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Cystic Fibrosis: Issues from the Sibling Perspective

by

Daryl W. Simourd

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ABSTRACT

Cystic Fibrosis: Issues from the Sibling Perspective

Daryl W. Simourd

This paper is a qualitative study of young children's perceptions of having a sibling with cystic fibrosis. The 5 participants ranged in age from 6 to 10 years. The sandplay scenes and narratives of the sandworlds they created were examined to determine recurrent themes and level of well-being of the participants. The children lacked an understanding about cystic fibrosis and this was expressed as "battling the unknown". The other theme was "feeling left out".

A secondary objective was to explore the effectiveness of sandplay as a research tool. Sandplay was found to assist in rapport building and in facilitating expression. Sandtray assessment tools were helped identify themes, but they overlooked the voices of the children. Qualitative analysis of the data revealed the lived experiences of siblings of children with cystic fibrosis.

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PART I: BACKGROUND INFORMATION

INTRODUCTION

I have worked as a Child Life Therapist with chronically ill children in a hospital setting for several years. In this position, my role has been to support hospitalized children and their families in dealing with the psychosocial, emotional and developmental issues of the hospital experience. I have used therapeutic play to enable children to express their feelings associated with illness or with hospitalization in general. Landreth (1991) noted that play can be children's symbolic language of self-expression. Play allows children to express themselves and to cope with stressful situations. Through play, children can assimilate hospital experiences. They can learn to make sense of the experience by playing it out, repeatedly if necessary.

Whereas the majority of my work has been with the ill child, I became curious about the effect the illness has on the healthy siblings. I have observed that some families completely abandon their normal family routines when a child is hospitalized. Sometimes, the mother moves into the hospital with the ill child and the father commutes from work, to the hospital, to home late in the evening. When this happens, the healthy sibling is cared for by grandparents, other family, or neighbors. I began to wonder about how the healthy siblings integrated their experiences of having a chronically ill sibling. I also began to ponder the impact that having an ill sibling had on the healthy siblings' sense of self and on their sibling relationships.

Feeman and Hagen (1990) noted that sibling relationships can have a significant impact on future adult relationships. They stated that children learn how to communicate

and socialize in sibling relationships. Sibling relationships prepare children for interactions in peer relationships. Lobato (1990) noted that sibling relationships influence each other's self-identity and personality development. Sibling relationships are also a source of support for children. Thus, it may be hypothesized that having a sibling with a chronic illness may have considerable impact on sibling relationships. Eiser (1993) declared that when one child in the family is chronically ill, the siblings may have limited opportunities to interact with one another and that all the children in the family may experience limited opportunities for social experiences. The relationship between the siblings may be dominated by worry over the well-being of the ill child. Additionally, the needs and interests of the healthy siblings may take on a lower priority than those of the ill child.

Rather than try to generalize the impact that chronic illness in a child has on healthy siblings, I chose to focus on one specific disease. I decided to investigate siblings of children with cystic fibrosis because I have been intrigued by the disease since my first experiences in a hospital setting. At that time, I became acquainted with an active, outgoing, 8-year-old girl with cystic fibrosis. The last time I saw her, she was running and jumping down the halls of the hospital. I was stunned to hear one month later that she had died. It was difficult for me as an adult to comprehend and I became curious about how children make sense of the experiences of their siblings with cystic fibrosis. I also wondered about how children make sense of being the healthy sibling to a child with a visible, confusing, degenerative chronic illness.

Cystic fibrosis is a complicated disease and it is difficult to comprehend the biological processes that are involved in the various manifestations. Because cystic fibrosis is almost always diagnosed in early childhood, the disease impacts the entire family. Treatments are often time-consuming and unpleasant. Children with cystic fibrosis develop distinctive physical characteristics -- it is a visible disease. For example, they may have a frequent productive cough, become barrel-chested, develop digital clubbing (the tips of the fingers and toes become thicker and the nail meets the fingers at a flatter angle), have small stature, and have delayed sexual maturity (Genentech Inc., vol. 3, 1993). There are several notable stages in the course of cystic fibrosis -- diagnosis, a relatively healthy period to first exacerbation, a period when hospitalizations become more frequent, a period of increased complications and finally, the deterioration to the terminal phase (Bluebond-Langner, 1996). See Appendix A for more information on the physical aspects of cystic fibrosis.

It was important to me that I conduct the research with the children themselves. Bluebond-Langner (1996) claimed that siblings of children with cystic fibrosis rarely have the opportunity to express their feelings. Christian and D'Auria (1997) asserted that most research relies on parental reports of siblings functioning even though children as young as 6 years have the ability to describe their daily life stressors and how they cope. My experience has also been that children can and will express themselves when given the opportunity to do so.

Whereas I wanted to gather information directly from the children, I felt that a non-verbal, play-based medium may be more useful than interviews. Asking healthy siblings directly about their feelings might not be the most informative method to enable them to express themselves. Landreth (1991) stated that children naturally communicate through play. Therefore, using a play-based approach may be more effective in allowing children to explore and express their feelings. One particular appeal of using sandplay with children is that it is primarily non-verbal, and therefore accesses the thoughts and feelings of young children who may not have the language skills to express themselves verbally. It can provide a medium for expressing what the child may not be able to put into words. One child expressed the power of sandplay in his statement, "I talked lots about everything that happened but here I been very quiet, I been thinking. Thinking is hard 'cos no one hears you but this sand picture is a sort of thinking picture isn't it and you can see it out loud" (Harper, 1988, p. 19).

Sandplay is an enjoyable technique that appeals to young children. It seems to be an ideal medium to use in encouraging school-age children to express themselves. Literature abounds on the use of sandplay as a therapeutic tool. Even though sandplay appears to meet most of the criteria of research methods, there is a paucity of literature on the use of sandplay in research. Sandplay is a standardized method with clearly defined and controlled instructions, responses, and interpretation guidelines. Thus, I became interested in further exploring the effectiveness of sandplay in research, particularly with school-aged children.

I also wanted to carry out the research in the children's homes where they were comfortable and relaxed. I hoped that this familiar setting would allow the children to express themselves naturally. This necessitated being mobile. Logistically sandplay was an appropriate choice since it is contained and not too difficult to transport the materials.

The outcome of these questions was to create a research project that uses sandplay to explore the life experiences of siblings of children with cystic fibrosis.

CHAPTER TWO: LITERATURE REVIEW - CYSTIC FIBROSIS

The Effects of Cystic Fibrosis on Siblings

In this chapter I will consider the research on having a sibling with cystic fibrosis in order to identify the influences on the life experiences of healthy siblings. I will consider both parental reports of siblings' experiences with cystic fibrosis as well as the data from siblings themselves. Whereas there is considerable research on the impact of cystic fibrosis on the family, I will focus on the impact that cystic fibrosis has on healthy siblings. Eiser (1993) reported that healthy siblings often suffer numerous difficulties. They are impacted by recurrent separations from both the parents and from the ill child and by upheaval in normal routines. Derouin and Jessee (1996) confirmed that healthy siblings of children with cystic fibrosis reported feeling that they were the most unhappy person in the family. Both the behavioral manifestations and the psychological impact will be examined.

Much of the information regarding siblings is derived from parent reports, usually the mother. However, Derouin and Jessee (1996) noted that maternal reports may not be accurate because the mother may not be fully aware of the siblings' feelings, thoughts, and concerns. Parents and the healthy siblings may simply look at the issue from different perspectives. Christian and D'Auria (1997) reported that "...patients and family members have different trajectory perceptions of the course of chronic illness" (p. 9). Eiser (1993) stated that parents tend to underestimate the impact that cystic fibrosis has on the healthy sibling. It could be that parents are so preoccupied with the treatment of the ill child that they do not notice or are not capable of dealing with the concerns of the healthy sibling.

Seldom are the siblings themselves interviewed (Reed, 1990). This chapter will consider the parental reports of siblings' coping with cystic fibrosis as well as the data from siblings themselves.

Research on the Effects of Cystic Fibrosis on Healthy Siblings

In this section, I will review the literature that has attempted to identify the repercussions of having a sibling with cystic fibrosis. It is important to be aware of how cystic fibrosis can effect the healthy siblings. However, the conflicting results will illustrate that the impact is not easy to predict.

Cowen et al. (1986) noted that research regarding the impact of cystic fibrosis on healthy siblings has lead to inconsistent conclusions. They reported results ranging from high anxiety levels, sleep disturbances, enuresis, and behavior problems to positive self-image. At one end of the continuum, Patterson, McCubbin, and Warwick (1990) reported that siblings of children with cystic fibrosis were angry, resented the limited attention they received from their from parents, and had difficulties in school. Feeman and Hagen (1990) cited several studies that found healthy siblings have increased physical, social, behavioral, and academic difficulties. Rosenstein (1970) found healthy siblings to have behavior problems, particularly resentment, depression, and acting-out behavior. Eiser (1993) reported that siblings of chronically ill children have an increased probability of depression, anxiety, obsessive-compulsive disorders and social difficulties. Shepard and Mahon (1996) stated that healthy siblings may feel isolated, rejected, anxious, depressed, helpless,

resentful, or guilty. They felt that these difficulties were brought on by periods of separation, and lack of knowledge about the chronic illness.

Lobato (1990) commented that the issues presented by healthy siblings may not be to the degree of measurable psychological or behavioral problems. The healthy siblings may not demonstrate any serious behavioral effects from their unique experiences. Gayton, Friedman, Tavormina, & Tucker (1977) directly interviewed siblings of children with cystic fibrosis and found no evidence of negative psychological impact. Lobato (1990) reinforced that healthy siblings may not experience problems with their self-esteem, social competence, or behavioral adjustment.

In contrast, some research indicates that there is a positive impact in having a sibling with a chronic illness. Williams et al. (1993) noted that healthy siblings have been shown to have experienced personal growth. Higher ratings of prosocial behavior and social competence were observed in healthy siblings (Stewart, Stein, Forrest, & Clark, 1992). Lobato (1990) reported that some positive effects of being a healthy sibling to a chronically ill child include advanced maturity, increased sense of responsibility, increased tolerance, heightened self-confidence and greater independence. Healthy siblings may have the ability to empathize better (Eiser, 1993; Janus & Goldberg, 1995). However, Janus and Goldberg stressed that the ability to be empathic was not related to healthy siblings' behavior problems.

As can be seen, research indicates that the effects of having a sibling with cystic fibrosis run the gamut from emotional and behavioral difficulties to no discernible

differences to a positive growth experience. It is possible that the variations are due to differences in research techniques. Some research has utilized standardized forms of assessment while other research has relied on subjective interpretation of clinical observations (Cowen et al., 1986). It is difficult to draw conclusions on the pathological effects of cystic fibrosis based on the inconsistent and often contradictory results of research.

Healthy Siblings Perspectives on their Lived Experiences

In this section, I will consider the research that has been done directly with the healthy siblings. This research tends to reflect the range of reactions rather than searching for predictive variables. Therefore, I will attempt to illustrate the lived experiences of the healthy siblings to shed light on the influence of having a sibling with cystic fibrosis. Some researchers have spoken directly with the siblings and have given a voice to their perspective. In particular, the University of Calgary (1992) produced a video in which siblings of children with chronic lung diseases (including cystic fibrosis) were interviewed about their experiences. This video is notably informative in that the siblings are presented speaking for themselves. Bluebond-Langner (1996) has written a book articulating the perspectives of families of children with cystic fibrosis. She interviewed the healthy siblings and revealed their outlook. This section will consider the work done by both of these sources, along with others, to hear what healthy siblings say for themselves.

Rather than focusing on negative psychological impact of cystic fibrosis, it may be more beneficial to examine the specific issues that concern the healthy siblings. The

concerns of healthy siblings change over the course of the child's illness. Brown, Krieg, and Belluck (1995) stated that as the illness progresses the family must adjust to the new stage and mourn the loss of their previous life situation. Bluebond-Langner (1996) found that healthy siblings expressed jealousy at the time of diagnosis and again when the ill child deteriorates. During the interim period when the ill child is doing well, healthy siblings report having close relationships with the ill child. Parents add that the healthy sibling is protective of the ill child. Healthy siblings also expressed protecting and watching over the ill child (University of Calgary, 1992).

As the disease progresses, it becomes increasingly difficult for families to maintain routines and a sense of normalcy. When the manifestations of the disease become apparent, healthy siblings express worrying about the ill child (Bluebond-Langner, 1996). One sibling noted that he was always thinking about the ill child and worrying if she was okay when they were separated (University of Calgary, 1992). Another healthy sibling disclosed not being able to focus on his school because he was preoccupied with worrying about the child with cystic fibrosis. Yet another healthy sibling admitted to worrying about his ill sister all the time, unless he was playing (Bluebond-Langner, 1996).

Healthy siblings may feel guilty about their own health (Eiser, 1993; Lobato, 1990). They are also likely very aware that it could have been them who had been diagnosed with cystic fibrosis. One sibling of a child with cystic fibrosis questioned why she was lucky and her sibling was not. She expressed the desire to trade places with the ill child to take away the pain. (University of Calgary, 1992).

Healthy siblings often feel sad for the ill child (Gallo, Breitmayer, Knafl, & Zoeller, 1991). They may feel pressure to achieve and may also take on extra responsibility in the home. Healthy siblings may believe that they must succeed and excel since their ill sibling may not have the opportunity to do so. They may also feel a sense of distance in the family (Lobato, 1990).

Healthy siblings may be isolated from information about cystic fibrosis and about the condition of the ill child (Wright & Leahey, 1987). Parents often believe that they are protecting the healthy sibling by not giving them information about the disease and it's implications (Eiser, 1993). Healthy siblings stated that they did not understand what was happening in the family. They expressed the desire for more information in order to understand the situation of the ill child and the changing family dynamics (University of Calgary, 1992). The healthy siblings' lack of information regarding cystic fibrosis could lead to jealousy over the extra care that the ill sibling receives from parents (Reed, 1990). At the same time, healthy siblings seem to understand the ill child's need for extra attention and resign themselves to the reality of the situation (Eiser, 1993).

Nonetheless, healthy siblings often have a great deal of knowledge, even if the parents did not discuss cystic fibrosis with them (Eiser, 1993). However, the healthy siblings may have misconceptions about the chronic illness and the causes of it (Lobato, 1990). Parents interpret the fact that children do not ask questions about cystic fibrosis as an indication that they are not interested (Bluebond-Langner, 1996). In reality, the healthy sibling may be hesitant to discuss cystic fibrosis with their parents because they are worried

about how the parents are able to handle the conversation (Eiser, 1993). They keep their questions and knowledge to themselves in an effort to protect their parents. Healthy siblings reported responding to the unspoken cues of their parents. They recognized their parents' hesitation to discuss the illness. Even though the healthy siblings had questions, they did not feel free to ask them. One child stated that she "didn't want to bother them or get them more worried" (University of Calgary, 1992). When healthy siblings do talk with their parents about cystic fibrosis, it is usually about the physical aspects of the disease. Rarely do healthy siblings talk to anyone about how they feel about the disease (Bluebond-Langner, 1996).

Feeman and Hagen (1990) reported that parents often treat the healthy sibling differently than the ill child. This is especially noticeable in expectations regarding chores, discipline and limit setting. The unequal treatment may have an impact on the attitudes of the healthy sibling toward the ill child. The healthy siblings sometimes view the ill child as spoiled and receiving preferential treatment (Bluebond-Langner, 1996). The differential treatment can lead to conflicts between the siblings (Eiser, 1993).

Wright and Leahey (1987) noted that healthy siblings suffer from altered family relationships. They may feel neglected by their parents and resentful (Ievers & Drotar, 1996; Lobato, 1990; Wilson, Fosson, Kanga, & D'Angelo, 1996). They sometimes feel that parents are not available to give them even routine attention and nurturance (Derouin & Jessee, 1996). Healthy siblings voiced feeling left out (University of Calgary, 1992).

Some healthy siblings go so far as to demand chest physical therapy (Bluebond-Langner, 1996). The parents interpret this as appeals for attention.

Healthy siblings disclosed their techniques of attempting to gain attention. One sibling coped by becoming involved in activities, such as sports, to win the attention of her parents. Other siblings admitted to making noise in an attempt to be noticed. Another attention-seeking ploy was to mope (University of Calgary, 1992). Still another effort to gain attention was to feign illness or to exaggerate minor scrapes (Bluebond-Langner, 1996). One sibling internalized his need for attention by resorting to eating (University of Calgary, 1992).

Peer relationships were very important to healthy siblings (Gallo et al., 1991). Bluebond-Langner (1996) reported that healthy siblings sometimes used friends when establishing standards for what family relationships are normally like. One boy reported comparing the "brattiness" of his sister with cystic fibrosis with his friends who have healthy sisters. When healthy siblings are feeling left out at home, they may turn to friends for support (University of Calgary, 1992).

Healthy siblings may experience restrictions in their social activities because of the ill child (Lobato, 1990; University of Calgary, 1992; Wright & Leahey, 1987). Siblings reported having a sense of extra responsibility, both to care for themselves and in household chores (University of Calgary, 1992). Increased household responsibilities necessitate decreased social and school activities for the healthy siblings (Williams et al., 1993). They may need to spend their time doing chores or caring for younger siblings

which precludes the opportunity of socializing with peers. In fact, healthy siblings believed themselves to be the family member that had to give up the most, such as parental time and leisure activities (Derouin & Jessee, 1996).

I have presented some concerns of healthy siblings of children with cystic fibrosis. They spoke of their fears and their desire for more information. They also expressed feeling left out, burdened, guilty, and protective of both the ill child and their parents. The healthy siblings revealed some of their strategies for gaining attention and coping with their feelings. It became apparent that the issues for siblings changed with the stage of the ill child's disease process.

Mediating Factors in the Impact of Cystic Fibrosis on Healthy Siblings

There is no direct relationship between sibling adaptation and characteristics of the disease (Drotar & Crawford, 1986). Whereas cystic fibrosis may increase the family members' susceptibility to stress (Cowen et al., 1986), individual characteristics and family factors may serve as mediating variables to avert major psychological effects of having a sibling with cystic fibrosis (Drotar & Crawford, 1986; Eiser, 1993; Thompson, Curtner, & O'Rear, 1994). Resiliency has been defined by Linquanti (1992) as "that quality in children who, though exposed to significant stress and adversity in their lives, do not succumb to the school failure, substance abuse, mental health, and juvenile delinquency

problems they are at greater risk of experiencing" (as cited in Resiliency [on-line]). Hetherington and Blechman (1996) stated that rather than relating risk factors to outcomes; the emphasis has shifted to identifying factors that play a role in varied outcomes. Instead of trying to pinpoint specific risk factors and how they lead to distinct outcomes, the focus of studying resiliency is to explore various protective variables and how they contribute to the outcome of exposure to risks.

This perspective is useful in understanding the research on the impact of cystic fibrosis on healthy siblings. I will explore several mediating factors that may contribute to protective variables in being resilient to the effects of having a sibling with cystic fibrosis.

Age can be a mediating variable. Cowen et al. (1986) found that the age of the healthy sibling was a factor in the impact of cystic fibrosis. Preschoolers were found to be more affected by the hospitalization of an ill child than older siblings were. At the same time, older healthy siblings may be expected to become more responsible for chores and childcare thus making them more susceptible to difficulties (Thompson et al., 1994). The age of the healthy siblings seems to influence what will be problematic for them.

Gender may also be another mediating variable. Male siblings who are close in age to the ill child had higher scores of psychological impairment (Drotar & Crawford, 1986). Girls tend to be burdened with additional caregiving responsibilities and experience more social isolation than boys do (Eiser, 1993; Lobato, 1990). Girls are more likely to abandon their own needs and goals for the ill child (Williams, Lorenzo, & Borja, 1993). Lobato

(1990) reported that while, as children, healthy sisters may adjust better than healthy brothers; in adulthood, healthy sisters are more susceptible to anxiety and depression.

Another mediating factor may be the size of the family. Eiser (1993) noted that in large families, siblings can derive support from one another and diffuse the impact of having a sibling with a chronic illness. Having at least one healthy sibling can be a frame of reference for helping the healthy sibling to interpret the experience of having a chronically ill child in the family. In contrast, Thompson et al. (1994) reported that family size did not effect healthy sibling adjustment. Drotar and Crawford (1986) noted that the quality of the healthy sibling and ill child relationship influences the coping of healthy siblings. It has been suggested that family environment and family style may be the important factors. Supportive, nurturing, stable, and cohesive families may contribute to resiliency (Indiana Prevention Resource Center at Indiana University [on-line]).

It has also been hypothesized that socioeconomic status is a mediating variable. Goldberg et al. (1997) suggested that socioeconomic status has an impact on the families' ability to access social and economic resources. Being of upper or middle class is reported to be a protective factor (Indiana Prevention Resource Center at Indiana University [on-line]. However, Thompson et al. (1994) found that family income was not related to healthy sibling psychological adjustment.

I have presented several variables that may mediate the impact of having a sibling with cystic fibrosis. These factors include age, gender, family size, and socioeconomic status. These variables may be factors that effect resiliency.

This chapter has explored the reported manifestations of having a sibling with cystic fibrosis, concerns expressed by the healthy siblings, and some mediating variables that may be related to resiliency. I have shown that there is a diverse range of possible outcomes to the situation. When attempting to determine the effect of cystic fibrosis on the healthy sibling, it seems valuable to take the time to gather information from the healthy siblings directly, rather than relying on parental reports. It is also important to remember that, when speaking to the healthy siblings, the information may be reflective of that moment in time. Siblings are bound to experience different attitudes as they grow older and as the disease process changes the life of the child with cystic fibrosis.

CHAPTER THREE: LITERATURE REVIEW - SANDPLAY

Sandplay

In this section I will describe the technique of sandplay. I will also explore the history and theory behind sandplay in order to provide a background for using sandplay as a research technique. I will consider the results of studies using sandplay. Because sandplay can be both a therapeutic technique as well as a research tool, I will refer to the facilitator as therapist/researcher to incorporate both roles.

The Procedure of Sandplay

In this section, I will outline how sandplay is presented and used. I will discuss the role of the therapist/researcher and the structuring of the session. I will also address the issues of interpretation and theme development.

Sandplay is a tactile technique that uses sand in a sandtray and a wide selection of toys. The sandtray is a 20 x 30 x 3 inch waterproof tray with a blue bottom and blue sides. The size of the tray is specific to allow one to observe the entire sandtray at a glance. Sand can be dry or moist. Hundreds of miniatures should be available for the child to select from. The miniatures and objects should include the following categories: people, buildings, animals, vegetation, structures, natural objects and symbolic items (Allan & Berry, 1987).

The role of the therapist/researcher is to provide a free and protected space for the child. The therapist/researcher must also develop an atmosphere of empathy and trust (Bradway & McCoard, 1997). The therapist/researcher does not interfere during the

process of creating a sandplay scene, but the child is aware of the therapist's/researcher's presence as an observer (Ryce-Menuhin, 1992). Reed (1975) stressed that sandplay must be directed by the child. "To direct the process is to deny it meaning and purpose (p. 27)."

It generally takes children about 30 minutes to complete a sandplay scene (Buhler, 1951a). When the child indicates that he/she is finished, the therapist/researcher asks the child to talk about, or tell the story of the sandplay. Cockle (1993) found that it is important to elicit a narrative from the children about the sandtray. The theme of the sandtray can be more fully understood using the entire sandplay process, including both the sandtray and the narrative. It is vital to determine the child's interpretation of the sandtray (Carey, 1990). Allan and Berry (1987) noted that it is not necessary for the therapist/researcher to interpret the sandplay for the child. The psychological issues are tapped at an unconscious level. The value of sandplay is the process of the child expressing him/her self. This results in a release of tension, fulfillment, and healing (Reed, 1975).

Cockle (1993) noted that the child should complete at least 4 sandtrays for emotional themes to emerge. The narratives must be included with the sandtray in the consideration of the themes.

I have explained the method of using sandplay both for therapeutic and for research purposes. The size of the sandtray is specific. A wide variety of miniatures should be available for the child to use in making scenes. The therapist/researcher creates a safe environment and respectfully observes the participant. Upon completion of the sandplay,

the therapist/researcher encourages the participant to talk about the sandplay scene. Several scenes are generally required before themes can be identified.

History of Sandplay

Sandplay has been used a tool for research as well as a technique for therapeutic intervention since early in the century. Because sandplay is primarily a non-verbal technique, it is useful for helping persons of all ages express what they may not be able to verbalize.

In 1929, Margaret Lowenfeld initiated the use sandplay as a therapeutic technique. She recalled reading the account of H. G. Wells who wrote of observing his children work through issues using sand and toys. Lowenfeld added two boxes of sand and a variety of toys to her play room. This therapeutic use of the materials became known as the "the world technique" (Lowenfeld, 1988). Since that time, students of Lowenfeld have continued to refine and alter the technique. The world technique was brought to Sweden in 1942 where Dr. Gosta Harding standardized and further developed the method. This revised version of the world technique, "the Erica-method," is a diagnostic tool as well as a therapeutic one (Sjolund, 1981). In the 1960's, Dora Kalff combined the tool of the world technique with a Jungian orientation. Kalff called her technique "sandplay" (Carey, 1990). Kalff is considered to have had the greatest influence on the technique by developing theoretical principles and the approach commonly used today. Kalff has also been very instrumental in teaching sandplay. Charlotte Buhler was another student of Lowenfeld before she brought the technique to America (Carmichael, 1994). She used sandplay

primarily for research and diagnosis with children who were disturbed (Allan & Berry, 1987; Carmichael, 1994).

Theory of Sandplay

In this section, I will present the theory of sandplay. I will illustrate why sandplay is a valuable tool to use with children. Since sandplay is primarily used as a therapeutic tool, much of the literature explores the healing aspects of sandplay. I will also describe some literature in which sandplay was used for diagnosis.

Harper (1991) noted that sandtray can be an effective tool in assisting children to communicate their inner feelings and how they view their world. The sandplay may be representative of the child's outer world; or it may be an expression of fears or fantasies of the child's inner world (Harper, 1988). Sandplay is nonverbal and can provide a medium for expressing what the child may not be able to put into words. Early childhood memories tend to be nonverbal. Therefore, it may be more expedient to access early childhood trauma on a nonverbal level, as in sandplay (Ryce-Menuhin, 1992). Sandplay can be a conscious process where the child plans to create a scene. It also works at an unconscious level where the child is not aware of why specific miniatures are chosen (Bradway & McCoard, 1997).

Lowenfeld's intent was to develop a medium through "...which a child can demonstrate his own emotional and mental state..." (Lowenfeld, 1988, p. 267). Sandplay seems to release blocked psychic energy to allow the psyche to heal itself (Allan & Berry, 1987). Bradway and McCoard (1997) noted that sandplay connects the mind and the spirit.

Sand is an earth element and may provide the child with an opportunity for symbolic and realistic grounding (Carey, 1990). Allan and Berry (1987) added that sandplay allows children "the opportunity to resolve ... traumas by externalizing the fantasies and developing a sense of mastery and control over inner impulses" (p. 300). The process of sandplay also encourages growth (Bradway & McCoard, 1997). Grubbs (1995) stated that sandplay can assist in the accomplishment of developmental issues.

Two stage theories of sandplay have been developed. Both theories identify signs of progression when sandplay is used as a therapeutic technique. These stages are a reflection of the healing process and are not related to social or cognitive development. According to Allen and Berry's theory, there are three distinct stages in children's sandplay. They are chaos, struggle and resolution and may be cyclical rather than linear. In the chaos stage, there is characteristically a dumping of toys into the sandtray without apparent attention to selection. Alternatively, the sandplay may produce a barren scene where there is a lack of life in the sandtray. Both types of sandtrays may signify that the child is emotionally overwhelmed. The struggle stage involves intense battles where there are often no survivors. As the child proceeds through the struggle stage, the battles increase in intensity and balance. A hero may emerge. Instead of being killed; antagonists may become powerless. In the resolution stage, the sandplay scenes demonstrate balance and order. There is a sense of completion represented with scenes that often include miniatures organized in circles, squares and rectangles (Allan & Berry, 1987).

Kalff (1980) used three similar stages in her work. The first stage is the animal, vegetative stage. In this stage the child predominantly uses animals and vegetation. The second stage is the fighting stage. Battles predominate in the sandplay of children in this stage. The final stage is the adaptation to the collective. Dundas (1990) expanded on this by saying that the sandplay of individuals in this stage may depict movement of vehicles, construction, familial patterns, and communities and towns.

Sjolund (1981) noted that sandplay can be used in four diagnostic categories. Sandplay can be a source for a developmental diagnosis. The sandplay can be examined to provide information as to the developmental levels of the child in the areas of play, speech, fine motor, gross motor, intellectual and psychological functioning. The second diagnostic category is "milieu diagnosis." Here, the sandtray is examined to determine if there is a relationship between what the child expresses in the sandplay and the child's lived experiences, particularly concerning relationships with parents, siblings and friends. The sandplay may also be representative of the child's wishes or fears. Finally, sandplay may be used to diagnose somatic-psychosomatic and psychopathological problems.

Rationale for Using Sandplay as a Research Technique

There is limited data on the use of sandplay for research. Nonetheless, the work that has been done indicates that sandplay can be an effective research tool. Cockle (1993)

noted that sandplay is a useful technique for research because it is a controlled process and the results are contained. All of the emotional energy is focused on the sandtray and the expression is projected into the sandtray scene. Also, the sandtrays can be objectively examined and compared. I will support the rationale for using sandplay as a research technique by discussing two sandplay assessment tools.

