fine!*” sound like something the children may have heard during their many hospital visits, and they may have observed that even when their sibling received this kind of diagnosis, there was still
a need to go back to bed and receive medication of some kind. Consequently they incorporated this observation into their play.

From the analysis of Joshua’s conversations it is apparent that he is using psychophysiological terms when describing illness. He uses terms such as “she is not feeling good”, “she is not breathing well”, “it’s not beating that well” and “her heart is not beating at all” demonstrating that they can discuss symptoms in a more abstract way. The work of Buchanan-Barrow et. al. (2004) is supported in these play episodes. They suggest that increased exposure to, and experience with, illness increases children’s understanding, which causes structural changes enabling a much more sophisticated understanding of illness to evolve.

**X-rays and skeletons.** The children’s interest in and knowledge about x-rays and skeletons flowed through all five data collection sessions. Their initial interest was demonstrated during the first session when the children used the overhead projector as an x-ray machine. Joshua always identified himself as a brain and bone doctor and although most of the children had an understanding of x-rays and the x-ray machine he was the expert in this area. Joshua had a very sophisticated understanding of x-rays, which included knowledge of the machine that is used to take x-rays, how to read x-rays, who takes the x-rays and the parts of the body that are visible in an x-ray.

Due to the children’s general interest in x-rays we decided that this was a topic that we wished to investigate with them further, so we added a variety of different activities during work time. Building on our initial observations of their interest, at the end of the second session, we created a game that was aimed at determining the children’s understanding of doctor speciality. We were curious to understand what they
knew about the different medical specialities and whether they would be able to associate
the parts of the body with the identified specialities of interest. The children had
introduced belly button doctors, brain and bone doctors, knee doctors and doctors who
just take notes, so we provided pictures of the parts of the body involved with each
speciality and asked the children to identify the type of doctor they were and then when
the music stopped locate a body part that was associated with that doctor. The children
were able to collect all body parts associated with their choice of speciality. Joshua, being
a brain and bone doctor, collected pictures of brains and bones.

In the third session, because of the children’s interest in x-rays and wanting to
provoke the children to think a little more deeply about this topic, we brought in a full
size skeleton, covered the playdough table with black plastic and provided white
playdough for the children to manipulate. We also placed pictures of skeletons on this
table as provocation. We were curious to see what the children would do and say when
they saw ‘Gracie’ the skeleton. We wondered if they would connect their understanding
of x-rays with the white playdough and the black plastic covering. In the dramatic play
area we placed full sized x-rays of a child’s head, chest and feet on the light table next to
the overhead to stimulate discussion about x-rays in the children’s play.

For the fourth session we changed the medium available on the playdough table to
black paper and chalk. However, we still chose to keep the pictures of skeletons from the
previous session, because we wanted to use them as links to aid recall of the previous
day’s experience and to help the children reconstruct their thinking with a new material.
Tarr (2005) discusses young children’s ability to use drawing as a learning medium and
quotes Brookes (cited in Tarr, 2005) as saying, it is “through the process of drawing,
redrawing and retelling of events that real understanding happens” (p.140). Consequently, we wondered whether a change in the medium would provide the children with yet another language to represent their ideas about x-rays and skeletons, and help them build on their ideas that occurred in the context the day before. The following documentation demonstrates the children’s knowledge construction and understanding.

The opening of session 3.

Transcript 3: lines 14-76

The children were sharing ideas about the Teacher’s drawing on the white board, and the following conversation occurred:

*Joshua:* Looks like a heart and some of your bones.
*Martha:* Bones in your hand.
*Teacher:* Martha can you circle what you think looks like bone? What kind of bones do you think this looks like?
*Martha:* Finger bones.
*Teacher:* Finger bones ok! I am just going to write finger bones so that I can remember.
*Teacher:* What is this bone called?
*Emma:* It’s a skeleton.
*Teacher:* But it is this bone (Teacher touches her forehead).
*Claire:* It’s a skull.
*Teacher:* It’s the skull.
*Emma:* It’s a skeleton.
*Claire:* It’s a skull.
*Teacher:* It’s called a skull. And what’s another name for skull
*Claire:* It’s your head.
*Teacher:* But what’s inside your head
*Joshua:* Your brain.
*Chorus:* Your brains.
*Teacher:* And were we talking a lot about brains last time?
In this opening episode the Teacher is introducing the tasks of the day and helping the children recall what they had discussed about bones and brains from last time. She does this to reinstate the context from the previous session, before allowing the children to become engaged in the new activities that we hoped would enable them to continue to build on their understanding of this topic.

*At the playdough table.* As the Teacher manipulates the playdough she talks to the children, asking them which part of the skeleton they are going to make.

Transcript 3: Lines 303-389

*Teacher:* Tell us when you’re ready. What about you Katie? How are you doing? What are you gonna do? What part are you gonna do?
*Katie:* The face.
*Teacher:* The face? That’s good. I see your skeleton face. Well done!
*Katie:* Here’s a piece.
*Teacher:* Here’s the piece.
*Katie:* This is my, this is my. . .
*Teacher:* Okay, I’m gonna do, I need the whole, why don’t I do the whole skeleton?
*Joshua:* That’s what I’m doing.
*Teacher:* I’m just making a whole skeleton.
*Joshua:* I’m doing one too! I’m making the whole skeleton. It’s hard to make the whole skeleton but . . .

*Joshua:* Now I’m making the eyebrows.
*Teacher:* The eyebrows? Are eyebrows made of bone or what are eyebrows made of?
*Claire:* Just soft.
*Joshua:* They’re just soft.
*Teacher:* Are bones soft?
*Claire:* No, hard.
*Teacher:* They are? Have you ever felt a real bone before?
*Claire:* No.
Teacher: Would you like to feel a real bone?
Joshua: I have! I feele a real bone!

Katie initiates the dialogue in this play scenario by telling everyone that she is going to make a face. Joshua builds on the teacher’s conversation by telling her that he is going to make a skeleton like hers and articulates that he is going to make eyebrows. The teacher, wanting clarification around Joshua’s thinking, asks what eyebrows are made of. Both Claire and Joshua reply that they are soft. Understanding that there is some confusion evident about the texture and physical origin of eyebrows versus eye bones we chose this moment to introduce Gracie the skeleton.

Transcript 3: Lines 435-487

Joshua: Are those real?
Emma: A neck!
Joshua: Are those really live bones?
Teacher: They are bones!
Joshua: Real live ones?
Teacher: They are bones!
Emma: Oh, it’s a skeleton!
Teacher: It’s a skeleton!
Joshua: Are those real skeletons?
Teacher: It is a real skeleton. I have an idea. I have to ask this lady here. Is it a real skeleton?
Lynda: Mmm, Mmm.

Teacher: It’s a real skeleton.
Joshua: Then those are all real bones.
Joshua: I’m making one of those right now!
Teacher: Where?
Joshua: Here, on the table!
In this play scenario it is interesting to see how Katie’s announcement that she is
going to make a face leads to the confusion about eyebrow versus eye bones, and to
Joshua creating a skeleton out of the playdough. Through his playdough creation
Joshua’s knowledge of skeletons is visible. All the major skeletal parts can be seen. The
head, body, arms (with hands and fingers) and legs are clearly evident. It is interesting to
note that he tries to portray depth in this two dimensional structure by layering the
playdough in the chest cavity area and ensuring that the tail end of the spine is showing in
between the legs, just as it does on Gracie.

As the children continue to manipulate the playdough, putting the finishing
touches to their representations, a discussion of aging and death occurs and Joshua tells
the children how you get bones.

Transcript 3: Lines 1052-1088

Joshua: And my nanna died because she was too old.
Teacher: She was too old?
Joshua: Yeah.
Claire: Died of old age.
Teacher: How do you die of old age?
Joshua: I don't know. I don't know. Actually I know.
Teacher: Okay, tell me.
Joshua: The body gets too tired every day.
Teacher: So when I'm tired, does that mean I'm gonna die?
Claire: No.
Joshua: No. When you are tired when, if you're too, when you're too old (Teacher: Yeah) and, and there's too many days, that's when – when 101 weeks.
Teacher: 101 weeks?
Joshua: I mean, I mean that many weeks, and once you get too old, um, and then you, then your soul goes up to heaven and you can't move.
Teacher: Your soul goes up to heaven and you can't move.
Joshua: Yeah.
Teacher: Mmm!
Joshua: You'll only be in the bones.
Teacher: Only you'll leave, you'll only leave your bones behind?

This was existing knowledge he shared with the other children. Joshua introduced the topic of how you get bones through his theory about death and dying. The teacher questioned his understanding, and helped him to maintain his focus so that he could explain his theory of how you become a skeleton.

Later in the same session the theme of x-rays reappears. This episode was part of a medical examination where Joshua was checking the Teacher's brain and bones. It is apparent in this episode that he is reapplying the knowledge he used earlier to create the playdough skeleton when assembling the x-rays of the head, chest and foot and that he realises that x-rays are a diagnostic tool.

Teacher: What are you x-raying?
Joshua: I just need to check your bones!
In session four the children are provided with another opportunity to revisit their ideas surrounding skeletons and x-rays. This time the children are provided with black paper and white chalk. Again the pictures of the skeleton are placed on the table to support the children’s thinking. Gracie the skeleton is placed close to the table.

Transcript 4: Lines 514-570

*Teacher:* Oh, you might need Gracie to come out too so you can get a real picture of a skeleton.
*Joshua:* I’m not doing the skeleton, I’m doing the x-ray.
*Teacher:* Oh I’m sorry, I’m sorry.
*Emma:* I’m doing x-ray too.
*Teacher:* Ta daaaa! An x-ray! Sure, you can do an x-ray. There you go.
*Martha:* I want to do the x-ray!
*Teacher:* Okay, you can do an x-ray.
*Joshua:* You can do whatever you want.
*Teacher:* What’s an x-ray?
*Joshua:* I’ll tell you!
*Teacher:* Okay.
*Joshua:* An x-ray’s something that you, you check the bones.
*Teacher:* How do they see your bones though? I don’t see my bones when I look at.
*Joshua:* It’s a picture of your bones!
*Teacher:* How do they take a picture of your bones? I took pictures of you guys all weekend last weekend and I didn’t see your bones in any of the pictures.
*Joshua:* No, it’s not a camera.
Teacher: Oh.
Joshua: It's an x-ray. An x-ray, it kind of is a camera who doctors use.
Teacher: Oh it's a camera that doctors use.
Teacher: So can you see, can you see eyebrows in an x-ray?
Group: No.
Joshua: You can only see that because you see the whole part of that! (Points to Gracie.)
Teacher: The whole part of that?
Joshua: Yeah, through the skin.
Teacher: Oh you see through the skin.

Transcript 4: Lines 888-900

Martha: Guess! Guess what my drawing is?
Teacher: Draw something first.
Martha: No, I just want something, see? See? Here's my x-ray!
Teacher: I see! What body part is your x-ray?
Martha: It's a body, an x-ray isn't part of your body, it's an x-ray that you see your bones.
Teacher: Oh I'm sorry.
Martha: To look if they broke or not.

In this session the children insist that they are making x-rays – not skeletons – and Joshua explains what an x-ray is, how you take an x-ray, the type of machine an x-ray is and who takes the x-ray. The Teacher, wanting to revisit the previous day’s confusion about eyebrows, ask the children if you can see eyebrows on an x-ray and Joshua informs her that you cannot and clarifies his understanding by telling her, “You can only see that because you see the whole part of that!” pointing to Gracie the skeleton. He then continues by explaining that the camera sees the bones through the skin. Martha provides additional information about x-rays by explaining that x-rays are not a part of your body, they are to see your bones, to check if they are broken.

At the end of this play episode the Teacher asks the children if they have any
more questions about the skeleton or about bones.

**Teacher:** Is there anything else that you would like to know about the skeleton or is there any questions that you had about the skeleton before Gracie goes away?

**Joshua:** Um, yeah.

**Teacher:** What? Tell me!

**Joshua:** Um, how did you get the bones?

**Teacher:** How did we get the bones? Well you told me that yesterday.

**Joshua:** Oh.

**Teacher:** Do you remember what you told me yesterday?

**Joshua:** No.

Joshua’s question about “How did you get the bones?” is interesting because in the previous session he explained quite clearly how you get bones:

**Joshua:** I mean, I mean that many weeks, and once you get too old, um, and then you, then your soul goes up to heaven and you can’t move.

**Teacher:** Your soul goes up to heaven and you can’t move.

**Joshua:** Yeah.

**Teacher:** Mmm!

**Joshua:** You’ll only be in the bones.

**Teacher:** Only you’ll leave, you’ll only leave your bones behind?

On reflection this suggests two possibilities. The first is that there is confusion regarding the relationship between skeleton bones and the skeletal remains that people leave when they die, which suggests that he has not yet made a connection between these two separate incidents. However, he could be simply asking, “How did we get the bones?” meaning from where did we obtain them, but because of the reply to his question it is difficult to determine what he was asking.

When analyzing these three play episodes, although there is some evidence of confusion around labelling and generalization of understanding of skeletons to an individual’s remains, it is evident that these children have a very sophisticated understanding of x-rays, the process that surrounds the need to have an x-ray, as well as an understanding of the internal workings of the body and how that leads to an external
manifestation of illness. Joshua identifies that an x-ray is a picture of your bones, and that a special camera is used to take the image. Through observations and analysis of his play we know that he understands that x-rays are taken in a hospital. We also know that he understands that x-rays are used to look at your bones to see if “they are doing well”. Martha tells us that x-rays are used to check your bones to “see if they are broken”. However, Joshua in his play never talks about x-rays being associated with broken bones. This may be due to his understanding of x-rays. Joshua’s brother has brain stem failure and has had multiple surgeries on his bones. In fact while the data were being collected for this study, Joshua’s brother was having surgery on his hips. Consequently, Joshua’s understanding of x-rays may be related to bone health, rather than bones being broken, whereas Martha’s experience was probably related to broken bones.

From the analysis of the documentation it can be seen that the children’s level of comprehension is related to a much more mature understanding of illness than would normally be expected according to the traditional Piagetian view (Bibace & Walsh, 1980), and adds further support to the contemporary view citing experience as a contributing factor in understanding illness causation and remediation (Cary, as cited in Buchanan-Barrow et al., 2004). Within the traditional Piagetian paradigm, preschool children are considered as focusing on one aspect of illness at a time, finding it difficult to generalise their thinking from one experience to another. They identify illness as being caused by a concrete action, and recovery occurring as a result of adherence to a set of rules, tending to rely on external cues for information about illness, rather than internal causes.

Buchanan-Barrow et al. (2004) in their investigations of children’s beliefs around
illness and health provide support for the *theory approach* to children’s understanding of illness. The *theory approach* suggests that children acquire content specific systems of knowledge, rather than domain independent ones. The analysis of the play episodes above lends support to this theory. Understanding x-rays as they apply to illness as described by Joshua and Martha relates to specific content knowledge, rather than domain independent knowledge. Additionally, there does seem to be a relationship between increases in children’s content knowledge and the procedural and conceptual differences that have been observed. Because of the children’s experience, illness and its component parts are richly represented in their thinking, consisting of more features than one would expect in children of this age. These features become arranged in organisational categories, which provide readily accessible links between other facets of illness, thereby providing children the ability to talk about (using their many languages) the multiple processes involved in illness, including the use of x-rays as a diagnostic technique (Buchanan-Barrow et al.).

*Peripheral intravenous drip.* The sibling’s knowledge about a peripheral intravenous drip emerged over sessions three and four after the introduction of the material. This knowledge grew from a simple investigation of the material through a series of stages. These stages involved demonstrating how you administer an intravenous line; identifying that the saline bag could contain medication or water; understanding the bag’s mobility, and the understanding that additional substances could be added to the saline bag when needed through a syringe.

The children first demonstrated their interest in the peripheral intravenous drip during the third session. The children had just moved into the drama area and were very
excited to see all the new equipment that had arrived since the previous week’s session.
The peripheral intravenous drip was included in the area that had been set up like an
examination room, with a sink and hand cleansing materials, and an examination bed. In
the following photo essay the children are just investigating these new materials. Emma
and Martha use the hand cleanser to wash their hands and discuss their roles in the play
session. Claire investigates the intravenous equipment. The dialogue involved discussing
the *special squirting stuff* used to cleanse their hands and the roles that they wanted to
take in this play session. There was no supporting dialogue around the initial
investigation of the intravenous drip.

The second play episode occurred later during that same session and will be
discussed later as evidence of the sibling’s understanding the need for intravenous
medication. In the first set of images we see the children investigating the new material.
There is interest in the bag, and how you attach the line and how you regulate the flow. In
the second set of images the process of attachment and regulation of flow is now
incorporated into the children’s play. (The decision to include this series of images twice was taken because, placed in context with the previous and following sets, they demonstrate the children’s emerging understanding of a peripheral intravenous line, and provide an example of the Vygotsky Space at work.) In the third and fourth photo essay additional knowledge about a peripheral intravenous line and how it is used emerges, as the Teacher probes the sibling’s understanding and the material becomes an integral part of their imaginative play

Transcript 3: Lines 1716-1757

Joshua: Your room’s right there.
Teacher: Ok! Nurse Katie is going to help me out here. Tell nurse Katie where you want us to go!
Joshua: Right there! Go that way!
(Joshua takes the end of the intravenous fluid line and places it on the teacher’s hand.)
Teacher: Does it go in my hand like that?
Joshua: No! I will get you a band-aid. I have got a band-aid.
Teacher: Promise it won't hurt!
Joshua: It won't hurt.

Teacher: You had better put it on me if it won’t hurt.
Joshua: I will put it on!
Teacher: I am really scared!
Joshua: It won’t hurt a bit.
Teacher: Oh! It won’t hurt a bit. Oh! You’re going to put it over here. Oh! Is that where you are going to put it?
That will reinforce it.
Joshua: What does reinforce mean?
There it goes – right here.
Teacher: Well doesn’t hurt that much!
Is there medicine going into my body right now? (Teacher asks this question as Joshua is looking at the intravenous line and checking and adjusting the flow.)
Joshua: Yes!
Teacher: Can you stop the medicine from going into my body?
Joshua: No!
Teacher: How come?
Joshua: 'Cos when its over there it will not come out.
(Joshua turns the fluid bag to look at it, presses it with his hands to check what is inside and then adjusts the flow rate.)
Teacher: What does that do?
Joshua: It makes it go more!

Fourth session.

Transcript 4: Lines 2196-2222

Joshua: What bugging you?
Teacher: What’s bugging me is that I do not understand what is happening to my body!
Joshua: Ok! I’ll check. (Returns to read the chart, reads it and then goes over to the intravenous stand and starts to push it over towards the Teacher.)

Teacher: Hey that thing moves?
Joshua: Yes! Every one of these moves.
Teacher: What is it?
Joshua: I don’t know but every one of these has wheels, even those in real hospitals.
Teacher: Are you going to hook it up to me?
Joshua: I am just going to give you some medicine. I mean water.
Teacher: What is it – medicine or water?
Joshua: Water.
Teacher: Do you attach it to something? Where do you put the medicine? Where do you hook it up? Do you hook it up to my leg? Does it go in my mouth?

Joshua: No.

Katie: It goes in your arm.

Joshua: We don’t do it like that because it would have germs. (Here Joshua is referring to placing the line in a person’s mouth.)

In this fourth session Joshua demonstrates that he knows that the peripheral intravenous stand moves and answers confidently, “Every one of these moves . . . every one of these has wheels, even those in real hospitals”. He immediately adds this additional level of knowledge into his play, moving the peripheral intravenous stand to the Teacher’s bedside and then administering water this time, rather than medication. When the Teacher questions Joshua about where he should put the water, Katie replies, “It goes in your arm”.

Later in this fourth session Katie decides to incorporate the peripheral intravenous line into her play. In this play episode Katie first adjusts the flow of the drip, and then uses a syringe to inject what is presumed to be medication. Here, as in previous sessions, Katie’s play, although very complex, did not include language.
These four play episodes demonstrate the children’s emerging knowledge and the Vygotsky Space in process within the social context of play. From the first play episode it is clear that the children had a very sophisticated understanding of the intravenous peripheral drip and the medical procedures involved with its usage. They know how to regulate the flow, are aware of location in the body where it would be normally attached, understand that there is a purpose for the administration, and understand that the administration of this medical procedure can occur in a variety of locations because of its mobility.

As I analysed the play episodes it was interesting to see how each child contributed a piece of knowledge about this medical procedure. The knowledge
contributed by the children in the public/social quadrant is then transformed and considered in the private/individual quadrant. It is then used again later, either by the same child or another child in the individual/public quadrant, and added to in the public/social quadrant, thus completing and instigating yet another cycle of the Vygotsky Space. This cyclical progression is evidenced by the children’s increasing complexity of usage of the intravenous peripheral drip in their dramatic play. From the analysis it is apparent that the progression through the various cycles of the Vygotsky Space was facilitated by the children themselves and via the provision of the materials and the preparation of the context, as there is no evidence of the Teacher adding information.

**Oxygen.** Oxygen was an emergent theme that traversed the five sessions, but discussions occurred primarily during work and sharing time. Two of the children had a sibling who was utilizing a constant flow of supplementary oxygen delivered through a portable tank and a third child had a grandparent who was also using oxygen. Thinking that the siblings had quite a complex understanding of oxygen, we were interested to determine their knowledge base, and their questions that surround this area.

Oxygen is a difficult topic for young children to understand because of its properties. It is a gas, and as such, is a substance that they can feel, but cannot see. Ordinarily, it is probable that young children do not think about the air in their lungs and what might occur if breathing becomes difficult. Yet these children had siblings who experience breathing difficulties and could not go anywhere if they did not have a constant flow of supplemental oxygen. It is also probable that these children had experienced a number of emergency situations where the need to administer oxygen to their siblings was critical and anxiety within their family during these times was high.
The children's initial discussions about oxygen occurred within the first few minutes of free playtime during the first data collection session. This play episode starts with the children completing a medical examination of a baby doll. Claire asks Martha if the baby is doing fine, and Martha replies that the baby is doing fine. Part of this play scenario was discussed earlier in relationship to emergency play. As provocation the Teacher asks if there are any broken bones or lumps and the following conversation ensues.

Transcript 1: Lines 1389-1407

**Martha:** We had better do something.
**Teacher:** What kind of something? Is the baby going to be ok?
**Martha:** We need this (brings a syringe) I am pumping some more air in her
**Teacher:** You’re pumping some more air in her.
**Martha:** Just squeeze air in!
**Teacher:** Just squeeze air in with what?
**Martha:** With this.
**Teacher:** I think you’re oxygen expert! I think you had better go and show her how oxygen works.
**Joshua:** I am just putting signs up!

**Teacher:** Ok but afterwards you better go and help because she does not know how to put the oxygen tube in.
**Joshua:** I am hurrying!
**Teacher:** Hurry! Hurry! She does not know how to put the oxygen tube in. What will happen to the baby if we do not get it in in time?
**Joshua:** (Lifts the syringe) Is this oxygen?
**Martha:** That’s the oxygen breathing thing?
**Teacher:** Did you get the oxygen in ok?

**Joshua:** The baby is going to be just fine!

In this play episode Joshua relate lack of oxygen to the baby dying. This play episode and the accuracy of the procedure that is followed supports the earlier premise
that these children have experienced an emergency situation where lack of oxygen has created difficult circumstances for their sibling or another member of their family, and anxiety was high. An interest point in this episode is the children’s play around the administration of a supplementary oxygen supply. It is apparent that they think that in order to help someone breathe more easily you need to “pump air in” or “squeeze air in”, rather than the air being enriched and then inhaled.

At the end of this first session the Teacher asks the children what is needed in the hospital for the next day and provides them with paper and pencils to encourage them to draw or write their ideas on a sheet of paper, and then to share these ideas with the group.

During this sharing time the following conversation occurs:

Transcript 1: Lines 1497-1519

**Claire:** When you go into the hospital you need gloves the shoes things and the hat – that’s all I have just yet because I have not drawn the other things yet!

**Teacher:** Well you keep drawing and I will take the second page of notes.

**Joshua:** We need some medicine, we need.

**Teacher:** What else do we need?

**Martha:** We need oxygen that’s the air and . . . err . . . and the thing that goes on your knee and the thing that goes in your mouth that pumps more air in.

**Teacher:** So the thing that goes on your knee, do you mean the thing that goes kkk? (hits knee and makes a sound)

**Martha:** Yeh! Here’s the notes

**Teacher:** Do want something for over there Katie while I am doing my list?

**Katie:** (Shakes heard to indicate no.)

**Teacher:** Would you like me to find out what a tummy doctor’s called?

**Katie:** Find out what a tummy doctor’s called

**Teacher:** Ok! I will find out what a tummy doctor is called, a back doctor is called, a bone doctor is called and what a doctor that just takes notes is called. I will find out about oxygen. Hey Joshua, I have way too much to do, do you think you could sit with your mommy, your friend and your brother and figure out how oxygen works?

**Joshua:** Well my brother can help me ’cause he has oxygen.

**Teacher:** So he probably is the best person to do it. So let’s make a deal, you’ll come to school tomorrow with all the information on oxygen. And Claire you’re going to find out what we need to put on our bodies to protect ourselves from germs.

In this conversation we can see the children clearly articulating their requirements
for next time, and this includes an oxygen tank. The Teacher, understanding the children’s confusion around oxygen, asks Joshua to help her find out more about this gas. Joshua agrees and he offers his brother’s assistance in this task, identifying that he might be able to help because “he has oxygen”. Katie asks the teacher to determine what a tummy doctor is called.

In the following session, to continue to provoke the children’s thinking about air and oxygen, we placed a variety of tubes, straws and playdough in the meeting area for the children to experiment with on arrival. We wanted to use this experience to connect the previous day’s discussions on oxygen. The children were blowing through the tubes, feeling the air and listening to the sounds that were being made as the air flowed through. The Teacher then asked them if they had remembered to do their homework.

Transcript 2: Lines 15-165

Teacher: So you say the sounds travels through here? Put it close to your ear and I am going to whisper something through it.
Emma: I didn’t hear anything!
Teacher: You did not hear anything?
Teacher: Put your hands
Joshua: There is play dough in it
Teacher: It’s stuck. The air cannot get through it.
Teacher: Try that end again. Can you hear that Martha?
Teacher: Can you feel it?
Joshua: No.

Claire: Let me try!
Teacher: Do you want to try?
Teacher: Joshua put your hand on the end of this. What is going through this tube right now?
Joshua: Air.
Teacher: Air! Did you do your homework?
Joshua: Yeh!
Teacher: What did you find out about air?
At this point the Teacher moves the children to the carpet area to continue the discussion.

**Teacher:** Tell us what your brother told you about his air tank!

**Joshua:** Mmm! Um, he told me about, he told me about some stuff about oxygen.

**Teacher:** Tell me about that.

**Joshua:** He told me that oxygen, if he has oxygen, my brother has oxygen, he said oxygen never makes you sick.

**Teacher:** Oxygen never makes you sick.

**Joshua:** And he told me that oxygen is good for the bones.

**Teacher:** Is good for your bones! Fantastic! And how do we get oxygen boys and girls?

**Joshua:** Um, we get oxygen, people who doesn’t have oxygen without a hose can’t, doesn’t have oxygen.

**Teacher:** Do you know why the oxygen, we have oxygen in our air but you’re right, your brother has oxygen through a hose. So put your hand on here and I am going to blow.

**Teacher:** And so, now you were saying something about a tank. What were you saying? So this would be attached to a –
Claire: An air tank and it would go through your nose or your mouth.
Teacher: And where does it go on Joshua’s?
Joshua: It’ll go on my nose and my mouth.
Teacher: On his nose! So would you have two pieces or one?
Katie: Two.
Teacher: You’d have two pieces, one out of each nostril.

In this sharing time the Teacher reinstates the context from the previous session and then encourages the children to share what they had learned from home about oxygen. She encourages the children to place their notes and drawings on the floor and brings the tubes to the carpeted area to act as visual reminders of their findings. From the children’s comments it is evident that they have a great deal of knowledge about oxygen. Joshua tells the group that he has found out that oxygen is good for you, that it is good for your bones and that people who have difficulty breathing need to use oxygen. Claire adds to Joshua’s comments by explaining that the “hose” would be attached to a tank and would go through your nose or mouth. The Teacher, interested in determining what additional information they might have about the “hose”, asks if the “hose” would have two pieces or one and the Katie replies by stating “two”, clarifying that she understands
what the cannula looks like. The children’s drawings, which they brought from home, show figures with oxygen tanks and airways going to their nose and their mouth. On one of the drawings it can be seen that the child’s parents have sat down with the child and labelled all of the important components involved in the use of supplemental oxygen.

Later in this second session the topic of oxygen occurs again. This time it involves a discussion around a clogged airline. Wanting to pursue the children’s understanding of oxygen, the children returned to the playdough table where we had placed tubes and straws. The children alternately pushed the straws into the playdough and then pulled them out and blew through them. The Teacher responded to this play with the following comment:

Transcript 2: Lines 399-416

Teacher: Claire, that’s really interesting, when you’re blowing the air’s not getting there ‘cause it’s clogged.
Martha: It’s not?
Teacher: Well what happens to grandma Kathy if she had her airways blocked, if someone put their finger on the other end and she couldn’t get any air through the tube. What would happen?
Martha: You’d die.
Teacher: Would she die or would she stop breathing?
Martha: She would stop breathing and die.
Teacher: So you die when you stop breathing.
Martha: Yeah.

In this short statement Martha demonstrates that she clearly understands the relationship between breathing, lack of oxygen and death. However it seems from her comments that she presumes death from lack of oxygen to be swift and immediate. Joshua, hearing her statements, provides the following information:

Transcript 2: Lines 422-453

Teacher: Do you think that too?
Joshua: Um, no because my, do you know why? Because when my brother’s not breathing, he doesn’t die.
Martha: I’m right.
Teacher: So maybe he can breath on his own as well as he needs a little bit of assistance with oxygen?
Joshua: No.
Teacher: No. How does it work?
Joshua: I don’t know.
Joshua: I don’t know how he doesn’t die if he’s not breathing.
Teacher: It’s a good thing though, don’t you think?
Joshua: It is, cause every time he does that he doesn’t die.
Teacher: So have you ever by accident stepped on his airway?
Joshua: What’s an airway?
Teacher: One of these things. Like this from his nose to his tank. Have you ever by accident stepped on it?
Joshua: Um, yeah but he still didn’t die.

This scenario provides yet another opportunity to see the Vygosky Space in action. Martha provides her ideas surrounding lack of oxygen and death into the public/social quadrant. Joshua, hearing this information, adds it to his own understanding in the social/private space. During the transformation process he concludes that this information does not fit with his understanding and following the Teacher’s prompt tells the group “... when my brother’s not breathing, he doesn’t die”. Martha, via her reply, “I’m right”, demonstrates a second cycle of the Vygotsky Space. She has heard Joshua provide his ideas that surround death and lack of oxygen and is not yet able to transform her existing ideas to include this new knowledge. The Teacher, understanding her difficulty, provides an explanation to support Joshua’s position and to help Martha think a little more deeply about the flow of oxygen. These additional comments from the Teacher create yet a third movement through the Vygovsky Space. However, from the transcript it can be seen that Martha does not pursue this line of thought following the Teacher’s statement, suggesting that she now needs more time in the individual/private quadrant of the Vygotsky Space for transformation to occur, and causing new questions
to be published in the individual/public quadrant.

Later in the second session, as the children are working together on a collective mural, the topic of oxygen occurs again. This time Claire provides evidence of how you see oxygen.

*Claire:* I'm making oxygen right now.
*Teacher:* You're making oxygen right now.
*Teacher:* Oh, you can't see oxygen?
*Claire:* I am going to show you what, how you can see oxygen. I'm going to show you —
*Claire:* You cannot see oxygen but you can feel the wind and air.
*Teacher:* Wow! What do you think about that Joshua?
*Joshua:* Yeah, sure.
*Claire:* And sometimes wind can see it and it looks like that. It can look even like this. It can look like even numbers!
*Teacher:* It can look like even numbers?
*Claire:* Yeah, only you can't see it.

Here in work time it is apparent that Claire has been grappling with the ideas introduced earlier about how you see and feel air. In the earlier part of this session the children had been experimenting with blowing air through plastic tubes, listening to the sounds that it made and feeling the air move across their hands. In this session Claire is trying to make sense of her growing understanding through her drawing. She tells the Teacher that she is making oxygen and the Teacher questions her thinking by telling her that you cannot see oxygen. Claire replies by agreeing that you cannot see it but you can feel it. She uses the reference to numbers to conceptualise a property of air (pressure or
force?) for which she does not have the appropriate vocabulary. Her drawing created during this conversation is cloud-like, with lines traversing across it. She has smudged the charcoal by rubbing it with her fingers, which provides a sense of movement in the drawing, and adds to our understanding of what she understands about air movement.

Due to the children’s interest in the topic of oxygen and the confusion around what it was and how it was delivered, for the third session we acquired a compressed oxygen tank with an airway delivery system and provided an opportunity for the children to investigate it during sharing time.

Transcript 3: Lines 121-248

*Claire:* It's the oxygen.
*Teacher:* It’s the oxygen. This is in a bag so that when it’s in a bag its called portable. Can you say portable
*Martha:* Portable.
*Teacher:* Portable. So this is a portable oxygen tank! Does this look like your brother’s?
*Joshua:* No!
*Teacher:* What’s different?
*Joshua:* The difference is I do not know where it comes out of and the hoses that make it come in are a little bit longer.
*Teacher:* The hoses are longer! You know what if you had a short hose what would it fit? A child! An adult or a teenager?
*Joshua:* A kid.
*Teacher:* A kid.
*Joshua:* But if it was a teenager or a grown-up it would be able to go very long.
*Teacher:* Exactly, so therefore you are correct. Some have short hoses and some have long hoses! Now what are these guys all about?
Claire: They go in your nose.
Teacher: In your nose?
Joshua: Or in your mouth.
Teacher: Do you think that these would go in your mouth? I think it would look different if it went in your mouth.
Teacher: I think there is probably oxygen that goes in your mouth.
Children: There is!
Teacher: There is! Do you know this?
Claire: Yes!
Teacher: There is! Where did you find this?
Claire: My mom told me.
Teacher: Your mom told you!
Claire: Yes! She had a book and it was on hospitals and it had oxygen and it went over your mouth.
Teacher: Does Grandma Kathy have an oxygen tank that goes into her nose and her mouth?
Martha: Just her nose.
Teacher: And does it look exactly like this?
Martha: Yes.
Teacher: Has she ever let you put it in her nose?
Martha: No.
Teacher: Has she ever let you feel the air that comes out of it?
Martha: Yes.
Teacher: She has, and what does it feel like when the air comes out like oxygen?
Martha: I can’t remember.
Teacher: Is it cold or is it warm?
Martha: It’s cold.
Teacher: It’s cold. Have you ever felt your brother’s oxygen Joshua?
Joshua: Yeh and it looks exactly like that.
Teacher: It looks exactly like this fantastic. Now what on earth are these gauges? Why do you need a clock for an oxygen tank?
Joshua: It’s not a clock.
Teacher: It’s not a clock. Well it has numbers like a clock, it has got to be a clock.
Joshua: But it isn’t!
Teacher: Well what is it then?
Claire: It could be a timer.
Joshua: I know! I know!
Teacher: Tell me tell me!
Joshua: One of them shows the temperature and I do not know about the other one.
Teacher: So one of them shows the temperature and the other one is a clock. Look I am going to show you something here. I am going to read this out here. It says REFILL. That means refill, does any one know what that means?
Joshua: I do it means that you need more oxygen.
Teacher: Oh! Is that what it means. I thought that you had an endless supply of oxygen here! So maybe what this tells you is when you are running low on oxygen.
Joshua: It does!
Claire: Let's see how the nose looks like.
Teacher: (As she shares the children’s investigations of the cannula she reminds them that they need to be careful because they do not want to stop the air getting up someone’s nose.) Perhaps we will be able to put this in our hospital.
Teacher: My next question is can someone tell me why someone would need oxygen?
Joshua: I know if someone can’t breathe by themselves then they need mm oxygen.
Teacher: How do you stop breathing... how does that happen?
Joshua: If someone is born like not having, having oxygen to breathe by themselves then they need oxygen.
Teacher: Ok so you can be born with not enough oxygen.
Joshua: Yeh!
Teacher: So where does oxygen come from?
Joshua: I don’t know.
Teacher: I don’t know either. That’s a question because I do not know where oxygen comes from either so I am going to write that down on our board.

The introduction of the oxygen tank and accompanying airway created a great deal of interest during sharing time and the children’s conversations about oxygen, the tank and the need to use oxygen took up a large block of time during the opening of session three. However, it is interesting to note that the children did not incorporate this knowledge into their free playtime nor did they choose to discuss the topic again while involved with other activities.

Through their discussions the children demonstrate that they had a depth of knowledge about supplementary oxygen that one would not expect in this age group. They were able to identify the tank, label the dials on the top of tank, and discuss their
function after only a small amount of provocation. They seemed to understand that there was oxygen in the tank, even though they could not see it, and talked quite freely about relatives who need to use oxygen. When questioned again about the airway they understood that the airway supplied with the tank fits into the nose rather than the mouth, yet they confidently noted that there was another type of mask that fits over the mouth and the nose. In this episode the children also provide a rationale for needing to use supplementary oxygen, “If someone is born like not having, having oxygen to breathe by themselves then they need oxygen”, and articulate quite clearly that they do not know from where oxygen is obtained.

In the fifth and final session it was exciting to see that Joshua had chosen to bring in some items from home to share with the children. This experience provided yet another opportunity to see the depth of understanding the children had about the oxygen tank.