Charlotte Buhler developed The World Test as a projective test using sandplay. She stated that the test identifies personality trends and characteristics and that these may be signs of certain personality disorders (Buhler, 1951b). Buhler described seven signs that may be apparent in the sandplay.

- Aggressive world signs include accidents and acts of violence. Aggressive signs alone tend to signify acute or temporary, superficial problems. Because they are common in the sandplay of most children, aggressive signs may only be significant if apparent in the first sandplay created by a child. Repeated depictions of accidents may indicate deep resentment or disturbances.

- Empty signs are sandplay scenes that contain less than 50 elements, less than 5 categories of elements, or no people (excluding soldiers). Empty world signs are not significant in children under the age of 5 years. They may also be typical of children with mental disabilities. However, empty world signs may be indicative of resistance to the task, or of emotional blocking or fixation. Using only soldiers and police may be indicative of concealed aggression.

-Distorted world signs are sandplay scenes that are very bizarre. Buhler did not expand on the description of this sign. Distorted world signs may indicate deep emotional disturbances. They may indicate insecurity, rigidity, confusion and the need for confinement. Distorted world signs are representative of regression.

- Closed world signs are sandplay scenes that have enclosures in the form of fences or in the manner that the sandplay scene is constructed. These may be symptomatic of anxiety in children over the age of 5 years. Enclosures may represent the need for protection.

-Disarranged world signs may be chaotic or they may include one or more symbols clearly out of place. This is more symptomatic if the child does not recognize the disarrangement. Disarrangement world signs may indicate a disturbed sense of reality, confusion, or personality disorders. They may be representations of wishes or fears of the child.

- Rigid world signs include exaggerated rows or patterns. According to Buhler, the rigid world signs are the most serious in children over the age of 4 years without mental disabilities. They may be indicative of obsessive-compulsive tendencies.

- Symbolic arrangements are those where the child expresses an important issue symbolically, either in the sandplay or in the verbal narrative of the scene.

In the analysis of children's sandplay, Buhler (1951b) noted that it is common for the sandplay of most children to contain one sign. Two signs, especially if one is a distorted world sign, may indicate an emotional disturbance in older children. Children

under the age of seven frequently have 2 - 3 signs in their sandplay (Buhler, 1951a). Buhler (1951b) stated that the order in which the sandplay is created is important. Generally, children put in houses and cars before people. Anxious children put fences in first.

Grubbs (1997) developed The Sandtray Categorical Checklist (SCC) for Sandtray Assessment. The checklist consists of 19 qualitative and descriptive categories to highlight the theme of the sandplay and the process of the creation, the child's narrative of the sandplay, and the changes in subsequent trays. Grubbs listed numerous indications of disturbances in children over the age of 5 years. Sandplay scenes that appear empty or lonely may indicate withdrawal, apathy, or inaccessibility. Large portions of the tray left unused, unless the remainder of the sandplay is highly symbolic, may be indicative of disturbances. Animals devouring other animals or people, unless it is a realistic scenario, may be problematic. Disorganized worlds may be indicative of regression. Sandplay scenes with numerous fences and no gateways may be representative of fear of impulses, of the need to protect the self, or of obsessions. The emphasis of unrealistic rows may indicate difficulties. Burying objects, pushing people into the sand or pouring sand over figures may show regression or a sadistic attitude toward the self and others. Alienation or fear of threat may be portrayed in sandplay scenes that have no people. Repeated violence toward family or victims may show trauma, abuse or self-abusive tendencies. Bizarre or primitive sandplay may represent psychotic tendencies.

Grubbs (1997) also outlined positive signs in sandplay. Molding the sand to create land formations shows an ability to use creative resources to adapt to reality. This is rare in children under 7 years. The progression of conflict and working through the conflict in subsequent sandplay scenes is indicative of growth and integration. The expression of aggression may be a release of pent-up emotions. The movement from chaos to order in subsequent sandplay scenes may indicate growth. Other signs of growth include increase in imagination, more complex narratives of the sandplay scene, and progression in arrangement, patterns and designs. Symbolic or mythical sandplay scenes may represent spirituality, as do circles in the center of the sandtray.

I have discussed two sandplay assessment tools that are useful in interpreting the results of sandplay research. The World Test (Buhler, 1951b) categorizes symptoms that may be expressed in the sandplay and suggests diagnoses based on this information. The Sandplay Categorical Checklist (Grubbs, 1997) uses both descriptive and qualitative methods to illustrate potential areas of difficulty and signs of strength and growth. The SCC clarifies themes that become apparent in a series of sandplay scenes. Although sandplay is a projective technique, both assessment tools have standardized the interpretation of sandplay scenes of children as young as preschool-age.

Research using Sandplay

In this section, I will report the results of studies using sandplay. These studies tended to be diagnostic in that sandplay was used to identify differences between various groups. The majority of the work has been done with children who have been abused.

There has also been sandplay research done with children who seem to be experiencing difficulties coping, children with cancer, and children with minimal brain damage.

Harper (1991) found that sandplay was effective in differentiating between varying types of abuse that children experienced. She compared the sandplay scenes of 40 children, ages 3.5 to 10 years, who were sexually abused, physically abused, both physically and sexually abused, and non-abused. The children created a series of 4 sandplay scenes that were analyzed for themes, clinical characteristics, and level of representativeness. There were notable differences in the sandtrays of control children and children who were physically abused, sexually abused or both physically and sexually abused. The themes of the sandplay of the control children were generally domestic or wish fulfillment. The abused children portrayed themes of need for protection or nurturance. The sexually abused children's sandplay was notable in the absence of fantasy. They also tended to create the same scene in subsequent sandtrays. Physically abused children tended to have conflict and chaos in their sandplay. Their sandplay was often dynamic in that fighting was acted out in the sandplay. Children who were physically and sexually abused did not create domestic scenes in their sandplay. They were also dynamic in their approach. That is, they did not merely create static scenes; but rather, their scenes included acting out what was being depicted.

Grubbs (1995) also studied children who were sexually abused and compared them to a group of controls. Her study comprised of 5 children ages 9 to 11 years who were either sexually abused or non-abused. The children completed 12 sandplay scenes that

were analyzed using an instrument constructed by the author -- the Sandplay Categorical Checklist. She found that sexually abused children created sandplay scenes that demonstrated death and destruction whereas control children portrayed positive domestic scenes. Children in the control group created boundaries that were open to others. Open boundaries include gates, bridges and pathways. The sexually abused children created boundaries that were either isolating or not effective.

Cockle (1993) worked with children who were identified by their teachers as coping or as having difficulty coping. There were 5 children in each group. The children were in grades 2 and 3. The children created 4 sandplay scenes that were analyzed using the Sandbox observation scale for children (Reed, 1975), clinical characteristics, themes, and story sequence analysis. She found that the children who were identified as having difficulty coping used the death and destruction themes in their sandplay. On the other hand, the children who were coping demonstrated fantasy and dependency themes. The depiction of dependency themes would have been developmentally appropriate for the children who were having difficulty coping but it was not illustrated in their sandplay. The children who were having difficulty coping created sandplay scenes that were characterized as barren and lacking in life, growth and health.

Ryce-Menuhin (1992) reported on work done with children with cancer by the Jungian analysts (Marinucci, Montecchi, Nagliero, and Tortolani) who found that the sandplay scenes were predictive of the children who would and would not survive the illness. The children who ultimately survived the cancer created sandplay scenes that

recognized their struggles. The children who died denied the experiences in their sandplay. Time stood still in the sandplay of the children who died, whereas this was not the case for the survivors. The survivors illustrated a sense of self in their sandplay scenes. The sandtrays of the children who died indicated that they did not have a sense of themselves as separate from their parents.

The stark and dramatic nature of this research raises serious questions. Could the children who create sandplay scenes predictive of a terminal outcome be counseled to alter their outlook? Would this have an impact on the course of their medical condition? Could research such as this lead to outcome indicators that would limit resources and spare these children from the intrusive medical treatment while supporting them in enhancing the quality of the short remaining period of their lives? What would be the impact of working with the parents, and not the children, to alter the meaning that the parents give to the illness? Would it be possible to work with children before diagnosis to instill the outlooks that were predictive of survival?

In her ongoing therapy work, Reed (1975) found that sandplay is effective in validating diagnoses of minimal brain dysfunction and emotional disturbances in children. She noted that sandplay of children with emotional disturbances with no underlying brain dysfunction shows progression in arrangement, patterns and design. Children with brain dysfunction do not show improvement in sequence or logic and may show perseveration. Children with brain dysfunction and emotional disturbance may show improvement if the neurological deficits improve. This coincides with a lessening of the emotional difficulties.

Reed also found that children with schizophrenia tend to use more fantasy in their sandplay.

The literature that has been discussed validates the use of sandplay as an assessment and as a research tool. Sandplay is effective in identifying children who have experienced abuse, children who are not coping, children who have a negative outlook to surviving cancer, and children who have brain damage.

The assessment tools appear to categorize the results of the sandplay to enable diagnosis of disorders or difficulties. However, Lusebrink (1995) stressed that using sandplay exclusively in a quantitative approach may overlook important data. The use of symbols and emergence of themes are two major aspects of sandplay that can not be captured in quantitative analysis (Grubbs, 1995).

Sandplay is an appealing medium for engaging children in communicating their inner worlds. Whereas it is primarily a therapeutic play technique, it has also been used for diagnosis and research. Strides have been made in standardizing sandplay thus making it an efficient diagnostic tool.

CHAPTER FOUR: METHOD

There was a twofold purpose for this research. The researcher was interested in the life experiences of having a sibling with cystic fibrosis and was curious about the usefulness of sandplay as a medium for qualitative research.

Participants

The 5 participants in this research were between 6 and 10 years. The age range of 6 - 10 roughly coincides with Piaget's concrete operational stage of development. Children in this stage acquire the ability to use representations and to manipulate symbols (Piaget & Inhelder, 1969). Christian and D'Auria (1997) indicated that children as young as 6 years old have the ability to identify and express their stressors and coping techniques. At the same time, 10-year-olds are still actively involved in playing and a play-based approach would be inviting to them.

Two of the families in this research project were identified by the Cystic Fibrosis Clinic at the Alberta Children's Hospital from a sample of children ages 6 - 10 years living in the vicinity of Calgary. Families who were experiencing family transition -- birth of a new child, divorce, or marriage were excluded from the research. Siblings who have medical or developmental problems -- autism or developmental delay, were also excluded. Two other families were identified from a brief description of the study that was included in the cystic fibrosis newsletter (Appendix B). Because of the very small number of potential participants, all identified families were included in the research.

Setting

This research took place in the homes of the participants, either in the living room or the kitchen depending on space and other family activities occurring at that time. The sandtray and figures were placed on a kitchen or dining room table, or the floor. Family members were present during some of the sandplay sessions because the sessions were in the middle of daily family activity space. One child insisted that at least one family member be present for each of the four sandplay sessions. Family members of the other children in the study casually observed the sandplay sessions for short periods of time.

Procedure

The researcher made telephone contact with a parent in the families that indicated an interest in participating in the research and explained the purpose of the study and what would be involved in participation (following the outline in Appendix B). The researcher obtained informed consent from both the parents and the children (Appendix C).

At the first session, the researcher set out the materials and explained to the children what was involved in participating in the research. The research was introduced to the children as follows... "My name is Daryl and I go to school at the university. For my homework I am trying to find out what it is like to have a brother or sister with cystic fibrosis. What I am asking you to do is to make a picture or scene in the sandtray using these toys. I have people, vehicles, buildings etc. (going through the entire inventory of 19 categories). You can use up to 30 minutes to make your picture or scene, but you do not have to use all that time if you do not want to. When you are finished, I will ask you to tell

me the story of your sandplay scene. I will audiotape your story on my tape recorder. I will also take pictures of your sandplay scene. The audiotape and photographs will help me to remember exactly what your sandplay scenes were like when I look at them again. I will come back 3 more times so that you will make 4 sandplay scenes in total. Do you have any questions?"

The procedure of each sandplay session followed the standard sandplay process as previously described on page 19. During each of the 4 sessions, the researcher presented the participants with a 20 x 30 x 3 inch sandtray and the baskets of miniatures. The miniatures were separated into 19 categories. They included people; army figures; buildings; fences and structures; pets; farm animals; wild animals; birds; water animals, amphibians, and insects; dinosaurs; fantasy creatures; trees and flowers; natural items; household items; yard items; transportation; food; medical; and miscellaneous. The researcher instructed the participants to make a scene or picture in the sandtray using the miniatures. They were allotted up to thirty minutes to create their sandplay scenes. The researcher alerted the participants when there were 5 minutes left and allowed them to complete the scene if they were almost finished when the allotted time was up. While the participants made the sandtray scene the researcher silently watched, or followed the participants lead in engaging in conversation. After completing the sandplay, the participants created a narrative about the scene. The standard sandplay protocol was modified to record the products as data. The researcher audiotaped the narrative and photographed the sandtray scene. The audiotapes were later transcribed.

Each participant created sandplay scenes on 4 separate occasions. The sessions were scheduled at one to two week intervals. For the first two sessions the participants did not receive any specific instruction regarding the content of their sandplay scenes. This established a baseline of each participant's play. The participants also became comfortable with the task and with the researcher. A further modification of the standard sandplay protocol was introduced when the researcher directed the participants to consider topics while creating their final two sandplay scenes. In their third sandplay scene, the researcher instructed the participants to include what they thought or felt when they thought about their sibling with cystic fibrosis. The researcher advised the participants that this could be a part of, or the entire content of the sandplay scene. In the final session the children were asked to include something about their family in the sandplay scene. Again they were advised that this could be a part of, or the entire content of the sandplay scene.

Instruments and Methods of Analysis

Each participant was considered an individual case study with the initial two non-directed sessions as a baseline for comparison with the last two more directed sessions. The four sandplay scenes were analyzed to determine any recurring themes and metaphors. Themes were initially determined using concept mapping wherein all of the ideas expressed in each sandplay were identified and related to each other. Each area of the sandplay scene was studied to determine the idea being expressed. For example, in one sandplay scene a man alone in a picnic area was identified as 'alone'. The brother getting married with no family present was also identified as alone. The sister being far away, surrounded by a

fence was identified as separate/alone. Linking several ideas such as these together revealed the theme of separation/aloneness. The resulting constructs were compared to determine the recurring themes. The researcher also repeatedly read the narratives and studied the photographs to understand the underlying messages being expressed.

In addition to concept mapping, portions of the Sandplay Categorical Checklist (SCC) for sandtray assessment (Grubbs, 1997) were used to analyze the content of the sandplay scenes. Several themes were identified in the SCC and these were used when applicable. Other themes were inspired directly by the content of the sandplay scene. The setting of each sandplay was identified. Grubbs (1997) stated that the theme and the environment of the sandplay scene combine to establish the setting. The SCC contains a list of settings that were used in this research. Additionally, the overall interpretation of the sandplay scenes was informed by the SCC (as described on page 27).

The World Test (Buhler, 1951b) was also used to determine any signs that were indicative of emotional disturbances (as described on page 25). The figures were counted and categorized to conclude if the sandplay scenes had empty world signs. This includes sandplay scenes with less than 50 figures, less than 5 types of figures, or no people (not including soldiers). Types of figures were categorized using the lists outlined in the SCC and The World Test. Aggressive world signs were noted if the sandplay scene demonstrated accidents, or people or animals fighting. Animals fighting was not included as a sign if it was realistic, as in wild animals searching for food. The sandplay scenes were analyzed for distorted world signs including closed, disarranged, or rigid signs. Signs

of closed worlds are fences with no openings or other arrangements that divide and separate the sandplay scene. Disarranged signs are chaotic organization of the figures in the sandplay, or a couple of items clearly out of place. Rigid world signs are unnatural, exaggerated rows or repetition. The sandplay scenes were also examined for symbolic signs which are clear symbolic messages.

The researcher created a table to present the trends in the sandplay scenes of each participant. The table consists of the categories found to be useful from the SCC (Grubbs, 1997) and The World Test (Buhler, 1951b).

Finally, the researcher identified story imports (Arnold, 1962) from the narratives. Arnold stated that story imports are one or two sentences giving the essence of the story. The details of the story are left out in the summarization of the intent, or moral, of the story. A series of imports can reveal the storyteller's values and attitudes toward life. The story imports were discovered by reducing the themes of each sandplay to a dominating message. For example, in one sandplay scene of one child there were several powerful figures depicted who randomly harmed powerless figures. The clear message from this sandplay was that being strong and powerful allows one to act without consideration of others.

The researcher consulted with a Chartered Psychologist who specializes in Play Therapy and frequently uses sandplay in her practice for assistance in interpreting the results. See Appendix D for the checklist of the SCC. Information from the World Test

Manual of Directions was used, but not a World Test form. Therefore, it is not included in the Appendix.

PART II: CHILDREN'S CASE STUDIES

INTRODUCTION TO PART II: CHILDREN'S CASE STUDIES

This section will present case studies of each of the five children who participated in the research. A case study approach was chosen to highlight the lived experiences of the children and to allow their voices to be heard. Each case study will begin with an introduction to the child including a description of the child with some family information.

The case studies will continue with the description of the sandplay scenes. Because this is a study of sandplay as a technique, I have chosen to include full and detailed descriptions of the childrens' actions. Each sandplay scene will be described in the order it was created. The children sometimes chose to work from different sides of the sandtray and the scene will be described from the perspective that the child predominantly worked from. The language of the children will be incorporated when possible. The children's exact words and paraphrases of the children's expressions will be indicated by the use of italics. If the child told a story when talking about the sandplay scene, the story will be recounted after the description of the child's sandplay.

The case studies will include a detailed analysis of each sandplay scene using a variety of methods. Interpretation of the sandplay scenes will consist of identification of the themes and symbolism and the indications of level of well-being. Each case study will be considered separately, noting any changes from the first two baseline sandplay sessions to the last two when the researcher asked for specific concepts to be considered. The interpretation will take into account the placement of figures, the number and types of figures used, and the narrative describing the sandplay. Concept mapping will be used to

reveal themes and symbolism in each sandplay scene and the interpretation will involve discussion of these. Any overriding themes that remained constant throughout the research will be explored. The results will also be interpreted using the Sandtray Categorical Checklist (SCC) (Grubbs, 1997) and The World Test (Buhler, 1951b) to identify any indications of level of well-being. When appropriate, the scripts will be examined for imports based on the Story Sequence Analysis (Arnold, 1962). In summarizing the overall interpretation, the researcher will compare the results to the literature on siblings of children with cystic fibrosis.

Finally, I will conclude each case study by summarizing the lessons I have learned from the children's sandplay in the form of a note to the child (although these will not actually be shared with the children). One of the motivations of this research was to learn about the children's lived experiences. Therefore, I felt that it was important to accentuate the voices of the children so they are not overshadowed by the formal analysis of the data.

CHAPTER FIVE: ALLISON - THE RESOURCEFUL LITTLE SISTER

Allison's story

Allison's mother responded to the newsletter advertisement. Mrs. A is very supportive of research done at the Alberta Children's Hospital and has participated in previous studies.

Allison appears to be an outgoing, energetic and enthusiastic child with numerous friends. She participates in Girl Guides and soccer. She spends her spare time playing with friends at the local leisure center. She is 10 years old and is the youngest of three children. The oldest child, James (age 16 years) has cystic fibrosis. He also appears to be a typical adolescent with an active social life. Allison's 13-year-old sister is healthy.

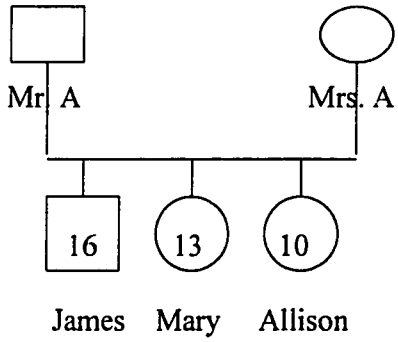

figure 1. Genogram of Allison's family

James was diagnosed with cystic fibrosis at 3 months of age and has not been hospitalized since. He attends CF clinic every 3 months for routine monitoring. James' CF is manifested in abdominal complications. He has night feeds through a nasal gastric tube to meet his nutritional requirements. James is reticent about his disease. He hides his medical supplies in his closet and does not share information readily. Allison volunteers to

assist Mrs. A with the preparation of James' feeds but is not involved with his other treatments. Mrs. A states that Allison does not want to talk about cystic fibrosis. Although both parents are in the home, Mrs. A is the primary caregiver and attends clinics with James.

Mrs. A was a 'stay at home' mother until a couple months before the research began. The family has a system of dividing the chores and each person participates actively in the household maintenance. Family life includes weekly bible study evenings at home. According to Mrs. A, the family previously had a foster son who was recently placed elsewhere.

Allison appeared apprehensive about the sandplay the first session. However, once she knew what to expect, she approached each of the sandplay sessions enthusiastically. She worked continuously without pausing, except to locate appropriate figures. Allison worked quietly and appeared to be giving a lot of thought to what she was creating. She completed her sandplay scenes in approximately 15 minutes. The assortment of figures seemed to be the source of Allison's inspiration. Allison's sandplay scenes depicted her concerns and her dreams. She expressed many ideas and her sandplay scenes were full of life and hope. Spirituality was a component in each of Allison's sandplay scenes. When asked to consider cystic fibrosis in her sandplay, Allison created a moving scene portraying what she believes cystic fibrosis will do to her brother. Allison's narratives described the content of the sandplay and further revealed her hopes and worries.

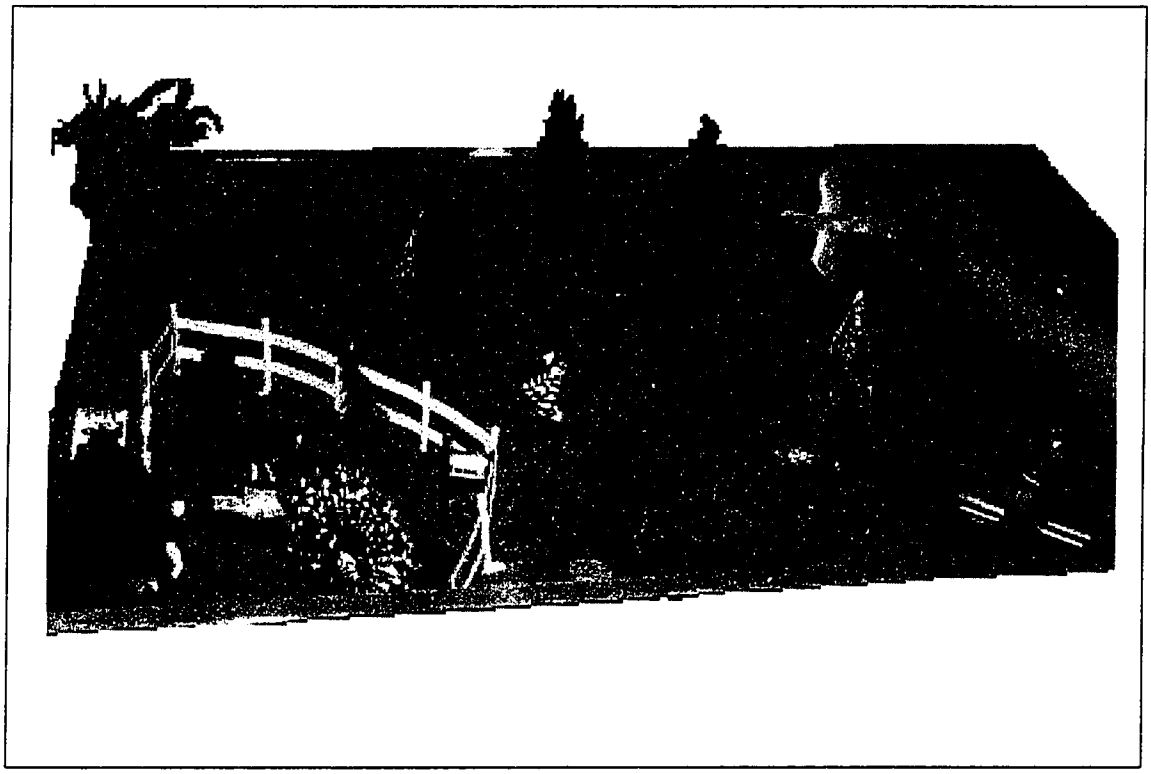

figure 2. Allison Sandplay 1

Sandplay 1. Allison began putting figures in the upper right corner of the sandtray. She depicted her brother with cystic fibrosis (James) getting married in a fenced-in church. There were no guests in the sandplay scene. (Unfortunately this is blocked in the picture by Allison's hand.) Allison stated that *there were other people there but she just could not find any to put in.* In the bottom left corner was her sister's home with numerous possessions and pets. This corner was also fenced in. Allison stated that her sister *would be living far away.* Allison placed herself in the bathtub surrounded by prized possessions (toys, books, flowers, and a dog). Allison's area was in the bottom right corner of the

sandtray but there were no boundaries to shield her exposed position. Between Allison and her sister was a treed area with two dogs attacking a cat and a bird flying overhead. Allison placed some plants, trees, and logs in the remaining areas of the sandtray. She identified the center of the sandtray as *a picnic area.* As Allison completed her sandtray, she quickly put a figure in this area and stated *that at least someone would be able to enjoy it.* Allison stated that she *would like to have a dog someday.* She also stated that she is planning to become a veterinarian and *so the dogs and cats would probably be coming into her care.*

In this sandplay scene, Allison used 51 figures. Twenty-one of the figures were vegetation. Allison included a total of 8 animals in this sandplay. An aggression sign, animals fighting, was present. Allison used 3 fences to divide her sandplay scene. (Table 1 provides an overview of the use of figures, identified setting and themes, and signs of emotional difficulties.)

Careful review of the sandplay scene and concept mapping revealed the following themes. Separation and aloneness seemed to be themes in this sandplay scene. Allison put a lone man in the picnic area. The tone of Allison's comment that *at least someone got to enjoy it* seems to indicate a longing for something that is typically associated with family activity. None of her family was portrayed participating in this section, and the person who was there was all alone.

Another indication of separation and aloneness in the first sandplay scene was the placement of Allison and her two siblings in separate corners of the sandtray. She put her siblings far away in situations that represented adulthood. Her brother was getting married

and her sister was in her own home with numerous possessions. Allison was in a more childlike situation -- having a bath with her toys around her. The separation was accentuated by the fences she put around the corner sections of her brother and sister. Allison even commented that her sister was *far away.*

Vulnerability was also a theme in Allison's first sandplay. Allison placed herself in the bathtub surrounded by favorite or desired possessions and completely vulnerable. There was nothing shielding her from the outside world. This was a contrast to the boundaries that both of her siblings had. The vulnerability was associated with a sense of distance. Lobato (1990) stated that siblings of children with cystic fibrosis indicated a sense of distance in the family. Allison portrayed each sibling surviving independently. The parents were not present in the scene. Even James was married without anyone present.

There was some aggression depicted in the first sandplay with the two dogs attacking the cat. This aggression does not seem out of place as cats and dogs stereotypically do fight. Allison did not expand on any violence. On the other hand, it could be interpreted as bullying. Two dogs, generally considered bigger and stronger, "ganged up" on the smaller, solitary cat.