Several times in our discussions with the children about the compressed oxygen tank, Joshua had been very clear that although the hose was the same, the tank was different. When he brought in his brother’s tank we could see why he was so concerned. His brother was on liquid oxygen rather than compressed air, so the tank was completely different, and had ice on the outside, which created a lot of interest for the other children. Emma decided that she needed to taste the ice and only asked Joshua’s permission afterwards.

In this sharing episode we see Joshua confidently talking to the children about his brother’s oxygen tank.
Teacher: It's Joshua! Joshua is going to tell us something. He is going to sit in this red chair and tell us about some of the things he brought today. Are you excited? I sure am! I am going to switch spots with you Joshua and you can get started on telling us what you know.

Teacher: I need to tell you guys something before we start this process. I need to tell you that Joshua's brother really uses all this stuff. So it is not pretend it is for real and I don't know if we can touch it. It is going to be up to Joshua to tell us if we can touch it or not! Joshua you need to tell us your rules and we will listen to your rules.

Joshua: Ok! Those, those are bigger and those guys are smaller.

Teacher: Ok!

Joshua: You might not want to touch them because they might have germs because he puts these and these in his mouth.

Teacher: Ok! We will figure that out later, 'cause Joshua has told us that we are not allowed to touch it. There is something else that you brought. What is that thing there?

Joshua: It's my brother's oxygen tank and his hose.

Teacher: His hose? And where does his hose connect?

Joshua: His hose connects to there (pointing to the top of the tank). That's his hose and that's his oxygen. He has different kinds. When he goes in water . . . he never uses that when he goes in the water (pointing at the airway).

Teacher: Boys and girls do you have any questions for Joshua about oxygen . . .?

Claire: Is it like air?

Teacher: Is it a liquid or is it a solid?

Joshua: I do not know what a liquid or a solid is.

Teacher: Oh! Ok! Water is a liquid and a block is a solid.

Katie: I know about those things because I have seen them.

Teacher: Tell me about them.

Joshua: It's liquid!
Teacher: Its liquid Wow!
Emma: Is that a short or long hose?
Joshua: (Opens the package.) Do you want to see what the hose looks like? It looks just like the one you brought in!

Emma: I want to see how long it is – the children straighten the line to see how long it is and they agree it is the length of two and half three year olds.

Our original thoughts that these children had a very complex understanding of oxygen were supported over the five sessions. The children were able to not only describe the medical equipment involved in oxygen therapy, but were also able to relate the need to use supplementary oxygen to the inability to breathe. Confusion remained around how the oxygen was inhaled, but clarification around different types of oxygen (liquid versus compressed) and the different types of facemasks occurred. The important conversation that arose between Joshua and Martha regarding limited access to oxygen and imminent death was never revisited, so we were unable to take this conversation any further. There was lots of evidence that the children understood the presence and the effect of oxygen even though it was a substance that they could not see. Katie contributed to this discussion by telling everyone that she knew about the materials that Joshua was presenting because she has seen them.

The results in this section challenge once again the traditional view on children’s
understanding of illness that is grounded in traditional Piagetian stage theory and provide additional evidence of these children holding a very sophisticated understanding of illness and the illness process that is so rarely discussed in the literature. These children provide examples of an intermediate mechanism as the cause of illness, rather than bad behaviour. They relate the need to use oxygen to a specific cause – one that you may have been born with. Joshua tells us, “If someone is born like not having, having oxygen to breathe by themselves then they need oxygen “

**Surgery.** Surgery is another topic that is difficult for young children to comprehend because of the secrecy that surrounds it. It is something that normally occurs behind closed doors, providing very little chance for the children to observe what happens in order to make sense of the process. Frequently when people experience surgery they are initially in more discomfort than they were prior to the surgery. Consequently the mismatch between what the child is being told about the surgery and their own observations causes confusion. In our preparations for discussing this with the children we realised that surgery was something that they had probably observed the preparations for, and seen the results of, yet did not understand. Over the five sessions the topic of surgery came up several times, mostly briefly, and it was a general consensus of the children that surgery was a mystery and that some surgeries hurt and others did not.

**Session 3.**

Transcript 3: Lines 955-963

*Teacher:* What is surgery exactly?
*Emma:* I don’t know.
*Teacher:* I don’t either.
*Teacher:* What is surgery?
Joshua: I don't know!
Teacher: You don't know?
Joshua: I don't know anything about surgery. The only thing I know about surgery is some surgeries hurt you and some surgeries don't. That's the only thing I know.

The teacher, wanting to investigate these ideas a little more deeply, suggested a need to find out more about surgery and posed a question about whom they should ask.

Transcript 3: Lines 965-980

Teacher: Yeah. I think I need to find out a little bit more about surgeries. Who do you think would know?
Joshua: Oh maybe God and Santa would know.
Teacher: God and Santa would know?
Emma: God and Santa would know!

In this discussion there is evidence of magical, illogical thinking that is thought to be prevalent in this age group, according to the traditional literature base on children's understanding of illness. However, this particular comment is interesting because it was only the second time this type of thinking occurred over the five data collection sessions. It as also interesting to see that Joshua applied this type of thinking to someone that he believed could provide them the answer to something they could not see – God or Santa. Although suggesting God or Santa might know “what is surgery” may seem irrational and illogical and so suggest that he is functioning at the preoperational level in this area, I would argue that many adults use this kind of thinking when faced with a situation they cannot explain. Raman and Winer (2002) discuss what they have termed the “irrational adult outlook”, and they apply this term to adults who appear to use imminent justice to explain misfortunes that they find difficult to comprehend. Surgery is part of the prescriptive process of illness; someone has surgery because they are ill and need to have a particular surgical procedure to alleviate illness. Therefore, surgery relates to the medication process. Yet unlike prescriptive medication it is surrounded in secrecy,
especially for children, and so is likely to create the type of thinking that involves irrationality, hence Joshua’s idea that God or Santa may be able to tell them “what is surgery?” It is interesting to note that he did not apply the same kind of irrationality to other illness processes that he was able to observe. This supports the proposition that, given the right information and the opportunity to learn about an illness process, children can make sense of it. But when they, like adults, are given insufficient information they revert to magical or irrational thinking. Consequently, this would suggest that these children’s understanding of illness is less different from that of adults than the traditional thinkers have propounded.

_G-tube_. Both of the well sibling’s brothers were fed via a low profile Gastrostomy tube (G-tube). Consequently, we were curious to know what the sibling’s understood about the G-tube and being fed via the stomach rather than the mouth. To investigate this we decided to introduce the subject of food and eating during the first session in the “getting to know you time” when we were talking to the children about their families. As part of the “getting to know you time” the children were asked to make a puppet of their brother or the sister and then contribute, during the “sharing about their puppet time”, something that their brother or their sister might say. The Teacher was helping the children remember about the different parts that would be needed on the puppet and then as provocation asked the children what they would need a mouth for, and
they replied to "eat and talk". The children did not take this conversation any further at that time. However, later in the first session when the children were identifying what they needed to find out about for the next time, Katie states that there is a need to find out about a "tummy doctor". This was an interesting contribution to the discussion because her brother had recently had his G-tube fitted and therefore this comment served to reinforce our initial curiosity about the children’s interest in finding out about G-tube feeding.

At the beginning of session two, during sharing time, the Teacher asked the children about their homework and what they needed to find out from home and the topic of the "tummy doctor" occurred again, but only in the form of a reminder to find out more about this type of doctor. During this session we were interested to explore further the children’s understanding of medical equipment and procedures, different types of doctors and body parts. Therefore we provided an opportunity for the children to work together on a mural. We felt that providing an opportunity for the children to work together would enable us to look a little more closely at their understanding of medical procedures, body parts and the process of co-construction of understanding. We placed a large white sheet of mural paper on one of the tables, along with pictures of doctors and body parts, band-aids, cotton wool and various types of gauze, and other types of materials that could be used by the children to represent their thinking. The
children started by handling the various materials and saying, "These are lungs" and "This is your stomach" as they picked up the pictures of the body parts we placed on the table. Katie announced that she was going to draw a tummy doctor and started to work immediately on her drawing. In front of her was a picture of the intestines. After a short while the Teacher looked at her drawing and the following conversation occurred.

Transcript 2: Lines 695-793

**Teacher**: Okay can I look at your person yet? Is your person done? Okay! Tell me about yours, . . . That's a very interesting picture. Can I show you what I found when I was doing research on a tummy doctor 'cause it looked exactly like that and I found a real picture of a tummy. I'll get it. I'll be right back.

**Claire**: I want to show you something here, okay? I want to show you something in this box.

**Teacher**: Look at this. This is what I want to show you. Doesn't it look exactly, almost exactly the same? That's a real tummy. And it looks almost exactly the same as your drawing.

**Teacher**: Now would you put a band-aid on your tummy?

**Katie**: Yeah!

**Teacher**: Do you want a band-aid? We have band-aids on the table too you know!

**Katie**: (Shakes her head to indicate no!)
Teacher: I was listening to your story. Claire, tell me about your story!
Claire: Ok! Tummy is like. Tummy can change how you feel. If you eat something yucky your tummy does not feel so good!
Teacher: How come it does not feel so good? What part does not feel so good if you eat something?
Claire: That I did not figure out!
Katie: (Points to the part on the picture where she thinks it hurts when you eat something yucky.)
Teacher: That part is the part that hurts when you eat something yucky?
Claire: Yeah! I think!
Teacher: Where does your food go?
Claire: Here, I'll show you a picture. It goes from here.
Teacher: Does your brother have something on his belly button? (Katie shakes her head.)
Teacher: No? Does he ever get band-aids on his tummy?
Katie: He has food through his stomach.
Teacher: He has food through his stomach? (Katie nods in agreement.) Have you ever heard that before Claire?
Claire: Mmm!
Teacher: Where does he get his food from?
Katie: His stomach?
Teacher: Can you draw how that looks or how that works? I'm not sure how that works!

Teacher: Did you hear that Emma? That Gary gets his food through the tummy. Can you draw that Katie? Does it come through a tube? A tube like an oxygen tube? Like we were talking about over there or a different type of tube?
Katie: Oxygen tube.
Teacher: It looks like an oxygen tube?
Katie: (Nods agreement.)
Teacher: Is that what it looks like? (Points to the picture of the tube on the drawing.)
Katie: Nods yes!
Teacher: Does it come from the side?
Katie: Nods yes!
Teacher: Where does it attach to his body?
Katie: (Looks at the Teacher)
Teacher: Are you thinking?
Katie: No!

At the same time as this conversation was occurring between the Teacher and Katie, Claire continued to complete her drawing of the tummy. She drew the intestine and the location of the intestines in the body and the food digestion process from ingestion to elimination. This process is identified on her drawing by a line in the body that goes from the person’s mouth to the anus area. Katie completed her drawing by sticking gauze over the top of the picture.

In this image we see Katie cutting the gauze to the correct size in order to make it fit over the picture of
her tummy with a G-tube. What is very interesting about this play scenario is that when
the Teacher asked Katie if her brother had a band-aid over his "owie" on his tummy she
was very insistent that this was not so, yet when she completes her picture she places a
gauze dressing over it. We were very confused about this behaviour until the final session
when one of the parents brought in a G-tube kit for the children to use and inside the
package was a gauze covering just like the one Katie had chosen in the image above. Her
choice to use a gauze dressing to complete her drawing suggests that she has an
understanding that her brother’s G-tube should be covered with a dressing, rather than a
band-aid; that she clearly understands the difference between a dressing and a band-aid;
and that she was demonstrating this understanding when questioned.

In this play scenario it was interesting to see how these two children working
together on the same topic provided mutual support to each other’s ideas; each pushing
the other a little further in their thinking. Claire’s discussions about tummies and how
they could change how you feel provided the necessary cognitive support for Katie to
start to explain her understanding of how her brother was being fed through his tummy.
This play episode provided another opportunity to see the Vygotsky Space in action.

When considering the first quadrant of the Vygotsky Space - public/social - it can be seen
how the opening sharing time reintroduced the idea of tummy doctors. One of the
children’s tasks was to find out about different types of doctors. The Teacher’s request to
share these ideas in the public/social space pushed the children through the other two
quadrants - social/private and private/individual - into the individual/public with Martha
identifying that they needed to find out about belly button doctors. The need to find out
more about these type of doctors was then provided for and supported through the
discussions of the other children and materials supplied for the group mural. Working collectively on the group mural is an example of a second visit into the public/social space on this particular theme, and provides visual evidence of the spiral effect that occurs in the Vygotsky Space. The discussions of the children and the materials provided both visual and linguistic supports, pushing the children yet again through the two quadrants of social/private and private/individual, thereby enabling Katie and Claire to draw tummies in the public/individual space. Finally, Claire’s discussions about tummies and how they can change how you feel, is yet a third example of the Vygotsky Space at work. Claire’s discussion about tummies in the public/social quadrant provided sufficient provocation to push Katie through the two quadrants of social/private and private/individual to access her understanding about her brother’s G-tube and share that information through her two drawings in the individual/public space. This spiralling effect that occurs within the social context allows children to continue to build on their ideas, both individually and collectively, and subsequently leads to the major shifts in understanding.

Throughout the study Katie continued to demonstrate both her knowledge and interest in her brother’s G-tube as she played. In session three we see Katie playing with a doll. She has placed a square of gauze on the doll’s tummy and secured it with a band-aid in the same location as the G-tube would be found on her brother. She then located a pink tube, which she placed under the band-aid to keep it in position, and a medication syringe. Katie then placed the syringe inside the pink tube and then began to pretend to feed the doll through this pretend G-tube. The intensity of her focus on this task is evident.
In session four Katie repeats this same play behaviour on two separate occasions with another child who assumed the role of patient. Because this play was nonverbal the following documentation piece is presented without any accompanying language transcript.

*Session 4: First observation.*
Session 4: Second observation.
In the final session Joshua brings a G-tube kit to the sharing time. The Teacher explains to the children that this item is real. Joshua, although familiar with the kit, finds it difficult to explain what it is and how it works, so Katie, full of confidence, takes over and explains to all the children how to assemble a G-tube.

*Teacher:* Does anyone know what this is?
*Katie:* I know what this is.
*Teacher:* Listen did you hear Katie?
*Katie:* I know what this is! It’s the belly button thing that goes into his belly button.

*Teacher:* Oh! Does anyone know how this works?
*Teacher:* How does this work? Oh! It opens! Joshua what is going on there? It opens and it closes!
*Katie:* That means it stops and it goes.
*Teacher:* Can you point to the part that goes in the belly button?
*Katie:* (Points)
*Teacher:* Wow!
*Katie:* Gary has one of those.
*Teacher:* Really? That’s interesting. Can you see that? Do you want to try it? It’s got another one here. It clicks and it un-clicks.
*Katie:* This closes the belly button.
*Teacher:* What does this one do? What does this one do here?
Much of Katie's play throughout this study was non-verbal, yet when analysing the digital video and discussing her play with the Teacher and the other researcher involved with this project, it was evident that she was fully engaged in investigating the many aspects of the illness process. Her play about the G-tube grew over the five sessions. Initially she explained, through her drawing, that her brother was fed in his tummy. Then she modelled, with a doll, what she had obviously seen her mother and nurses do when feeding her brother. Later she performed the same actions with another child. Finally, she explained and demonstrated how to use a G-tube kit.

Katie's ability to label and reproduce accurately the common procedure when feeding a child through a G-tube demonstrates that she had observed very closely what happens when her brother was fed, and as such was able to reproduce this behaviour in her play. She always started by inserting the syringe into the tubing that we had provided.
for her and others to play with in the drama area, and then continued by pretending to
draw off some stomach fluid. Katie would then go over to the sink to pretend to squirt out
what she had drawn out of the tubing by depressing the syringe. She then returned to the
patient and pushed the syringe back into the tube as if inserting a liquid of some kind.
Throughout the procedure she was always very gentle, patient and careful, holding the
tubing in one hand gently while depressing the syringe with the other. Other examples of
Katie’s knowledge of the illness process included the peripheral intravenous drip and
oxygen.

The Brain. The brain was of great interest to children, especially to Joshua who
insisted throughout the data collection sessions that he was a brain and bone doctor. The
ideas surrounding the investigation of the brain initially occurred at the end of the first
session, when the children were working out what they needed to do for homework, and
then continued to emerge throughout all five sessions. The topics the children discussed
included different types of brain doctors, the brain itself and its location within the body,
what the mind is able to do, and medical examinations that are performed to investigate
its health. The next four play episodes focus on how the children, by exchanging their
theories about the brain, demonstrated their growing understanding of its location,
function and health.

The second session commenced with the children playing with the playdough at
the playdough table. Once the teacher felt that the children were comfortable with each
other she invited them to join her on the carpet to discuss their home. One of the children
introduced the idea that they are going to make a brain and the conversation about brains
begins.
Martha: I am making a brain.
Teacher: Come on down. You can make a brain after.

Teacher: Okay, this is your homework. Martha found one of these, Martha found a website. Do you guys know what a website is?
Group: Yeah.
Teacher: Martha found a website that talks about all the different types of doctors and what they study. So you learned about a brain doctor, didn’t you Martha?
Martha: Mmm, Mmm.
Teacher: And a brain, there’s two different types of brain doctors. Did you know that?

Joshua: Yeah, and I don’t know which. I don’t know which type of doctor I have seen.
Teacher: Pardon?
Joshua: I’ve been that guy, that brain doctor who fixes your brain. I’m the one, I want them, the brain doctor who fixes people’s brain.
Teacher: The brain doctor that fixes people’s brains.

Second discussion of the brain.

Teacher: What’s underneath your skull?
Claire: Brain.
Teacher: Your brain.
Joshua: I already knew that.
Teacher: How did you know that?
Claire: I’ve seen a real brain!
Teacher: You haven’t. How have you seen a real brain?
Claire: Yeah.
Teacher: How have you seen a real brain?
Claire: Um, well like as, like sometimes you can do like pictures of the, like the real, like you can sometimes see pictures of them that look real in my book.
Teacher: Have you seen a brain?
Joshua: No, but guess what? I’ve been in the mind. I’ve been inside a mind.
Teacher: Inside a mind? How? Tell me about that experience!
Joshua: It’s not the kind of mind that’s inside you.
Teacher: What kind of mind is it?
Joshua: It’s a mind that –
Joshua: It’s a mine you dig tunnels in.
Teacher: Oh.
Joshua: That kind of mine.

Third discussion of the brain (same session).

Transcript 2: Lines 623-644

Martha: That’s your brain.
Emma: That’s your brain.
Martha: And that’s the brain. That is inside the brain and this is really the brain.

Claire: I am going to show you what a brain looks like. I’m going to show you what a brain looks like in your head. A brain looks like this.
Researcher: You have seen a brain before. Tell me about it it’s amazing!
Claire: Yeah. Sometimes it goes this way and it comes out that way. There are always tubes going through your head.

Claire: The brain can change your thoughts. The thoughts will enter your brain but your brain intakes your thoughts. The brain can suddenly change your thoughts.

Researcher: The brain changes your thoughts?

Examination of the brain.

Transcript 2: Lines 1003-1039

Joshua: I check the brain and bones. Teacher: How are you gonna check my brain? Child: (Points to the bed and says) . on there! Teacher: I'm a little busy right now I am having my brain checked. Joshua: and your bones checked . . . stay there I will be right back. Teacher: Do you need a nurse? Joshua: No. Teacher: Can I sit up while I wait for you?
Joshua: (Leaves to put on foot covers and then picks up the notes.) I'm afraid you will not be able to sit up for a couple of days.
Teacher: How come? What is my diagnosis?
Joshua: 'Cause I need to check the bones and the brain. I'm afraid the bones don't look that good.
Teacher: Why don't they look that good?
Joshua: 'Cause of the needle and the bones and I need to check your brain.

Teacher: You'll check my brain? I hope my brain is doing better than my bones.
Joshua: Your brain is fine.
Teacher: Did you check my whole brain?
Joshua: (Nods yes.)
Teacher: Can you point to the part of my brain that is not doing so well?
Joshua: Actually none of the parts are mmm! All of the parts are fine.

From these four work and play episodes it is evident that these children have a very complex understanding of the brain and how it works or not, and the type of doctor who would be involved with the care of the brain. In the opening discussions we see Joshua identifying himself as a brain doctor and associating that role with the brain doctors being discussed by the teacher. However when presented with information about there being two different types of brain doctors he demonstrates his understanding of his own role by stating I don't know which type of doctor I have seen [but] I'm the one . . . the brain doctor who fixes people's brain.

The children provided concrete examples of the location of the brain within the
body - behind the skull - and they introduce the concept of the mind. Joshua in his
discussions about the mind does not talk about the mind as such, but his comments do
lead one to question if he is developing a concept of the mind or whether he is confusing
the word mind with brain. When the teacher asks, "Have you seen a brain?" he replies
with, "No, but guess what? I have been in the mind. I've been inside a mind." When the
Teacher questions this statement, he replies, "It's not the kind of mind that's inside you!
It's a [sic] mind that you dig tunnels in."

Martha and Emma’s conversation about the outside versus the inside of the brain
encouraged Claire to draw what they were discussing. She started off by telling everyone
that she was going to draw what is inside your head, and when reviewing her drawing
you can see that it is a grey swirling mass. She then explained the relationship between
the brain and thought when she stated, "The brain can change your thoughts. The
thoughts will enter your brain but your brain intakes your thoughts. The brain can
suddenly change your thoughts!" To ensure that everyone understood what she was
explaining she drew two-way arrows inside her drawing of the brain, with one going in
and the other going out. Providing clarification for her drawing she said, "Sometimes it
goes this way and it comes out that way. There are always tubes going through your
head." Although Joshua was not part of these two conversations he was sitting at the
table when the conversations occurred and as can be seen from the images was clearly
listening to the conversation.

In the final play episode where Joshua is examining the teacher’s brain and then
tells her that her whole brain is fine, we see the play episode stall when the teacher
introduces a discussion about the parts of the brain. This concept was not introduced by
the children and therefore may not have been part of Joshua’s knowledge about the brain. When examining the children’s drawings and their conversation about the brain, at no other time did the idea of brain parts arise. Claire came the closest, in her contribution about thoughts entering the brain, but when examining her drawing there is a definite pathway through the brain from in to out, which traverses the brain as a whole, suggesting that the children may see the brain as a whole unit rather than separate parts conjoined together into a whole.

Williams and Binnie (2002), in discussing interventions that improve children’s knowledge of illness, describe structured peer discussions as helpful. They state that providing children an opportunity to discuss their naïve concepts with others who have experienced similar circumstances allows for reflection and refinement of their ideas, which leads to conceptual change. This can be seen in these four episodes. The verbal and written contributions of the children enabled them to continue to build on their ideas. Claire’s discussions about the brain enabled Joshua to discuss the concept of mind. Martha and Emma’s discussions of the brain and its inside and outside triggered Claire’s drawing and her discussion of thought. This discussion then triggered Joshua’s dramatic play episode where he diagnoses a problem with the teacher’s brain. From this it can be seen that each child’s contribution enabled another child to take that idea further and with increasing abstraction of thought.

**Conceptual Differences in Understanding**

**Discussions of death.** Understanding death is a complex issue that incorporates social, cultural, as well as biological beliefs. Within the literature base on children’s understanding of illness there are three separate bodies of work: the Psychoanalytic
Approach which addresses emotional responses to death; Piagetian stage theory which focuses on children’s cognitive understanding of death, and biological understanding of death, which is the most recent work in this area and emphasises causal explanations. All three bodies of work suggest that young children’s (3-6 years) understanding of death is often primitive, involving misunderstandings and mirroring their cognitive development. Most recently there has been some discussion that children’s understanding of death may be related to their lived experiences and their emerging biological understanding. Consequently, when examining the children’s conversations about death these theories were considered.

Death was a topic that was constantly being discussed by the children. The first discussions of death occurred in the first data collection session, during the first work-time period.

Session one.

Transcript 1: Lines 1335-1370

Joshua: I don’t remember Jack and Squeaky. (Jack and Squeaky were Joshua’s dogs.)
Teacher: Why don’t you remember them?
Joshua: Just the cat and the hermit crab lives with me.
Teacher: Does the dog live with you?
Joshua: My two dogs don’t live with me any more.
Teacher: Where do they live?
Joshua: They died.
Teacher: They died?

Claire: Did all of your pets die?
Joshua: No! But my fishes didn’t die.
Teacher: Martha you just had a pet die in your house. Come sit! Who died in your house?
Martha: My Chirpy.
Teacher: Martha tell Joshua who Chirpy is!
Martha: Joshua!
Martha: Joshua, my bird died and her name was Chirpy and she just mmm closed her eyes she just mmm did not open them up again.
Joshua: Is that how she died?
Martha: Yeh!

Joshua: Oh! How does she die like that (stresses that)?
Teacher: Did your dog die like that?
Joshua: No! Do you want to know how my dog died?
Emma: I want to come to your house and see your fishy.
Joshua: My fishy is not dead – do you want know how my first dog died?
Teacher: OK!
Joshua: My first dog died, Squeaky died by a car hitting it.
Teacher: Oh!
Joshua: And, and Jack died because he ate a marble.
Teacher: He ate a marble?
Joshua: He really did that!
Teacher: You know what my cat died because it ate tooth floss!
Joshua: He died because he ate tooth floss!
Teacher: Yes!
Joshua: My crabs did not die!
Teacher: Your crabs did not die?
Emma: My first cat died!
Claire: And then we got a new one.
Joshua: I am going to go and play.

Prior to the initial session Joshua’s mother had indicated that Joshua had recently lost his second dog and that he was still very upset about it. She told us that from time to
time he would just bring the subject up and then when he felt that he had discussed this
enough he would just drop it again, and this is what can be seen in this part of the
transcript. He talks about his experience and his knowledge about how his dogs died and
then quite definitely ends the conversation with “I am going to play!”.

I was curious to see what had triggered this conversation, so I reviewed the
earlier part of the transcript to see if there had been something in the previous
conversation that would have elicited this discussion from Joshua, but unfortunately there
was nothing, as the earlier discussions had just focused on foods the children did or did
not like. Conversations about food are quite typical when children are just getting to
know each other and are not yet familiar with each other’s likes and dislikes. Work-time
followed the first snack-time where the children had shared food together and had an in
depth discussion of their families. Their photographs had been reintroduced and there
was much laughter and discussion as the children continued to share their knowledge of
their families and talk about which foods they did or did not like. This conversation
continued into the first part of the work-time until suddenly Joshua began talking about
his dogs and the fact that they had died.

When thinking about this discussion on death a number of points arise that were
discussed earlier in the literature on children’s understanding of illness. First, there is
evidence of Joshua having a clear idea of a non-biological cause of the death as described
by Williams and Binnie (2002). This was evident from his descriptions of how both of his
dogs died. From the analysis of his discussion it is clear that he understands that it was
the impact of the car that killed one dog and the process of physically ingesting a marble
that killed the other. Kalish (1999) uses four models to describe children’s understanding
of illness – associative, physical, simple-biological and differentiated. Because Joshua was able to articulate two different causes of death in his dogs and because he chose to question Martha about how her bird “Chirpy” died, it is possible to conclude that Joshua has a differentiated model of illness. This implies that he understands that there are many different types and ranges of illness that can lead to death, which relates to an adult-like understanding of illness and death, and supports Kalish’s (1996) ideas that children’s understanding of illness may not be any different from that of an adult. In a later paper Kalish (1999) goes on to explain that experience with illness and death deepens and broadens understanding and that children who have had extensive experience with illness may have a more adult-like understanding than those who have not.

Following Joshua’s firm statement, “I’m going to go and play,” he enters the drama area of the room which has been set up to look very much like a doctor’s office, and begins a prolonged role play with Martha revolving around a hospital emergency situation. The topic of death and dying appears again.

Transcript 1: Lines 1412-1454

Martha: I need this (takes the stethoscope). I need to listen to the baby’s heart!
Martha: It’s not pumping. The baby’s heart is not pumping – it’s not!
Teacher: What will happen?
Martha: She will die!
Teacher: You have to be the on call emergency doctor. The baby’s heart has stopped.
Martha: What shall we do?
Teacher: What shall we do?
**Joshua:** We need this! (Holding the blood pressure cuff) *We had better put this round.*

**Teacher:** What is that? How can it help?

**Joshua:** It's just going to be – it's just going to check something!

**Teacher:** Ok!

**Joshua:** Ok I will put this around. (Places the blood pressure cuff around the baby's arm and pumps.)

**Martha:** (Using the stethoscope listens to the baby's heart.) *It’s pumping! It’s pumping!*

**Joshua:** (Looks at the dial on the blood pressure cuff) "Oh! Oh! It’s going to be bad"

**Martha:** Her heart has stopped pumping again.

**Joshua:** This is bad, very bad! Her heart is not beating at all!

**Teacher:** At all?

**Joshua:** Her temperature is all the way down! (Signals with his body and touches the floor) *All the way down here! That means she is not breathing very well!*

**Teacher:** Her temperature is all the way down!

**Joshua:** Guys! Guys! We have to fix her and quick 'cause her temperature is not doing very well!
Martha: We are doctors, right, and we have to save her!
Joshua: Yeh!
Teacher: Did you figure out how to get her temperature back up?
Joshua: I need to do some notes... I need to do lots of notes.
Joshua: Yeh!
Martha: We are gonna hafta hurry.
Joshua: I am gonna do some notes.
Teacher: Martha ask him what the notes say so that you know what you have to do!

Martha: What does the notes say? Joshua: I will tell you what they are saying. Everybody has to help.

Martha: (Using the telephone.) Hello! Can you help please? Can you come and help us? You have to help us because one of the babies are dying! Her heart's stopped pumping—bye!

This was a powerful scene. The accuracy of the play would suggest that this was a re-enactment of something the children had seen as part of their daily lives with their ill siblings, probably many times. There was evidence in this scene of the wrong use of terminology. Joshua used the term "temperature" to refer to falling blood pressure. Yet it
was very clear that he understood what falling blood pressure means. He placed the blood pressure cuff around the doll’s arm, read the dial and then called out that “It’s going to be bad”. He followed this with the statement, “This is bad, very bad! Her heart is not beating at all!” and then he stated, “Her temperature is all the way down!” and signalled with his body by touching the floor that he understands what all the way down means. To add emphasis to his physical demonstration, he repeated “All the way down here! That means she is not breathing very well!”

In this scene we are provided with more evidence of the child’s understanding of the internal workings of the body and how the malfunctioning of one system – falling blood pressure – can lead to the malfunctioning of another, heart failure. This enactment moves on from the earlier conversation on death where Joshua and Martha discuss how each other’s animals died. In the first discussion there is evidence that Joshua thinks that there has to be a cause of some kind for death to occur. By saying “Is that how she died?” and then going on to further stress “Oh! How does she die like that?”, he is stating that, in his opinion, you cannot just close your eyes and die. In play episode two described above, we see a re-enactment of a cause of possible death - falling blood pressure - leading to the heart malfunctioning and “stopping”. This play situation was very serious and frantic, with a given procedure following the realization that the patient’s blood pressure was falling. The children called for help. They understood that additional people were needed and that written notes would enable others to know what had happened. They knew about telephone numbers and the importance of giving exact information when calling for help.

This scene provides additional support to the earlier statement that these children
understand biological causes of illness (Buchanan-Barrow et. al, 2004; Kalish, 1996, 1997; Siegal, 1988; Williams & Binnie, 2002). Blood pressure and heart failure involve internal body processes and parts. The children use the stethoscope in conjunction with the blood pressure cuff to detect the falling of the blood pressure and the beating of the heart inside the doll. When considering Bibace and Walsh’s (1980) work on children’s stages of understanding (which as identified earlier is based on Piaget’s stages of cognitive development) with respect to both play sequences, it can be suggested that these children are at the physiologic stage because they are able to describe death as occurring due to the malfunctioning of a body system. Bibace and Walsh equate this level of understanding to Piaget’s formal operational stage.

Within the second play episode there is evidence of the Vygotsky Space at work. Microgenetic analysis allows the observation of the effects of both proximal and distal influences in the children’s play as the children move through the Vygotsky Space. The distal influences – the children’s prior knowledge of emergency situations observed in the public/social quadrant – are brought into the play and are built upon as the children and the Teacher interact, whereas the proximal influences that occur in the private/individual quadrant become evident in the individual/public quadrant as the children build on each other’s knowledge of death and the dying process.

**Germ theory.** Evidence of the children’s understanding of germ theory spanned the whole of the five sessions and occurred primarily during the free play sessions, when they were engaged in the roles of doctor, nurse and patient. Because of the discussions in the contemporary literature regarding children’s understanding of biological and non-biological causes of illness (Buchanan-Barrow et al., 2004), their emerging understanding
of invisible particles and how this relates to the understanding of illness (Kalish, 1997, 1999), great care was taken to prepare the environment. This was done to see whether the children could not only follow through with observed behaviours related to contamination prevention, but also to determine whether the children were able to demonstrate either physically or verbally that they understood why anti-contamination measures are needed. A variety of materials related to contamination procedures was chosen in the hope that they would be used by the children in such a way as to demonstrate their emerging understanding of invisible particles, as described by Kalish. These included a hand washing station with soap, paper towel and rubber gloves; a garbage pail placed close to the area where the dressings were kept and could be changed; scrubs that could be worn by either a doctor or a nurse, along with hair protectors, facemasks and shoe protectors.

The following series of images demonstrates the children’s knowledge of clothing worn by the medical profession to limit the transmission of various contaminants. It was apparent from the children’s conversations and their accompanying behaviours that they understood that these protective practices needed to occur prior to examining the patients. However, it remained unclear whether the children truly understood the purpose of these practices, because there was only one incident where the children provided the rationale of germ transmission as the reason for the need for a particular behaviour.

*The children demonstrate how to use shoe and hair protectors.* In this episode Joshua is starting to examine a patient. He leaves the examination area to put on the shoe protectors and pick up his file. The following dialogue occurs.
Teacher: How are you gonna check my brain?
Joshua: (Points to the bed and says). . . “On there!
Teacher: . . . I am having my brain checked!
Joshua: And your bones checked . . . stay there, I will be right back.

Joshua: (Leaves to put on foot covers and then picks up the notes and reviews them) I'm afraid you will not be able to sit up for a couple of days.

Here Martha is wearing a hair protector as well putting on the shoe protectors. Like Joshua, this behaviour occurred prior to examining her patient.

When observing how she has chosen to wear her hair protector it would seem that she understands that it must cover all her hair at the front because both photographs demonstrate similar placement, but it would seem that she has not realised that the back must be covered too!
In this photograph three of the children, all involved in the same complex medical play scenario, are wearing protective clothing. It is visible in these images that all the children have an understanding of how the hair protectors should be worn. Each child has it firmly pulled down, ensuring that the front of his or her hair is covered, but only Joshua has made sure that the back of his hair is covered as well.

*Katie and the facemask.*

Here Katie helps Claire put on her facemask before performing an examination of a patient. Notice how she is checking very carefully to ensure that Claire puts it on properly.

*The hand washing station.*

This is the hand-washing station set up and ready for use. The faucets are to the left, the liquid cleanser is behind and the latex gloves and dressings are to the right.
Here Claire is putting on her latex gloves after using a cleansing agent to clean her hands.

Emma wears a doctor’s coat as she performs a medical procedure.

The children’s behaviour in all of these images demonstrates they understand the importance of wearing protective garments and that there is a need to wash their hands and then use protective gloves before commencing physical examinations of any kind. The children’s choice of a procedure for hand washing appeared to be similar to observations they would have made in a typical doctor’s office. The children, when involved with physical examinations rather than emergency procedures, all followed a
similar procedure of having a conversation with their patient in order to determine the purpose of their visit before commencing the hand washing procedure and then putting on the protective clothes. Hand washing was not evident in the first emergency play episode.

_Germ transmission._ In session three evidence of understanding germ transmission appears. Joshua is sitting in the reception area of the ward answering the phone and taking lots of notes. He looks over towards the hospital ward where two children have assumed the role of doctor and patient. The doctor had been cleaning a child’s pretend wound and had dropped the cotton wool and the old dressings on the floor by the bed. Joshua gets up from his desk and walks towards them. The following conversation occurs.

_Transcript 3: Lines 1681-1690_

_Joshua:_ You have got to put all that back! It’s a mess! It’s a big mess.  
_Teacher:_ It is really important to clean up in the hospital because you want all those germs to go in the garbage.

_Joshua_ Else people will get sick
_Teacher:_ Right!
The level of understanding of illness in this play episode demonstrates Bibace and Walsh's (1980) physiologic stage, which characterises children's understanding of illness as being triggered by some external event and causing a malfunction of an internal organ or process of some kind and is thought to occur during the formal-logical stage. In this play episode Joshua is able to articulate that by leaving dirty dressings on the floor "someone can get sick or stay sick", identifying that he sees a relationship between getting sick from the dirty dressings and not getting well because of the presence of the dirty dressings. When considering this play episode in relationship to Kalish's (1999) work on theories that surround children's understanding of illness, it would seem that it is best described by his simple biological model. In this model children understand that germs are living and have the ability to affect other living organisms. This finding goes beyond the level of understanding Kalish (1997) was able to determine in his work with children in this age group. He explains, "We do not (yet) have compelling evidence that young children have biological conceptions of infection" (p.3). However, the play episode does support his proposition that children with extensive experience with illness
can be expected to have an understanding that would exceed what could be expected from typically developing children, and Sigelman, Carpenter, Epstein and Maddock’s (1995) work regarding domain specific development as it relates to understanding disease causality. They describe developmental understanding about illness to be knowledge-driven, rather than maturationally-driven, and see this development as a novice-to-expert shift which occurs in response to a accumulation of knowledge or information about illness.