The majority of space in the sandtray was a natural area with trees, logs and flowers. Aside from the man in the picnic area the space was uninhabited. This could be viewed as a vast, lonely space, or as a peaceful, serene environment. Cockle (1993) stated that scenery often represents a sense of life and growth.

	session 1	session 2	session 3	session 4
			CF theme	family theme
SETTING	family	people/animal	symbolic	family
DOMINANT THEMES	separation vulnerability	separation aloneness	death/loss	conflict spirituality
TYPES OF FIGURES				
1. Transportation	2	1	5	3
2. People	5	11	11	12
soldiers				28
3. Domestic animals	5	2	4	5
4. Wild animals	3	14	14	
dinosaurs				
fantasy creatures				2
5. Buildings	2	1		1
furniture/household items	9	19		
food		2		
6. Fences	3	10		11
7. Vegetation	21	9	22	1 (dead)
natural items		2	1	
8. Medical				
9. Misc.	1	6	3	1
TOTAL FIGURES	51	77	60	64
SIGNS				
1. Empty World signs				
< 50 items				
< 5 types				
people omitted				
2. Aggressive World signs				
soldiers fighting				1
animals fighting	1			
accidents				
3. Distorted World signs				
closed worlds		1		1
disarranged worlds				
rigid worlds				
4. Symbolic World signs				

Table 1. Synopsis of Allison's Sandplay (adapted from Buhler, 1951b and Grubbs, 1997)

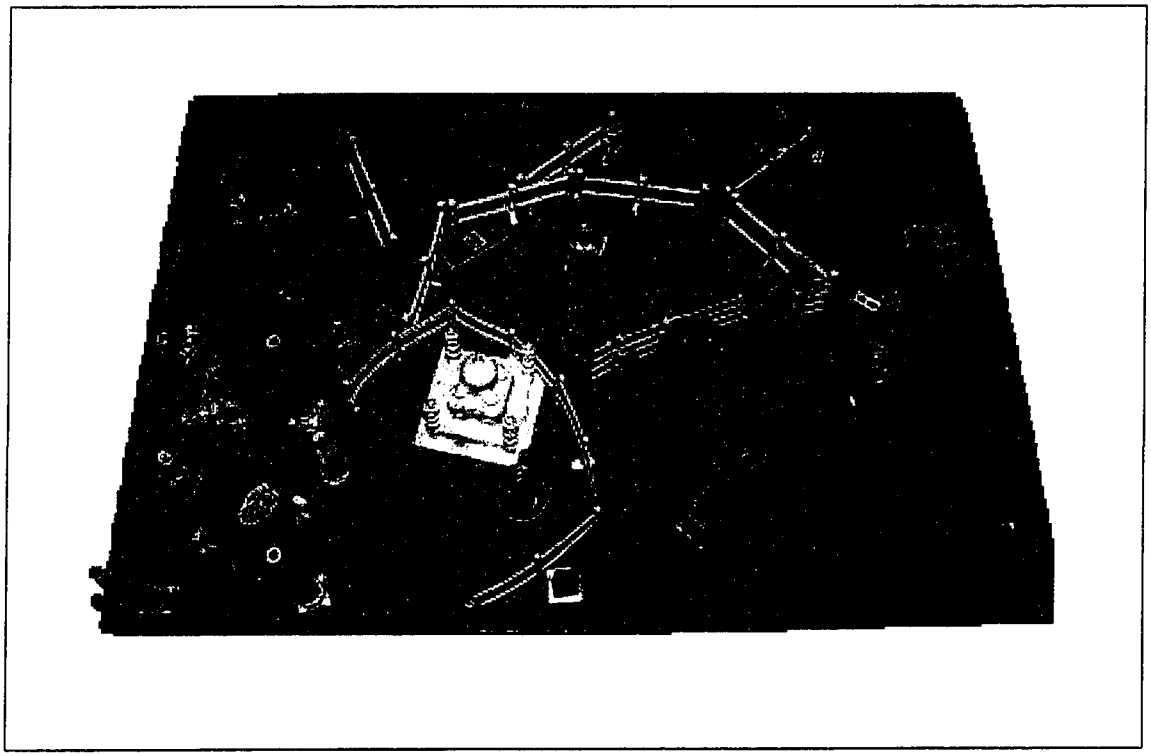

figure 3. Allison Sandplay 2

Sandplay 2. In the second session Allison divided the sandtray into eight sections in succession. She placed the figures in a scene and then put the fence around it before focusing on the next scene. The first scene Allison created was in the bottom left corner. It was a nativity scene that she described as *around her church.* She pointed out the figure that was *baby Jesus.* To the right of this scene Allison made a wedding scene where she was *marrying a man who had lived in Japan.* Allison sometimes referred to her groom as *the Japanese guy.* They were wed in a *Japanese place* with no guests or witnesses actually present in the scene. Allison later added that *there were people there but she just didn't put them in.*

Allison proceeded to make three scenes of herself. In the lower right corner (next to the wedding) Allison made a large kitchen with herself going to the beach, two large dogs, food, dog food, books, a statue of a mother holding a child which *had been passed on by her grandmother*, a decorative rock, plants, and kitchen furniture. Allison stated that this scene took place before the wedding. In the top right corner Allison made a bathroom including a bathtub, toilet, sink, vanity, and toy box. This scene also took place before the wedding. Allison made her room in the center of the sandtray. In it she put a bed, a desk, and herself brushing her hair and watching the television. Allison stated that this scene took place one year after the wedding. This scene was her *getting ready because her husband was taking out to a special place for her anniversary.*

On the top of the sandtray to the right of center Allison made a scene of her *great, great grandmother filling the car with gas.* There was also a stop sign in this scene.

The remaining two scenes were wildlife. Along the top of the sandtray to the left of center was a scene of bears. Four were *playing around and listening*. A fifth one was approaching *to join the fun.* In the final scene in the top left corner Allison put a *mother zebra with her three babies, two lions playing, and three tigers looking for food.* This scene was divided by trees and behind the trees were *two pandas trying to be alone.* One of the hunting tigers had *spotted them and was going to eat the little panda.*

In this sandplay, Allison used 77 figures. The type of figure that Allison used most was household items/furniture. She continued the pattern of using several vegetation

figures (9 in this sandplay). Allison also used numerous people (11), animals (16), and many fences (10). (See table 1.) The use of fences created a closed world.

Analysis of this sandplay scene revealed many similarities to the first one. The themes of separation and aloneness recur in this sandplay. Allison represented herself alone in her kitchen and in her bedroom. Even in her wedding section Allison was alone with her groom. There were no family or friends present. Allison's great, great grandmother was alone *filling the car with gas*. The two pandas hid behind the trees because *they liked to be alone*. The manner in which Allison organized the sandtray also gave the feeling of separation. Each section was very compartmentalized and isolated.

There is also an indication of vulnerability in the second sandplay. The tiger was attacking the small panda. The larger panda was nearby, but did not protect the small one.

In contrast to the vulnerability of the small panda, Allison depicted herself as capable of taking care of herself when she was an adult. She showed herself as self-sufficient in her three apartment sections. The tigers could be interpreted as being self-sufficient as they successfully sought out food.

There was some socialization in this sandplay with *the four bears playing and listening*. A fifth one seemed to be welcomed to join in. There were *two lions playing*. And, a *mother zebra was playing around with her children.*

Allison alluded to her spirituality in the church scene section. Although she did not label it, she created a nativity scene. She did point out *baby Jesus*. Allison stated that this was *by her church.*

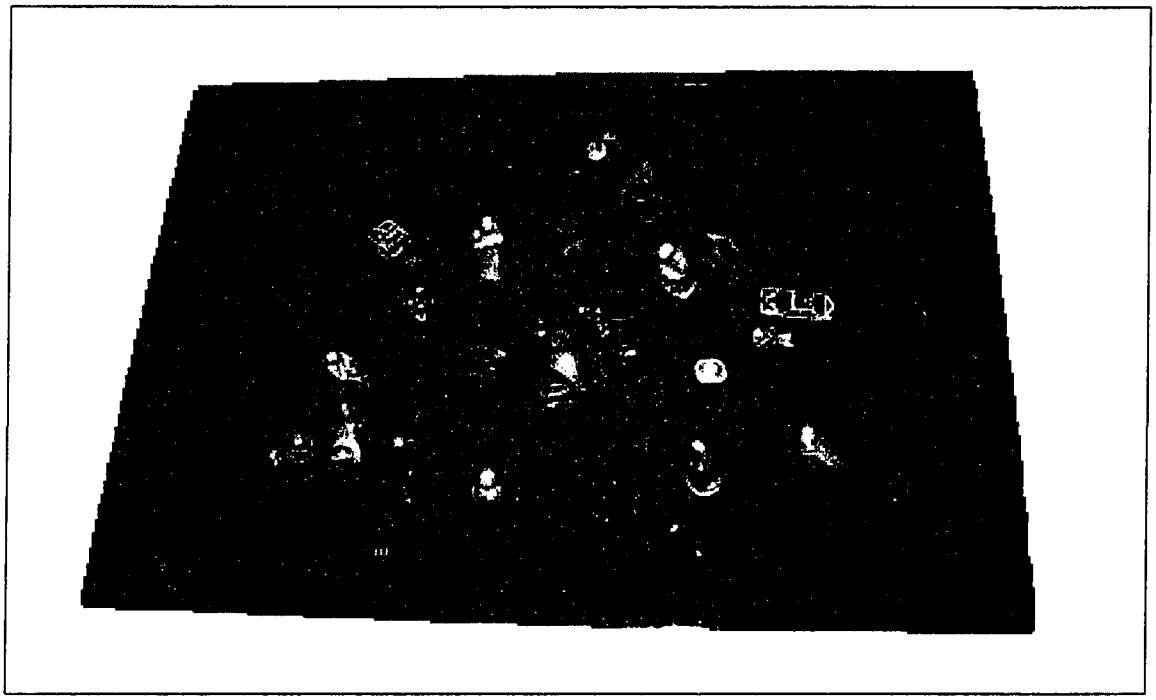

figure 4. Allison Sandplay 3

Sandplay 3. The researcher instructed Allison to include what she thinks or feels when she thinks about her brother with cystic fibrosis in this scene. Allison made one unified scene of her *brother's funeral when he was 25.* James is currently 16 years old. Allison stated that he *died of cystic fibrosis.* In the center of the sandtray, Allison placed a clear box with a person inside. There was a flower on the *coffin*, a crystal on a stand that *someone had given him in place of flowers*, and an angel standing over him *giving him a nice song so that he'll rest in peace.* Allison made a circle of figures around the *coffin.* In the circle were *church people, people James knew*, cars, trees, and birds. Beyond that circle Allison put in four bears in the bottom right corner, tigers playing in the bottom left corner, and two horses on both the right and left sides. There were also two ducks

swimming in a pond on the right side of the sandtray. Allison stated that James chose to be buried out in *the middle of nowhere* and that *the people would return to the grave every once in a while.* Allison would not identify any of the funeral attendees other than to say they were *people James knew.* The animals were watching because *they were interested in seeing what was happening.*

This sandplay was different from the first two in the absence of fences. Allison created a solitary scene rather than dividing it into several sections. She used a similar number of figures (60) and there was consistency in the types of figures -- 11 people, 22 vegetation, and 18 animals. (See table 1.)

It is apparent that the dominant theme in this sandplay was death and loss. This sandplay represented James' funeral. He had *died of cystic fibrosis when he was twenty-five. People who knew James and church people attended the funeral* and left gifts. None of the mourners were identified as family members. Allison indicated that James would not be forgotten because these people would come and *visit the grave every once in a while.*

It is noteworthy that the funeral was *out in the middle of nowhere* rather than in a church. There is a component of spirituality in the angel who stood by James and *helped him to rest in peace.*

There was a sense of vulnerability with the curious animals watching. This gives the impression of lack of privacy from the prying eyes of the wild world. Other animals were around that did not seem to care what was happening. They continued to play.

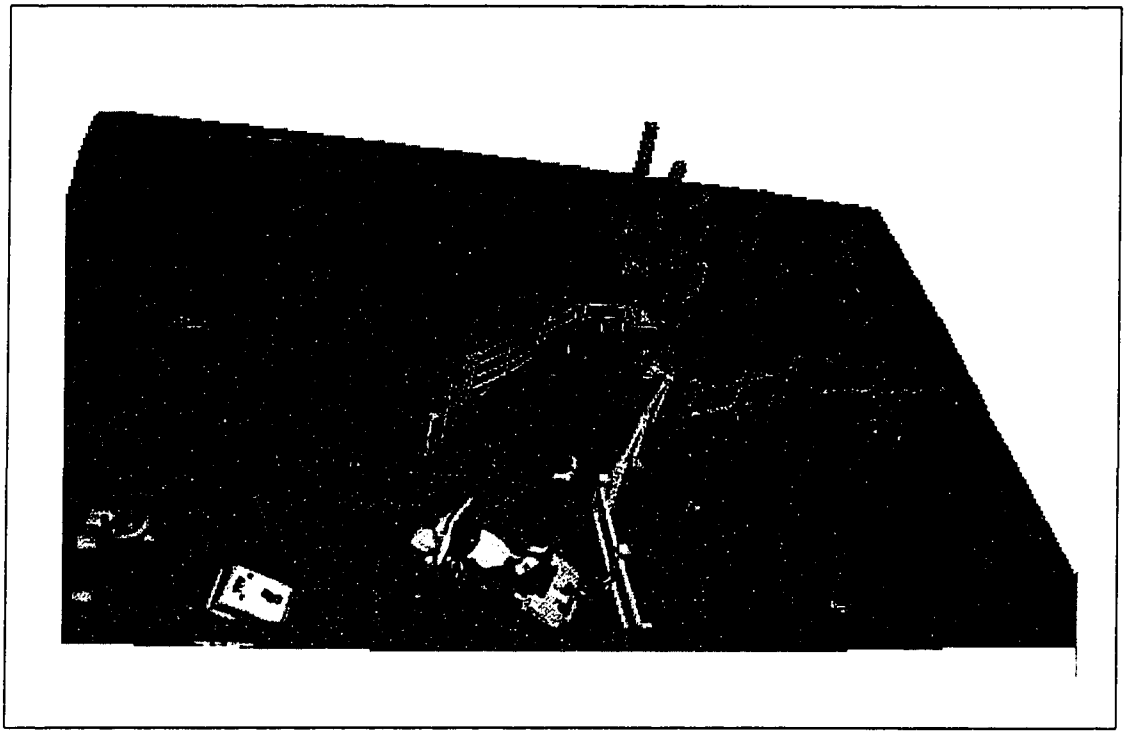

figure 5. Allison Sandplay 4

Sandplay 4. The researcher instructed Allison to include her family in this sandplay. Allison divided the sandtray into five scenes. She returned her pattern of the first two sessions by creating a scene and then fencing it in before focusing on the next scene. In the bottom right corner, Allison put in five people and an *angel sculpture.* Allison, her mom, and her sister made a circle around James and her father who were *play fighting.* The angel was chosen because *we go to church most of the time.*

In the upper right hand corner of the sandtray Allison depicted herself *getting into the church.* She placed herself in the center of the section facing *four church men* and

surrounded on the other three sides by four horses and a mule. Allison explained that the animals were statues because *they worshipped horses in her church.*

In the bottom left side and corner Allison put a house that she identified as her house. There was one police motorcycle beside the house and another police motorcycle and police car approaching. Allison explained that *something bad had happened at her house the day before.* She expanded by saying that *her sister had stolen something and "they" lied to the police.* The police were *really angry* and were lecturing them about *not lying to the police.*

Allison put her brother fighting two *monsters* in the center of the sandtray. She stated *they were imaginary monsters and it was a nightmare.*

The top left hand quarter of the sandtray contained a war scene with numerous soldiers and one standing tree stump that had been *shot down by a bazooka.* Allison identified two figures as *her father and her brother fighting in World War IV.* Some of the people had died in the scene.

Allison used 11 fences and only one (dead) sign of vegetation. There were 5 animals but she described them as statues. For the first time, Allison used soldiers. She used 64 figures in total. (See table 1.) This sandplay had signs of aggression and was closed.

Concept mapping revealed that conflict was the overriding theme in this sandtray. Mr. A and James were *play fighting* in one section. The female family members stood passively in a circle around the men and watched. The sister had committed a crime and

was being reprimanded by the police in another. Mr. A and James were *fighting in World War IV* in another section. In the very center of the sandtray James was *fighting monsters*.

Spirituality was a theme in this sandplay as evidenced by several symbols of spiritual practice. Allison was *getting into the church.* There were *four church men who were bringing her into the church.* In the section with the family circle, an *angel sculpture* stood in the corner. Allison stated it was there because the family *usually attended church.*

Interpretation

Allison was the only girl participating in this research. The literature has indicated that female siblings of children with cystic fibrosis suffer more social isolation and are more involved in caregiving activities than male siblings are (Eiser, 1993; Lobato, 1990). The A family is openly spiritual. They attend church regularly and participate in bible study at home. The researcher will consider the impact of these primary influences in the interpretation of the results.

Themes and symbolism

Separation and aloneness were the dominant themes in Allison's first two sandplay scenes. The A family is a busy family with lots of activity both inside and outside of the home. Allison is the youngest, with two adolescent siblings. The natural task of adolescence is separation from the family and movement toward peers (Erikson, 1963). Both of Allison's siblings are in that stage of development and she is not yet there. It is possible that Allison is experiencing this developmental difference as being left behind.

Mrs. A has recently returned to work for the first time in Allison's life. This new experience paired with the older siblings' movement away from the home may be the source of apprehension for Allison. She may be expressing some concern about a perceived lack of familial support.

The expressions of loneliness, alienation and vulnerability may be indications of Allison's responses to the changing family situation. However, they may also speak to her experience of being the sibling of a child with cystic fibrosis. Other siblings have stated

that they feel left out and like neglected members of the family (University of Calgary, 1992).

Allison alludes to family relationships in each sandplay. In the first sandplay, Allison separates each sibling with a great distance. There seems to be no relationship between them as there are no features to link them together. There are no roads or pathways to allow them to reach one another. In fact, both of the siblings have fences around themselves to reinforce the boundaries. No family members are present at James' wedding. The parents are not present in the sandplay, nor are they alluded to. Only Allison is present in the second sandplay. No family members attend her wedding and she does not even get married in her own church. A great, great grandmother is in a section by herself, separated from all the other sections. Again, the parents are not referred to. In the third sandplay no family members attend James' funeral. The only mourners are church people and people he knew. The relationships of the animal observers are friendships, not familial.

The researcher asked Allison to specifically include family in the fourth sandplay. She created a section of her father and brother play fighting with the female family members standing around watching. Allison was near her father. Each other family member was equidistant from Allison. James was in close proximity to all the family members except Allison. This was a large, empty section of the sandtray. The interpretation could be made that Allison is distant from her family members, except her

father. Lobato (1990) reported that siblings of chronically ill children expressed feeling a sense of distance in the family. Allison seems to be expressing this sense in her sandplay.

Whereas James and Mr. A are play adversaries in that section, they are fighting together against the enemy in another section. Kalff (1980) stated that fighting soldiers often represent fighting energies. They may indicate insecurity, or feeling an external threat. Allison may be expressing the recognition that James is involved in a fight against cystic fibrosis and that family is by his side.

Allison included an aspect of spirituality in each sandplay. In the first sandplay scene, James was getting married in the family church. Allison put a nativity scene in her second sandplay. She commented that it was *like at her church.* However, Allison also created her self getting married next to the church scene. She was not getting married in her own church. In the third sandplay, Allison depicted James' funeral. She stated that he chose to have his funeral *out in the middle of nowhere.* This is a significant event generally associated with religious support. Allison represented herself *getting into the church when she is older* in her final sandplay. She was vague about what that meant and gave the impression of not completely understanding this significant event. It appears that spirituality is important to Allison. The absence of the church at expected times -- her wedding, James' funeral -- may indicate Allison's questioning of religious values. It also seems that Allison may not fully understand some religious symbolism and rituals. Allison does seem to draw support from her spirituality as metaphorically represented by the presence of the angel at James' funeral.

In the first three sandplay scenes there were abundant signs of life and growth in the form of trees. In the fourth sandplay the only tree was a stump that had been blown up in the war. There are also animals in every sandplay. However, the only animals in the fourth sandplay are statues. This would seem to indicate that Allison generally experiences a connection to the environment. Perhaps the absence of signs of life in the family sandplay scene symbolizes a perceived lack of life in the home. The family is moving in separate directions and is not available to provide nurturance. Cockle (1993) stated that barren sandplay scenes may represent inner and outer worlds that are bleak and lacking growth, life and health. Similarly, Bradway and McCoard (1997) noted that the absence of vegetation may indicate lifelessness.

Cockle (1993) stated that the representation of many ideas in the sandplay may indicate numerous emotional issues fighting for expression. Allison put a lot of separate ideas into her first, second and fourth sandplay scenes by separating the sandtray into distinct sections. This gave the impression of several organized containers. Buhler (1951a) noted that enclosures may signify an inner strength and are an expression of personal need. Fences may provide a safe, protected space by keeping something out. They may also close the self off from others. In the sandplay depicting James' funeral, the only container was *his coffin*. The remainder of the scene was open to curious observers. Perhaps this is an area where Allison feels out of control. She tries to make sense of and control the other issues expressed in the sandplay. Allison may feel overwhelmed by cystic fibrosis and unable to master the issues associated with the disease.

Mrs. A stated that Allison does not like to discuss cystic fibrosis. When the researcher asked her to include her thoughts and feelings about James' disease, Allison quickly came up with the idea to depict his funeral. This would seem to indicate that Allison does think about the implications of the disease, and has a realistic understanding of the potential course it will run. The literature (Eiser, 1993; University of Calgary, 1992) has indicated that children may choose not to talk about cystic fibrosis to their parents in an attempt to avoid burdening them. It seems that this may be what Allison is doing. She does not share her thoughts with her parents, and yet she contemplates the death of her brother. Allison was able to readily share this issue with the researcher because she does not feel the need to protect the researcher.

Indications of level of well-being

Allison's sandplay scenes were heavily fenced with no openings or connections. Grubbs (1997) noted that fenced worlds are common in children of Allison's age. However, she also reported that numerous fences with no gateways may indicate fear of impulses or feeling the need for self-protection. The need for self-protection relates to the themes of aloneness and vulnerability and the expressed dependency and lack of familial support. Perhaps Allison feels that she needs to take care of herself because she feels there is no one else around to do so. The repeated expression of the themes of vulnerability, separation, and aloneness suggest depression.

The content of Allison's sandplay was generally realistic. Even the scenes that were oriented in the future were plausible dreams of a 10-year-old girl. Grubbs stated that the sandplay of children Allison's age begins to emphasize reality.

Using the criteria set out by Buhler (1951b), Allison's first sandplay showed only signs of aggression. Buhler noted that children who are emotionally healthy commonly exhibit one sign alone in their sandplay. She also stated that aggression signs alone indicate superficial problems. However, Buhler stated that aggression signs in the first sandplay may indicate pronounced aggression. In the fourth sandplay scene, Allison scored with signs of aggression and closed world signs. Buhler noted that two signs may be a more intense emotional expression. She declared that closed world signs may indicate insecurity and the need for enclosures. Allison's second sandplay scene scored as a closed world. It is possible that Allison is feeling vulnerable and feels the need for more security which she creates with boundaries. It could also be that Allison feels the need for more security and is angry at not receiving it. There were no signs in Allison's third sandplay.

Summary

The dominant themes in the first two sandplay sessions related to vulnerability and aloneness. When asked to consider cystic fibrosis, the theme was death and loss. The theme for the family was conflict. This suggests that Allison was using the sandplay to express her most pressing issues (Reed, 1975). She was able to adjust her focus when requested to do so and express herself in specific areas.

Despite some suggestions of depression from the interpretation of Allison's sandplay, she presents as a relatively emotionally healthy child coping with significant issues. It is positive that she was able to utilize the opportunity to express herself in a healthy manner. She may be experiencing unmet dependency needs and may be harboring some feelings of aggression. Allison does have some typical responses of siblings of children with cystic fibrosis. She seems to be feeling left out and that her needs are not being met. She is impacted by the disease of her brother and does not share her thoughts and feelings with her mother. Allison seems to have made her own meaning of James' illness and is comfortable with it.

Allison's spiritually was evident in each of her sandplay scenes. Whereas she may be experiencing some confusion, her spirituality is a source of support for Allison. Allison's sandplay was different from that of the boys in the research. Her sandplay was very complex with many separate ideas being expressed in each sandplay, with the exception of the cystic fibrosis scene. Allison was realistic and future-oriented in most of her sandplay. Allison does not seem to experience the social isolation from peers and caregiving responsibilities indicated in the research (Eiser, 1993; Lobato, 1990). This difference is likely because Allison is so much younger than James and she is the youngest child in the family. Therefore, caregivng responsibilities have not fallen to Allison and she has not experienced the limitations in social activities that commonly results from burden of caring for siblings and increased household duties.

A note to Allison

Dear Allison:

From the way that you approached each sandplay session, I see that you are organized and like to think out one thing completely before moving on to the next one. You have told me that sometimes you feel alone and vulnerable. You feel that your family is far away and you miss them. You have shown me that you are very strong and resourceful. When you see your family moving away, you have been able to seek out your friends for companionship and support.

Even though you have questions and confusion about your formal religion, your spirituality is comforting for you and is an important part of your life.

It seems that cystic fibrosis has made some impact on your life. It may be hard to think about cystic fibrosis when your brother is so much older and you have limited contact with him anyway. You see that James is involved in a struggle and believe that he will die when he is a young man. He will not be forgotten though. At the same time, you have shown James with alternative futures. Dying is not the only thing you think about when you think of James having cystic fibrosis.

Thank-you for sharing so much of yourself with me,

Sincerely,

Daryl

CHAPTER SIX: THOMAS - STRONG AND SILENT

Thomas' story

Mrs. B contacted the Cystic Fibrosis clinic in response to the newsletter advertisement. She was intrigued by the topic of the study.

Thomas is a 9-year-old who presents as being quiet, but readily engages in conversation. He physically resembles his 13-year-old brother, Lucas, who has cystic fibrosis. Thomas states that he has similar hobbies to Lucas, including an interest in army paraphernalia.

The B family is a nuclear family with four children. The two other children, Ethan (age 7 years), and Samantha (age 4) years are both healthy. Lucas was diagnosed as an infant and remains in good health. He attends clinic every 3 months and has Day Surgery yearly for the removal of nasal polyps. Lucas had minor surgery during the course of the research. Mrs. B is the primary caregiver and attends clinics with Lucas.

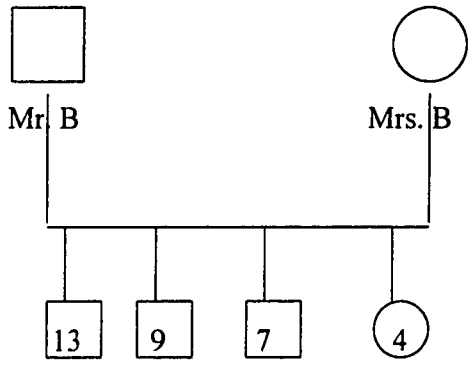

figure 6. Genogram of Thomas' and Ethan's family

Mrs. B is a 'stay at home' mother. This family gives the impression of being close and of participating in activities together, including spending many summer weekends camping.

When conducting the sandplay with Thomas, the researcher noticed that he spent a moment in silent contemplation before beginning each sandplay session. He seemed to be planning the theme or content of the sandplay. Once he began creating the sandplay, Thomas worked quietly and purposefully. He was completely focused on what he was doing. Thomas spent a great deal of time on his sandplay. Generally, he used the entire time allotment to create his complex sandplay scenes. All of Thomas' sandplay scenes had similar themes of violation and protection. They all included an invasion and a battle to defeat the enemy. Thomas' sandplay revealed a resistance to expressing his feelings and a belief that he could make a difference in the world. Thomas told a story in his narrative. The stories included a beginning, a middle with a dilemma, and an ending with resolution.

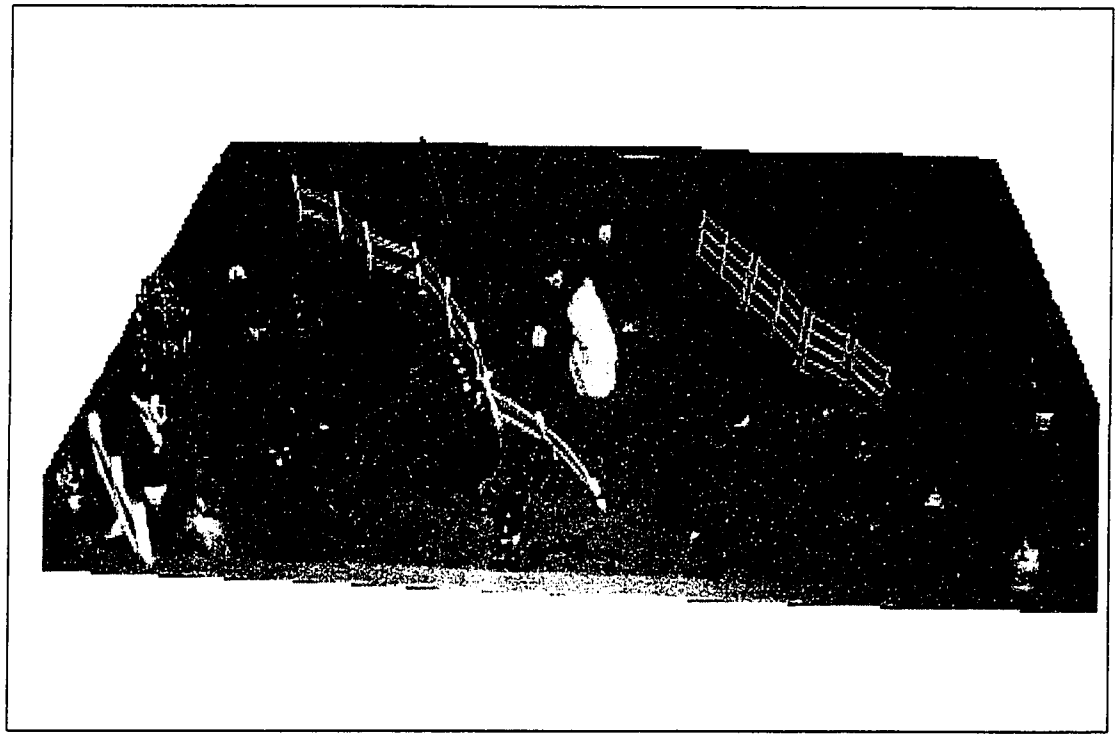

figure 7. Thomas Sandplay 1

Sandplay 1. Thomas' first sandplay was a complex, chaotic scene. He began by placing a ghost in the center of the sandtray. Thomas then put in treasure along the left side of the sandtray, directly in front of the ghost. Next Thomas added a cannon between the ghost and the treasure, facing the ghost. He put in more monsters, and then soldiers confronting the monsters. Throughout the entire sandtray Thomas put in soldiers and cowboys in opposition to monsters, knights, Ninjas, and Indians. Thomas proceeded to add more treasure in the bottom left hand corner and on the bottom side near the center of the sandtray. The treasure in the corner was surrounded by a fence that separated it from the rest of the sandtray. He put in two more fences diagonally across the sandtray. These

fences did not reach from edge to edge and the purpose of the fences was to *protect the treasure*. There were rocks placed throughout *for the soldiers to hide behind* to protect themselves. Thomas included a snake along one fence. The snake had a dog in its mouth. A tiger was approaching the snake. Thomas later explained that the *tiger was going to kill the snake to protect the dog, and because it wanted lunch.* There were also three *hunting dogs* in the sandplay scene. One had been *almost shot and was half buried in the sand.* A horse was also half buried in the sand. Thomas explained that it had been shot and was *trying to get the pain away.* Thomas put a bear in the upper right corner. The bear was observing the action. On the top right side of the sandtray Thomas included a buffalo that was eating.