Creating a list of medical equipment. Because the impetus behind this research was to determine the children’s conceptual understanding of this difficult life experience, it was important to encourage the children to continually focus on their own ideas. Consequently at the end of each play session we invited the children to share with us what they felt they needed for the following day. In order to focus the children’s attention on the importance of what they were doing and to provide a visual trace of the request, we encouraged the children to make their request in the form of a written list. At the end of each session the children would be asked what they needed for next time. This information was then used the following day as a starting place to reinstate the context from the previous day and to act as an opening to begin a dialogue about what we had all learned in the subsequent session. In the following episode the children are reading the lists they have made to tell us what they need for next time in order to make it “more like a real hospital”. Once again the children’s emerging understanding of germ protection appears as they identify the need for a number of different requirements, including the need for protective clothing.
Teacher: Joshua and Martha, Claire is ready to talk right now. She is going to tell us about our reminder list.

Claire: When you go into the hospital you need gloves, the shoes things and the hat – that's all I have just yet because I have not drawn the other things yet!

Teacher: Well you keep drawing and I will take the second page of notes.

Joshua: We need some medicine.

Teacher: What else do we need?

Wearing latex gloves and the medical examination. In the next two play episodes we see examples of the children using their emerging understanding of germ theory in their play. In this first episode Joshua, while preparing for an examination, explains to the Teacher why he needs to wear latex gloves.
Transcript 1: Lines 1474-1477

**Teacher:** *Why do you need to wear the gloves?*

**Joshua:** *'Cause I am going to put this stick in her mouth.*

**Teacher:** *Why are you going to put the stick in her mouth?*

**Joshua:** *To check that her mouth is fine!*

**Teacher:** *How can you tell if her if her mouth is not fine?*

**Martha:** *She is not feeling good!*

In this play episode it is evident that not only is Joshua linking the need to wear latex gloves to the examination of his patient, but that he has linked a problem in the patient’s mouth to an illness of some kind. Kalish (1996) describes this kind of knowledge about illness as a property cluster and he describes these features as being associated with a prototype of some kind. Rosh (as cited in Kalish, 1997) describes a prototype as “a probabilistic summary, or a best instance, and provides predictions about likely features” (p.10). Kalish (1997) claims that most young children (3-6 years) have a prototypical understanding of illness as a contagious childhood infection. In this episode you can see that Joshua’s reasons for using the gloves are linked to features of illness associated with a sore mouth/sore throat prototype, which conforms to Kalish’s description of the young child’s typical understanding of illness.

**Medical examination.** In session four the children create another play scenario involving a medical examination and a diagnosis.
Transcript 1: Lines 1474-1477

Joshua: I am a patient. (This is the first time that Joshua plays at being a patient.)

Claire: What's wrong with you?

Joshua: That's the problem, I don't know!

Claire: Let me see then! I will have to see what kind of sickness you have.

(Checks a chart on the wall and says)

"Here we go, earache! It would be hurting a lot!"

In this play episode Joshua tells Claire that he is a patient, but when asked what is wrong with him, he replies he does not know. Claire suggests a probable cause – earache – only to be rebuffed by Joshua who tells her that his ear does not hurt enough to be earache and consequently he provides her with additional symptoms in order to help her think more clearly about a probable cause. Claire, taken aback by Joshua's statement, provides another diagnosis, which involves a made up sickness "Likeshamper". It is
obvious from Claire’s new diagnosis that she understands Joshua’s symptoms of not
being able to walk as much more serious than an earache and as such provides what she
thinks to be a much more serious diagnosis - “Likeshamper”. Claire adds seriousness
and clarity to the diagnosis by stating that this disease is “like when you have panic”.
Joshua, understanding the seriousness of his illness – his legs can move but he cannot
walk – accepts her conclusion.

When reflecting on this play episode and Kalish’s concepts of children’s
understanding of illness it would appear that this play exchange could be described as a
natural kind, because it involves ideas and causal connections between features that are
related to experience. Joshua opens the play scene by telling Claire that he is a patient but
he does not know what is wrong with him. Claire investigates this and states, “You have
earache! It must be hurting a lot!” Joshua replies by dismissing the symptoms because he
feels that his ear does not hurt enough to be earache, and in fact it is his legs that do not
work and as such this should be the focus of her diagnosis, not his ears. Her new
diagnosis, even though it involves a made up illness, demonstrates that she clearly
understands that not all illnesses are caused in the same way. This play episode is
suggestive of a very sophisticated understanding of illness that is normally associated
with adult understanding, and demonstrates a change to what would normally considered
a young child’s prototype of illness – *likeshamper* is obviously not just an infectious
disease because it involves the psychological symptoms of panic, rather than the
physiological symptoms of pain described in her earlier diagnosis. However as we were
unable to pursue this topic with Claire we were unable to determine whether she
understood the term *panic*. 
Contamination and contagion. The first example of the children discussing the
difference between contamination and contagion grows out of a conversation of how you
determine whether someone is a doctor or a patient during the second session.

Transcript 2: Lines 949-985

Martha: I'm not a doctor, I'm a patient!
Teacher: So what is a patient if a patient is not a doctor?
Martha: You go to the doctor and when someone calls them it is their turn.
Teacher: But why do you go to the doctor?
Joshua: I know why.
Teacher: Why?
Joshua: If you get sick you go to the doctor, sometimes if you are very, very sick you go
to the hospital or, or if you're hurt you go to the doctor but if you are very, very hurt you
go to the hospital.
Teacher: Did you hear that guys? Joshua was explaining the difference between going to
the doctors or the hospital. Joshua, what is the difference again?
Joshua: Sometime if you are hurt you go to the hospital and if you are sick you go to the
hospital.
Teacher: Have you ever been sick and gone to the hospital?
Joshua: I have been hurt and gone to the hospital.
Teacher: How about you brother has he ever been to the hospital?
Joshua: He has been lots of times.
Teacher: How come he has been lots of times?
Joshua: 'Cause he's sick!
Teacher: 'Cause he's sick?
Joshua: Now he's not.
Teacher: Now he's not! He's all better now?
Joshua: Oh! Yeah!

In this session the Teacher asks "But why do you go to the doctor?" and Joshua
replies by saying "If you get sick you go to the doctor . . . or if you're hurt you go to the
doctor", clarifying that he understands the difference between contamination ("hurt")
and contagion ("sick"). In his answer he also provides an understanding of the
progression of illness, "Sometimes if you are very, very sick you go to the hospital . . .
[or] if you are very, very hurt you go to the hospital". The Teacher, in order to check his
understanding, asks him to repeat what he has said to the children, and then follows up
with an additional question about illness just to make sure that he really understands the difference between contamination and contagion, "Have you ever been sick and gone to the hospital". Joshua replies, "I have been hurt and gone to the hospital."

Another play episode where the children demonstrate an understanding of contamination was described earlier. In this play episode Claire, in the role of the doctor, tells Joshua, in the role of the patient, that he has an earache. In this episode Claire is not only able to suggest the possibility of an illness that would have been caused by a contaminant - an earache - but she was also able to articulate some of the symptoms that the contaminant may have caused - it must hurt!

"Beliefs about contagion and contamination represent causal relationships surrounding illness" (Kalish, 1997 p.2) and this can be seen in the children’s play. Joshua quite clearly articulated that he understood the difference between contamination and contagion and their relationship to illness in an individual on a continuum from being a little bit sick, to very sick. Claire readily changed her initial diagnosis from a simple earache to the more complex likeshamper, demonstrating her understanding of an incorrect diagnosis and the sickness continuum. Kalish, as already described, states that most children’s understanding of illness revolves around the understanding of an infection of some kind. However, within the play of the well siblings this level of understanding, although present, as identified in Claire’s role as doctor in the description above, mostly revolved around much more serious illnesses and demonstrating a clear understanding of the difference between the two separate concepts of contamination and contagion and how they were linked together on the illness continuum. Understanding that the children’s model of infection involves both contamination and contagion, and
that there is a process to disease, provides strong evidence to begin thinking about how we can communicate with them more effectively regarding their sibling’s treatment and possible consequences.

**Internal sources of illness.** According to Piaget (1952), the children participating in this study were in the preoperational period of cognitive development which spans an age range from approximately two years to six or seven years. He describes children’s understanding of illness during this period of development as pre-logical and with a tendency to focus on one aspect of illness. He describes them as having difficulty in generalizing their thinking from one experience to another, and being unable to distinguish the physical symptoms of illness from its probable cause. Preoperational children are described as seeing illness in a more global non-specific way, relying on external cues for information rather than internal symptoms (James, 1995). During the preoperational period young children are thought to interpret illness as being caused by a concrete action and see recovery occurring by adhering to a set of rules. Magical thinking is often evident in their play. According to Piaget it is not until the period of concrete cognitive development that children attain the ability to describe illness via internal and external causes. However, during this period of cognitive development children still feel that all children can get well by taking care of themselves and doing what the doctor tells them to do. During the formal operational period children are able to think about illness hypothetically and make generalizations from past experiences of illness to inform the present. Children are now able to understand illness as an internal state, whose symptoms manifest themselves in an external way. Children during the formal operational period are able to describe symptoms in an abstract way and use language to articulate feelings
of health and wellness. Formal operational children are aware that not all children get well (Hergenrather & Rabinowitz, 1991). The formal operational period spans from eleven years of age to adulthood.

Prior to discussing children’s understanding of internal sources of illness it was necessary to consider again evidence presented earlier about the expected understanding of children in this age group, before going on to describe the findings, because the findings are so significant. The findings demonstrate that these children have an understanding of illness at the formal operational level. Consistently over three consecutive sessions the children demonstrate via their play that they understand that internal sources of illness cause external symptoms, and external sources of infection can cause internal problems. These children are also aware that doctors cannot always make you well – sometimes you are just too sick or too hurt!

In this section a number of the transcripts and images are included for a second time because of the importance of revisiting the various play scenarios with a different focus. The focus this time is to determine children’s understanding of internal sources of illness.

Transcript 1: Lines 1412-1432

*Martha:* I need this (takes the stethoscope). I need to listen to the baby’s heart!
*Martha:* It’s not pumping. The baby’s heart is not pumping – it’s not!
*Teacher:* What will happen?
*Martha:* She will die!
*Teacher:* What shall we do?
*Joshua:* (Rushes over and says) We need this! (Holding the blood pressure cuff) We had better put this round.
*Teacher:* What is that? How can it help?
In this play episode it is evident that the children understand that a problem with the baby’s heart – *it’s not pumping* – which is an internal source of illness, will cause an external problem - *the baby will die!* Here not only do the children demonstrate that they understand that an internal source of illness can cause an external problem, but they also demonstrate that they understand that there is a need to monitor the baby’s vital signs via the use of the blood pressure cuff and the stethoscope in order to determine her prognosis.

**Session two.** In this second session we see the recurrence of heart problems in the children’s play. This time it involves one of the children, Claire, rather than a doll as in the previous session.

Transcript 1: Lines 1112-1118

*Joshua: Ok! I will check you.* (Joshua takes the stethoscope and listens to Claire’s chest.)

*Joshua: Your heart’s not beating that well.*

*Claire: How did you feel it?*

*Teacher: Is it beating fast or slow?*

*Joshua: It’s not beating that well!*
Here is another demonstration of Joshua’s understanding of an internal cause of illness. In this image it is interesting to note how intently he is listening to the beating of Claire’s heart, demonstrating that he understands that listening to the beat is important. However, he does not demonstrate that he understands the relationship of the beat of the heart to illness causation. When he is questioned by the Teacher about the beating of the heart he replies with the statement “It’s not beating that well”. Here, it is also evident that he understands what the stethoscope should be used for and how it should be used.

Session three. In session three we see further evidence of the same child indicating his additional knowledge about internal sources of illness as he reviews the Teacher’s x-rays and uses standard infusion equipment.

Transcript 2: Lines 1791-1798

(Joshua drags the Teacher over to the light table in the wheel chair.)
Teacher: What are you x-raying?
Joshua: I just need to check your bones!
Teacher: Ok!

Joshua: Your foot is fine, you head is fine and your tummy is fine.
Teacher: Oh! Head, foot, tummy.
(Points to the x-rays.)
In this last photograph Joshua has assembled the series of three x-ray images demonstrating his understanding of the skeletal system inside the body.

The next play scenario is part of a larger play episode where Joshua, in the role of doctor, and Katie, in the role of nurse, administers medication to the Teacher through standard infusion equipment which includes a plastic bag, drip chamber, long sterile tubing and a flow regulator and IV pole. Joshua places the line into the back of her hand, securing it with two band-aids, and then covers it with a gauze dressing. He checks the flow and then provides a rationale for the peripheral intravenous infusion.
Transcript 3: Lines 1744-1761

Teacher: Well it doesn’t hurt that much. Is there medicine going into my body right now?
Joshua: Yes!
Teacher: Can you stop the medicine from going into my body?
Joshua: No!
Teacher: How come?
Joshua: 'Cos when its over there it will not come out.

(Joshua turns the fluid bag to look at it, presses it with his hands to check what is inside and then adjusts the flow rate.)
Teacher: What does that do?
Joshua: It makes it go more.
Teacher: Do I need more?
Joshua: I need to check your temperature. Right now it’s high.

In this complex play episode the children provide two examples of their understanding of internal illness. In the first example above Joshua is reading the x-rays to determine if the Teacher’s bones are “Ok!” and in the second episode Joshua and Katie place a peripheral intravenous line into the back of the Teacher’s hand, to give her medicine. From the children’s conversations it is clear that they understand that if the Teacher’s bones were not “Ok!” there would be a health issue, and that there is medication in the saline pack that is hung on the intravenous pole. The rationale provided for the need for medication was due to a physical issue – right now your temperature is
high – demonstrating that the children see the relationship between illness symptoms and the need for medication.

Katie’s role in this play episode is very interesting because throughout the play scenario she portrays a very capable nurse who is very aware of the procedure occurring. She helps Joshua with the correct placement of the line on the back of the Teacher’s hand and quickly obtains a band-aid to secure the line. However all her communication about the procedure is non-verbal. She even confirms the fact that inserting the intravenous line will not hurt by nodding her head.

Session four.

Transcript 4: Lines 541-570

Joshua: There are doctors that, that you check the bones!
Teacher: How do they see your bones though? I don’t see bones when I look at -
Joshua: With a picture of your bones.

Teacher: How do they take a picture of your bones? I took pictures of you guys all last weekend and I didn’t see any of your bones in those pictures.
Joshua: No it’s not a camera!
Teacher: Oh!
Joshua: It’s an x-ray! An x-ray is a type of camera that doctors use.
Teacher: Oh! It’s a camera that doctors use. So can you see eyebrows in an x-ray?
Children: No!
In all four play episodes the children seem to have a coherent theory relating internal origins of illness, the external manifestations of that illness, and its treatment. From the analysis of the sessions it is also evident that the children are not simply reproducing observed medical procedures, but are creating causal connections and the medical treatment models that surround those causal connections. In the two play sessions where the children are discussing broken bones they never discuss the origins of those broken bones, but they do discuss the need to check the bones via an x-ray; demonstrate an understanding of the parts of the body that the individual x-rays represent; and recognise that a special camera is needed to take pictures of your bones. They also understand that on x-rays all that can be seen is an image of your bones.

When Katie and Joshua decide that the Teacher needs intravenous medication it is decided after the fact that the rationale was because she had a high fever. So here we see a causal connection – high fever to the internal administration of the medication. It was interesting to realise that the children not only knew how to set up the peripheral intravenous drip, but also the rationale for its use. The other interesting observation was
that the children realised that the liquid in the plastic bag was medication, when normally one would think they would think it to be water. This observation brings the work of Flavell et. al., (1986) on the appearance reality distinction into question. These children would have numerous opportunities within the hospital setting to see the administration of intravenous fluids, and therefore clearly understood that the substance inside the plastic bag was medication even when it looked like water. Through the process of imaginative play, these children demonstrated that they were able to make the mental transformation, understanding that something that looked like water was in fact medication, and they were able to carry this understanding into their play.

Kalish (1997) states that young children are not generally aware of internal body processes, yet this does not seem to be the case in this particular study. As described earlier in the section under germ theory, Joshua identifies that dirty dressings can make someone sick or keep someone sick. This is another example of the children’s emerging understanding of the internal processes of the body. In this example Joshua obviously understands that contact with these soiled dressings can cause illness, and that the healing process can be limited. These comments suggest that he is not ignorant of the internal processes that occur in illness, but it is not apparent from his comments whether he understands the risk from soiled dressings to be imminent or whether he realises there is a time lapse between contact and onset of illness.

Williams and Binnie (2002), investigating young children’s understanding of causal factors, time between cause and symptoms, and recovery factors, supported Kalish’s (1997) findings in that generally children will predict that illness will occur immediately after contact. When considering Joshua’s play behaviour as it relates to the
episode on soiled dressings there does seem to be a palpable urgency in his behaviour and in his instructions. He says, "You have got to put all that back! It's a mess! It's a big mess ... people will get sick ... or still be sick!" Because of the urgency in his behaviour surrounding this incident it does suggest that Joshua considers the effects of the soiled dressings to be immediate.

Williams and Binnie (2002) suggest that one of the issues surrounding children's understanding of time from contact of illness to onset of symptoms is that young children have a limited understanding of the process of illness. However, this is not true for the children involved in this study, due to their sibling’s illness. Because their sibling’s illness has been protracted and progressive these children live with the illness process, and consequently the illness process can be seen in their play. Falling blood pressure, failing heart rate, use of intravenous fluids and medications, understanding when you go to the doctors versus when you go to the hospital, x-rays of internal parts of the body and germ protection are all part of the illness process for children with a progressive illness, and consequently are the catalysts for the conceptual differences in understanding of illness in the well sibling.

Summary

This study was interpretive in orientation, and used a qualitative case design, and microgenetic analysis to answer the questions that form the foundation of this study. These were:

- What is the nature of young children’s knowledge of their sibling’s progressive illness?
- How do young children (3-6 years) represent their understanding of their
sibling's progressive illness?

- How does their knowledge develop as a result of participating in a group?

From the analysis of the results it would seem that the children's knowledge about their sibling's illness involves sophisticated understanding of medical equipment and procedures, and major differences in the level of understanding between the observations and what would be expected according to the published literature. Through the process of analysing pedagogical documentation, microgenetically as the children move through all four quadrants of the Vygotsky Space, it has been possible to show how the children construct and represent their understanding of their sibling's illness and how this knowledge develops by being part of a group. When analysing the play episodes that surround the children's conceptual differences in understanding it was noted that many of the play episodes revolved around the illness process, rather than the illness itself.

However, it is important to highlight that the topics of interest seemed to grow out of the difficulties their siblings were experiencing. Katie's brother had just been fitted with a G-tube and was now receiving supplemental oxygen. Joshua's brother had brain stem failure and had been on oxygen for a long period of time. While participating in this study Joshua's brother received surgery on his hips. Although the focus of this study was the young, well child's understanding of their sibling's progressive illness, and as such all the themes and questions discussed arouse from their interests, it was apparent that all the participating children presented an understanding of illness that was far more sophisticated than had been previously claimed in the published literature in this area.

The results of the qualitative analysis will be discussed further in the next chapter.
Chapter V

Discussion

The primary goal of this study was to investigate the young, well child’s conceptual understanding of their sibling’s progressive life limiting illness. This involved stepping away from the traditional models used to investigate this area and opening up new dialogues with other disciplines in order to provide a deeper understanding of what these young children know. The following questions guided this investigation:

- What is the nature of young children’s knowledge of their sibling’s progressive illness?
- How do young children (3-6 years) construct and represent their understanding of their sibling’s progressive illness?
- How does their knowledge develop as a result of participating in a learning group?

This chapter provides a discussion of the observations and interpretations which were used to build the investigation and to answer these questions.

General Impressions

From the analysis of the documentation it can be seen that the children in the study have a far deeper understanding of illness and death than what might be expected of most children of their age. They appear to be more serious and reflective players than one would expect from same age peers. The findings in this study as they relate to the question “What is the nature of young children’s knowledge of their sibling’s progressive illness?” fall into two major categories – sophisticated understanding of illness and major conceptual differences in understanding.
The work of Rittle-Johnson, Siegler and Alibali (2001) was helpful in trying to make sense of how the two major categories of procedural and conceptual knowledge work in tandem to support the growth of knowledge in each category. This was especially so when it came to considering the difference in understanding between Joshua and Katie. On reviewing the data it was apparent that Katie’s knowledge fell into the area of procedural knowledge whereas Joshua demonstrated understanding in both categories.

Rittle-Johnson et al. (2001) describe conceptual and procedural knowledge as two distinct types of knowledge that lie on a continuum. Procedural knowledge is identified as the ability to execute a series of actions to solve a problem. It tends to be tied to a particular task, and as such is not easily generalized to another task. In contrast conceptual knowledge is thought to be generalizable and is defined as an explicit understanding of a set of particular principles that govern a particular knowledge domain. Furthermore, Rittle-Johnson et al. identify that individuals may or may not have the ability to verbalize this knowledge. This is an interesting point to reflect on when one considers the findings. Katie on several occasions demonstrated, non-verbally, procedural understanding that was previously thought to be beyond what one would normally expect from a three-year-old.

Within the literature on knowledge change there is considerable debate about which type of knowledge develops first - procedural or conceptual knowledge. Rittle-Johnson et al. (2001) argue for an inter-relationship between these two concepts, citing that each one develops as a consequence of the other, and providing a model to illustrate this process. In this model problem representation is inserted centrally and identified as the catalyst that causes the movement between the two different knowledge types –
procedural and conceptual. Rittle-Johnson et al. state that movement through the cycle is iterative and is supported via problem representation, which includes problem solving, observing other people’s interactions and experiences and/or direction, instruction and reflection (Figure 5.1).

![Figure 5.1 The Iterative model for the development of conceptual and procedural knowledge. (Rittle-Johnson et al., 2001)](image)

Through the analysis it became very evident how Joshua’s sophisticated understanding of procedural knowledge, which included, emergency procedures; taking, reading and utilizing x-rays as part of a diagnostic procedure; inserting and monitoring the administration of a peripheral drip, and consultation with a doctor where a prognosis given, led to major conceptual differences noted in this study.

*What is the Nature of Young Children’s Knowledge of their Sibling’s Progressive Illness?*

*Major conceptual differences in understanding.* The findings supported what is known in the literature about content and domain specific versus domain general knowledge, and how experience increases knowledge (Sigelman, Carpenter, Epstein & Maddock 1993; Myant & Williams, 2005). Via the process of observation, the siblings
have been able to develop a very sophisticated understanding of illness and the process of
dying. Through their play they demonstrated this understanding as a number of major
conceptual differences and sophisticated understandings of a number of medical
procedures not mentioned in the existing literature. Conceptually, the siblings were able
to identify that not all children get well; that they understood the difference between
contagion and contamination; that bodies have internal parts, and that dysfunction with
these parts could cause illness and death. These observations demonstrated that these
children’s thinking had moved away from solely using observable, concrete features to
inform their understanding about illness, to using knowledge of unobservable features
such as hearts, bones, blood pressure and brains, and philosophical features. The children
provided clear examples that they understood that a body is made up of many layered
parts. One of the siblings clearly articulated that he understood all the parts that form the
head - the outside features of the face, the skull, the brain inside the skull, and the mind.
The children related the x-rays provided in the drama area to the skeleton that was
provided for their investigation and related skeleton parts to parts on their own bodies.
From Joshua’s discussions on death it was evident that the he understood that when you
die your body deteriorates and that you are just left with bones.

Traditionally it has been held that preschool children’s knowledge about illness is
poor and is limited to obvious symptoms of the disease. Many studies have found young
children’s understanding of illness to be at the preoperational level, which involves a
focus on the obvious features and a set of characteristic features (Kalish, 1996a).
However, this type of reasoning was not noted in the thinking of the well sibling in this
study. For example, falling blood pressure was associated with an emergency medical
situation that could ultimately lead to death. There was a demonstrated understanding of such illness attributes as time (how long you needed to stay in hospital for various procedures or different types of illnesses), different types of doctors for different types of illness (belly doctor, bone doctor, brain doctor and doctors who just take notes), death and how it might occur, and that a brief restriction of the air line will not cause death. The children also understood that their siblings were not like other children of the same age. They provided examples of this understanding by saying that their sibling talked with their eyes, wore a diaper, could not walk, were fed through a hose and needed oxygen to breathe.

**Contagion and contamination.** Much of what has been reported in the contemporary literature (Buchanan-Barrow et al., 2004; Kalish, 1996a, 1997, 1998, 1999; Williams & Binnie, 2002) was supported by this work. As already identified, Joshua was able to articulate the difference between contagion and contamination and make the distinction between being sick and needing to go to the doctor and being sick and needing to go to the hospital.

*Teacher:* But why do you go to the doctor?
*Joshua:* I know why.
*Teacher:* Why?
*Joshua:* If you get sick you go to the doctor, sometimes if you are very, very sick you go to the hospital or, or if you're hurt you go to the doctor but if you are very, very hurt you go to the hospital.
*Teacher:* Did you hear that guys? Joshua was explaining the difference between going to the doctors or the hospital. B, what is the difference again?
*Joshua:* Sometimes if you are hurt you go to the hospital and if you are sick, very, very sick you go to the hospital.

From this discussion surrounding the different reasons why you may need to go to hospital – you are either very sick or very hurt - it can be seen that Joshua has a clear idea of *contagion* (something that has a complex causal chain and can be transmitted between
individuals) and *contamination* (a harmless object being negatively affected by contact with another object). In this statement he also provided a definition of the difference between being sick and needing to go to the doctor’s, being sick and needing to go to hospital and being too sick for doctors to make you better. He also applied this reasoning to being either very sick or very hurt, "*sometimes you are just too sick or too hurt*". This is a substantial finding because this level of differentiation between being very sick or very hurt and needing to go to hospital and being either too sick or too hurt for the doctor to make you well, has not yet been identified within the literature base on children’s understanding of illness in this particular age group and developmental stage.

**Germ theory.** Because of the contradictory views in traditional and contemporary literature involving children’s understanding of contagion and contamination, and because Kalish (1996a) had identified that young children (3-6 years) had a rudimentary understanding of germs, I was interested to determine whether the siblings had an understanding of contagion. In order to investigate this, the children were supplied with hand cleanser and paper towels on a child-sized sink to see if they would initiate hand washing and then put on latex gloves before seeing their patients. As can be seen from the results, not only did the children initiate and follow through with the hand washing before seeing the patients, but they also provided additional examples of their knowledge of germs. They made it very clear that bandages could not be reused for another patient; masks should be worn to prevent germ transmission; and, the hospital environment had to be kept clean because germs could be passed on that way too. However, it was interesting to see that the children did not initiate hand washing after seeing a patient. On reflection it was determined that this was probably because the siblings had never seen a doctor
perform this action due to the fact that it normally occurs after the patient has left the examination room. Consequently, because the children did not have the opportunity to observe this procedure it is not part of their knowledge base on germ protection procedures. This finding provides evidence for the conclusion that the well sibling’s knowledge grows from personal observations of the illness process. Additional support for this probability occurs in the following transcript.

**Joshua:** I recognize this and this.
**Teacher:** What are those? Can you use words to describe what you’re seeing?
**Joshua:** Um, those masks you need!
**Teacher:** Okay. You know what? Sophie, when you were doing your homework, did you figure out what these shirt things are called?
**Claire:** Gowns.
**Teacher:** They’re called gowns?
**Claire:** Yeah.
**Teacher:** Or scrubs.
**Claire:** Gowns.

In this example the children are discussing the clothing that nurses, doctors and patients wear in a hospital. The children discuss gowns. The teacher introduces the word *scrubs*, which is the term that doctors and nurses use for their protective clothing. However the children correct this information supplied by the teacher, reaffirming that they are called gowns, not scrubs. This is probably because in their experience this clothing item has been referred to as a gown. Gowns are what patients wear, scrubs are what doctors and nurses wear and these children have probably not had the opportunity to hear doctors or nurses refer to the name of the clothing items that they wear for protection.

**Sophisticated understanding of medical procedures.** The siblings had a very sophisticated understanding of medical procedures. They knew how a hospital ward should be set up. They knew how to use a blood pressure cuff, and understood the
significance of low blood pressure. They understood the importance of taking notes ("I'm gonna have to do some notes! I gonna do lots of notes!"), making emergency phone calls ("... the baby will die! You need to come quick! Someone had better come quick else the baby will die! Her heart's stopped pumping!") and complex medical consultations.

Joshua: I check the brain and bones.
Teacher: How are you gonna check my brain?
Joshua: (Points to the bed) ... on there!
Teacher: I'm a little busy right now. I am having my brain checked.
Joshua: And your bones checked . . . stay there I will be right back.
Teacher: Can I sit up while I wait for you?
Joshua: I'm afraid you will not be able to sit up for a couple of days.
Teacher: How come? What is my diagnosis?
Joshua: 'cause I need to check the bones and the brain. I'm afraid the bones don't look that good.
Teacher: Why don't they look that good?
Joshua: 'cause of the needle and the bones and I need to check your brain.
Teacher: You'll check my brain? I hope my brain is doing better than my bones.
Joshua: Your brain is fine.
Teacher: Did you check my whole brain? Can you point to the part of my brain that is not doing so well?
Joshua: Actually none of the parts are mmm! All of the parts are fine.
Joshua: You have to stay here.
Teacher: Here?
Joshua: Yeh! Because, because if she doesn't go in the hospital she will have to stay in the hospital . . . and if she does not have air then she will have to stay even more days.
Teacher: If I don't have air? But remember if I don't have air you can put an oxygen tube in me and then I would have air. So am I that bad that I need oxygen?
Joshua: Bad but you need two glasses of medicine everyday.

Both of the siblings knew how to administer and monitor the flow of a peripheral intravenous line, demonstrating, both physically and verbally, an understanding of increasing the flow rate and where the procedure could occur on a person's body. They understood how to read an x-ray by placing it on a light table and looking for the parts that were broken or "not doing so well". They also had a very sophisticated understanding of oxygen, which included knowledge of different types of oxygen.
cylinders, how to read the dials on the oxygen tank and how oxygen is inhaled. The siblings were also aware that although a constant flow of oxygen was important, just stepping on the oxygen line would not cause a person to die. However they had a lot of questions about this substance and initially there was some confusion about whether the same tubing was used for oxygen and for food delivery. The sharing time and work time enabled the children to raise their questions and to discuss their confusion about this gas. In the final session Joshua brought in his brother’s oxygen tank to show the other children. This experienced clarified much of the confusion that still existed for the children about this substance.

Joshua and Katie understood how a G-tube worked and demonstrated this understanding both in their play and verbally in sharing time. Although initially there was some confusion about whether the same hose could be used for oxygen and food, by the third session the children were clear that there were hoses for oxygen and hoses for food.

**Medical play.** There was no evidence of doctor’s office play in the dramatic play of the siblings involved in the study, even though the initial set-up was similar to a doctor’s office. The siblings moved directly to hospital play, and more specifically emergency play, with the children calling out:

*Martha:* It's an emergency! It's an emergency! Need this (takes the stethoscope). I need to listen to the baby's heart! It's not pumping. The baby's heart is not pumping — it's not!
*Teacher:* What will happen?
*Martha:* She will die!
*Teacher:* What shall we do?
*Joshua:* We need this! (Holding the blood pressure cuff!) We had better put this round.
*Teacher:* What is that? How can it help?
*Joshua:* It's just going to be — it's just going to check something!
*Teacher:* Ok!
Joshua: (Looks at the dial on the blood pressure cuff) Oh! Oh! It's going to be bad. Her heart has stopped pumping again. This is bad very bad! Her heart is not beating at all!

Hospital play was a very important part of the play sessions for the children. It seemed as though they had a need to play out what they had been observing in their lives. At no time did they ever participate in doctor's office medical play. Their play always involved the hospital and hospital procedures. The focus of the first session was emergency play. However the second and subsequent sessions involved complex medical procedures that the children would have observed either as part of a regular hospital appointment for their sibling, or procedures that occurred following their sibling being admitted to the hospital. When asked at the end of the second session what the children wished to have included in the drama area for the next time they identified the need for it to be more like a real hospital with more beds and more real equipment.

For the third and fourth sessions the drama area was set up with three quite distinct parts to the hospital - a ward area, an examination room and area that could be used for medical procedures. The children made full use of all three areas, moving the patients between the ward area and the procedure and examination area in the wheelchair, and moving equipment and materials into the ward area when they understood that patients might need that particular type of care. From their play it was evident that the well siblings had a clear understanding of doctor's rounds and the importance of taking notes following rounds. They also understood that others needed to see the notes because they might need to know what had happened, and consequently, great care was needed in making the notes and then filing them in the appropriate file holder following rounds and other hospital procedures that needed notes to be taken.
From our observations of the children we understood that the process of taking notes was important to them, so we provided an office area with appropriate materials for writing, with file folders and a simple file holder. By the end of the first four drama play sessions the children had created twenty-three pages of notes for the files, most of which had notes on both sides of the paper, and three pages of telephone messages. The three pages of telephone messages were written during the first session, which focused on emergency play, and occurred while the children were talking on the phone trying to solicit help. The notes were written following the process of rounds and were reviewed during the next process of rounds. Each page consists of squiggles, letters and numbers, demonstrating their emerging knowledge of the writing process and their understanding of the importance of those notes.

**How do Young Children (3-6 years) Construct and Represent their Understanding of their Sibling’s Progressive Illness?**

The second research question asked *how children construct and represent their understanding of their sibling’s progressive life-limiting illness*. From the results obtained it would appear that these children construct their understanding from their day-to-day, lived experiences of the illness process. All the children’s representations involved conceptual and procedural understandings that would have grown out of observations made as part of their daily life experiences. The children represented this knowledge through their play experiences as they participated as members of a learning group. Via their dramatic play the children were able to re-enact and therefore communicate their lived experiences involving emergency and routine medical procedures that surround an individual with a progressive illness. The socio-dramatic
play scenarios required the children to pool their knowledge and to negotiate their various understandings. This very process enabled us to create a framework of their understanding of this very difficult life experience.

It was evident that the medical scripts were created from common experiences with the illness process. The sibling’s were very confident in their abilities to complete various medical procedures. Their conversations frequently provided accurate descriptions of what would have occurred or should be occurring in a given medical situation. Reynolds and Jones (1997) describe skilled pretend play as mirroring cognitive and social competence. Consequently, as the children played and worked together as part of a learning group, the explorations and examinations, along with opportunities to ask questions and discuss opinions, provided the children with a myriad of opportunities to represent their understanding.

There was much evidence to support the role of the more able peer in enabling the children to represent their understanding more clearly. By the simple act of taking on a specific role or questioning the child’s understanding, the more able peer stretches the child’s thinking beyond that which could be accomplished by the child alone. The opportunity for the child and the teacher to engage in dialogue and share power through the process of play enabled the child to continuously represent their understanding and to support their growing competence.

The list below provides a synopsis of the many ways in this study in which the well siblings were able to represent their understanding, and were supported in representing their understanding, in this study.

- Sharing their experiences in a small group.
• Through the teacher’s ability to summarise questions, and refocus play situations to enable the children to stay on task with their thinking.

• By having the opportunity to experiment with materials that grow out of their interests and understandings that surround their sibling’s illness.

• By having the opportunity to share ideas and build on their ideas from their own experiences.

• By revisiting topics of interest with the teacher and other more able peers it enabled them to think more deeply about a given topic and thereby create new understandings.

• Through having their thinking challenged.

• By being provided with the opportunity to use other languages to represent and make visible their understanding.

How Does the Children’s Knowledge Change as a Result of Participating in a Learning Group?

The third question involves understanding how the children’s knowledge changed by being members of a learning group. However, when reflecting on the findings, there seems to be no clear evidence that the children’s knowledge changed. In retrospect five sessions was probably not long enough for any significant change to occur in the children’s understanding of their sibling’s illness. In order to address this question a list of the themes that arose out of the children’s interests over the five sessions was generated, and the data surrounding these themes was re-examined to determine if and
how the children's thinking had changed. On re-examination of these data it did seem probable that the children were still in the process of presenting what they already knew individually and then building this individual knowledge into a collective understanding via their play and group discussions in work time and sharing time.

The themes that were reanalysed to answer this third question involved the children's play and discussions around death, oxygen, G-tubes and medical diagnostic procedures. It was decided not to include the topic of the children's understanding of surgery in this analysis, because this was a topic that was only introduced briefly by the children, and only became part of their discussions during the last two sessions. At no time did surgery become part of the children's symbolic play. Consequently, it was determined that there was insufficient data on this topic to determine if the children had learned anything about it as being part of a learning group.

Within the field of education and more specifically, among individuals who believe in the importance of social construction in education, there is a strong belief that learning groups can provide a powerful context for learning (Giudici, Rinaldi & Krechevsky, 2001). Consequently it seemed important to address this idea in this study. In retrospect what can be concluded is that the learning group provided the Vygotskian framework that enabled the children to demonstrate their understanding and to maintain their focus. When reviewing the results of the analysis it can be seen how the learning group enabled children of varying levels of competence to be pulled into the zone of proximal development by the more able peers, who then provided the necessary scaffolding that enabled the demonstration of their understanding. Reflecting on the results obtained from Katie and her understanding of a G-Tube and Joshua's concerns
about the appropriateness of the oxygen tank that was provided for investigation, it can be concluded that without the support of the learning group the clarity that now surrounds their understanding of these two topics would never have been apparent to the research team.