Thomas told the narrative as a story. *There was a city full of riches. One day soldiers heard a strange noise coming from all around. When they went to explore the source of the noise, they saw ghosts and goblins attacking and attempting to steal the treasure. There was a huge battle but most of the soldiers survived. However, as the battle continued the thieves were wounded. The soldiers won the battle and saved the treasure.*

Thomas used 115 figures in this sandplay scene. The vast majority (84), were soldiers and other fighting figures (cowboys, Indians, Ninjas and knights that were classified as soldiers in the interpretation). Thomas also included the aggression sign of animals fighting. There were no people other than those classified as soldiers and this is an empty world sign. (Table 2 provides an overview of the use of figures, identified setting and themes, and signs of emotional difficulties.)

Thomas' first sandplay appeared chaotic and there was struggle included. It was overwhelming to look at and to understand. Concept mapping revealed that the overriding theme was violation and protection. The ghosts, goblins, and an assortment of other *bad guys* attempted to *steal the treasure*. It was a surprise attack and the soldiers suffered losses before they defeated the invaders. Thomas identified two of the soldiers' animals that were injured during the battle. The would-be thieves entered the city to steal the treasures. The violation had the impression of boundaries that were invaded. Fences that had been set up to protect the city were not effective and the thieves passed right by them. The fences gave a false sense of security. There were extra guards around the treasures that were effective in protecting them.

Not all of the figures that Thomas placed in the sandplay scene were involved in the battle. A bear sat in the corner and observed the action. A buffalo was also present, and he occupied himself with eating.

	session 1	session 2	session 3	session 4
			CF theme	family theme
SETTING	primitive	primitive	primitive/war	war/family
DOMINANT THEMES	violation	violation	violation	violation
	protection	protection	protection	protection
TYPES OF FIGURES				
1. Transportation			8	15
2. People			1	1
soldiers	84		44	45
3. Domestic animals	4	9		
4. Wild animals	5	14		
dinosaurs		14	17	
fantasy creatures	4			1
5. Buildings				1
furniture/household items				4
food				
6. Fences	3			1
7. Vegetation		13		
natural items	4			
8. Medical				
9. Misc.	11		1	1
TOTAL FIGURES	115	50	71	69
SIGNS				
1. Empty World signs				
< 50 items				
< 5 types		1	1	
people omitted	1	1		
2. Aggressive World signs				
soldiers fighting	1		1	1
animals fighting	1	1		
accidents				
3. Distorted World signs				
closed worlds				
disarranged worlds				
rigid worlds				
4. Symbolic World signs				

Table 2. Synopsis of Thomas' Sandplay (adapted from Buhler, 1951b and Grubbs, 1997)

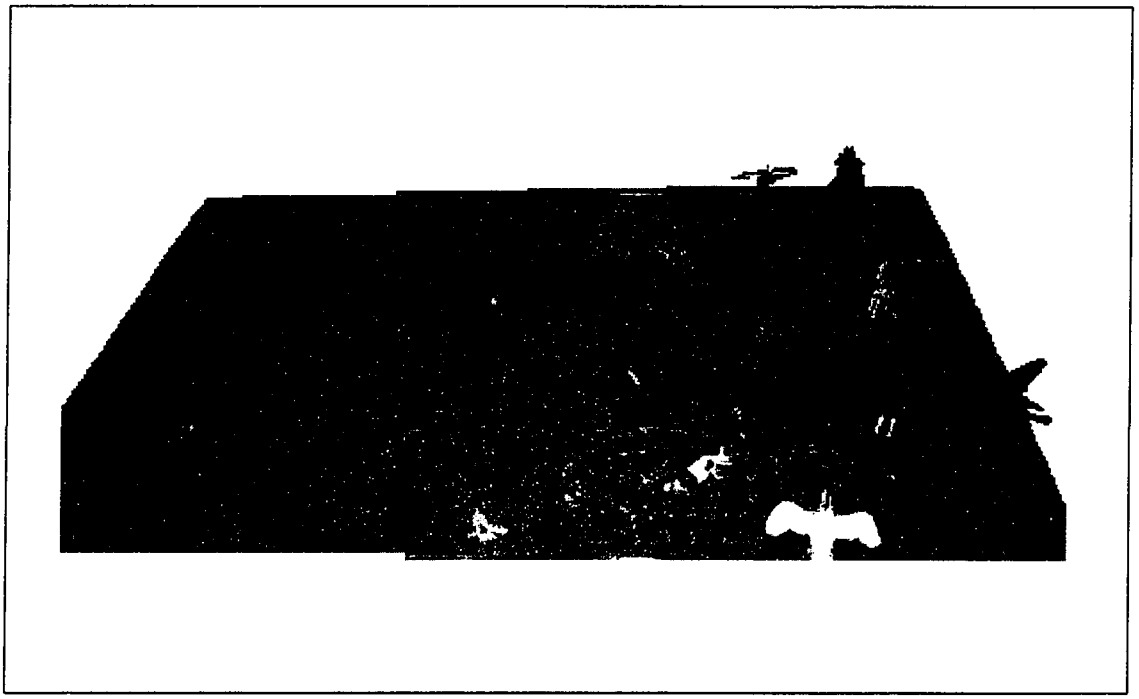

figure 8. Thomas Sandplay 2

Sandplay 2. Thomas made another single, complex scene that was less chaotic than the first sandplay. He started with a large dinosaur in the lower right section of the sandtray. Circling the dinosaur were smaller dinosaurs, horses, a cow, a dog, an elephant, a buffalo and a tiger. Approaching this circle were more horses, an ostrich, and dinosaurs. Thomas placed three birds on the edge of the sandtray, also focusing on the large dinosaur. Two bears were observing from the top right side of the sandtray. A large dinosaur and three smaller ones were also observing. Their perch was to the left of the center of the sandtray. A gorilla was *getting ready to climb a tree* on the left side of the sandtray. An anteater was *eating ants* near the gorilla. In the center of the sandtray was a *dinosaur*

eating leaves from a tree. This dinosaur was facing away from the focal dinosaur. Thomas put in trees in every quadrant of the sandtray, except for the bottom right which was the focus of the sandtray. There was a large log extending from the top left corner along the top of the sandtray.

Thomas explained his sandplay in a story. *A long time ago there was a forest with lots of animals living in it. One day a big dinosaur that no one liked charged in. This dinosaur was a big bully. The animals wanted to fight it. The dinosaur attacked the animals. Some animals fought back immediately. Others were backup and were prepared to fight if necessary. Some animals remained bystanders, merely observing the action. After the animals killed the dinosaur, they decided to keep peace.*

In this sandplay scene, Thomas used only 50 figures. There were no people at all, and there were no soldiers. Thomas included 13 vegetation figures. Thomas used only 3 types of figures. The dominant action of the sandplay was animals fighting. (See table 2.)

It was rather apparent that the theme of Thomas' second sandplay was violation and protection. A bully arrived in the forest and attacked the animals. They fought back and killed the bully. As the soldiers did in the first sandplay, the animals banded together to fight the common enemy.

This sandplay included observers and uninvolved bystanders. Some of the observers were waiting to help if their assistance was required. Other observers were simply curious about the activity. Yet others seemed oblivious to the struggle. A dinosaur had his back to the battle and was eating. An anteater was also occupied by eating.

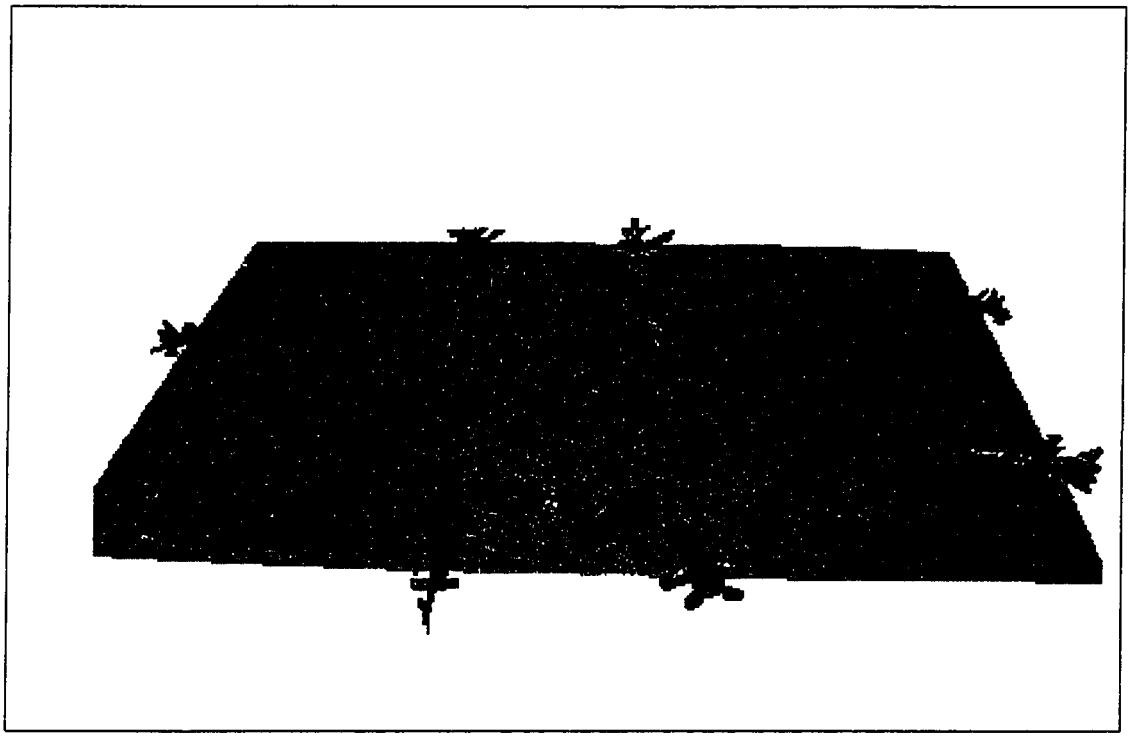

figure 9. Thomas Sandplay 3

Sandplay 3. The researcher asked Thomas to include what he thinks or feels when he thinks about his brother with cystic fibrosis in this sandplay. He made a unified scene about dinosaurs roaming free. Thomas put in a doctor (scientist) in the bottom left corner. He scattered several dinosaurs throughout the sandtray. The dinosaurs were facing different directions. Some were moving to the center of the sandtray; others were moving to the sides. Most were solitary, but there were two dyads and one triad of small, similar dinosaurs. These groupings were facing the center of the sandtray. One was near the top right corner, one was on the top left side, and the third was near the center on the left side of the sandtray. One large solitary dinosaur was lying down, partially covered with sand.

Thomas put numerous soldiers surrounding the dinosaurs. There was a cannon in the lower left side of the sandtray and two army trucks on the bottom center. Thomas placed six fighter airplanes and one helicopter on the edges around the sandtray.

Thomas told the story of his sandplay. *One day a scientist somehow brought dinosaurs back to life. Soon all the dinosaurs had escaped from zoo he had built because it was not very strong. There was panic across the country because the dinosaurs were destructive. They sent in several hundred troops, airplanes and a helicopter. The troops finally killed all the dinosaurs.*

The researcher asked how this sandplay related to Lucas, his brother with cystic fibrosis. Thomas explained that *Lucas likes soldiers and he does too.* The sandplay related to Lucas because it made Thomas think of him because he likes soldiers.

Thomas used 71 figures in this sandplay scene. There was one person who was not a soldier, and 44 soldiers who were fighting. Thomas used only 4 types of figures in this sandplay. (See table 2.)

Again the theme of this sandplay was clearly violation and protection. A scientist created dinosaurs and accidentally let them escape. The dinosaurs scared people and destroyed property until the army was able to work together to defeat them. The soldiers fought heroically, but it was the airplanes and helicopter that were finally effective in killing the dinosaurs.

There was an observer in this sandplay -- the scientist who inadvertently created the situation in the first place.

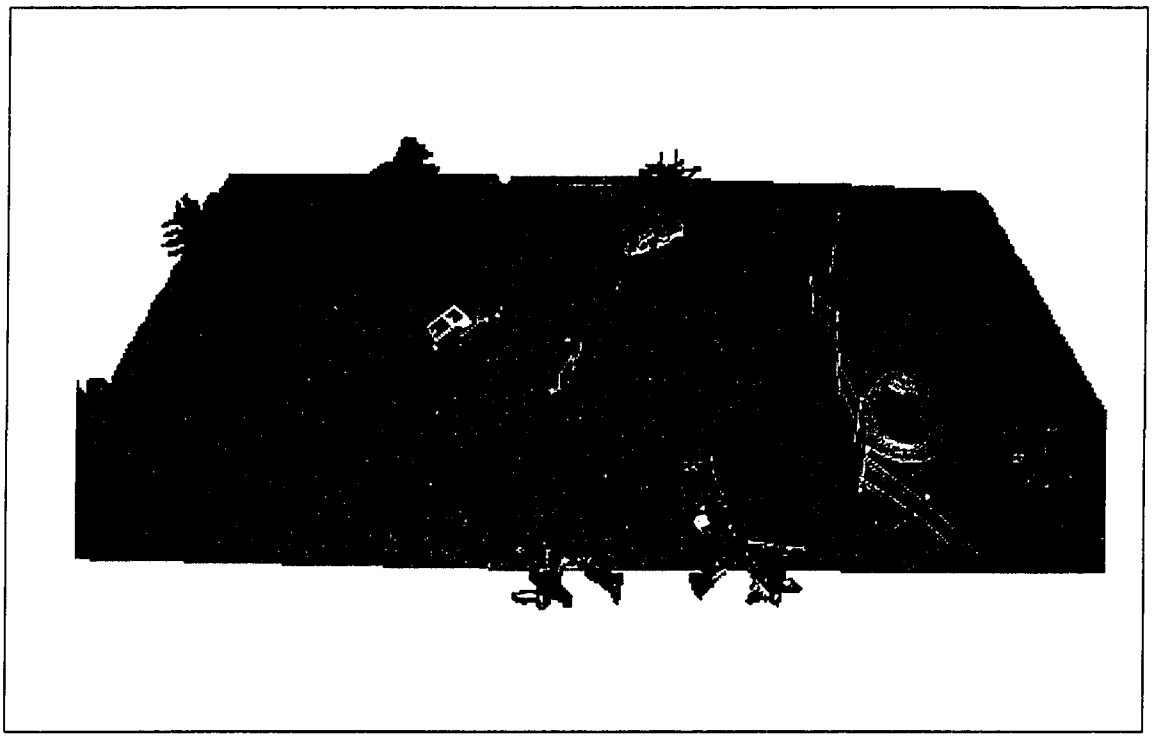

figure 10. Thomas Sandplay 4

Sandplay 4. The researcher instructed Thomas to include his family in this sandplay. Thomas made another battle scene using the majority of the sandtray. After completing the battle scene, Thomas put in a fence at the end of the sandtray and included a family component. Thomas was thoughtful and deliberate in creating the battle scene. He appeared to randomly select items to include in the family component of the sandplay.

The focus of Thomas' sandplay was *an alien from Mars* that he placed to the right of the center of the sandtray. He put one soldier on top of the alien and stated it was Lucas *stabbing it*. He put in a cannon aiming at the alien. There were also two army trucks with their guns aimed at the alien. Thomas put in numerous soldiers facing the alien. Most

were standing, but some were lying down. Thomas stated that *the alien had thrown unexploded shells from the cannon back at the soldiers. The shells hit the soldiers in the head and then exploded.* Thomas included an army ambulance and four civilian vehicles that were half buried in the sand. He explained that *the alien had gotten them.* Thomas made a mound and placed the helicopter on it to represent the helicopter flying. Thomas put six airplanes on the edges of the sandtray to represent them flying. He also put one soldier on the edge and explained that he *was parachuting.*

Beyond the fence Thomas put in a house, swimming pool, hot tub, lounge chair, and some toys. Thomas put one figure in which he identified as *his dad.* Thomas put the family's mailbox on the other side of the fence with the battle scene.

Again, Thomas told the story of his sandplay. *An alien from Mars wanted to take over the universe. He landed on earth and began trying to invade army bases. When the army knew he was there; they set up an ambush and shot him. The alien went back to Mars and never bothered anyone again.*

Thomas did not mention the family component in his narrative. When questioned about it, he curtly stated that it was *his house* and would not elaborate without further prodding. Thomas identified each figure and explained that *the fence was to show where his yard was and to keep it separate from the battle scene.*

Thomas used 69 figures in this sandplay scene. He used 45 fighting soldiers and one other person. For the first time, Thomas included a building and furniture/household items. (See table 2.)

Once again, concept mapping categorized the theme of this sandplay as violation and protection. An alien from Mars invaded the earth. Soldiers ambushed him. The alien fought back and killed soldiers with their own weapons. He also killed people and destroyed cars. The alien eventually *went back to Mars and never bothered anyone again.* Lucas was an active participant in fighting the alien. He was *on top of the alien and stabbed it.*

Across a boundary Thomas created a peaceful scene to represent his family; although, only Mr. B was actually in the scene.

Interpretation

Thomas physically resembles his brother with cystic fibrosis and clearly identifies with him. Drotar and Crawford (1986) stated that male siblings close in age to the child with cystic fibrosis often have increased risk for psychological impairment. The researcher will consider the impact of this primary issue in the interpretation of the sandplay.

Themes and symbolism

Each of Thomas' sandplay scenes was very similar. All involved an invasion by unwanted and dangerous outsiders. In each instance the dominant group was able to work together to save themselves by defeating the invader. Grubbs (1997) stated that fighting is common in the sandplay of boys this age. It would appear healthy that the heroes were able to join together and to defeat the antagonists. Whereas there was invasion of boundaries, the invaders were stopped before they could do much, if any, harm. The scenes gave the impression of vulnerability. One may be attacked regardless of how careful one is.

Thomas' third sandplay varies from the other three. Here it was a human who created and released the invaders. In the other sandplay scenes the attacks were unpreventable. Perhaps Thomas' was expressing an underlying misconception about the cause of cystic fibrosis (since that was the requested theme of this sandplay). Thomas may have been expressing the idea that cystic fibrosis is preventable if appropriate precautions are taken. This could be an indication that Thomas blames someone for Lucas' illness.

Thomas' refusal to directly address his feelings regarding cystic fibrosis is notable. He stated that he created the scene because both him and Lucas like soldiers. It is possible

that he did not directly address the topic because he is unable or unwilling to express his feelings. Perhaps he did not feel safe in revealing himself to the researcher. Or, perhaps he was conscious of the presence of his family members and did not want to express himself with the knowledge that they may overhear his disclosure. It is also possible that Thomas was unable to address this sensitive material because of his identification with Lucas. He may feel too threatened to contemplate any associated emotions.

Another hypothesis is that Thomas had planned out his sandplay before the researcher gave him the instructions. He may have been too intent on his pre-planned sandplay to alter it at the researcher's request. This final hypothesis seems plausible in considering the content of his final sandplay where Lucas actively battled the invading alien. It seems that Thomas may have included his thoughts or feelings about Lucas' illness a week after the initial request. The fourth sandplay is a noticeable change from his previous sandplay scenes where none of the heroes are identified. Additionally, Thomas' reluctance to include his family in the sandplay supports the hypothesis that he had predetermined his sandplay and resisted the interference of the researcher.

Thomas did not initiate discussing the family component of his family sandplay. He grudgingly responded to the questions of the researcher when she initiated that discussion. Thomas' reactions indicated that he randomly chose figures to put in and could not pull them together into a cohesive narrative. It could be hypothesized that it was too threatening for Thomas to include his family. He may have been symbolically separating them from the battle.

Indications of level of well-being

The setting for the first two sandplay scenes was primitive. The third one was primitive and war. The final sandplay setting was war and family. However, the family was reluctantly included. Whereas Thomas seemed to resist the instruction given by the researcher, there was a slight shift in the setting in the two sessions when he was given the instructions.

Thomas' sandplay was very fantasy-based. Grubbs (1997) stated that children ages 8 - 10 years generally create sandplay scenes that are based on reality. Fantasy sandplay scenes are common in younger children and may imply immature emotional expression. The absence of human figures may indicate feelings of alienation or threat. This symptom was present in Thomas' second sandtray, but the others included people.

The expression of conflict can be interpreted as the release of repressed feelings and is therefore a sign of strength and progress. The movement from chaos to more order is also a sign of progress (Grubbs, 1997).

Grubbs (1997) stated that the use of an observer in the sandplay may be representative of the observing ego of the person making the sandplay scene. Thomas had observers in the first three sandplay scenes. There were indications of repression in Thomas' sandplay. It may be that he was using the sandplay to release some of these emotions and included himself as an observer of the action.

The SCC seems to indicate that Thomas may be experiencing some difficulties. Yet, there are also signs of growth and progression. It is positive to note that although he may be delayed in some emotional expression, he is not remaining stagnant.

Using Buhler's (1951b) criteria, Thomas scored with aggression signs in all four of his sandplay scenes. In the first sandplay, the aggression was in the form of animals and soldier fighting. Thomas also scored with no people in his first sandplay. Buhler (1951a) noted that children clearly differentiate between people and soldiers. She also stated that the absence of people is more symptomatic if soldiers are used. It could be an indication of concealed aggression. Using less than five types of elements as Thomas did in his second and third sandplay sessions may indicate a fixation on certain objects. This certainly seems to be the case with Thomas. He obviously was engrossed with the army and dinosaur figures. Thomas' resistance to the direction of the researcher reinforces the theory that he was fixated on certain objects and unwilling or unable to be distracted from using them in a predetermined manner. Buhler (1951a) noted that fixation is common in children who are experiencing difficulties. Military themes may indicate a need for power that is met through aggression (Cockle, 1993). However; Grubbs (1995) stated that in children ages 7 - 11 years, war scenes are a natural way to release pent-up anger. Reed (1975) also noted that destructive and aggressive feelings may be expressed in the use of army and cowboy and Indian figures. She added that the theme of good versus evil often becomes apparent.

There are several imports identifiable in Thomas' scripts. If we work together we can overcome difficult situations. Good prevails over evil. There are sometimes casualties

in the battle. These are healthy statements that suggest a willingness to do whatever it takes to attempt to succeed.

Summary

Thomas seems to have some difficulties in redirecting himself when asked. Eiser (1993) noted that siblings of children with cystic fibrosis have an increased tendency for obsessive-compulsive disorder. Thomas has an age-appropriate interest in soldiers and fighting. At the same time, he may be expressing aggression and anger. Patterson, McCubbin, and Warwick (1990) stated that siblings commonly are angry at their parents for the amount of attention they pay to the child with cystic fibrosis.

Thomas may also have some difficulty in expressing himself. It is unclear whether this is resistance or an inability to do so. It would seem that Thomas may be experiencing some difficulties in coping with Lucas' illness. The identification Thomas has for his brother with cystic fibrosis may influence his coping. As was suggested by Drotar and Crawford (1986), the closeness in age between Thomas and Lucas may be a factor in Thomas' adjustment. At the same time, Thomas seems to value taking an active role in attempting to overcome adversity.

A note to Thomas

Dear Thomas:

You appear to be thoughtful and methodical. You carefully think through what you are doing. I can see that you really enjoy dinosaurs and army stuff. You have told me that Lucas does too. This common interest seems very important to you.

Lucas seems to be a significant person in your family. It must be tough to look so much like your brother who is sick. I wonder if you identify with Lucas because you appear so much the same. It could be that you worry that you will also get sick since you are similar in so many other ways.

As important as Lucas is to you, you are at the same time a role model for Ethan. He looks to you for information and for guidance about how to act in various situations.

You had a hard time telling me about your feelings, and maybe you do not even like to think about them.

You believe that there are often struggles, and that eventually, with effort, things will work out. You see Lucas actively fighting the disease that has invaded him. And, you believe that he will be successful in this battle. You do not seem to understand about cystic fibrosis.

I have enjoyed watching you work out the battles.

Sincerely,

Daryl

CHAPTER SEVEN: ETHAN - SEARCHING FOR HIS PLACE

Ethan's story

Ethan is the third child in the family described in the previous chapter. (See genogram on p. 63). Ethan is a small child with red hair and freckles. He presents as being shy and quiet. Once a rapport had been established Ethan became more outgoing and talkative. Ethan is a member of the community soccer team.

Ethan initially approached the sandplay timidly. Once he became familiar with what was expected of him, Ethan became more forthright and interactive. He was quietly enthusiastic about doing the sandplay and appeared to get great pleasure out of it. At times he seemed a little unsure of himself. Ethan completed his sandplay scenes in 10 - 20 minutes. After the first sandplay session Ethan observed the sandplay of his brother, Thomas, and appears to have been influenced by the content of Thomas' sandplay. Ethan demonstrated that he does not have an understanding of what cystic fibrosis is, but he realizes that it influences his family. His sandplay gave the impression that he feels left out and is trying to find his place in his family. Ethan sounded self-conscious as he presented his narratives that were descriptive of the content of the sandplay.

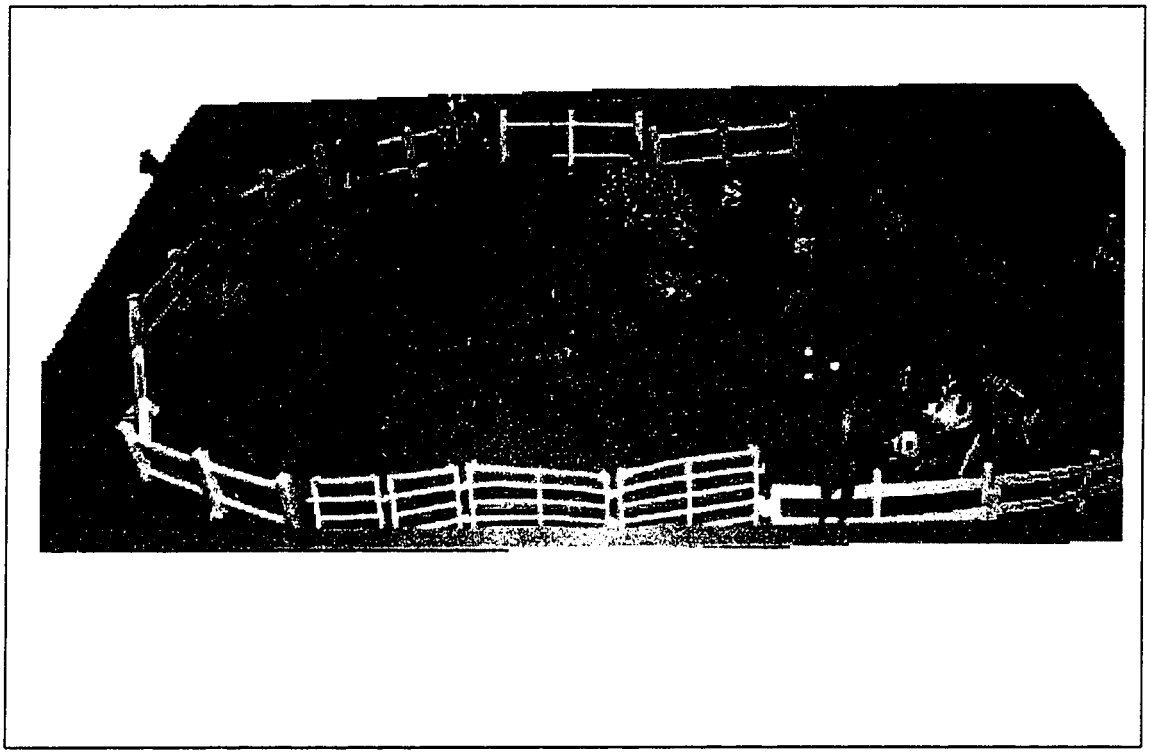

figure 11. Ethan Sandplay 1

Sandplay 1. Ethan's first sandplay was *a zoo* scene. Ethan began by placing a variety of animals (buffalo, elephant, hyena, tiger, zebras, gorilla, elk, 2 pandas, and a koala bear) on the right side of the sandtray that were looking or moving toward or through the center of the sandtray. In the center he placed a cheetah on a log. To the right of the cheetah was a *zebra family* -- an adult and three small ones. *A tiger was chasing one small zebra.* The tiger had singled out a particular zebra to eat. Two turtles and two bears were on the bottom side also looking or moving toward the center of the sandtray. A giraffe stood at a tree to the left of the cheetah facing the left side of sandtray, away from the center. The left side of Ethan's sandplay contained several trees. A large log separated

some more animals and the watering hole from the majority of the scene. Ethan explained that the animals could *easily reach the water by climbing over the log.* There were two more small logs in the sandtray. There were two birds in the trees. One was *visiting the zoo, and was preparing to fly away.* Ethan put a fence around the zoo that encompassed the entire sandtray, except for the corners. In the center bottom side a giraffe faced out with its two front feet on the outside of the fence. Ethan stated that it *was chasing an animal away.* There were three animals to the right of the giraffe looking out. A cheetah and tiger pair were *playing* near these animals. In the top left corner a snake had *escaped and a turtle was climbing out* through the fence. In the bottom left corner a camel was outside of the zoo and blocked by another piece of fence. Ethan stated that *the camel might be attacked.*

In this sandplay scene, Ethan used 72 figures. The majority of these were animals (33) and vegetation (23). Ethan used a series of fence pieces (11) to make one large fence. There were no people in Ethan's first sandplay, and he used only 4 types of figures. These are both empty world signs. (Table 3 provides an overview of the use of figures, identifies setting and themes, and signs of emotional difficulties.) Ethan included depictions of animals fighting (aggression signs) in this closed world.

Concept mapping and detailed analysis revealed that the dominant theme in Ethan's first sandplay was boundaries. Most of the animals were contained in the zoo. A few stood by the fence and stared out. Three others were able to escape. These animals were escaping in order to chase an animal away.

Another theme in Ethan's first sandplay was vulnerability. A camel was locked on the outside of the zoo. It seemed to be a perilous place for him as he was in danger of being attacked. At the same time, being inside the zoo could also be hazardous. The small zebra was going to be eaten by the tiger, and its parent was seemingly unaware. The third child of the zebra was apparently overlooked by its parent.

Boundaries were violated by the escaping animals. They were powerful and escaped to attack other animals. The boundary limited the camel's ability to escape his fate of being attacked. He was more vulnerable because he could not overcome the boundary.

	session 1	session 2	session 3 CF theme	session 4 family theme
SETTING	animal	war	war	home/family
DOMINANT THEMES	boundaries vulnerability	vulnerability	danger/struggle	vulnerability
TYPES OF FIGURES				
1. Transportation			12	12
2. People		2	4	4
soldiers		36	1	5
3. Domestic animals				
4. Wild animals	33		4	
dinosaurs				
fantasy creatures				2
5. Buildings				
furniture/household items			1	7
food				11
6. Fences	11	3	2	
7. Vegetation	23	1	4	
natural items	4		1	
8. Medical		12	12	9
9. Misc.	1	11	6	3
TOTAL FIGURES	72	65	47	53
SIGNS				
1. Empty World signs				
< 50 items			1	
< 5 types	1			
people omitted	1			
2. Aggressive World signs				
soldiers fighting		1		
animals fighting	1			
accidents				
3. Distorted World signs				
closed worlds	1			
disarranged worlds				
rigid worlds				
4. Symbolic World signs				

Table 3. Synopsis of Ethan's Sandplay (adapted from Buhler, 1951b and Grubbs, 1997)

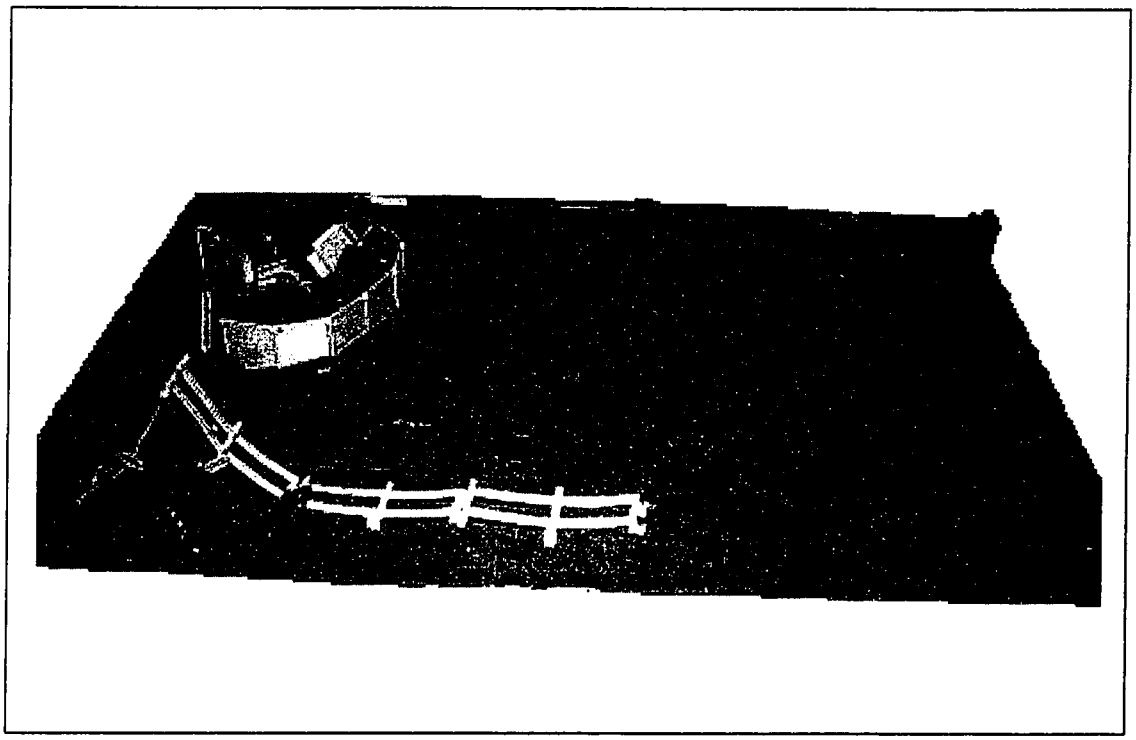

figure 12. Ethan Sandplay 2

Sandplay 2. Mrs. B informed the researcher that Ethan had pre-planned the content of his second sandplay in the time between the first and second sessions. He created a battle scene. Ethan started by placing figures in the top left hand corner where he partitioned off a hospital scene. There was a patient on the operating table who had been *hurt fighting*. Ethan had not thought about the fate of the patient. He stated that *the operating room was part of the good guys' fort. A bad guy was sneaking around the corner* of the partition. In the center of the left side of the sandtray was *a trap.* It was not effective in catching the *bad guy* as he was able to *stick his knife in and avoid harm.* There were also some soldiers battling beside the trap. Along the bottom left side of the sandtray

was a fence that had been *kicked over by people trying to get around it.* Several soldiers were battling under and around the upturned fence.

A cannon pointed out from in front of the hospital partition. Soldiers were fighting all around the cannon. In the center of the top of the sandtray was a totem pole. Ethan stated that *Indians used to live there.* In the bottom right corner Ethan cleared away the sand to reveal the bottom of the sandtray. He placed a treasure chest in the corner. Shielding the bottom right corner was a large log that reached across to two adjacent sides of the sandtray. Some soldiers were around the treasure. Ethan explained that this was the *bad guys' fort and that the bad guys had stolen the treasure belonging to the good guys.* The *good guys* were in the fort capturing their treasure back. The cannon belonged to the *good guys* and was a protection *in case they were attacked.* There were two small shields placed in the sand to symbolize which fort belonged to which group. It was difficult to determine which were the *good guys* and which were the *bad guys.* Ethan's only explanation was that *the good guys would help the bad guys when they were injured, and then they would capture the bad guys.*

Ethan used 65 figures in this sandplay scene. Thirty-six of these were soldiers fighting. Ethan included medical figures in this sandplay. (See table 3.)

Detailed examination and concept mapping revealed that vulnerability was a theme in Ethan's second sandplay. The *bad guys* were able to steal the treasure of the *good guys*, and the *good guys* were also able to retrieve it. There were sneak attacks, and traps set up to *stop the bad guys.* However, these traps did not work. They were ineffective at

protecting the fort. The fence was not an effective boundary either. The soldiers merely kicked it over to make it easier to get around it.

Ethan included attempts of concealing in his second sandplay. The large stick shielded *the view of the bad guys' fort* and thus protected *the good guys* as they went for their treasure. The screen around the operating room section of the *good guys' fort* hid that section from view and offered some protection against the lurking bad guy. In both metaphors, concealing made the *good guys* less vulnerable.

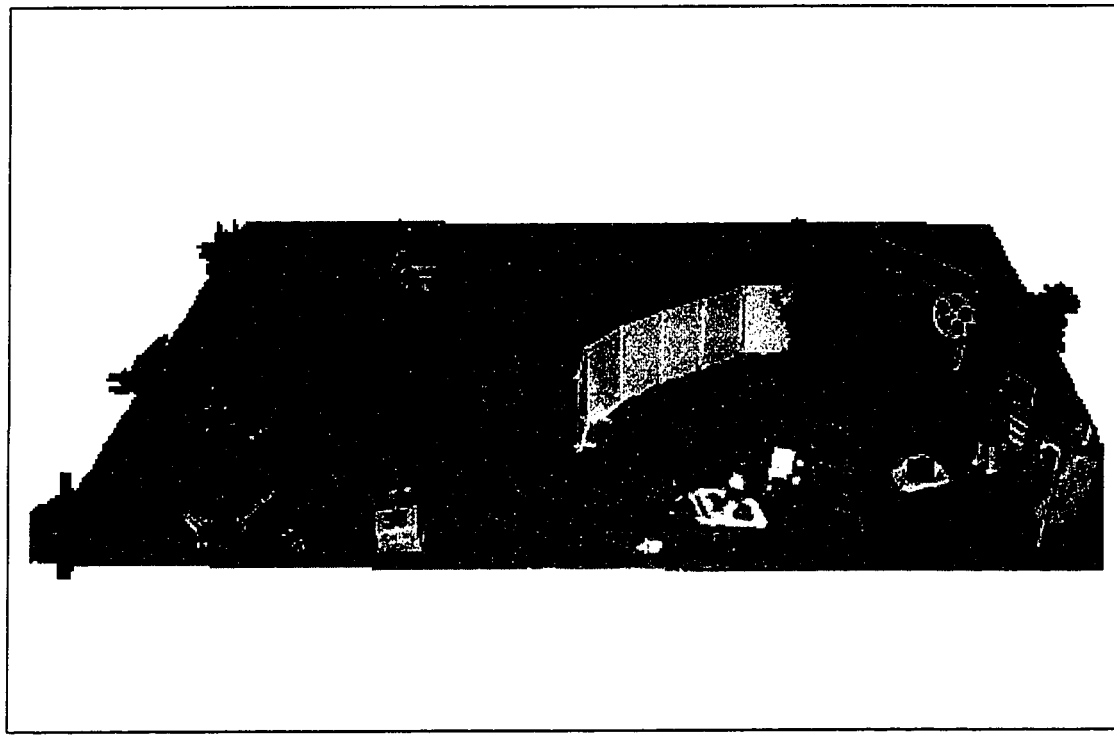

figure 13. Ethan Sandplay 3

Sandplay 3. The researcher instructed Ethan to include what he thinks or feels when he thinks about his brother with cystic fibrosis in this sandplay. This sandplay was similar to the second one in that it contained both a hospital component and an army component. The bottom right quadrant was a hospital scene. Lucas was on the operating table. Ethan had not decided on what type of operation Lucas was having. There were bugs on the equipment and on Lucas. There were two snakes in the operating room that were *eating the bugs*. There were also plants and a seashell in the operating room. A partition shielded the left half of the sandtray. The purpose of the shield was so that *people could not see*. This was still *part of the operating room* and it was filled with army and

emergency vehicles, including airplanes. A soldier lay on a bed. He had been *injured and was waiting to have an operation.* There were two airplanes and a helicopter on the left edge of the sandtray. One of the snakes extended from the army side into the operating room with its head in the operating room.

Ethan fenced off the top right corner and put a turtle and a crocodile on the outside of the fence. *The crocodile was about to attack the turtle.*

In this sandplay, Ethan used only 47 figures. Again, he included 12 medical figures. (See table 3.)

Danger and struggle were evident in the theme of Ethan's third sandplay. The setting was war which inherently suggests danger. One soldier had been injured and was awaiting necessary surgery. Kalff (1980) stated that an injured soldier may represent one who has been hurt and has had to give up the fight. An operating room also suggests a struggle for wellness or health. Outside of the barrier, a crocodile was attacking a turtle. As in the first sandplay, it was dangerous for some to be on the outside, and for others, that was a position of power.

There was also concealment in Ethan's third sandplay. The partitions were set up to shield the view of the operating room. The partitions were not effective in keeping the bugs and snakes out. Shielding the view could not protect Lucas from these pests. It is interesting that Ethan had not decided what type of operation Lucas was having. This implies a shielding or concealment of knowledge.

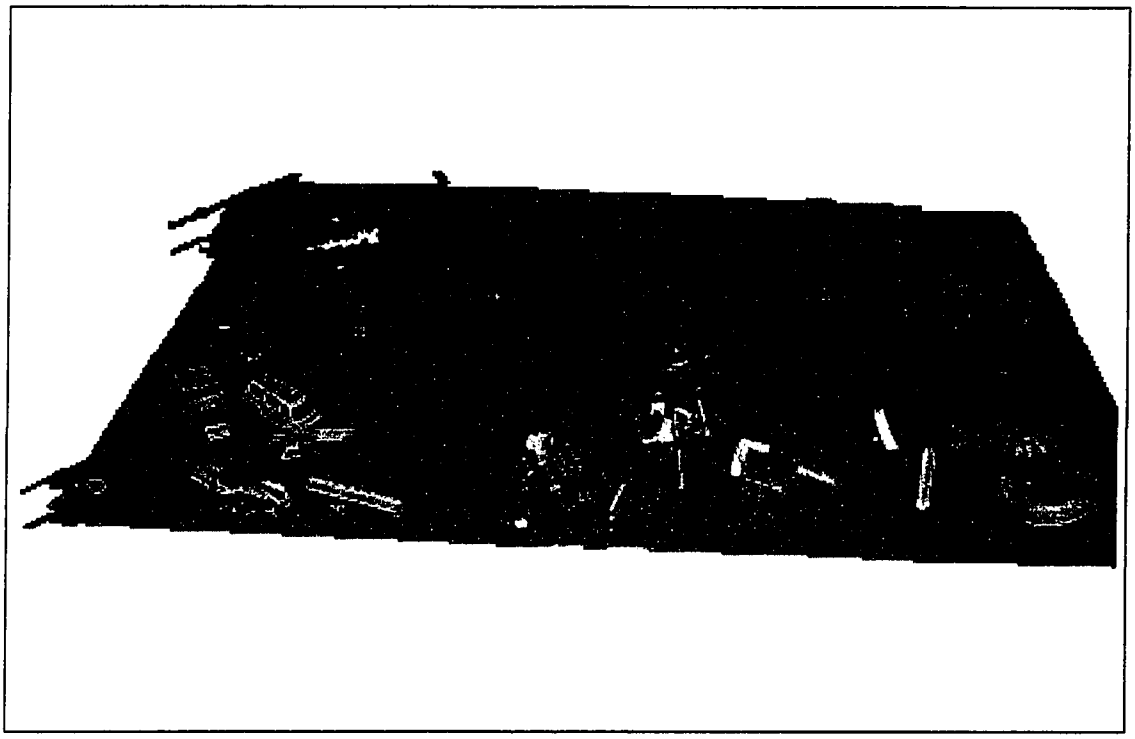

figure 14. Ethan Sandplay 4

Sandplay 4. The researcher instructed Ethan to include his family in this sandplay. Ethan separated the sandtray into five sections. He marked a line in the sand and then put figures in the section before repeating the process in the next section.

In the top left corner Ethan put an army scene. There were two teepees, three airplanes, two army vehicles, and a cannon all pointing toward the corner. There were four soldiers around the cannon. There was a helicopter on the edge of the sandtray. *The good guys were going to win the war.* Ethan identified this as a war scene *for Thomas because he likes to play war a lot.*

The bottom left corner was identified as *Dad's corner*. Ethan stated that he chose this scene because his father *likes to ride motorcycles a lot and had once been in a motorcycle accident*. A motorcycle lay on its side. It was surrounded by two fire trucks, and ambulance and a police truck. A fire helicopter was on the edge of the sandtray. Ethan explained that the fire vehicles *were putting out the fire because the motorcycle had caught on fire. The ambulance was getting Dad. Dad would get better after going to the hospital because he was not badly hurt. The police were keeping bystanders away.*

In the center of the bottom was Lucas' scene. Lucas was *walking into the operating room. A doctor was standing on a table filling up the intravenous with anesthetic*. Ethan had not thought about what kind of operation Lucas was having. He stated that Lucas was *feeling okay* about having this operation.

Samantha's scene was placed on the right end of the sandtray. There was a Barbie, a chair, a pool and a sand scene. Ethan stated this was because Samantha plays Barbies *a fair bit.*

The top right corner contained a table, a kitchen cabinet, a stove and numerous items of food. This was the scene for Ethan's Mom because *she likes baking.*

The top center of the sandtray remained empty. Ethan did not include himself in the sandplay. He was unable to state why he had left himself out.

In this sandplay, Ethan used only 53 figures. He used similar types of figures as in the third sandplay. (See table 3.) The males were all associated with dangerous situations that implied a sense of vulnerability. Ethan used a war scene to represent Thomas. One

army in the war scene displayed *the flag for someone else*. Mr. B was identified by a hair-raising accident in which he was injured. Lucas was walking in for an operation. Again the type of surgery Lucas was undergoing was undecided.

To the contrary, the females were apparently safe. They were depicted in traditional, innocent settings. Samantha played with her dolls while Mrs. B baked. Bradway and McCoard (1997) stated that food may be representative of nurturing or the need for nurturance.

Ethan left himself out of his family sandplay even though there was an empty space after he completed the scenes of his other family members.

Interpretation

Ethan is the youngest of the three boys and he is older than his sister. Eiser (1993) noted that family size may be a mediating factor in the impact of having a sibling with cystic fibrosis. She stated that having more siblings can both provide a frame of reference and more support. That is to say, the siblings can rely on one another for support, rather than solely on their parents. Additionally, they have other healthy siblings to model themselves after, not just a sibling with a chronic illness. This primary issue will be considered in interpreting Ethan's sandplay.

Themes and symbolism

Ethan's sandplay may have been influenced by Thomas. Both children completed their sandplays in the same session. The children freely walked through and observed each other working on the sandplay. On occasion, they listened to one another's narratives. This may be the reason for the change in setting from people/animal in Ethan's first sandplay to war in the second and third ones. Ethan was visibly disappointed that Thomas did not follow his lead in the setting of the final sandplay.

Vulnerability was a theme that was apparent in Ethan's first two sandplay sessions. In the first sandplay, the camel and the zebra were in danger no matter what they did. The zebra's parent seemed to be unaware of the zebra's situation. This may be a metaphor for dependency that would be age appropriate for Ethan. In the second sandplay, the dependency metaphor was demonstrated in the ineffective trap and the need for backup

from another soldier. The metaphor could be explained as the need of the help of others for survival (Cockle, 1993).

There was concealment in Ethan's second and third sandplay scenes. Partitions were set up to block the view of others. This was beneficial in protecting the operating room and the *good guys* in the second sandplay. The metaphor suggested is that one should be protected from seeing or knowing too much, or having too much known about oneself. In the third sandplay, while the vision was obstructed by the partition, the bugs and snake were still able to intrude. In this instance, concealment did not protect. Because this was the cystic fibrosis sandplay, it could be extrapolated that not having the information about cystic fibrosis does not protect from the impact of the disease.

Ethan seems to be lacking information or understanding about cystic fibrosis. Both times that he depicted Lucas having an operation, he had not decided what type of operation it would be. One hypothesis would be that Ethan knew his brother had regular surgeries, but was not told about what the operations were for. Another possibility is that he had been told but did not understand. Perhaps he felt that he was disturbing his parents by asking too many questions. This concept was articulated in the literature (Eiser, 1993; University of Calgary, 1992).

Danger and struggle were present in all of Ethan's sandplay scenes. Bluebond-Langner (1996) reported that children worry about their siblings with cystic fibrosis. Eiser (1993) added that they also worry about themselves and the rest of the family. Perhaps Ethan was expressing some of this concern in his third and fourth sandplay scenes. He

depicted Lucas in the sensitive position of having an operation. In the third sandplay, Ethan also included a turtle being attacked by a crocodile in a small fenced off corner of the sandtray. Lucas is admittedly very interested in turtles. It is intriguing to note that this is the animal Ethan chose to have attacked. Ethan seems to have represented Lucas' surgery in a more symbolic way. The turtle, probably Lucas, is in a concealed area and at the mercy of the attacking crocodile, metaphorically the doctor performing surgery.

Ethan placed both his dad and Lucas in precarious positions in the fourth sandplay. Mr. B was depicted having a serious accident requiring hospital attention. Lucas was again going in for surgery.

Interestingly, Lucas was depicted in two sandplay scenes. The other family members are implied in the fourth sandplay scene, but not actually included. This may be suggesting that Lucas is a focus of the family and his presence is most strongly felt. In contrast to that, Ethan did not include himself in the family sandplay scene even though there was room. When questioned about his absence, Ethan appeared stunned and was speechless to explain it. He had not considered putting himself in. This could be a developmental omission. He looked at his family from his own perspective and therefore depicted what he saw them being or doing. It could also be that he feels left out, isolated, or rejected. These feelings were issues discussed in the literature (Shepard & Mahon, 1996; University of Calgary, 1992).

Harper (1988) stated that soldiers carrying flags are a representation of identity. The metaphor involves the soldiers knowing who they are and where they have come from.

In his final sandplay, Ethan depicted the soldiers with a flag belonging to another group. This seems to imply a sense of false identity -- not being who they say they are. Perhaps Ethan is experiencing some identity confusion. Since this portion of the sandplay represented Thomas, it is possible that Ethan was expressing a perception of Thomas experiencing some difficulties with his identity.

Indications of level of well-being

Ethan does not having any indicators of difficulties according to the SCC. His use of figures and space are appropriate for his age range (Grubbs, 1997). Ethan's first sandplay scored with signs of aggression, emptiness and closed world, according to the criteria of Buhler (1951b). Empty worlds often have fewer than five types of figures and have no people. This seems to indicate emotional deficiency. Closed worlds may indicate insecurity. Ethan's second sandplay scored with signs of aggression. The third sandplay scored with signs of emptiness. Buhler indicated that it is common for children to have one sign in their sandplay scenes. There were no signs in Ethan's fourth sandplay.

There were a couple imports in Ethan's scripts. It may be a struggle, but it will turn out okay in the end. Females just carry on with no struggle. These imports resemble those of his brother Thomas and may be family values that the children are internalizing.

Summary

Ethan may be experiencing some concerns about being left out. He also appears to have age appropriate issues about dependency and the need for protection. He may also have some need for knowledge about cystic fibrosis. Overall, Ethan seems to have minimal

issues about having a sibling with cystic fibrosis. It is likely that, as Eiser (1993) suggested, he is positively impacted by being a member of a large family.

A note to Ethan

Dear Ethan:

From the way you approached the sandplay, I could see that you would like to express your ideas. You seem to be a little unsure of yourself. You look to Thomas as a role model and you learn from him. You seem to feel left out in your family because you do not quite fit in with Lucas and Thomas, and you do not fit in with the girls (your Mom and Samantha). Therefore, you are relegated to be the little guy and you are left out of the action.

You have similar values to Thomas. You expect to encounter struggles and believe that things will turn out okay in the end. It is dangerous and exciting to be a guy and safer to be a girl.

Lucas is an important figure in your family. You do not seem to understand about cystic fibrosis. You know that Lucas has operations, but you can not explain what happens.

You are a special young boy.

Sincerely,

Daryl

CHAPTER EIGHT: CHARLES - LET'S JUST PLAY

Charles' story

Staff from the Cystic Fibrosis Clinic approached Mrs. C to invite her to participate in the study. She has historically volunteered to participate in their research projects and it was surprising to them that she had not done so with this study. Mrs. C readily agreed and reported enjoying the experience after the data was collected.

Charles is a 6-year-old who has just completed ECS. He presents as having age-appropriate apprehension about interacting with an adult. Once a rapport had been established, Charles became very interactive and talkative. He then took obvious delight at being the center of attention.

The C family is a nuclear family with 3 boys. The oldest (age 16 years) is healthy. Thirteen-year-old Adam was diagnosed with cystic fibrosis as an infant. He has had several exacerbations and has been hospitalized numerous times for antibiotic therapy. The last hospitalization was 3 years ago. Adam attends clinic every 3 months for monitoring. Mrs. C is the primary caregiver and attends clinics with Adam.

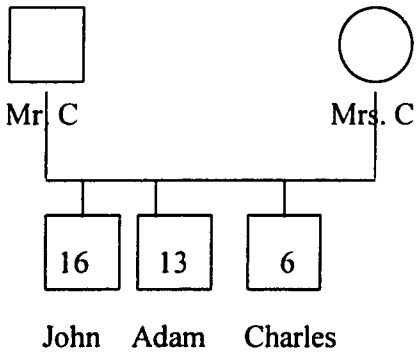

figure 15. Genogram of Charles' family

Mr. C went on a medical leave for a foot injury one week before the research began. Mrs. C baby-sits and works with the local recycling program. This family appears to spend a lot of time together, although the oldest son also spends time socializing with peers.

Charles became more comfortable once he understood the task he was being asked to do. Charles quickly became at ease with the researcher and once this rapport had been established he elaborated in great detail on his sandplay. He was very eager to participate in the sandplay. He enjoyed the sensation of the sand and would run his hands in it frequently. Charles asked if he could just play rather than complete one sandplay scene. Charles accepted the limit of making a sandplay scene and tried to fulfill the requests made of him. He was very dynamic in his approach. He acted out his narrative, moving figures around the sandtray. Charles was reticent to participate in the research without at least one member of his family observing. He waited quietly before beginning his sandplay until at least one of his parents was in the room with him. This pattern persisted for each of the four sessions. Charles talked about the figures as he placed them in the sandtray. Charles' sandplay was reflective of his young age. He used many unrelated figures and it was difficult to recognize what he intended to create. His sandplay scenes were very imaginative and exciting. Charles did not understand the direction of the third session when he was asked to include in the sandplay what he thinks or feels when he considers his sibling with cystic fibrosis. Most of his narratives were descriptive of the content of his sandplay.

figure 16. Charles Sandplay 1

Sandplay 1. Charles' initial sandplay was chaotic and disjointed. Whereas he did not separate his sandplay with boundaries, it was made up of several unrelated ideas. Charles placed a giraffe family in the central part of the sandtray. The family consisted of *a mother, father and three babies*. To the left of the giraffes was *a zebra with three kids*. There was also a kangaroo. Charles identified this as *the jungle* with the animals being *neighbors*. The zebras and giraffes were *playing together.*

On the left side of the sandtray Charles created *IGA*. There was a basket of food that he stated was his Mother's. Next to IGA were two planes. They were *sitting there while the pilots took a break.*

In the bottom left corner was *the army guys*. There were two airplanes, a helicopter, a cannon and two soldiers. *The army guys were fighting the cowboys that were running in front of them. One horse had been shot in the leg. It could only walk, and then suddenly it was dead. Another horse was eating grass. Two more were at home.* The army airplanes were shooting at a cheetah that Charles had added as he told his narrative. He explained that *they were shooting at it from the air, and kept missing so they landed to get a better shot with the cannon.*

The center of the bottom of the sandtray had a sandcastle with a *princess inside.* Knights surrounded the castle on three sides. They had set a trap *to catch the good guys.*

There were several dinosaurs in the top left corner. *One dinosaur was bumping into another one of the same kind* that was not actually present in the sandtray. Others were *eating or having fun.*

The top center of the sandtray was *the beach.* There was *a mama turtle with another hatching turtle*, two sharks and two frogs. A scuba diver was swimming and there was a *treasure that was buried.*

The top right side of the sandtray was a house that belonged to Charles' family. There were trees on two sides. In the center of the right side was a car at a stop sign and *a man crossing the street.* In the bottom right corner was a *bear family* consisting of *a*

mother, father and two kids. The bears were playing. In the very center of the sandtray was a motorcycle that was *driving along*.

In this sandplay scene, Charles used 78 figures, 21 of which were wild animals. The sandplay scene could be described as disarranged and included soldiers fighting. (Table 4 provides an overview of the use of figures, identified setting and themes, and signs of emotional difficulties.)

It was difficult to organize all of the ideas that Charles' included in his sandplay. Concept mapping revealed that nurturance was a theme in Charles' first sandplay. He included zebra and giraffe families interacting together. The bear family was playing together. A turtle was hatching a baby. Both the horse and the dinosaurs were eating. There was a basket of food for his mother. And, the pilots were self-nurturing by taking a break.

There were also many examples of aggression in Charles' first sandplay. The army guys were fighting the cowboys. The people in the airplane were shooting the cheetah. A horse had gotten shot at and was suddenly dead. The knight was fighting evil knights and the dragon.

	session 1	session 2	session 3 CF theme	session 4 family theme
SETTING	disorganized	disorganized	disorganized	family
DOMINANT THEMES	aggression nurturance	aggression nurturance	suspicion nurturance	work/play
TYPES OF FIGURES				
1. Transportation	8	9	5	2
2. People	7	8		4
soldiers	2			
3. Domestic animals	5		3	
4. Wild animals	21		5	1
dinosaurs	8		2	
fantasy creatures		1		
5. Buildings	2	4	1	1
furniture/household items				9
food	13			
6. Fences				
7. Vegetation		5	6	
natural items	3		1	
8. Medical	6	5		
9. Misc.	3	2		
TOTAL FIGURES	78	34	23	17
SIGNS				
1. Empty World signs				
< 50 items		1	1	1
< 5 types				1
people omitted			1	
2. Aggressive World signs				
soldiers fighting	1	1		
animals fighting				
accidents		1		
3. Distorted World signs				
closed worlds				
disarranged worlds	1	1		
rigid worlds				
4. Symbolic World			suspicion	

Table 4. Synopsis of Charles' Sandplay (adapted from Buhler, 1951b and Grubbs, 1997)

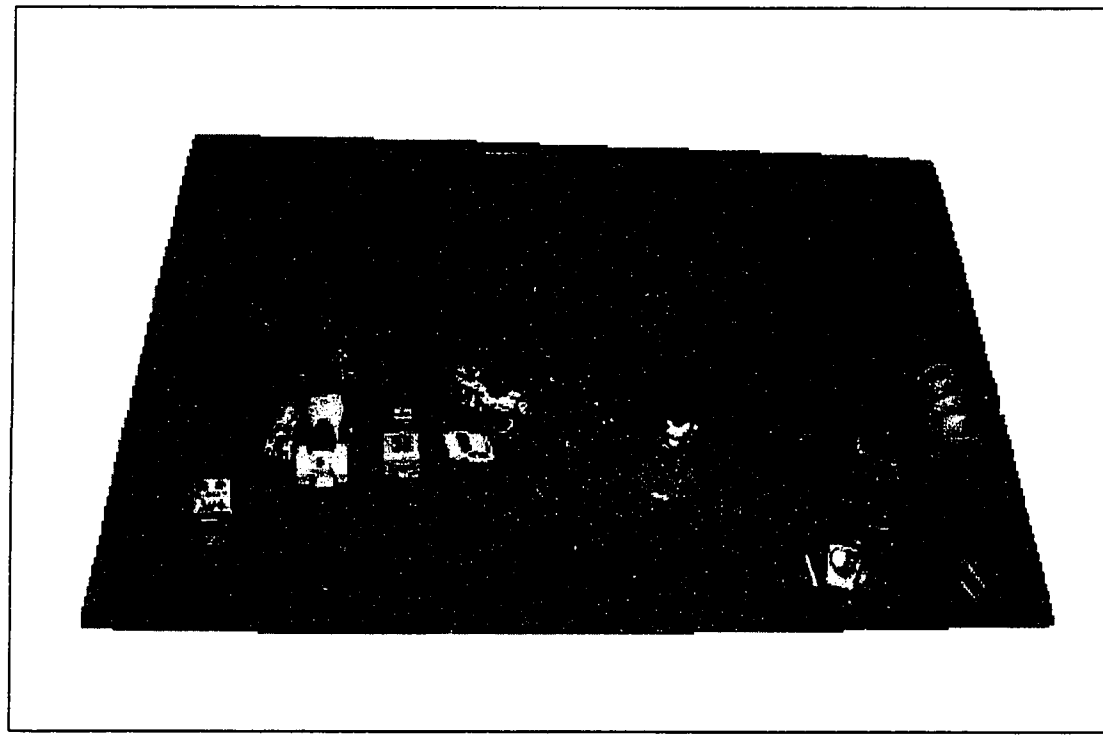

figure 17. Charles Sandplay 2

Sandplay 2. Charles suggested at the beginning of the second session that, instead of creating a sandplay, scene he *should just play*. He accepted the limitation to make a scene. However, in telling the narrative, Charles became very active with the figures.

Charles put a hospital scene in the bottom right corner of the sandtray. The patient on the operating table *had been shot*. Charles stated that *he was very sick*. Charles worked diligently at putting slippers and casts on the patient. He repeated the action several times as they kept falling off when he moved the patient. Charles was ultimately successful and then he covered the patient with a blanket.

The sandcastle, two knights, the queen, a dragon, and a trap were in the center portion of the sandtray. The knights were *fighting a dragon.* The trap was intended for the dragon. *Sometimes the dragon did not feel the ax trap, and sometimes the trap hurt the dragon.* Near the castle was a scuba diver *searching for treasure.* When he found it, *he would give it to the knights and queen.* Charles explained that the scuba diver *lived in the castle with them.*

A chuckwagon was traveling up the right side of the sandtray. It was *going to a house to visit.* The house was facing out with trees in the yard. Charles did not know who lived in the house.

The bottom on the left side was *the beach.* A large log indicated *the parking area.* One truck was parked at the beach. His cat was apparently *stuck in the nearby tree and a firetruck was coming to rescue it.*

There were two teepees in the top left. *Indians lived in the teepees* and were planning to *shoot out the top at a truck passing by.* A motorcycle was *trying to catch the truck to warn him* of the danger.

There were several vehicles in the center left side of the sandtray. A second motorcycle was *wiped out* by an ambulance who *bumped him.* The motorcycle driver was *hurt badly* so the ambulance attendants cared for him, *and he died.* An army truck had his guns pointed at the ambulance because *he did not know* the ambulance. To avoid being shot, the ambulance *drove off the road* to another road. Another car also *jumped off the road and got a big sore owwy.*

In this sandplay scene, Charles used only 34 figures. There were actually only 8 people, but several more were implied as inside vehicles and the teepees. Whereas there were not actually any soldiers in the sandplay, Charles indicated that the army vehicles were fighting. Therefore, it was interpreted as soldiers fighting. There were also several accidents. This sandplay could also be described as disarranged. (See table 4.)

Aggression was a theme in Charles' second sandplay. The knights were *fighting the dragon* as in Charles' first sandplay scene. There was a *trap set up to hurt the dragon. A man had been shot and was in the hospital. The Indians were shooting out of the teepee.* The truck had its' guns pointing at the ambulance. *The ambulance had bumped the motorcycle off the road* and ultimately the motorcycle rider died. There were also a couple of accidents. One car *drove off the road* and another *jumped off one road and onto another* before crashing.

Nurturance was also a theme recurring in Charles' second sandplay. The firetruck was saving the cat from the tree. The diver was searching for treasure that he would give to the queen and the knights. Charles' also linked the aggression and the nurturance. After the ambulance bumped the motorcycle off the road, the attendants administered medical aid. The man who had been shot was having an operation to try restore his health. There were also links between aggression and protection. The knights were fighting the dragon to protect the queen. One vehicle was trying to warn his friend that the Indians were going to shoot at him.

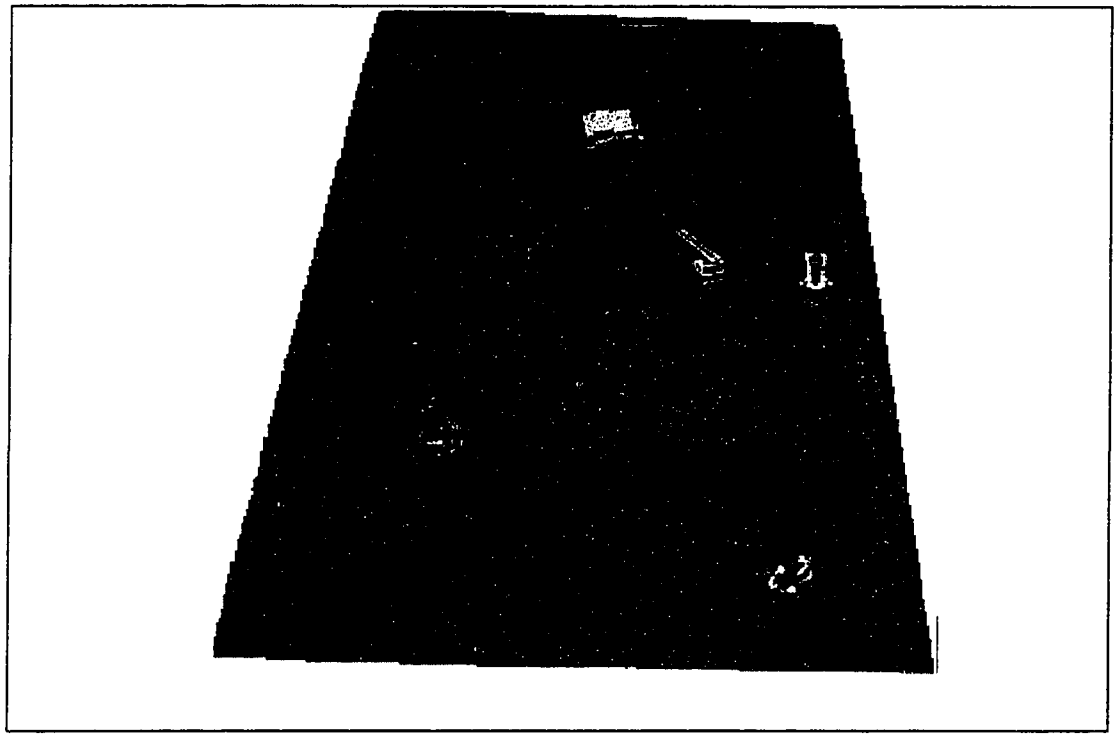

figure 18. Charles Sandplay 3

Sandplay 3. The researcher instructed Charles to include what he thinks or feels when he thinks about his brother with cystic fibrosis in this sandplay. Charles worked from the end of the sandtray. Charles placed a house in the bottom right corner. He stated that it was his house. Two dogs were playing in front of the house. Both dogs had the same name, which was the same as the family's actual dog who had died. Charles stated that *one dog was his and the other belonged to Adam*, his sibling with cystic fibrosis. Behind the house was a large stick that was *a tree that had fallen*. The stick extended across the width of the sandtray.

Behind the stick on the bottom left side of the sandtray was *the forest.* There was a *wild horse eating and a bear family.* The family consisted of *a dada, mama and two cubs. The cubs were playing while the mama looked at a rainbow in the sky. The dada watched the wild horse because he was convinced that the horse was spying on the cubs.*

A dinosaur was in the center of the sandtray. As in the first sandplay scene, Charles indicated that *it was bumping into another similar one* that was not actually present in the sandtray. A second dinosaur stood next to the first one. The center of the left side of the sandtray was *the dinosaur tree.*

A boat and dolphin were in the center right side of the sandtray. The boat was *sailing to Mexico. The dolphin was swimming and jumping.* The dolphin was buried in the photograph because it had *dove down.*

Along side the boat and dolphin was a firetruck moving toward the bottom right corner. It was *speeding to put out a fire at Charles' house.* An army truck with guns was *shooting at the firetruck because he was trying to stop the firefighter from getting to the house.* A helicopter was in the top left corner. He was *about to take off to also shoot at the firetruck.* Charles added that *the helicopter and truck were trying to save the house.* They were shooting at the firetruck because *they thought he was not going to the fire.* The firetruck was *too fast* and avoided being shot. The firefighters were successful and the house was not *broken down.* An ice cream truck was in the center of the top of the sandtray. He was driving to Charles' house *to bring the family some ice cream.*

The researcher asked Charles about the significance of this sandplay in relation to his sibling with cystic fibrosis. Charles was unable to answer. Charles' reaction gave the impression that he had created the sandplay without any conscious attention to the question.

Charles used only 23 figures in this sandplay. There were no people actually used, but people were implied in the vehicles. There was a tone of suspicion throughout the sandplay scene. (See table 4.) *The Dada bear thought the horse was spying on the cubs.* This was an important point as Charles mentioned it three times. The truck with guns and the helicopter *thought the firetruck was not going to the fire.* They responded aggressively by shooting at the firetruck.

There were also signs of nurturance in Charles' third sandplay. The ice cream truck delivered treats to Charles and his family. Someone had prepared a large fishbowl for the dolphin. The horse was nurturing himself by eating grass.

Family relationships were depicted in this sandplay. Charles included his family and dogs belonging to himself and to Adam. The bear family was together although the parents were not interacting with the playing children.

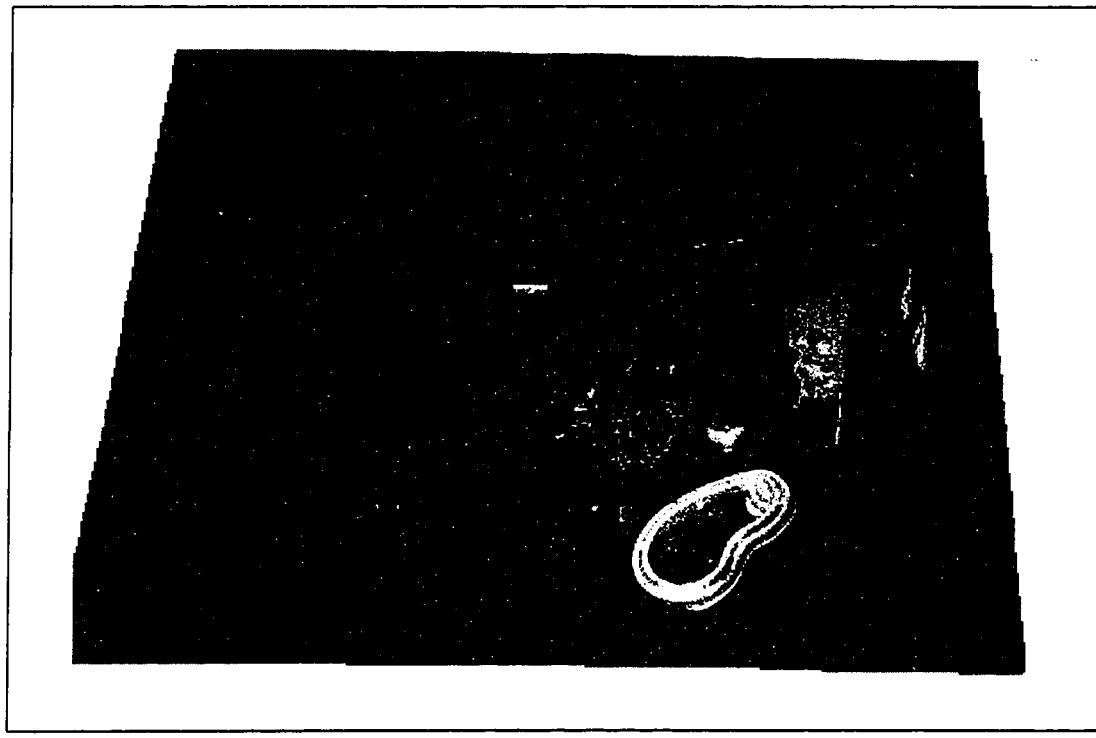

figure 19. Charles Sandplay 4

Sandplay 4. The researcher instructed Charles to include his family in this sandplay. Charles completed this sandplay in only fifteen minutes. In his previous sandplay sessions, he had used most of the allotted time. It is also significant to note that Charles had had a fight with Adam earlier in the evening where Adam punched Charles in the stomach. At times, Charles appeared to be suffering from a stomach ache.

Charles worked from the end of the sandtray and used only a small portion of it. In the center of the end he placed a campfire with four people around it. Charles said *it was night time and they were roasting marshmallows around the fire.* Charles identified the people as his mother and father, his oldest brother and himself. Charles stated that *he could*

not find a figure for Adam. The researcher questioned what he was looking for in an Adam representative. Charles immediately picked up a figure and stated that it would look like that one. Charles did not choose to add that figure to the sandplay.

To the left of the campfire was a house facing away from Charles. There was a mailbox in the front of the house. Near the campfire Charles put in a swimming pool, a slide, a seesaw, a wagon, a swing, and a sand set. There was also a lounge chair which Charles stated his mother sat in. He demonstrated this with the figure representing his mother. There was *a scooter* that Charles stated his father *used to drive to work.* Although Charles stated that his father was not a policeman, the figure he chose to represent his father was. Charles continued this imagery and stated that his father *drove the scooter to the police station to work, and even out chasing criminals.* There was a motorcycle that Charles stated his mother *drove to her work.*

Charles indicated that he was pretending that Adam and a friend were on the seesaw. Later, that the same two were playing in the wagon. There was a set of three geese on the right side. Charles stated that *they were walking beside a pond* that was the edge of the sandtray. Next to the geese was the sand set. Charles stated that it was *his sand box because he liked to play in the sand.*

This sandplay was very reality-based for Charles. In his narrative, Charles repeatedly reinforced the fact that the entire family enjoys basketball. He stressed that he was like the other boys in that interest. He also explained how this sandplay was not an exact replica of reality. For example, he discussed how his mailbox looked different than

the one in the sandplay. He talked about people that were actual family friends and described his mother's job.

In this sandplay Charles used only 17 figures and only 4 types of figures. (See table 4.) The setting of the sandplay was family and the theme was work/play. Charles depicted his family having a campfire together and he left Adam out of this family interaction. He later pretended to include Adam playing with a friend. Charles stressed the common interest of the family. He emphasized the point that he was included as one of the boys.

Interpretation

Charles was the youngest participant in this research. He had just turn six years old. The researcher will be noting whether he had the cognitive ability to use the sandplay to express his potential issues regarding having a sibling with cystic fibrosis.

Themes and symbolism

Aggression was one recurrent theme in Charles' sandplay. There were several instances of good versus evil and good generally prevailed. This is a common expression (Reed, 1975). The recurring theme of vulnerability also suggests an age-appropriate dependency. It was interesting to see the link between aggression and nurturance in Charles' second sandplay scene. In two separate instances an aggressive act caused harm and then assistance was rendered to help the injured party. In one case it was even the ambulance driver that hit the motorcycle that then attempted to save it.

The third sandplay had the cystic fibrosis content. Charles seemed to not understand the request and could not verbalize how his sandplay related to cystic fibrosis. He included in this sandplay two dogs, both of which had the same name as the previous family pet that had died. This may demonstrate a lack of imagination on Charles' part to come up with a different name for the pets. However, the presence of the dog in this sandplay seems significant. He represented a painful loss for the family. Perhaps Charles was expressing the finality of the disease or the knowledge that Adam's illness is related to family losses. These losses could include activities restricted by Adam's health, financial stresses related to the cost of treatments, or the eventual premature loss of Adam's life.

Charles made repeated references to suspicion in this sandplay. Each time, they were in fact false accusations -- the horse suspected of spying, and the firetruck surmised to be not doing its job and putting out the fire. The metaphor expressed here could be that incorrect information could be dangerous. It could be hypothesized that Charles does not have reliable knowledge about cystic fibrosis. He does not know about the disease and is fearful about the facts that he believes he has.

In the family sandplay scene, Charles emphasized the similarity between him and his brothers. He stressed that he is included as one of the boys. It is likely that he is feeling left out of the sibling group. Whereas this is reportedly a common characteristic of siblings of children with cystic fibrosis, it is also probably a realistic depiction of the family. Charles is only six years old and both of his siblings are adolescents. Just as in Allison's family, they are developmentally moving away from the family unit and toward peer socialization. Because of the large age difference it is probable that Adam and his older brother resist including Charles in their activities.

Charles symbolically rejects Adam in his family sandplay. He did not actually include Adam in the family activity even though he was eventually able to find a figure to represent Adam. It is probable that this was a lingering effect from the fight that the two boys had had earlier in the evening. Charles may have been expressing a desire that Adam was not in the family as a means of expressing his anger and hurt about the fight. Charles later pretended that Adam was included in the sandplay and the narrative included Adam in a couple of instances. It may be that Charles symbolically expressed his anger and then

was able to forgive Adam and include him as part of the family unit. Alternately, Charles may have felt guilty about leaving him out or not wanting him in the family and later pretended to add him to assuage his own guilt. It may also be that not including Adam is of great significance. Charles may have be symbolically expressing the recognition or fear that Adam will not always be a part of their family and that he will only be present in their thoughts. More information would need to be gathered before making this conclusion.

Indications of level of well-being

Apart from the family sandplay scene, the setting of Charles' sandplay scenes was disorganized. This is likely telling of his cognitive level of development. Grubbs (1997) said that very disorganized worlds may indicate regression to the preschool age. Charles had just turned six years old and was just completing ECS. He may not yet have developed the cognitive skills to organize his thoughts. Buhler (1951a) stated that in young children the content of the sandplay may not be clear because these children frequently use only a few items to represent complex ideas. For example, in his first sandplay scene, Charles represented the jungle with only giraffes, zebras and a kangaroo. Another hypothesis is that Charles may also have been overwhelmed by the vast array of toys. He may not have been able to organize his thoughts when presented with the opportunity for so much expression.

Grubbs (1997) noted that children of Charles' age often create sandplay scenes that include a great deal of dramatic play. This was the case with Charles. All of his narratives were very dynamic with the actions of the figures being played out. Charles had even

asked if he could play rather than create one static scene indicating that preference for style of sandplay.

Grubbs (1997) stated that large portions of the tray left unused may be indications of disturbance. Charles' fourth sandplay scene used only one third of the sandtray whereas in the other sandplay scenes the trays were evenly used. Again, it is difficult to draw conclusions because this may be the result of the fight earlier in the evening rather than an indication of an emotional disturbance. He was in some physical distress during the session and indicated that his stomach was sore. He may not have felt like extending himself to play.

Buhler (1951a) reported that children ages 4 - 7 years frequently score with 2 - 3 symptoms. She explained this finding by stating that young children are less able to cope with having their needs frustrated. Charles scored with aggression and disarranged signs in his first sandplay. His second sandplay also scored with aggression and disarranged signs, as well as empty signs. Charles had accidents in his sandplay. Buhler (1951b) noted that accidents are frequent in the sandplay of children who are troubled. She also noted that disarrangement signs in children over the age of four years may indicate a disturbed relationship to reality. However, Lowenfeld (1979) noted that children with low intelligence, very young children and those under great pressure frequently use unrelated figures. The use of unrelated figures would result in a sandplay scene that appears disarranged. Charles third and fourth sandplay scenes had neither aggression nor disarranged world signs. As noted earlier, Charles may have been overwhelmed with the

sandplay due to the selection of toys and therefore been unable to organize his thoughts. This is consistent with Buhler's research when disorganized and empty world signs are scored in the same sandplay. Charles' third and fourth sandplay scenes scored with empty world signs. Buhler noted that this is normal in children under five who are egocentric and may live in a more protected environment.

The researcher could not identify any script imports from Charles' sandplay and narratives. It is possible that his age is a factor in not having the ability to express any imports.

Summary

It was important for Charles to be included with his siblings. This would imply that he worries about being left out. This is consistent with the literature on siblings of children with cystic fibrosis. Charles also suggested a lack of factual knowledge about the disease. Charles demonstrated age-appropriate dependency needs in his sandplay. Charles may not be at his age level in emotional or mental abilities as he appeared to have difficulty in organizing his sandplay. His abilities seemed to be at a preschool level. Whereas Charles demonstrated some developmental immaturity, sandplay was an effective mode for his self-expression. It may be that children as young as Charles need more than four sessions for themes to emerge. Additionally, the extenuating circumstances of the fourth session make it unrealistic to draw any conclusions from that sandplay.

A note to Charles

Dear Charles:

I could tell that you really enjoyed playing. It was hard for you to make a single picture each time. You liked the toys and wanted to enjoy playing with them in your own way. Thank-you for trying to follow my instructions. It was fun for me to come to your house and do this research with you. I enjoyed spending time with you and your family.

It seems that family is very important to you. Several times you talked about families being together. It also seems important that you are included in your family. That is harder now that you brothers are teenagers. You are proud that you have the same interests as your older brothers. Because you are so close with your family, you will be able to ask them questions when you have them.

For now, you do not seem to understand cystic fibrosis. It may be hard for you to think about cystic fibrosis when your brother is so much older than you and does participate in activities without you. You do not seem to be impacted by cystic fibrosis at this time.

I had fun watching you play.

Sincerely,

Daryl

CHAPTER NINE: DAVID - A BOY WITHOUT HOPE

David's story

Staff from the Cystic Fibrosis Clinic invited Mrs. D to participate in this study. She expressed excitement at the idea that David would be the focus because Amy, the child with cystic fibrosis, is so often the center of attention.

David is a slight, dark haired, 9-year-old. He reportedly has severe dyslexia that was detected when he was is grade one. Mrs. D has since home-schooled David. He does not participate in any structured activities. Mrs. D reports that he makes friends easily although he does not have a 'best friend.' David's birth parents are divorced. Mrs. D reports that his father abandoned them. Mrs. D is also divorced from the father of David's sister. She reports that he rejected and ignored David. Mrs. D remarried again when David was in grade one. This partner remains in the home and involved in the care of the children.

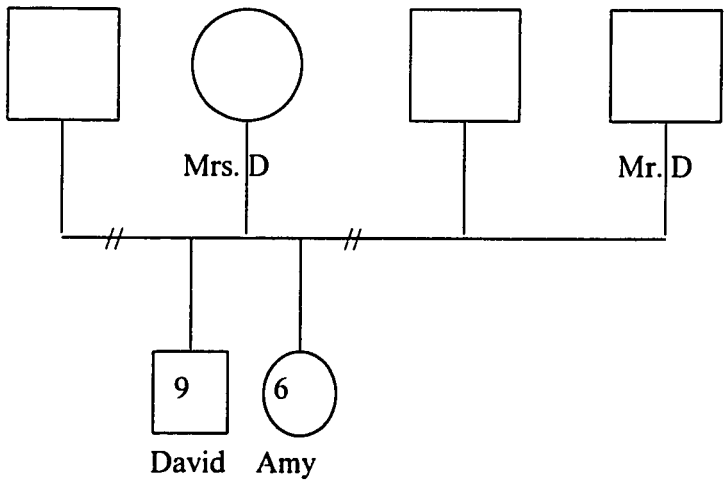

figure 20. Genogram of David's family

The D family is unique to this research in that David is the older sibling of the child with cystic fibrosis. Amy (age 6 years) was diagnosed with cystic fibrosis at 18 months of age after surgery to remove a foreign body from her lungs. Amy is relatively healthy, but is susceptible to viruses and becomes quite ill if she catches a cold or flu. She also has asthma. Amy is also home schooled due to her compromised health. Mrs. D is a day home provider to 6 other children.

The D family participates in activities together, such as weekend camping excursions. Mrs. D reports that David has not participated in structured activities because they do not have financial resources to make that possible.

David was very enthusiastic to participate in the sandplay. He quickly became comfortable with the researcher and the task at hand. He was enthralled with the figures. For the first two sessions, David took the entire thirty minutes and was dynamic in his narrative. He acted out the story as he told it. In the third and fourth sessions, when David was given specific direction about something to consider when creating the sandplay scene, he completed his sandplay in 5 - 10 minutes. David did not change his attitude toward the researcher, but his sandplay was dramatically different. All of David's narratives were descriptive of the content of the sandplay with actions to link the separate components together.

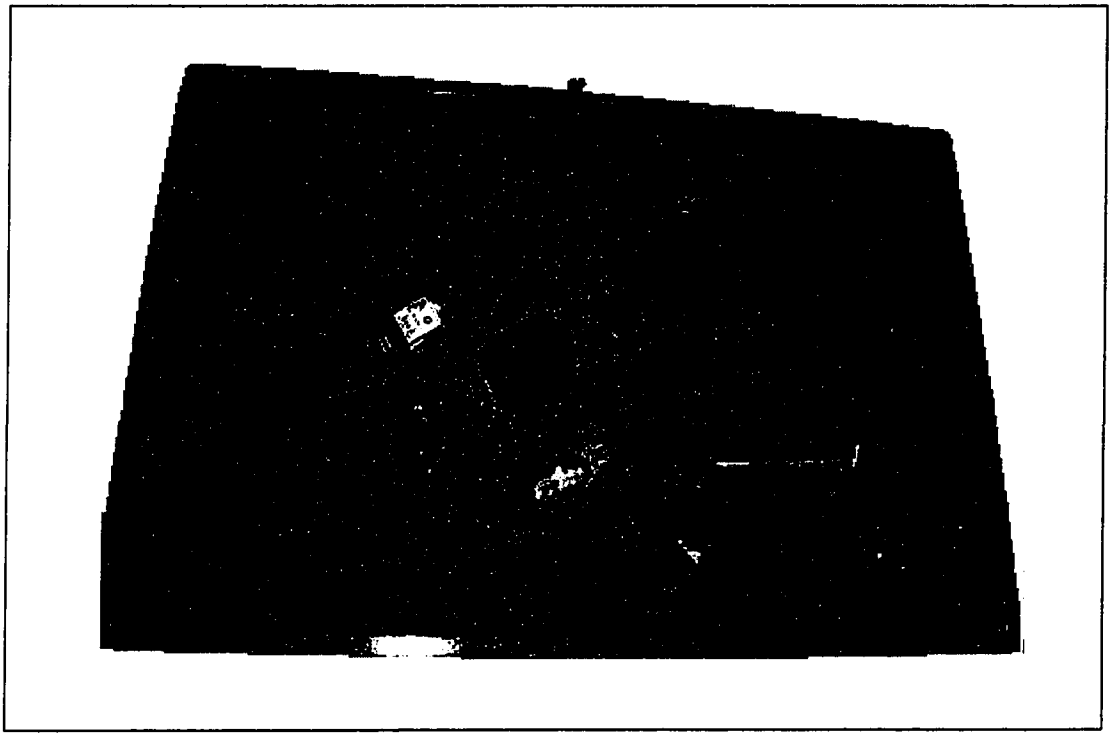

figure 21. David Sandplay 1

Sandplay 1. David's first sandplay consisted of several separate ideas, most of which he linked together in the narrative; although, there was no cohesive story. In the bottom right corner David placed a castle for *the frog king*. He stated that *the frog king had treasure, lots of bugs to eat, a chest of toys and lots of friends*. The treasure consisted of *a treasure chest full of coins and gemstones, more gemstones around the chest, bottles, and bugs to eat*. The treasure area was surrounded on two sides with fences and was guarded by frogs and turtles. The other two boundaries were the edges of the sandtray. There was a slinky tunnel that led from the treasure to the front of the *king frog's home. The frog became king because he was very big and he did not do anything with his treasure.*

In the center right side was a frog in a swimming pool, a tree and a dinosaur. In the top right corner were two bears, *a king and his friend, talking.*

A cannon was in the top left corner. *"Some people"* (who were not in the sandtray) *were having a war and trying to steal the treasure.* The cannon *did not work* so they were unsuccessful at getting the treasure. A bear sitting in the top right side of the sandtray was also admiring the treasure.

In the bottom left corner was a sandcastle and two turtles. The sandcastle belonged to the turtles. There were more turtles throughout the sandtray. One was *hiding under some sand to catch bugs.*

The center of the sandtray contained a house. *A monster was about to walk over the house and destroy it. A dragon was going to help.* The woman who owned the house was *very angry* as she watched.

In the center of the right side was a helicopter. A bear was sitting close by watching. *A jeep had just driven up to the helicopter.* A lizard was approaching the jeep *to crush it.*

There were several dinosaurs throughout the sandtray. David stated that they were *leaving footprints.* There were also two logs, one with a frog sitting on it. David included some trees in the top right quadrant.

David used 74 figures in this sandplay scene. Thirty of these were classified as miscellaneous (e.g., bugs, treasure). There were 18 animals. This sandplay scene was

disorganized. (Table 5 provides an overview of the use of figures, identified settings and themes and signs of emotional difficulties.)

With concept mapping it was easy to see that violation and aggression were themes in David's first sandplay. *The giant was walking on the house of the woman. "They" were having a war and trying to steal the treasure. The big lizard was crushing the jeep.* Closely linked to the violation was power. The giant was able to destroy the woman's house and she could do nothing about it. The dragon was helping the giant in this destructive act. It was a big lizard that was crushing the jeep. *The frog was king because he was so big. He had lots of friends, treasure, food, and had a very big place*. Other animals *guarded the treasure of the frog king*. There was also a *bear king*.

Several of the figures had homes. The woman had a home until it was destroyed by the giant and dragon. The frog had a home. There was also a sandcastle for the turtles.

	session 1	session 2	session 3 CF theme	session 4 family theme
SETTING	disorganized	disorganized	death	family
DOMINANT THEMES	violation aggression	violation aggression	death/loss	protection
TYPES OF FIGURES				
1. Transportation	2			
2. People	1			3
soldiers				
3. Domestic animals				
4. Wild animals	18	27	11	
dinosaurs	6	6		
fantasy creatures	2	3		1
5. Buildings	3	5		1
furniture/household items	2			
food				
6. Fences	2	2		2
7. Vegetation	6	2		
natural items	2	2	1	1
8. Medical				
9. Misc.	30	29		1
TOTAL FIGURES	74	76	12	9
SIGNS				
1. Empty World signs				
< 50 items			1	1
< 5 types			1	
people omitted		1	1	
2. Aggressive World signs				
soldiers fighting				
animals fighting		1		
accidents			1	
3. Distorted World signs				
closed worlds				
disarranged worlds	1	1		
rigid worlds				
4. Symbolic World signs				

Table 5. Synopsis of David's Sandplay (adapted from Buhler, 1951b and Grubbs, 1997)

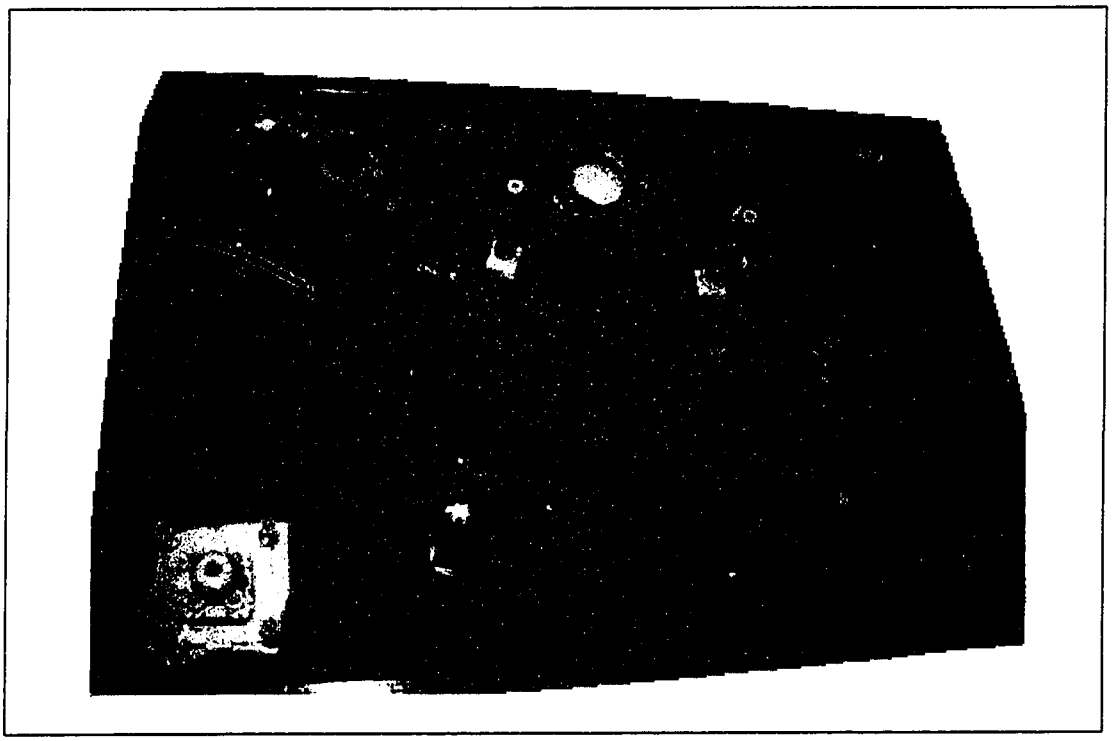

figure 22. David Sandplay 2

Sandplay 2. David's sandplay was similar to the first one in many of the figures that he used, and some of the theme. It was also similar in being disjointed and linked together only by the narrative.

David began by placing a *mouse palace* in the bottom left corner. *The mouse waved to his friend the panda who was sitting on a tower in front of the palace.* Beside the panda and tower, *two elephants were drinking water from a trough.*

There was a sandcastle in the top left corner. A ghost clung onto the castle. Behind the castle was *treasure that belonged to the turtles.* The treasure was fenced on two sides. The third side was the edge of the sandtray, and the fourth was the sandcastle. A large

dinosaur was preparing *to smash over the gate and steal the treasure.* The turtles watched and recognized what was going to happen, but did nothing about it.

There were four more homes in the sandtray. In the top center *was a frog in a pond protecting himself from the rain with a shell on his head.* In the top right corner was a house for the pandas. The house was *guarded by trees.* In front of the panda house was a shell that was home for *a tiny dinosaur*, and in the bottom right corner was *an apple house for a bug.*

A large stick extended through the center of the sandtray. *A snake and bugs climbed over the stick. Another bug climbed under the stick.* There were several other bugs and snakes throughout the sandtray. There were also numerous frogs and turtles in the sandtray that David did not mention in the narrative.

In the right center of the sandtray *a lizard was attacking a dinosaur.* Another *dinosaur was attacking the lizard.* In the top right area were *two giraffes chasing a chicken.* Near the frog home was *a dragon smashing a pole.* Two dinosaurs were walking side by side in the center of the sandtray. They had strong tails and were going to *whack each other because they were walking so close.*

David used 76 figures in this sandplay scene. There were 27 wild animals, and 29 miscellaneous figures. There were no people. This disorganized sandplay scene included animals fighting. (See table 5.)

Again, it was not difficult to recognize that the themes of violation and aggression were also dominant in David's second sandplay. The *dragon was smashing one pole* while

a *monster was smashing another. A lizard was attacking a dinosaur who was in turn attacking a frog. A snake was attacking another snake. The giraffes were attacking some chickens. The dinosaur was smashing down the gate to steal the turtles' treasure.*

There were signs of protection in this sandplay scene. *The trees guarded the pandas' house. The frog protected himself from the rain.* In contrast, the turtles were unable to protect their treasure. They were passive against the attack of the thieving dinosaur. They simply watched him break down the gate and did nothing about it.

There were several homes in David's second sandplay. The mouse was in his palace. The pandas had a house. The bug was in his apple house. The tiny dinosaur had a shell house. The turtles had their castle. They all seemed to be safe in their homes.

David identified several friendship relationships. The mouse and the small panda were friends. The large panda was friends with both the giraffes and the snake. The dinosaurs were walking along together. However, this was a painful alliance as they kept *whacking their big tails* against one another because they walked so close together.

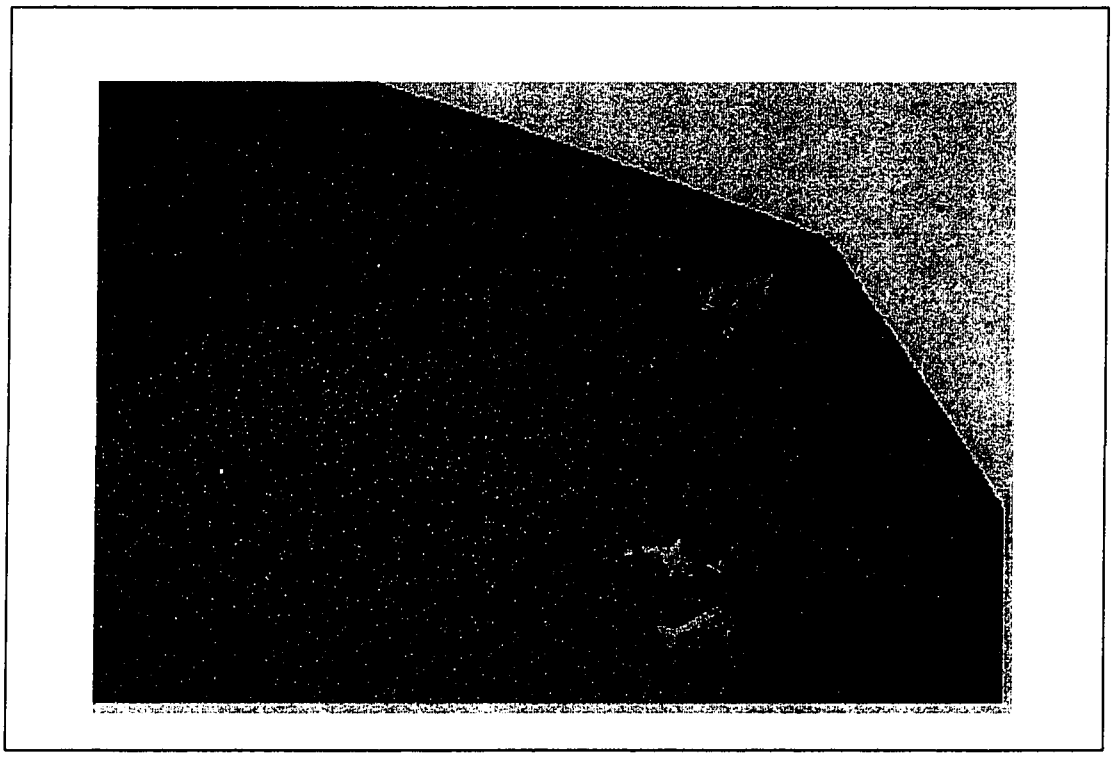

figure 23. David Sandplay 3

Sandplay 3. The researcher instructed David to include what he thinks or feels when he thinks about his sister with cystic fibrosis in this sandplay. David completed this sandplay in five minutes. His narrative was also very brief. David's demeanor changed from happy and excited to downcast as he created the sandplay and talked about it. Mrs. D indicated that David is always non-communicative when he is asked to express his feelings.

David moved the sand away from the bottom right area of the sandtray. He placed one shark upside down and two other fish the normal way in this clearing. David buried a snake in the lower left quadrant and placed another snake beside on top of the sand. He put a large stick next to the snake. In the top right corner David buried a zebra and put one

large and one small zebra on the sand near the buried one. David did the same thing with turtles in the lower right side of the sandtray.

In his narrative David stated, *it's sad.* He went on to explain that *the shark was shot and died and the other sharks went by to see him. The snake had been stepped on and was buried because he was dead. The turtles were at the grave of the other turtle who died after being bit. The zebras were by the grave of the little zebra that was killed when it was hit by a car.*

David used only 12 figures and 2 types of figures in this sandplay scene. There were no people. The sandplay scene depicted the result of several accidents. (See table 5.) The overriding theme of this sparse sandplay was death. The shark, turtle, snake and zebra had all died violent, accidental deaths. The survivors were sad.

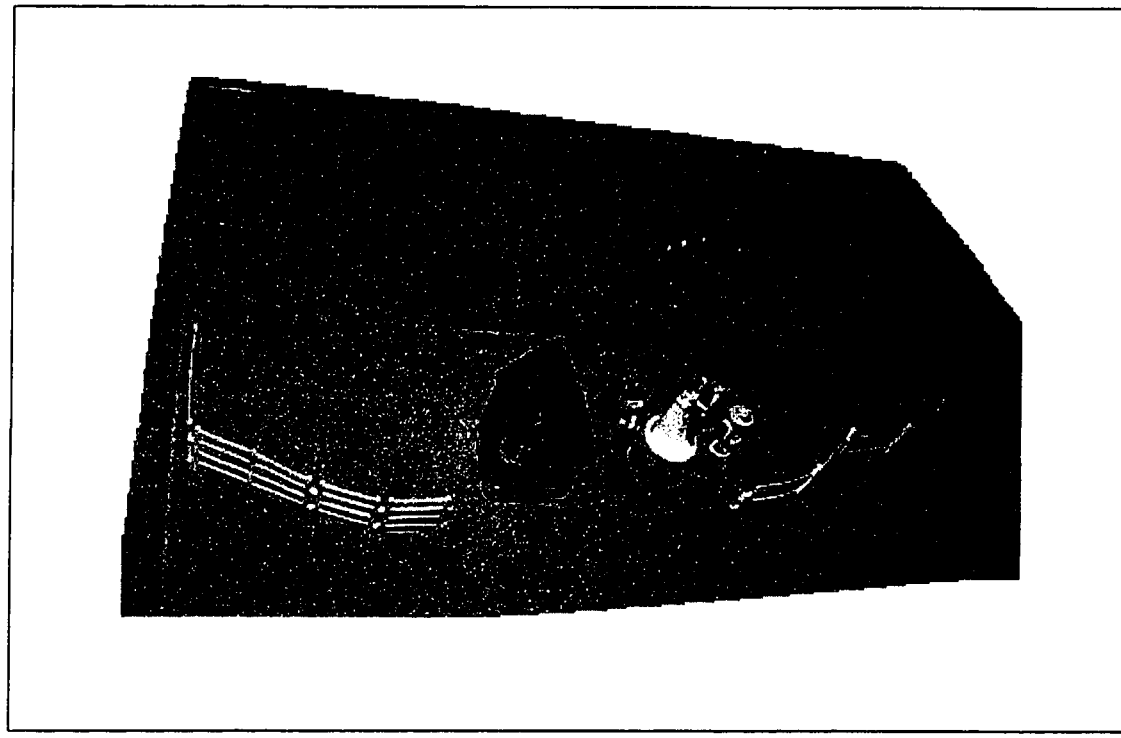

figure 24. David Sandplay 4

Sandplay 4. The researcher instructed David to include his family in this sandplay. It took David only 10 minutes to complete this sandplay. Whereas he was focused on the sandplay, David was quiet and not as animated as he had been in the first two sessions. Mrs. D reiterated her theory that David's attitude and lack of playing were related to the fact that he was asked to explore his feelings.

David put a house in the lower side of the sandtray, just to the right of center. He added a bride and groom pair, a girl to the right of the groom and a boy to the left of the bride. Behind the house and people, David placed a large stick. Behind the stick to the left

he placed the treasure and to the right he placed *a monster*. In front of the figures he placed two fences, one on the left of the house and one on the right of the people.

In his narrative, David identified the bride and groom as his mother and her current husband. The boy was identified as himself, and the girl as his sister Amy. The stick was *in the backyard because that's were it was when they bought the house. The treasure was in the backyard so no one would find it.* It belonged to his mother and her husband. The *monster* was his pet, although it did not have a name. *The monster was protecting the treasure. It was not a scary monster.*

In this sandplay scene, David used only 9 figures. (See table 5.) This was another sparse sandplay scene that lacked the life and activity of the first two sandplay scenes. Protection was the dominant theme of the sandplay. The treasure was in the backyard so no one would find it. The pet guarded the treasure.

In this sandplay scene the family stood in the front. The treasure, stick, and pet monster were behind their backs.

Interpretation

David was unique to this research because he was the older sibling of the child with cystic fibrosis. Older siblings may be more susceptible to problems because of added household responsibilities (Thompson, Curtner, & O'Rear, 1994). This was also the only family with only two children. It has already been noted that large family size may be a mediating factor in adjustment to having a sibling with cystic fibrosis (Eiser, 1993). The absence of any other siblings may be another primary issue that will also be considered in the interpretation of David's sandplay.

Themes and symbolism

Power and vulnerability were themes in David's first two sandplay scenes. There were several powerful figures who exerted their power on more vulnerable figures who were unwilling or unable to protect themselves. The powerful figures seemed to randomly pick on the weaker ones. There was a message of passivity on the part of the victims. The victims demonstrated an absence of positive action, thoughts, or plans in the face of adversity. The woman in the first sandplay whose house was being broken down expressed anger. There was no other emotional expression from the other victims. The turtles expressed only slight dismay that their treasure was being stolen. They seemed almost resigned to the fact that this violation would occur. They did not act in any way to defend themselves. Even though the turtles built a protection around their treasure, the dinosaur was able to intrude upon their boundary and steal their treasure. Only the powerful king frog was able to successfully protect his treasure against attack.

David included several homes in his first two sandplay scenes. Cockle (1993) noted that houses represent a focus on home life. Castles may represent a safe, secret place (Dundas, 1990). The animals were always safe in their homes, which included castles for some animals. This may symbolize a need for security and a belief the home is a safe place to be.

Whereas David's first two sandplay scenes were rich with life and symbolism, his final two were sparse and bleak. It was in these final two sandplay scenes that David was asked for specific content that was emotional in nature. David may have demonstrated an inability to express his emotions, or a resistance to being asked to do so. There was a lack of signs of life in these final two sandplay scenes that was abundant in the first two. This may be symbolic of a lack of emotional connection. Buhler (1951a) noted that empty worlds may indicate emotional deficiency. They may also connote rejecting a threatening task, or an unhappy, empty life of the creator of the sandplay. It has been previously noted that barren sandplay scenes may be representative of dismal inner and outer worlds that lack growth, life, and health (Cockle, 1993). Barren sandplay scenes may also be indicative of being emotionally overwhelmed (Allen & Berry, 1987)

The theme of David's cystic fibrosis sandplay was death. There was an overwhelming sense of sadness. Again there was the message of passivity. The survivors were sad and inactive. There was no sense of hope or strength.

Whereas David's family sandplay scene appeared normal on the surface, there was an underlying feeling of peril. The activity of the sandplay was happening behind the

backs of the family. The family pet was an unnamed monster. Because the monster did not have a name, there was a sense of disconnection and distance from the pet. Even though David claimed the monster was not scary; he did not identify it as friendly or nice. This sends the message that it is tolerable, but not engaging. Buhler (1951a) stated that changing the intention of dangerous elements may be an attempt to deny anxiety and may be an indication of insecurity. David altered the association of the monster from frightening to the protecting family pet.

The passivity continued in this fourth sandplay. The stick was in the backyard when the house was bought. David's parents simply left it there even though it was not desirable or useful. In the first two sandplay scenes, the treasure was fenced in and attempts were made to protect it. Although David added that the monster was guarding the treasure, it appeared to be out in the open and unprotected. The family seemed oblivious to this fact.

Indications of level of well-being

The setting for both of David's first two sandplay scenes was disorganized. Grubbs (1997) noted that very disorganized sandplay may indicate regression to the preschool level. As previously mentioned, children under great pressure may use unrelated figures in the sandplay (Lowenfeld, 1979) resulting in disorganized sandplay scenes. The setting for the cystic fibrosis sandplay was death, and for the family sandplay it was home/family. This would seem to indicate that David had the ability to organize his thoughts or emotions in some situations.

David buried several figures. Generally, this is representative of a preschool level. However, it could be appropriate given the context of the burying was mostly graves in the third sandplay. Cockle (1993) noted that burying may imply an attempt to hide feelings or a frustrating part of the self. Grubbs (1997) stated that burying objects may suggest a repression from what the object represents. That act may indicate repressed rage or a protected ego (Carey, 1990).

The heavy use of animals instead of people is also common in the preschool level. This tendency carries over into the 5 - 7 year age range too. David anthropomorphized animals in the first three sandplay scenes. Cockle (1993) reported that using animals in place of people suggests emotional delays as it is common in the preschool age. It may also be an attempt to escape or defy people. Further research is needed to support these conclusions (Buhler, 1951a). The absence of human figures may be indicative of feeling alienated or a fear of threat. Only when he was directly instructed to represent his family did David use people.

Dramatic play is also common in children ages 5 - 7 years. David was very dynamic in his sandplay, especially during the recounting of the narrative. David appears to be a very imaginative, creative child. By his age, children's sandplay usually becomes more grounded in reality. Grubbs (1997) stated that if the child creates one or two immature scenes it may indicate a temporary relapse. However, if continuous scenes are immature, the delay may be indicative of a regressive approach to life.

Empty, lonely sandplay scenes may connote withdrawal and inaccessibility. Both of the sandplay scenes where David was given direction would be classified as empty and lonely. This seems to suggest that David's emotions are inaccessible, and that he withdraws when asked to express his emotions.

According to Buhler's (1951b) criteria, David scored with disarranged signs in the first sandplay. One symptom alone is common and may therefore not be significant. However, disarrangement in children over the age of four years may be indicative of difficulties with reality. Disarranged signs were also present in David's second sandplay, as were empty and aggressive signs. Empty and aggressive signs were in David's third sandplay, and the final sandplay contained empty signs. Accidents, which were present in David's third sandplay, are commonly present in children who are emotionally disturbed. Several accidents may indicate deep resentment.

Empty signs may indicate either resistance or emotional blocking. Use of less than five types of figures is a key sign of emotional blocking (Buhler, 1951b). David used less than five types in his third sandplay. Empty, unpeopled, aggressive sandplay scenes that are also chaotic may imply an inability to face situations and represent surrender (Buhler, 1951a). This description illustrates David's third sandplay.

David expressed some imports in his sandplay and narratives. Being strong and powerful enables one to act without consideration of others. When adversity strikes there is nothing one can do to avoid it or, or make the situation better. Passivity is a response to adversity. David seems to be expressing a victimized world view.

Summary

It would appear that David is experiencing some emotional difficulty. When self-directed, David presents at a younger age emotionally. When other-directed, David appears emotionally blocked. David displays a victimized approach to difficult situations. This likely goes along with the emotional blocking. David seems to have learned that there is nothing he can do to make his situation better so he may as well not acknowledge any internal emotional response. Because David is home-schooled, he has limited access to his peers. Perhaps this limited socialization has impacted his emotional development. It may also be that being dyslexic has interfered with David's emotional growth. Another hypothesis is that David's signs of disarrangement are directly related to his dyslexia. Disarranged signs may indicate difficulties with reality. David may have problems accurately perceiving the real world and therefore retreats into a fantasy world. Without the structure of formal schooling and the influence of peers, he may have less pressure to conform to societal standards.

David is clearly effected by his sister's illness. He expressed overwhelming sadness and the expectation that she would die. Again he demonstrated passivity and inaction. This helplessness was reported by Shepard and Mahon (1996). They stated that it may be the result of lack of knowledge about cystic fibrosis, or it may be due to periods of separation. Whereas one would assume it was separation from the primary caregiver, in David's case it may be absence of a male attachment figure in the period of his early development.

There are many complicating variables in David's life. Whereas is it clear that he is experiencing emotional difficulties, it would be impossible to delineate what is the direct result of having a sister with cystic fibrosis. Perhaps being the only sibling of a chronically ill child is negatively effecting David. It may also be that being the older sibling of the child with cystic fibrosis is the important variable in his emotional well-being. It is more likely that David's problems are the cumulative effect of his life situation. Mrs. D indicated that David will begin in counseling in the fall.

A note to David

Dear David:

You are very different when you participate in self-directed play and when you participate in activities to deal with difficult issues. I can see that it feels good to play and you look forward to the opportunity to do so. You prefer not to think about difficult issues. I know that you are exposed mostly to children that are younger than you are. You observe them play and play with them. I wonder if that is why your play is like that of younger children. I also wonder if you get attention for acting younger than you are.

You told me about how mean and scary others can be. You talked about big and powerful creatures picking on others that are smaller and weaker. These smaller creatures are unable to protect themselves from the acts of the powerful ones. They do not even try to. This made me wonder if you get picked on where you live.

You are very sad about Amy's disease. You believe that she is going to die. That is what you associate with cystic fibrosis. This is both sad and overwhelming to you.

It seems like you are having a tough time.

Sincerely,

Daryl

CHAPTER TEN: DISCUSSION

This section will consider the influence of cystic fibrosis on the healthy siblings as indicated in the sandplay of the participants. Whereas this study is very small and results can not be generalized, there were some trends that were exhibited across the sample.

Most of the children with cystic fibrosis are all relatively healthy and not yet in the deterioration stage of the disease. Although Charles' brother, Adam, has had exacerbations, he has been reasonably healthy for the past three years. Bluebond-Langner (1996) reported that difficult times for siblings are at diagnosis and in periods of deterioration of the child with cystic fibrosis. The fact that none of the families in this research are in either of those stages is an important point to keep in mind.

Most of the families who participated in this research have provided the children with secure and stable home experiences. The exception is David, whose relatively unstable early childhood likely plays a significant role in his emotional well-being. It would be impossible to determine the unique effect of Amy's cystic fibrosis on David in light of his other life circumstances.

The other participants in this research are children who appear to be well-adjusted with no mention of any concerns. At the same time, they are dealing with big issues. This research seems to support that having a sibling with cystic fibrosis does not predict maladjustment in children (Gayton et al., 1977; Lobato, 1990). Whereas there are no indicators of maladjustment, all the siblings expressed some concern about having a sibling with cystic fibrosis. Most of the children revealed themes of feeling left out and lack of

knowledge. It is notable that most of the children had a common battle metaphor in their sandplay. These organizing themes will be explored in further detail.

Feeling Left Out

The sandplay scenes of 3 of the children indicated themes of being left out within their family. In her first sandplay, Allison separated all of the children in her family. She accentuated this separation by fencing in the areas of her two siblings. The only time she depicted her family doing anything together was in the fourth sandplay where Allison created a scene of her father and brother *play fighting* while the rest of the family watched. Ethan neglected to include himself in family sandplay scene. Charles gives the impression of struggling to be included by repeatedly stressing the similarities between himself and his brothers. This isolation within the family may be a response to having a sibling with cystic fibrosis. This is consistent with the literature (Derouin & Jessee, 1996; University of Calgary, 1992). Alternately, it could be an indication of the developmental stage of the children or of the family. Ethan is only 7 years old and therefore likely in the early phase of the concrete operation stage outlined by Piaget (Piaget & Inhelder, 1969). He may still have difficulty considering concepts from the perspective of others. Therefore, leaving himself out of his family sandplay scene may be nothing more than looking at his family from his own point of view. Likewise, the isolation that both Allison and Charles expressed may be reflective of the stage of development of their families. Both children are younger siblings of adolescents and are possibly experiencing being left out by siblings who are moving away from family and toward peers as a source of activity and support.

Further research is indicated before coming to any definitive conclusions on the source of the children's feelings of isolation in the family.

Fighting the Unknown

Fighting the unknown combines two significant themes - the lack of knowledge and a battle metaphor. For 4 of the 5 children the image of the child with cystic fibrosis fighting the unknown or unexplainable dominates their sandplay. In her final sandplay, Allison represented James fighting monsters. In his final sandplay, Thomas depicted Lucas stabbing an alien. Ethan portrayed Lucas having surgery in both his third and fourth sandplay scenes. The doctors' operating on Lucas implied others assisting him in his fight. In contrast, David's reference to fighting was surrender. There was no struggle; the victims all died but there was still a battle with the unknown.

A battle metaphor in relation to cystic fibrosis is not surprising given that 'fighting illness' is a commonly accepted metaphor in society and in medical discourse. It is notable that the metaphor is strong even though the children with cystic fibrosis referred to in these metaphors are still relatively healthy. For these children, medical treatment is still preventative. All of the children have some form of chest physiotherapy to keep their airways clear and enzyme supplements to assist in digestion. They all attend clinic on a regular basis (every 3 months) to monitor their lung functioning and weight. James has night feeds to help him maintain adequate weight gain. Lucas has surgery on a yearly basis to remove nasal polyps. This is for comfort and is not an indication of progression of the cystic fibrosis. Amy has no additional medical involvement for her cystic fibrosis. Charles

was the only child who did not refer to his sibling with cystic fibrosis being involved in a battle and Charles' brother is the only one who has been hospitalized for exacerbations of his cystic fibrosis. He requires the treatment because the disease is progressing.

Perhaps the battle metaphor was common because the parents explained cystic fibrosis to the healthy siblings by referring to fighting the disease. Cystic fibrosis is a very complicated disease and it would be difficult for such young children to understand the abstract nature of it.

The children expressed different expectations about the outcome of the battle against cystic fibrosis. Thomas indicated a hopeful outlook that Lucas would be successful in his battle. In Thomas' final sandplay scene, Lucas and the army sent the invading alien back to Mars where it would never bother anyone again. In contrast to Thomas' optimism, David was hopeless. He expressed the notion that fighting was useless and death was inevitable. David seemed to be overcome with grief at this eventuality. Ethan recognized that Lucas had help in his battle. He was in the hands of the expert doctors in Ethan's third and fourth sandplay scenes. Whereas Allison depicted James' future death in her third sandplay, in the fourth one she depicted him fighting monsters. She may believe that the disease will eventually conquer, but that the battle must still be attempted.

Most of the children used fewer figures in the sandplay regarding cystic fibrosis than they did in the first two sandplay scenes. For some children the difference was substantial. David used 74 and 76 figures in his first two sandplay scenes, and only 12 in his third one. Ethan went from 72 and 65 figures to 47 in his third sandplay scene. For

Charles, the decrease was from 78 and 34 to 23. Allison used a consistent number of figures but she only expressed one idea in her third sandplay scene whereas she expressed several in each of the first two sandplay scenes. This seems to imply a lack of expressiveness around cystic fibrosis.

It could be that it is not permissible for the children to talk about cystic fibrosis. The disease may be treated as a family secret. The families may discourage the discussion of cystic fibrosis and therefore the children may not have felt free to express themselves when asked to do so. This hypothesis is not likely or the families would not have agreed to participate in the research.

The children may have had limited opportunities to express their feelings about cystic fibrosis in the past and therefore do not know how they feel. The healthy siblings may not know how to express how they feel about cystic fibrosis. For example, Thomas indicated the impact of cystic fibrosis for him by refusing to address it and therefore seemingly denying it.

The children's lack of knowledge about cystic fibrosis may have been the reason for the decrease in use of figures. If they do not understand the disease, then they can not express how they feel about it. Ethan could not identify the types of surgeries he depicted Lucas undergoing. He also had numerous references to shielding for protection. Charles included suspicion in his sandplay relating to cystic fibrosis. He suggested questionable intentions that resulted in fear and danger. These reactions may indicate that the children do not know and believe that they are better off not knowing.

The fact that the children were directed to include their thoughts or feelings about cystic fibrosis, rather than being allowed to choose their own topic may be the reason that the children used fewer figures. They may have merely been less expressive on a topic that was not of their choosing.

The participants in this research are influenced by the illness of their siblings while remaining well adjusted. They may feel left out and that they do not understand cystic fibrosis. They seem to have the perception that the child with cystic fibrosis is involved in a battle. The children differ in how they conceive the battle being resolved.

A Note to Siblings of Children with Cystic Fibrosis

Dear Healthy Siblings:

Your brother or sister has a very confusing disease known as cystic fibrosis. It is difficult to understand and explain what cystic fibrosis is. Doctors know how to help your brother or sister stay healthy, but they do not really know exactly what is wrong inside his or her body. They are working hard to figure out what makes the bodies of people with cystic fibrosis not work like everyone else's. It seems that there is something not quite right that can cause lots of problems, mostly with how your brother or sister breaths and digests food.

Most of the time your brother or sister may look and act like every other kid but he or she needs to work hard to stay that way. To avoid sneak attacks from cystic fibrosis your brother or sister probably needs to do things to protect his or her body. Most people with cystic fibrosis spend a lot of time keeping their lungs clean and healthy by doing physiotherapy every day. The other favorite sneak attack of cystic fibrosis is in digestion of food. Your brother or sister probably needs to take pills with every meal so it does not hurt when he or she eats and to help the food be digested properly. Most people with cystic fibrosis have to go to the doctor regularly, even when they are feeling well. That is so the doctors can keep them feeling healthy and strong and make sure they have the correct weapons to avoid the sneak attacks of cystic fibrosis.

It probably seems like your brother or sister gets a lot of extra special attention. Many healthy siblings feel left out. It would be a good idea to make sure your parents

know how you are feeling. Do not be afraid to ask them questions about cystic fibrosis. It is better to know the facts than to worry and wonder by yourself.

Sincerely,

Daryl

CHAPTER ELEVEN: CONCLUSION

This chapter will revisit the two goals of the research and will discuss the implications of the results. I will review the procedure followed for the sandplay sessions and discuss the strengths and limitations of it. The usefulness of the assessment tools used will be discussed. I will reflect on the strengths and limitations of the research design and future research ideas. Finally, I will explore my reactions to this experience.

Implications of the Research

This research has resulted in some interesting preliminary information. In this section I will identify some of the audiences that may find this research useful. I will review the results and how the implications may be put into practice.

A logical audience for this information would be with the professionals of the Cystic Fibrosis Clinic who might find knowledge on the natural concerns of the siblings of their patients useful. The clinic staff could prepare parents regarding some anticipated reactions of healthy siblings. As a part of the family-centered care approach, it is important to include the siblings in the treatment of children with cystic fibrosis. The literature indicates that siblings may be experiencing difficulties which are overlooked in the family. A clinic staff, perhaps the social worker or clinic coordinator, could make a point of assisting parents to be alert to the confusion surrounding cystic fibrosis and to suggest ways to discuss cystic fibrosis with healthy siblings. This would be important to do when the child with cystic fibrosis is doing well, as well as in periods of deterioration.

This research suggests that siblings of children with cystic fibrosis are lacking in knowledge about the disease. It may be important to offer the healthy siblings frequent opportunities to ask questions. It would also be beneficial for parents or staff of the Cystic Fibrosis clinic to explain to the healthy siblings what is happening with the child with cystic fibrosis on an ongoing basis. Staff and parents need to be aware that, even though the healthy siblings may not have the ability to formulate their questions, they are likely confused. They may also not want to trouble their parents by asking and thus need the support of other forums to ask questions and discuss cystic fibrosis.

The other primary concern that was detected in this research was that healthy siblings often feel left out. Parents should be made aware of this so that they can be sensitive to the healthy siblings' needs. They may need suggestions on how to include the healthy sibling in the care of the child with cystic fibrosis. Mrs. A was able to do this by having Allison help prepare James' night tube feeds. The parents may also need to be reminded to encourage the healthy siblings to participate in leisure activities and to socialize with peers.

Sibling groups could be helpful for the healthy siblings to interact with other children in similar situations and to provide a forum for expressing issues and clearing up misconceptions. A group of healthy siblings could meet on a regular basis with professionals from the Cystic Fibrosis Clinic to discuss issues. They would also network and share their experiences with others who understand what it is like to have a sibling with cystic fibrosis. The establishment of peer buddies would be another ongoing source of

support for healthy siblings. They could be encouraged to develop friendships with other children who share similar lived experiences.

Usefulness of Sandplay

In this research project the participants were asked to make a scene or picture in the sandtray and then tell the story of the scene. The sandtray was placed on either a table or on the floor depending on the preference of the child and the availability of space in the home. The baskets of figures were laid-out around the sandtray. Before the initial sandplay scene was created, the researcher pointed out the variety of figures that were available. The participants created sandplay scenes on 4 separate occasions. For the first two sandplay scenes the participants were not given any further direction. For the third sandplay scene, the participants were directed to include how they think or feel when they consider their sibling with cystic fibrosis. For the final sandplay scene, they were directed to include something about their family. Photographs were taken of each sandplay scene and the narratives were tape recorded.

The participants were enthusiastic about participating in the research once they understood what was being asked of them. Sandplay was effective in enhancing the development of rapport between the researcher and the participants. Allison spontaneously initiated a discussion about school difficulties as we put the toys away. The parents of the participants all reported that the children eagerly anticipated each session after the first one. Charles waited at the door for me to arrive each session after the first.

The setting of the research was effective but would have been better with some modification. It was beneficial to collect the data in the homes of the families because the children were relaxed and the researcher was able to gather information about the family interactions through observation. At the same time, it was difficult to create the 'free and protected space' that Kalff (1980) stated was necessary. Family members, particularly in the B family, attempted to engage me in conversation as I was observing the creation of the sandplay scene. Frequently family members observed the sandplay sessions, and sometimes even commented on the scenes created. Thomas and Ethan created their sandplay scenes immediately after one another. The child who went last would sometimes come in and observe the sandplay scene of the other child while he waited for his turn. On some occasions, one boy would walk through the room and glance at the sandplay of the other. Allison's mother gently chastised her for some of the things she depicted. Mrs. A reminded Allison that James expressed that he would not get married after Allison depicted James' wedding. Mrs. A explained to Allison that the structure she used as her Japanese church was actually the Taj Mahal. Instances like these may have influenced the participants future sandplay scenes. In retrospect, the researcher should have insisted on private sessions. I should have asked that the child and I be alone, with no interruptions until the session was complete.

The set up of the sandplay materials was not ideal. In an attempt to organize the figures and make them easy to transport the researcher separated them into baskets according to type. For example, figures representing modes of transportation were in one

basket, army figures were in another basket, farm animals were in another basket, etc. The baskets were full and the participants had to dig through the baskets to see the figures. The baskets were placed around the sandtray. Space limitations forced the participants to work from only one or two sides of the sandtray. Due to the size of the sandtray and the number of baskets, the baskets were crowded around the sandtray. This restricted the children's ability to work from all sides. Ideally, all of the figures would be on shelves in plain view and they would not be directly next to the sandtray. The children could then move around the sandtray to look at it and work from all four sides. Sacrifices were made in the layout of the toys and the set up of the sandtray. Although the set-up of the sandtray and figures was not ideal, it was functional.

The literature states that a minimum of four sessions is necessary for themes to evolve (Cockle, 1993). The researcher would suggest more sessions, especially in consideration of the fact that the content of two of the scenes was manipulated by the research design. Perhaps three sessions before the cystic fibrosis and family sandplay sessions and one after would reveal more information.

According to the literature, sandplay must be non-directive to be effective therapeutically (Reed, 1975). However, in this study, the researcher chose to give some direction with these healthy children to ensure that the objective of the research was being addressed. This was beneficial in being able to clarify the issues of being a sibling of a child with cystic fibrosis. Allison expressed many ideas in her first two sandplay scenes. When given direction, she focused on specific topics. She seemed to have many pressing

issues to express and may never have dealt with cystic fibrosis without encouragement. Both Charles and David enjoyed the medium and playing. They needed some direction and limitations for the purpose of the research to be met.

Sandplay was useful in engaging the participants to deal with difficult material. This was most evident in Allison and David. Mrs. A stated that Allison does not like to talk about cystic fibrosis, yet in the third sandplay session she clearly expressed her concerns about the effect of the disease on her brother's lifespan. Allison created the scene of her brother's funeral when he is 25. She stated that he died of cystic fibrosis. Mrs. D stated that David does not express his emotions. He becomes quiet and withdrawn when he is asked to do so. Whereas this was the case in his third and fourth sandplay sessions, he did share a great deal of information symbolically. In the third sandplay, David depicted the death of several animals and commented that the survivors were sad. He seemed to be expressing the belief that Amy would die and that he would be very sad.

The methods of recording the sandplay scenes were useful, but not foolproof. Photographing the completed sandplay scenes from each angle was advantageous for reference when analyzing the data. At the same time, it is difficult to distinguish some of the figures in the photographs. The photographs only depict the end product of the sandplay scene. Some participants made changes to their sandplay scenes as they created them or altered them during the narrative. This information is not recorded in the still photographs. Videotaping the entire session would have captured this information as well as the dialogue of the participants as they worked on their sandplay scenes. The use of

videotaping may also have been intrusive to the participants and either made them self-conscious, or distracted them from the focus of the sandplay. Videotaping may also have been awkward in the limited space available in the homes of the children.

Tape recording the narratives also had pros and cons. As with the photographs, the tape recording of the narratives only captured the final statements of the participants and the ongoing dialogue of the participants was missed. The children sometimes explained components of the sandplay scene while they were creating it and did not repeat that information while the narrative was being recorded. Although some of the participants were self-conscious about being tape-recorded, it was beneficial to have a recording rather than trying to write the narrative verbatim. The researcher was able to focus on the participants and engage them in further discussion and not be preoccupied with noting every word. This allowed the researcher to actively listen to the children and fully attend to the narratives. The tape recordings were useful in the analysis. The researcher transcribed the narratives. However, no additional information was gathered from this process.

Sandplay was a useful medium for children to express themselves. The children enjoyed participating in the research and revealed some of their lived experiences. Whereas the procedures were not ideal, they showed promise for future research.

Research Analysis Processes

In this section I will discuss the research tools used in the analysis of the data and evaluate how effective they were in this situation. It is important to use these therapeutic tools cautiously for they are generally used with a set of treatment assumptions that are not

consistent with research assumptions. The participants had indications that could be symptomatic of serious emotional difficulties even though they were considered well adjusted and did not present any difficulties outside of the research, with the possible exception of David. Thus, while there is no reason to presume pathology, the children's realistic concerns about the presence of serious events in their lives may lead to misconceptions.

The assessment tools were standardized primarily on troubled children. Therefore, the results focus on negative criteria that could be indicative of emotional problems. The results of the analysis supported the literature on issues for siblings of children with cystic fibrosis and do not imply that these children are experiencing major emotional disturbances.

Concept mapping was very useful in assisting in the identification of metaphors and recurring themes. This technique also helped in framing the expressions of the children as those persons without pathology. It was most beneficial in organizing information on the lived experiences of the children.

The Sandtray Categorical Checklist (Grubbs, 1997) was also very useful in organizing the material and bringing out themes and trends. It could be seen that this approach would be beneficial in a therapeutic setting. Using the SCC on a series of sandplay scenes made by the same person assists in the recognition of trends in the use of figures, themes, and settings. There are numerous other sections to the SCC that were not used in this research. These sections addressed issues that would be useful in a therapeutic

setting, and were not relevant for use with the children in this research. Refer to Appendix C for the complete SCC checklist. Interpreting the results was difficult using only this tool. The instructions of the SCC are not clear in all sections. The researcher was not certain how to complete some of the sections. Some of the sections also called for interpretations that were difficult to make if one is not experienced in sandplay. For example, one section looks at coordination of the parts of the scene. The instructions state that this is determined by a 'judgment' call on the part of the therapist/researcher.

The World Test (Buhler, 1951b) was designed for use with children who are experiencing emotional difficulties and allowed for interpretation of the implications of the results. The sandplay scene is analyzed to identify the presence of seven signs. These are aggression, empty, distorted, closed, disorganized, rigid or symbolic. These interpretations suggest pathology and do not recognize strengths. The researcher did not feel comfortable in reducing the sandplay scenes of the participants to numbers, especially when that information was translated only into indications of emotional problems. The richness of the expressions of the participants was overlooked, as were their strengths.

Whereas using Story Sequence Analysis to determine the story imports (Arnold, 1962) was not designed specifically for use with sandplay, it was useful in uncovering the underlying messages being given in many of the narratives. Story sequence analysis was designed to use with the Thematic Apperception Test. The story imports revealed valuable information. For example, the imports identified in David's sandplay revealed his victimized approach to life. The instructions for use of this tool are specific and were not

strictly adhered to by the researcher. The researcher did boil down the narratives to the moral of the story. However, to fully use the story sequence analysis, the imports are rated on a scale of negative to positive messages. At the same time, the directions for interpretation were vague. The instructions were primarily in the format of examples. As in the SCC, the author suggested that experience with the tool is necessary for correct interpretations of the narratives. This would be a very useful qualitative tool if more instruction on how to interpret the story imports was available.

The combination of qualitative analysis and descriptive measures fostered a thorough analysis of the data. The published assessment tools provided a standardized framework that was useful in interpreting the significance of the results. The qualitative analysis allowed the lived experiences of the children to remain prominent.

Strengths of the Research Design

This research gave the siblings of children with cystic fibrosis a voice. It enabled the siblings an opportunity to express themselves both about having a sibling with cystic fibrosis and about their general issues. The research was a positive experience for all who participated. Additionally, the research was approached from a positive, strength perspective. Rather than focusing on the negative impact of having a sibling with cystic fibrosis, the researcher focused on the resiliency and life experiences of the healthy siblings.

Limitations of the Research Design

Participants in this study are not representative of all siblings of children with cystic fibrosis. An advertisement was placed in the Cystic Fibrosis newsletter and some participants volunteered after reading the article. Staff of the Cystic Fibrosis Clinic also approached other participants if they met the criteria for the research. Eiser (1993) noted that families with open communication are likely to agree to participate in research and families that limit the information they share with healthy siblings may refuse to participate. This research was limited by the difficulty in finding families that felt secure in having a researcher enter their home for research that potentially reveals information on family functioning and emotional well-being. Therefore, this study represents a subset of families who are open and where the child with cystic fibrosis has not yet moved into the deterioration phase of the disease.

There were several limitations in this study as a result of the limited pool of participants from which to draw. Of the 5 children who participated, there were 4 boys and only 1 girl. A larger sample, and one with a more even gender distribution, would be informative. The literature indicates that when the child with cystic fibrosis is physically well, the family relationships are noted to be close. This research included only children who had been diagnosed several years earlier and had not yet begun to deteriorate. Siblings of children in all stages of the illness process would ideally be included. Four of the 5 participants were younger than the child with cystic fibrosis. A larger sample with more siblings both younger and particularly older than the child with cystic fibrosis would be

beneficial. Variety in family size and socioeconomic status could also be revealing. The study could also be extended to children over the age of 10 years. These older children would have the cognitive ability for more abstract thinking and may have more insight into how cystic fibrosis has influenced them.

Future Research

It would be interesting to expand the research to include siblings of children with other chronic illnesses such as cancer, diabetes, asthma, crohns, lupus, or cardiac conditions. This could reveal similarities and differences in the effect of these different chronic illnesses on the healthy siblings. Do these siblings also feel left out? Are they lacking in knowledge about the disease that is effecting their sibling? Do they use a battle metaphor when considering the disease? A similar research design would be most informative especially with conditions that are more easily identifiable and less abstract.

Inter-generational family scripts would be another avenue for future research. It would be interesting to see if the healthy siblings are internalizing messages passed from generation to generation. Sandplay is frequently used as a therapeutic technique with adults and therefore could be used to gather this data. Alternately, a narrative approach would also be effective.

Another focus on using sandplay in research could be to examine the symbols used and the meanings associated with them. For example, the battle metaphor in relation to illness could be explored in greater depth. This would necessitate an expertise in interpreting symbols and metaphors. Future research could also include other projective

tests such as Thematic Apperception Test or Rorschach to enhance the validity of sandplay as a research technique. Sandplay could be used in conjunction with these techniques to determine if they reveal consistent results.

My Story

This research allowed me to become a part of the children's lived experiences. It was particularly rewarding to develop the relationships with the children and their families. I began by feeling apprehensive about entering people's homes and imposing myself on them. I gained confidence when I recognized the pleasure the children had in participating in the research. Despite the difficulties involved in doing the research in the homes of the children, I believe that this setting gave me greater insight into the lives of the children.

I was also concerned that I would not find any 'significant results.' It was very surprising to me when I began to analyze the data and discovered the depth of information revealed in the sandplay. It reinforced that hearing what the children had to say was more valuable than merely identifying characteristics or symptoms of emotional difficulties. One of the most valuable things I learned from this research was to approach all persons from an asset perspective. Even though assessment tools tend to focus on what is wrong with people, it is important to remember that people handle their life situations to the best of their ability. Identifying strengths is equally valuable in research and therapeutic settings.

At times it was difficult to separate the role of researcher from the role of therapist. I found it hard to learn about the concerns of the healthy siblings and then not to play a role

in assisting the children to bring them to a conclusion. This brought to mind the ethical consideration of being accountable for the impact that participating in the research may have on the children. In this study, I took comfort in recognizing that these are open families and the children are emotionally secure. It was also a relief to know that Mrs. D planned to initiate counseling with David.

Finally, this research attested to the value of play. I was able to learn a great deal about the children by observing their play. It is not likely that the children would have given so much information if I had used only verbal methods of gathering information. Play opened the window into the lived experiences of the children.

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APPENDIX A

Physical Manifestations of Cystic Fibrosis

Cystic fibrosis is a genetic condition that has implications for many aspects of the lives of those afflicted, as well as for their families. Persons with cystic fibrosis may present with a recurrent productive cough, susceptibility to respiratory infections, a deep hoarse voice, barrel-chestedness, decreased tolerance for physical activity, clubbing of the digits, diminished stature, and frequent foul-smelling stools (McMullen, 1996). Some of these symptoms appear to be minor inconveniences, while others have major implications for the lifestyle of the person with cystic fibrosis and for the family. To understand the breadth of the impact of cystic fibrosis it is important to be aware of the medical aspects of the disease.

Cystic fibrosis is the most common fatal genetic disease (Davis, Drumm, & Konstan, 1996). A large majority (90%) of persons with cystic fibrosis die of lung disease. Liver disease is the next most frequent cause of death for persons with cystic fibrosis accounting for 1-2% of mortality (Carter, Urey, & Eid, 1992). The average life expectancy for males with cystic fibrosis is 31.1 years and for females is 28.3 years (Rosenstein & Zeitlin, 1998). Approximately 50% of persons with cystic fibrosis live into their late twenties (Carter et al., 1992) and 40% live into their early thirties (Genentech Inc., vol. 3, 1993). Interestingly, Shepherd and Cleghorn (1989) noted that the historical trend of males having a longer life expectancy than females is now being questioned.

This paper will explore the genetic background, physical manifestations of cystic fibrosis, along with the etiology, diagnosis, and prognosis of the disease. This paper will also address the treatment of cystic fibrosis.

Genetic background of Cystic Fibrosis

Cystic fibrosis is an autosomal recessive genetic disorder (Thompson, Hodges, & Hamlett, 1990). Both parents must be carriers of the defective gene for the disease to be realized in the child. When both parents carry the cystic fibrosis gene, there is a 1 in 4 chance for the child to be afflicted with the disease, a 2 in 4 chance that the child will be a carrier of the gene, and a 1 in 4 chance that the child will be free of the disease (Rosenstein, 1970). A relatively recent advancement into detection of cystic fibrosis involves a test to determine whether a person with a family member with cystic fibrosis is a carrier of the disease. Additionally, prenatal screening can be done for couples who have a child with cystic fibrosis to determine whether the fetus has cystic fibrosis (Orenstein, 1989; Rosenstein & Zeitlin, 1998). Shepherd and Cleghorn (1989) noted that in 80% of the cases of cystic fibrosis there is no family history of the disease. Cystic fibrosis is usually diagnosed within the first two years of life (Carter et al., 1992). However, McMullen (1996) reported that 8 - 10 % of children with cystic fibrosis may not be diagnosed until after the age of 9 years. These children may experience minimal or absent manifestations of the disease.

Cystic fibrosis is the most common autosomal recessive disorder in the Caucasian population. It affects 1 in 2000 births. The incidence is lower for Black, Asian, and Aboriginal populations (McMullen, 1996).

Linkage analysis has determined that the cystic fibrosis defects are located on the long arm of chromosome 7 (Davis et al., 1996). The mutation of the cystic fibrosis gene leads to a defective CFTR (cystic fibrosis transmembrane conductance regulator) protein. The CFTR malfunction reduces the ability of chloride ions to cross the cell membrane. This is responsible for the clinical manifestations of cystic fibrosis (Genentech Inc., vol. 1, 1993). McMullen (1996) explained that the impermeability to chloride ions reduces the amount of water transit across cell membranes. This results in thick, poorly hydrated secretions. Over 600 different defects in the cystic fibrosis gene have been identified so far (Rosenstein & Zeitlin, 1998). The different mutations cause the gene to be defective in different ways. The most common mutation is the delta F508. Over 70% of cystic fibrosis chromosomes have this mutation. In delta F508, the deletion of 3 base pairs results in the absence of a single phenylalanine from the protein gene product. Different mutations are more prevalent in different geographical/cultural populations. Research suggests that differences in mutations may account for the variety of severity and disease manifestations (Davis et al., 1996; Genentech Inc., vol. 1, 1993).

Physical Manifestations

Cystic fibrosis is commonly typified as a triad of pulmonary disease, pancreatic disease, and abnormal sweat electrolytes (Davis et al., 1996; Shepherd & Cleghorn, 1989).

However, cystic fibrosis does effect the mucus secretions throughout the body. The secretions of the exocrine glands are thickened (McMullen, 1996). Shepherd and Cleghorn (1989) noted that there may be dysfunction in the sweat, bronchial, pancreatic, biliary, and reproductive glands. Whereas there is usually multisystem involvement, some persons with cystic fibrosis may have only one predominate clinical feature (Rosenstein & Zeitlin, 1998).

Sweat gland involvement. Persons with cystic fibrosis have high concentrations of sweat chloride. They are therefore susceptible to heat stroke and salt depletion in hot weather when sweating is essential for regulating body temperature (Genentech Inc., vol. 3, 1993). Sweat consists of sodium, chloride and water. As the sweat moves to the surface of the skin it passes through the sweat ducts. Normally, most of the sodium and chloride are reabsorbed. Because fewer water molecules are reabsorbed than sodium ions, the sweat is diluted (Genentech Inc., vol. 3, 1993). Persons with cystic fibrosis have defective CFTR protein that makes cells relatively impermeable to chloride ions. Few sodium ions are reabsorbed because chloride is minimally reabsorbed. The result is salty sweat (Genentech Inc., vol. 2, 1993). Davis et al. (1996) noted that the sweat of persons with cystic fibrosis has 5 times the concentration of chloride as compared to normal. The most common confirmation of the cystic fibrosis diagnosis is the sweat test where sweat chloride levels are measured (Shepherd & Cleghorn 1989).

Lung involvement. Davis et al. (1996) stated that the lung involvement in cystic fibrosis is different from that of other organs. Notably, the lungs are normal in utero and at

birth until the incidence of infection. However, the airways may have some dilation of the submucosal gland ducts. Sympomatically persons with cystic fibrosis have a recurrent productive cough (McMullen, 1996). These coughing spasms occur more frequently as lung damage progresses. This coincides with decreased tolerance for exercise and increased shortness of breath (Orenstein, 1989).

Infections lead to a recurring cycle that increasingly damages the lungs. In normal airways there is a layer of mucus that traps bacteria, viruses, dust and toxic gases. This mucus in the airways of persons with cystic fibrosis is dehydrated. It is not easily cleared from the airways and leads to obstructions. Gas exchange is interfered with and this promotes infections in the respiratory system. The immune system responds to the infection by becoming inflamed (Genentech Inc., vol. 3, 1993). Inflammation narrows the airways and makes it more difficult to clear the airways (Orenstein, 1989). Repeated exposure to infection results in progressive destruction of the respiratory tissue.

Neutrophils are a type of immune cell that become involved in combating the lung infection. Neutrophils produce a substance that damages the lung tissue in persons with cystic fibrosis (rather than destroy microorganisms as they are intended to do) (Genentech Inc., vol. 3, 1993). This substance is an enzyme called neutrophil elastase (MacLusky & Levison, 1992). Additionally, other components of the immune system become less effective due to the neutrophils. As a result of inflammation there is an accumulation of dead tissue cells and dead neutrophils in the lungs. Inflammation of the bronchi and bronchioles leads to tissue damage that causes these airways to dilate. The lung tissues

become stiffened and the thick mucus becomes even more difficult to clear (Genentech Inc., vol. 3, 1993). It is very common for persons with cystic fibrosis to cough up small amounts of blood in their mucus. This is the result of capillaries being irritated by increased infection (Orenstein, 1989).

Lung disease may eventually lead to respiratory failure. The lungs may be damaged to such an extent that oxygen can no longer pass through to the bloodstream. Breathing becomes too difficult for the ventilatory muscles. This is generally the culmination of progressive lung disease (Orenstein, 1989).

Upper respiratory tract involvement. Persons with cystic fibrosis frequently develop sinusitis or pansinusitis, and nasal polyps. These conditions generally do not require treatment as they do not cause discomfort. However; they may be determinants in the definitive diagnosis of cystic fibrosis (Genentech Inc., vol. 3, 1993).

Pancreas involvement. The pancreas is the third component of the diagnostic triad of cystic fibrosis. Nearly all persons with cystic fibrosis have pancreas involvement (Davis et al., 1996; Rosenstein & Zeitlin, 1998). Some persons with cystic fibrosis have pancreatic sufficiency. Those that do not are termed to have 'pancreatic insufficiency' due to the absence of various digestive enzymes. Pancreatic insufficiency prevents normal fat and nutrient absorption. This results in steatorrhea (abnormally large volumes of fat in the stool) (Shepherd & Cleghorn, 1989). Persons with cystic fibrosis frequently have decreased bicarbonate secretion. Digestion is affected because the stomach acid is not properly neutralized. Therefore, the function of pancreatic enzymes is decreased. The

absence of CFTR results in secretions containing less water. The ducts are then plugged by the secretions that are thicker and have a high concentration of protein. It is difficult for the pancreatic enzymes to reach the gut (Davis et al., 1996). Shepherd and Cleghorn (1989) noted that the exact cause of the pancreatic insufficiency has not yet been determined. Persons with pancreatic insufficiency are more prone to developing pancreatitis. This is a very painful inflammation of the pancreas. Pancreatitis may be caused by gallstones which block secretions from the pancreas (Orenstein, 1989).

Rarely, diabetes is a complication of cystic fibrosis. It may be that the pancreas does not produce insulin. Glucose may be lost in the urine (Orenstein, 1989).

Intestine involvement. Shepherd and Cleghorn (1989) reported that 10 - 15% of infants with cystic fibrosis have meconium ileus. This neonatal bowel obstruction is believed to be caused by the thick meconium. It is the CFTR that prevents chloride, and subsequently water, from secreting into the gut. As a result, there may be sludging of the intestinal contents, fecal impaction and intessusception leading to a bowel obstruction (Davis et al., 1996).

Distal intestinal obstructive syndrome (DIOS) occurs in up to 15% of adolescents and adults with CF, predominantly in those with pancreatic insufficiency. DIOS is a partial or complete obstruction of the right ileum (Shepherd & Cleghorn, 1989). While DIOS is more common in adolescents and adults, it is possible for young children with cystic fibrosis to develop the obstruction (McMullen, 1996). The cause