An additional discussion point that arose from this analysis involved the change in attitude by the children towards their own knowledge of this difficult life experience. From the analysis of the transcripts and the digital videotape the well siblings appeared to become more confident over the five sessions, both in what they knew and in their intention to share this knowledge with the other children. The children clearly articulated to their parents their interest in coming to what they termed their special preschool, and were always eager to share their homework during sharing time. Since the conclusion of the study it has been reported that the children frequently ask when it will be time for them to come again. These are important points to consider when thinking about the learning group and how it supported the well sibling’s knowledge change.

Even though there was always an air of seriousness around the children’s play in all five sessions, there was an increasing level of comfort with each other. It is suggested that this level of comfort grew because the well siblings had found other children who had experienced similar life experiences and who consequently wanted to play the same games. Even though the learning group only consisted of two children who had a sibling with a progressive illness, all the participating children had some experience with progressive illness or death. Consequently the children’s play scripts were based on experiences that they had in common, which then built a collective understanding of the illness process and so provided a safe place to share what they knew. On reflection we
wondered if this realization provided the well siblings with a sense of normality – perhaps even allowing them to move from denial of what was happening to them and their family, to acceptance, because their knowledge was validated.

Typical Children’s Understanding

After the first two data collection sessions a question arose that involved understanding how typically developing children would react to the presentation of the environment and how they would use the medical materials placed in the dramatic area of the preschool. Consequently, because the data collection occurred in a functioning preschool, it was agreed to leave the environment set up in exactly the same way for the typically developing children and then to observe how they played with the same materials the following day. What became quickly apparent to the observers was that typical children’s medical play was very different. Typical children used the drama area as a doctor’s office, with very clearly defined roles of medical secretary, patient and doctor. The behaviour they displayed was typical of what one would see in a doctor’s office, not a hospital. This included entering the office space, identifying oneself as a patient, sitting down, reading magazines and waiting to be called into the doctor’s examination room. There was evidence these children had knowledge of how a group practice worked because they would ask to see a specific doctor when they arrived, and that doctor would be called, “Dr. A! There is a patient for you!” The doctor would then appear, greet his or her patient and then escort them into the examination room. In the examination room the patient would lie down, but there was no concept of stating what was wrong with them. The doctor would just look in their mouth, listen to their chest, use cotton wool, give inoculations and use bandages and then tell them they were sick (no
definition of the sickness) and then prescribe medication. The illnesses described included coughs, colds, tummy aches and broken limbs, and they understood that wounds needed to be cleaned. They had a clear idea of how to take medicine through a dropper or syringe. The patient would then leave, and the doctor would return to the reception area to collect the next patient. The medical secretary demonstrated very efficient note taking abilities, talking on the phone and she used the overhead as a computer. No nurses were identified in this play.

The children in the preschool were very interested in the green doctor’s scrubs, the doctor’s white coat and the latex gloves. They knew what the facemask was for, but they did not know how to put it on. They did not attempt to use the shoe or hair protectors, and did not understand what they were for when questioned. Because the children in the research group had a very clear idea of doctors having a particular speciality, we were very interested in determining if this typical group of children had a similar understanding. So we questioned them and asked, “What kind of doctor are you?” and they replied by providing the following examples, "A people doctor", "A kitty doctor" and "A regular doctor", demonstrating that they understood there were doctors for people and animals but not that there were special types of doctors for different parts of your body as the siblings in the study had identified.

No hospital play was evident, and when questioned about the doll’s wheelchair and the walking brace they did not know why you would need to use one or what the brace might be used for. A sink was provided in the examination room with hand washing materials; however there was no evidence of children washing their hands prior to examining a patient or demonstrating knowledge of germ protection procedures. In the
dramatic play of the siblings there was no evidence of patient/doctor role-play described above, even though the set-up was identical. The siblings moved directly to hospital play, and more specifically emergency play.

These observations are important when considering the well sibling’s understanding of illness identified within this study. The observations of the typically developing children lend support to the ideas learned in this investigation that point to children’s understanding of illness as being contextually driven. This knowledge also provides guidance around what to tell parents and healthcare practitioners about what children like Katie and Joshua are likely to know about their difficult life experiences and how they acquire that knowledge.

Additional Findings

Significance of preparing the children to participate in the research. It was evident from the results that the children were ready for this experience because it was possible to obtain extremely good data even from the first session. Initially, it was thought that it would take at least one or two sessions for the children to get to know each other, form relationships and become familiar with the new environment. However, this was not the case and data collection was able to commence on day one. This ability to obtain good data from day one may be due to the prior preparation of the children and their families. Each well sibling received two home visits before the start of the study, with the primary researcher spending at least one hour with each child on each visit. With parental support it was possible to get to know the children and to explain where they were going and what they would be doing. Consequently, the children came to the group knowing that they were going to talk about their brothers and sisters.
Prior to the commencement of the study the children and their families were given disposable cameras and asked to take photographs of their families in a variety of situations and bring these photographs with them to the first session to share with the other children. Clear instructions were provided regarding what should be in the photographs and who should be responsible for what was taken. For the purposes of this study it was important for the participating children to have the choice of which photographs should be taken. This was a deliberate step taken to encourage the children to bring photographs they wanted to share, and of which they would have a very clear memory trace. This decision was made because it was hoped that the photograph sharing would work in the same way as show-and-tell does in a preschool environment. In show-and-tell the child brings a preferred article from home. It can be a toy, or a postcard or any other special item that a child wants to share. The item is then passed around for the other children to look at and comment on. The child comes to show-and-tell with this knowledge and has an understanding that other children may ask questions and/or add comments about the favourite object and also handle the object. It was hoped to scaffold the children’s existing knowledge of show-and-tell procedures into a discussion about the children’s families, thereby generating a shared understanding that would enable the children to see that they had similar life experiences.

Transcript 1: Lines 14-32

Teacher: We did not hear about that guy yet! Who is that guy?
Martha: My Dad!
Teacher: That's Martha's Dad! Show us your picture! Show us your picture! It looks like you guys are doing leg aerobics! Is that your brother and is that you? It looks like you have pink
pyjamas? Who else has pink pyjamas? Do you have pink pyjamas?

Martha: Mmm! Sometimes!
Teacher: Do you have pink pyjamas?
Katie: Nods yes.
Teacher: How about you?
Emma: Yes.
Teacher: You don’t have pink pyjamas do you?
Joshua: No!
Emma: We have girl pyjamas!

The initial sharing of the photographs was very successful. The children were very open to sharing their life experiences and information about their families. There was much laughter as the children shared their stories and found that there were many commonalities between them. At the conclusion of the first sharing time we asked the children to select photographs of their family to pin onto a line using clothespins. These photographs remained pinned to the line throughout all five data sessions. At the beginning of each subsequent session and following each snack time we continued to introduce photographs for discussion, using photographs from the previous session. We maintained the routine of placing the photographs into a basket and then passing the basket around for the children to select the photographs they wish to share and discuss with the other children. The children enjoyed sharing and talking about the photographs from the previous session; this helped to reinstate the context from the previous session and to provide another opportunity to explore the children’s ideas and their questions.

Importance of the context. The context – a preschool – was an environment with which all but one of the children were familiar. This generated a certain level of comfort and predictability in what they were experiencing. We maintained the typical preschool
routines of an opening circle where information is shared, work time, snack time and free play. In the second and subsequent sessions we added gym-time because we felt that the children needed time to run around and just play with each other prior to commencing the data collection. On reflection I think this free-play time was a very important part of the relationship building that occurred in this study.

The context and the teacher’s role were structured to enable the children to think about what was happening in their lives in a meaningful way. All the materials were authentic. An actual child-sized wheelchair, a stethoscope, blood pressure cuff, peripheral intravenous drip, latex gloves, face masks and other assorted medical items, along with child-sized hospital scrubs, hair and shoe protectors and a doctor’s white coat were used to add to the authenticity and aid recall of past experiences. Photographs of a doctor’s office and BC Women and Children’s Hospital were placed on the wall in the drama area.

The playroom we used in the preschool was divided into two separate areas. Sharing time, work time and snack time all occurred in one area of the room. The drama area, which was set up as a hospital, was in another part of the room. This area had doors on it, so we were able to shut these doors when we did not want the children to have access to the medical play materials. In the meeting area there was a whiteboard. This board listed all of the tasks that needed to be completed that day. At the beginning of each session the children were introduced to the tasks, and information about each task was shared and discussed before the various activities occurred. This provided a high degree of predictability for the children, as they always knew what would happen next and at what point in the day they would be going home.

*The teacher’s role.* Within this study the teacher’s role was crucial in establishing
continuity between the different learning encounters, both throughout each session and across the five data collection sessions. The analysis and planning of each session based on our previous observations enabled us to begin each session with an objective in mind. This objective provided guidance for the types of conversations and play activities that would be useful to sustain, in order to elicit the children’s understanding of this difficult life experience. Because there was a seriousness that surrounded the teacher’s conversations with the children, they understood their conversations to be important. This understanding enabled the teacher to enter into the child’s world in the role of playmate or facilitator and then out again into the role of summarizer and/or questioner. These various roles worked to sustain and improve the learning encounter for the children (Forman, 2005).

Close observation of the children at play, prior knowledge of the child’s life experience and her own knowledge of child development came together as the Teacher observed the children in the play process. She summarized and added questions when she wanted the children to clarify their understanding or challenge their thinking. The following transcript, taken from the second session and previously discussed in relationship to children’s biological understanding of illness, provides an example of her process. In this scenario we see the teacher jumping into the children’s play by asking a question. Notice how her question not only acts to clarify her understanding of what the child is thinking, but also acts a catalyst for the definition of how to determine whether you should go to the doctor’s or the hospital.

*Martha:* I’m not a doctor, I’m a patient!
*Teacher:* So what is a patient if a patient is not a doctor?
*Martha:* You go to the doctor and when someone calls them it is their turn.
*Teacher:* But why do you go to the doctor?
Joshua: I know why.
Teacher: Why?
Joshua: If you get sick you go to the doctor, sometimes if you are very, very sick you go to the hospital or, or if you're hurt you go to the doctor but if you are very, very hurt you go to the hospital.
Teacher: Did you hear that guys? Joshua was explaining the difference between going to the doctor's or the hospital. Joshua, what is the difference again?
Joshua: Sometimes if you are hurt you go to the hospital and if you are sick you go to the hospital.

As the play sequence continues notice how the teacher asks the child to reflect on his previous thinking. This encouragement initiates a dialogue about his brother’s illness and provides additional evidence of his understanding about how and when you might go to a hospital.

Teacher: Have you ever been sick and gone to the hospital?
Joshua: I have been hurt and gone to the hospital.
Teacher: How about your brother? Has he ever been to the hospital?
Joshua: He has been lots of times.
Teacher: How come he has been lots of times?
Joshua: 'cause he's sick!
Teacher: 'cause he's sick?
Joshua: Now he's not.
Teacher: Now he's not! He's all better now?
Joshua: Oh! Yeah!

In this episode it is apparent that the teacher’s attempt to provoke the child to reflect on his previous conversation, in order to clarify the difference between being hurt and going to the hospital, and being sick and going to the hospital, was successful because Joshua was able to apply his knowledge to his own and his brother’s experiences of hospital visits. Joshua’s explanation was quite clear. He went to the hospital because he was hurt but his brother went because he was sick. When reviewing the transcripts there were numerous examples of the teacher talking with the children in this way. The teacher or the children would introduce a topic, and then the teacher would question their thinking. The children, when possible, would expand on their thinking and then the
Teacher would revisit this same topic either later in the session or the following day. She would use language such as “Do you remember yesterday you said . . .” or “You know what? Earlier you said . . .” in order to help the children recall their earlier experience.

It is clear from these interactions that the teacher understood that “young children seem to know more than they can do.” (Forman, 2005, p. 2) and she uses this knowledge in deciding when to enter into the play situation and when to challenge or question the children’s thinking. It is partly because of the teacher’s beliefs and her ability to enter into the children’s play to sustain the learning encounter, that it became visible that the siblings had a deeper understanding of the illness concept, medical procedures and equipment than has been previously described in the literature.

One of the roles of the teacher within programs inspired by the Reggio Emilia Approach to education is to ask good open-ended questions which stimulate the children’s thinking and provoke discussion. Within the schools of Reggio Emilia there is an importance placed on facilitating, orchestrating and gently guiding the children so that the conversation does not stray too far from the subject of interest, and so that every child has an opportunity to participate. When reviewing the transcripts of the children’s conversations with the teacher and with each other, there was so much evidence of the teacher orchestrating the children’s interactions in this way. In the following transcript, note the teacher’s ability to facilitate the children’s conversations, ensuring that each child contributes. The children are discussing whether they recognise pictures presented by one of the children at work time.

*Teacher: And do you recognize those pieces? What do you recognize and where have you seen them before?*
*Katie: At the hospital!*
*Teacher: At the hospital? You’ve been to the hospital before?*
Joshua: Me too!
Katie: With my brother.
Joshua: I recognize this and this.
Teacher: What are those? Can you use words to describe what you’re seeing?
Joshua: Um, those masks you need (Teacher: Yeah) and the (unclear).
Teacher: Okay. You know what? Claire, when you were doing your homework, did you figure out what these shirt things are called?
Claire: Gowns.
Teacher: They’re called gowns?
Claire: Yeah.
Teacher: Or scrubs.
Claire: Gowns.
Teacher: Great. Okay, Joshua you’re the last one. Pick something. Or share something, whatever you choose.
Joshua: The bones.
Teacher: The bones. Can you point something on there, to something on there that you want me to read? What English do you want me to read on that bone picture?

In this conversation the importance of facilitating, providing intermittent provocation and gentle guidance of the children to ensure that they all have an opportunity to contribute, is evident. The teacher opens the conversation by saying, “And do you recognize those pieces? What do you recognize and where have you seen them before?”. From this starting point the children’s understanding of what they have seen, where they have seen it, and its use, becomes visible.

The teacher’s role in this study demonstrates her understanding of the pedagogy of listening that was so important in this approach. It is evident that she is fully in the moment with the children throughout all five data collection sessions. Her ability to question her understanding about the children’s thinking and then to formulate new questions based on their responses demonstrates her ability to fully engage, continuously, in the learning process and co-construction of knowledge with the children.

**Parental difficulties and changes to the final data collection session.** Following the fourth session the parents requested a meeting and explained that they had concerns
about what the children were disclosing. They requested that the dramatic play sessions be changed to reflect the types of things that the children would experience at home. The research team discussed these concerns and consulted with the clinical counselling psychologist who was part of the team. She identified this type of concern as normal for parents in this type of situation, and pointed out that the shock of disclosure is sometimes just too difficult for parents to address. On reflection I wondered if the difficulties I had experienced with recruitment was related to the parents concerns about what their children would disclose in the play setting.

Due to the importance of considering the needs of the families it was decided to honour the parents' wishes and change the dramatic play activities in the final session. These changes were introduced to the children by telling them that the patients were now well and that they had gone home. We reminded them when they went to the dramatic play area that the hospital would not be there. We explained to them that we had created a home like setting and the children could visit the patients there. The children were very angry about this change and demonstrated their dissatisfaction both physically and verbally and in their play. When we opened the doors to drama area they ran around the room climbing on the furniture, and using baby like talk. The complex, intense play noted in the previous sessions was missing. In retrospect I think that we should have continued with the hospital play, and worked to help the parents understand the importance of this type of play to these children. Prior to the start of the sessions the parents were provided with information about typical responses of children who have a sibling with a progressive illness, and information about contacting the counselling psychologist who was participating in the study. However I do not know if any of the parents made a
decision to contact her.

*Effects of the pedagogical beliefs in this study.* The present study was built around the underlying pedagogical beliefs of the preschools in Reggio Emilia, Italy. The educators within these schools see children as being competent and capable and having an incredible ability to abstract information and make meaning from their experiences. They treat children’s work seriously, describing the children as having a hundred languages, a hundred ways of demonstrating what it is that they know (Malaguzzi, 1998) and consequently use the languages of imagination, art, and relationships to help children demonstrate their understanding and to make meaning from what they experience.

Therefore the premise behind this study was that the well sibling was competent and capable of abstracting information and making meaning from their experiences. This premise was supported by the results. The languages of imagination, art and relationships were used to discover what the children understood about their sibling’s progressive illness. The documentation in Chapter Four acts as a powerful demonstration of the validity of using this approach with young children. Through the process of using photographs and digital video, along with collecting the children’s graphic representations, and then revisiting these documents with the children and with the members of the research team, it was possible to see that the children came with their own ideas and their own understanding of their difficult experience. This methodology also made it possible to explore these ideas with the children. Through the languages of imagination, art and relationships the children were able to share what they knew, what questions they had and what was confusing to them.

A major research issue that arose was how frequently the children would clearly
demonstrate through their play that they had a very sophisticated understanding of certain procedures, but would use the wrong linguistic label. Malaguzzi (1998) describes young children as having weak linguistic abilities, and therefore finding it difficult to explain what they know in this way. When Joshua was involved in the emergency play that surrounded falling blood pressure, he referred to it as temperature, even though his play demonstrated quite clearly that he was addressing issues that surround falling blood pressure. Katie found it difficult to talk about what she knew about her brother’s illness, yet when observing her at play, either individually or as part of a learning group, her knowledge and questions about her brother’s illness became visible. Her brother had been recently fitted with a G-tube and her concern and knowledge about this medical procedure was evident in her play and in her drawings. She drew tummies with G-tubes in position – stating that her brother was fed through his belly button. She used the tubing and the syringes supplied in the drama area to feed the dolls via their stomach. For both of these children the languages of imagination and graphic representation acted “as couriers for [their] ideas” (Malaguzzi, p.91) enabling them to demonstrate what they understood about hospital procedures, and their brother’s illness.

The Vygotsky Space. The use of the Vygosky Space as a tool for examining children’s understanding enabled the examination of how children built on each other’s understanding during each session and across the sessions in both the areas of conceptual differences and sophisticated understanding of medical equipment. The importance of the more able peer identified within the zone of proximal development was very evident in the Vygotsky Space. At times the more able peer was another child and at other times it was the teacher. It was very interesting to monitor the process of learning through the
cycle. When the children were familiar with the information, as evidenced in their knowledge about the peripheral intravenous line, the movement through the cycle was swift, often traversing through multiple cycles very rapidly in one session. However, when the children were presented with information that was related to their understanding but did not fit within their current conclusions, the movement through the cycle was interrupted, as evidenced in Joshua and Martha’s conversations about the relationship between lack of oxygen and death.

Through the process of microgenetic analysis it became very evident how closely the more able peer needed to monitor the play in order for the cyclic process to continue and for both children or the child and the teacher to remain in the zone of proximal development. Any mismatch between the play and the conversation that occurred would cause the child to move out of the zone and demonstrate an inability to understand. In the following transcript there is evidence of this mismatch occurring and the inability to understand arises.

Teacher: Why don’t they look that good?
Joshua: ’cause of the needle and the bones and I need to check your brain.
Teacher: You’ll check my brain? I hope my brain is doing better than my bones.
Joshua: Your brain is fine.
Teacher: Did you check my whole brain? Can you point to the part of my brain that is not doing so well?
Joshua: Actually none of the parts are mmm! All of the parts are fine.

Here we see that the Teacher introduces the idea that the brain has parts, and it would appear from Joshua’s response that this is a new concept for him. He stalls in his conversation as he thinks about what she has said and replies, but the play about brains stops. An analysis of this transcript and the one above supports the hypothesis that the zone of proximal development is the tool that creates the movement through the
Vygotsky Space. Any significant mismatch between the current information presented and present understanding causes the child to move out of the zone and the movement through the cycle to stall, leaving the child in the transformation process of the private/individual quadrant as evidence of their confusion is made public.

**Piagetian clinical interview versus the Vygotsky clinical interview.** When considering the traditional literature on children’s conceptions of illness and the extensive use of the Piagetian Clinical Interview, and now understanding the role that the teacher and the more able peers played in assisting and supporting the children as they made their knowledge visible, it can be seen why Vygotsky suggested the need for the clinical interview to be reworked in order to utilize more flexible methods of investigating children’s understanding. The transcripts and the digital video tapes of the five sessions provide numerous examples of the teacher and the children’s peers adding to the conversation, asking questions and using visual prompts that enabled the children to explain or add to their existing knowledge in this area. It was these very strategies that the Vygotskian Clinical Interview calls for, that enabled us to significantly extend what is known about children’s understanding of illness.

**The role of emotion in learning.** From the results it appeared that an argument could be made with respect to the emotional context that these children find themselves in as being a catalyst for the increased levels of cognitive understanding that were identified in this study. Klatter, Lodewijks and Aarnoutse (2001) shed some light on this possibility. They describe learning as a cluster of beliefs that includes both cognitive and emotional attributes, and explain that the affective and the cognitive aspects of the learning concept come together in the form of a given behaviour. This cluster of beliefs
about learning involves motivation, the nature of the learning, an understanding of the learning process and the demands that are being placed on an individual. Ainley (2006) adds support to this perspective and identifies affect as being central to understanding the learning experience. She describes affective, motivational and cognitive processes as interdependent in the learning experience, and explains that a person's affective state, which involves feelings of arousal, alertness, attention and concentration, is a key variable in the motivation to learn.

Therefore, when one considers the work of Klatter, Lodewijks and Aaronoutse (2001) and Ainley (2006) in relationship to the findings in this study, it can be argued that affect may provide a rationale for the significant difference in illness understanding reported in this study. The well sibling is living in a highly charged emotional environment, and consequently it is possible that it is the effects of living in this environment that create the increased motivation to learn. In order to make sense of their lives affectively, there is need for the well child to develop an understanding of what is happening to their ill sibling. Consequently we see evidence of this process in their re-enactments of emergency as well as routine medical situations, along with their developing understanding of the sophisticated procedures and equipment that are used this process. Through the process of reconstruction of past-lived experiences the well siblings are constructing an understanding of their physical reality and knowledge of the other people involved in that experience (Carpendale & Lewis, 2004). Taken together this provides strong support for the role of affect as a catalyst for the changes in understanding that have been observed in this study.
Significance of the Findings

These findings add support to Buchanan-Barrow et al.'s (2004) theory that children's understanding of illness takes the form of content specific knowledge rather than domain general knowledge and Carey's (cited in Buchanan-Barrow, et al., 2004) ideas that increased exposure to, and experience with, illness increases children's understanding. For these children, encoding specific information about their sibling's illness would have been important. Therefore the knowledge in this particular content area improved, enabling the children to process information and manipulate ideas that are thought to be well beyond what would be typically expected for children within this age group and developmental period. Myant and Williams (2005) point out the inappropriateness of using research on children's understanding of illness that is grounded in Piagetian stage theory, stating that it refers to children's capacity for certain types of thought, rather than understanding of a particular topic. They argue that illness should not be conceptualised as part of a domain general framework, as children's reasoning skills differ across domains. Therefore, it would seem that the domain general theories that have been typically applied to explain children's understanding in this area may no longer be appropriate.

Siblings' prototypical understanding of illness. From the results it can be seen that the well sibling has a different prototypical understanding of illness than one would expect from children in this age group. It would seem that the major changes in the children's conceptual understanding of illness, created by the constant interplay of procedural and conceptual knowledge, led to a more sophisticated understanding of the illness concept, which in turn has created an expansion in the children's prototypical
understanding of illness to include the illness process. The well siblings expanded prototype includes:

- A realization that there are medical specialities and that the speciality is related to an illness type;
- An understanding that there are different categories of illness (chronic or progressive) that requires extensive hospital care, rather than doctor’s office/surgery care;
- That there is a process to illness that includes multiple visits, extended hospital stays and a variety of different procedures;
- That protection from germs is important;
- Understanding that sickness can occur in parts of the body that would not typically be ascribed to childhood illness — *your brain and your bones are not doing well*;
- A requirement for multiple surgeries;
- A requirement for breathing (oxygen) and eating assistance (G-tube feeding);
- Difficultly with movement — specifically legs;
- Environmental adaptations for many ordinary aspects of daily living;
- A realisation that doctors cannot always make you well.

*Psychosocial issues that surround this study.* Numerous studies reported significant psychosocial problems in well siblings of children with a progressive illness. These included internalising disorders such as emotional withdrawal; high levels of anxiety; feelings of intense sadness, guilt and shame; or externalising problems that
include non-compliance, anger and acting out behaviours. These characteristic behaviours were used as evidence for the need for a support program such as the one completed as part of this study. However, over the five sessions very little of this type of behaviour was noted in these children. There was, as reported earlier, an overwhelming sense of sadness about these children. They were very serious players and did not present themselves to be as fun loving and mischievous as same age peers. They demonstrated checking behaviours that were associated with the location of their parents and concerns about when it was time to go home.

Katie took three of the five sessions to become totally involved in the children’s play, but that could be related to her personal functioning style or to the fact that she had previously never been to preschool. Joshua preferred adult attention and although he played quite comfortably with Martha and Claire, his preferred playmate was the teacher. Anger appeared only several times in Joshua’s response, and normally arose out of being pushed too far when questioned. Joshua obviously wanted to talk about death because he brought up the topic numerous times in his play and in his conversations during work time. However when the conversation went too far he would announce strongly that he was “going to play”.

At the end of the final session all the children were presented with a photograph album with photographs of them playing with the children in the study. We suggested that the children could use these photographs to talk to the mommies and daddies about their experiences at their special preschool because they would not be coming any more.

**Seriousness of the children’s play.** There was a profound sense of seriousness about the children in their discussions and contributions as well as in their play. They
tended to play on their own but as part of the group, in that their play was influenced by the comments and actions of the other children. There was an enormous amount of dramatic, yet solitary, play. It was evident that the children were interested in and bothered deeply by what was happening in their families. Joshua wanted to be a bone and a brain doctor; his brother had brainstem failure and had received numerous hip surgical procedures. At the time of data collection his brother was receiving yet another surgery on his hip. Katie was very interested in stomachs, belly doctors, G-tubes and how you are fed through a G-tube. This was very evident in her play. All the dolls had band-aids on their tummies and she was constantly drawing pictures of tummies and then explaining how her brother got fed in this way. During the final session one of the parents provided a full G-tube kit as a present to the research team. We took this kit into sharing time to show the children. We told them all about it and asked if any of them knew how to put it together. Katie quietly identified that she did and then quite confidently demonstrated how to assemble the G-tube for insertion and feeding. In the dramatic area she played feeding her dolls through the G-tube. It is important to note that Katie was only three years old.

As we moved through the data collection sessions it became very evident that the play sessions were just not long enough for the children. Although the work time, which was structured to invite questions from the children and to provide them with additional knowledge that they could then take into their play, was interesting to the children, they really demonstrated that they needed a longer time enmeshed in the hospital play. Therefore it was decided to increase this time and for the last three sessions the hospital play was extended to approximately one hour in duration.
Conclusions

From these results it can be seen that the young well sibling’s conceptual understanding of illness is quite different to what one might expect of typical preschoolers and involves major conceptual differences in understanding and a very sophisticated understanding of medical equipment and procedures. When considering conceptual differences it can be seen that the sibling’s understanding has expanded to include adult-like interpretations of contamination and contagion, which includes an understanding that there is a continuum of disease progression as it applies to either contamination or contagion that can at times lead to death – “Because sometimes you are just too sick for doctors to make you well!” Joshua expressed an understanding of death, how it could or could not occur and what happened to your body after you were dead. From the sibling’s play episodes it can be seen that they have developed a simple biological understanding of the origins of illness (Kalish, 1999) and a clear idea of the internal sources of illness – “Her heart is not doing well! It’s not pumping!”

The children’s understanding of doctor speciality was clearly articulated. They knew that there were brain doctors, bone doctors, tummy doctors, doctors who did surgery and ones that just took notes. In all of the play episodes Joshua clearly identified himself as a brain and bone doctor and had a very sophisticated understanding of the brain. When asked to articulate what he knew about the brain, he was able to identify its location inside the skull, and differentiated between the brain and the mind. Claire built on the children’s understanding of mind with her additional information about the brain. In her drawing she demonstrated what the brain looked like and discussed its ability to change your thoughts. Katie always identified herself as a tummy doctor and, although
only three years of age spent much of her play time focusing on the doll’s tummy area. All of the children discussed the doctor who did surgery but when questioned had little information on what they did. This was probably because the children were unable to observe this type of doctor at work. On reflection with the other members of the research team we considered the doctor who just took notes to probably be a psychologist. We came to this conclusion because the children’s siblings were in an end of life situation and consequently their families had probably met with a psychologist many times and as such the well sibling had extended their idea of what a doctor did to include this type of speciality.

The well sibling’s sophisticated understanding of medical equipment and procedures included:

- X-rays. Joshua was able to identify what an x-ray was, how you would take an x-ray and how you would read an x-ray. They were able to articulate that an x-ray took a picture of the inside of your bodies, and understood that it could be used as a diagnostic tool.

- A peripheral intravenous line. Joshua and Katie demonstrated how to insert a peripheral intravenous line into the back of a hand, and how to monitor and increase the flow. On one occasion there was some confusion surrounding whether the liquid in the saline drip was water or medicine. Joshua demonstrate that he knew the peripheral intravenous pole was mobile and could be moved to different locations.

- Blood pressure cuff. Joshua demonstrated an understanding of how to use and read a blood pressure cuff, and clearly understood that falling blood pressure
was a bad thing and could lead to death.

- Germ protection. The siblings demonstrated germ protection procedures involving washing hands, cleansing of wounds, wearing protective clothes and the need to disposal of contaminated dressings.

- Medical examination procedures and the length of hospital stay in relationship to the findings of the examination.

- Importance of note taking so that others would know what had happened.

**Future Directions**

The evidence presented clearly identifies a need for a support group for children who have siblings with a life-limiting illness. Consequently, future directions would include the development of such a group. The children’s sophisticated knowledge of medical procedures and conceptual understanding of their sibling’s illness exceeds anything that has been previously published in this particular area. However, it is also important to note that although these findings raise questions about how young children understand progressive illness as it relates to their siblings, the results can only be applied to this particular case because of the size of the group. Therefore future directions would need to include multiple cases of this particular population to determine if the results would support the findings of this investigation.

The age related differences in illness understanding between Joshua and Katie should also be addressed in future studies. Katie’s understanding of illness was primarily procedurally based and involved sophisticated understanding of medical equipment and procedures. However, Joshua’s knowledge involved both procedural and conceptual understanding and as such involved understanding death, how people die and what
happens to your bones when you die; germ protection procedures; an understanding of when you go to hospital and when you go to the doctors; the difference between a doctor and a patient, and contamination and contagion. Developmentally, it could be suggested that the difference in understanding is related to age and cognitive development. However, it is possible that the difference is due to life experiences - Joshua had approximately five years of experience with progressive illness whereas Katie had only approximately 18 months. Consequently, future studies could consider the relationship between length of experience with illness and children’s understanding, versus age differences as this could have implications around the type of support that would be needed.

The methodology used in this study demonstrates itself to be an effective tool for helping young children discuss and make evident their understanding of difficult life experiences. In support of using new methodologies when working with young children Brown and DeLoache (1983) pointed out that “in order to construct a realistic picture of the child’s competences it is sometimes necessary to use methods other than traditional experimentation. We sometimes gain our most interesting information from informally observing, questioning and playing with children, particularly the very young” (p.226). Vygotsky (1978) supports this stance. He states that “any fundamentally new approach to a scientific problem inevitably leads to new methods of investigation and analysis. The invention of new methods that are adequate to the new ways in which problems are posed requires far more than simple modification to previously accepted methods” (p. 58). He continues by pointing out the importance of using methods that are dynamic and that involve understanding the process of learning. He stresses the importance of using
methods of analysis that allow for the reconstruction of “all points in the development of a given structure” (p.65). Consequently when considering future directions, it would be important to continue to work with this study’s methodology, in order to facilitate its development and application to future research.

When replicating this study it would be interesting to look more closely at some of the questions within traditional and contemporary literature on children’s understanding of illness in the light of the findings of this study, particularly in the area of content specific knowledge as it relates to domain general knowledge. Within this study there is evidence of significant cognitive differences within a specific content area, which does not seem to generalize to other cognitive domains. Consequently any further studies could well address this factor in more depth. Additionally, it would be interesting to follow a group of young children from initial diagnosis of their sibling across time to see what contributes longitudinally to the conceptual changes in their understanding.

This methodology could also be used with other young children with different illness experiences to determine if conceptual understanding differs depending on the illness type and progression and, if it does, how it differs and what contributing factors may create the difference. The results from this work would then provide a better picture of whether children’s conceptual understanding differs across the various illnesses or whether there is a general, common shift in conceptual understanding, leading to a general change in the illness prototype that is similar in all populations of young children that are affected by someone within their family with a progressive illness.

In this study there was some suggestion of a general trend in changes in understanding. One of the issues to consider when completing research in the area of
progressive illness is the fact that the population is both small and diverse, making the possibility of generalizations from one illness to another difficult. Yet within this study it could be seen that there were general trends in the children’s interest which primarily focused around sophisticated understanding of medical equipment and procedures. It does seem from the results that this interest was a contributing factor in the significant conceptual differences. From the results, and understanding that young children’s general interest in the world is to understand reality, it is probable that most young children faced with similar life experiences would access understanding in a similar way. If this is so, then using this interest as a way to discuss their sibling’s illness could be the platform from which a support program could be built.

When considering other possible research areas for this type of investigation it is important to note that implementation of this study met with a great deal of difficulty. For this work to continue into future directions these difficulties would need to be overcome.

Additions to replications of this particular study would be to include parents as an active part of the program and would involve:

- facilitating a concurrent support group for the parents, much like the one that occurred in this study, with the primary focus of helping them to feel more comfortable with what the children are disclosing;
- developing a series of workshops and publications aimed at helping teachers and public healthcare professionals develop a better understanding of the young child’s knowledge base and how their conceptual understanding of illness changes through being a part of this very difficult family life experience, and
• continuing to work on methodology, particular as it applies to the Vygotskian Clinical Interview and how this facilitates movement through the Vygotsky Space.

Within the literature on social constructivism and the use of the zone of proximal development, which is used in the Vygotskian Clinical Interview, there is much discussion about the appropriateness of the level of support that the individual is given by the more able peer and the meaning that can be attached to those results. Vygotsky believed this stance to be problematic and identified it as a limiting factor in understanding the development of intellect. In his work on mediated memory he discussed the importance of social interaction between children and between children and adults as an effective means for remembering, citing the importance of the more able peer in lending their more highly developed memory skills to the other, so that a co-construction of understanding can occur. The use of pedagogical documentation in this study works to illustrate the importance of this process, and to reduce some of the concerns that surround this approach.
References


Kalish, C. (1999). What young children know about contamination and contagion and what that tells us about their concepts of illness. In M. Siegal & C. Peterson


Appendix A: Parent Information Handout
The Experience of the Well Sibling: A Guide for Parents & Health Professionals

Working with siblings of a child with a progressive, life-limiting illness is a relatively new area of research. Much of the research that is/has occurred in this area is still investigating the form and the frequency of supports that should be offered to these children, because of their changing needs over time.

Most of the current investigations have involved children who are 8 years of age and older. This is important to know when parenting or working with children who are below that age due to the type of supports that are typically offered to this other age group. Supports are normally offered utilizing a small group-counselling format, with opportunities to hear how others feel, provide information about the illness and its treatment, and time to play. This format may not be suitable for young children who have questions but are unfamiliar with the question and answer format for resolving them, and have a limited ability to articulate their difficulties, or to find support from being with peers.

Typical Response Patterns of the Well Sibling
Changes that are occurring within the family due to having a sibling with a progressive, life limiting illness tend to elicit the following response patterns.

Increase in attention seeking behaviours:
• Risk taking.
• Aggressiveness.
• Temper tantrums.
• Conduct disorders.

Anxiety Issues:
• Somatic complaints (often mirroring those of the ill child).
• Mood swings.
• Sleep disturbances.
• Separation anxiety.
• Decreased school performance/attention difficulties.
• Worry/fear (that they might get sick or that they may have caused the illness in their sibling).
• Overly compliant behaviours.

**Increased ability to Empathize with Others**
• Increased sensitivity to the needs of others (beyond what would be expected for their age group).
• Parenting or mothering roles frequently demonstrated by the well child.
• Checking behaviours observed.

**Feelings and Needs of the Well Sibling**
Understanding the well sibling's *feelings* as well as *needs* can help reduce the response patterns identified above. These can grouped under the following categories:

**Feelings**

**Fear:**
• The medical language used around them is strange, unfamiliar and scary.
• They may find the machines, medical equipment and the changes that occur in their sibling frightening. Depending on the child's age they may not even understand that the child receiving the treatment is still their brother or sister.
• Many siblings report that the scariest thing for them was seeing their sibling in hospital.
• That the illness is "catching".

**Loss:**
• Loss of attention from their parents, other family members and friends.
• Loss of the companionship of their sibling.
• Grief for their family as it previously existed.
• Loss of companionship of their friends due to school absence.

**Guilt:**
• They may feel that they have caused their sibling to be ill.
• They wonder why their sibling has become ill and not them.
• They may feel angry and resentful because of all the attention their sibling is getting.
Needs
For Support:
• Support is needed from their parents, grandparents, friends, teachers and health care professionals as they traverse this difficult time.

They need:
• Reassurance that everything that can be done is being done.
• Reassurance that you cannot catch their sibling’s illness.
• Reassurance that they did not cause the illness in their sibling.
• Help with meeting other kids who have similar experiences.
• Opportunities to feel “normal” again.

For Information:
• To help the sibling feel included and to make sense of the situation.
• To help build communication between the child and the other members of the family.
• To provides opportunities for questions and to be provided with age appropriate answers. Most children are not interested in the big picture; they only want to know what is happening now!

Other Resources:
The literature base that informs this study is primarily from the field of cancer due to the limited research in this area.

References:


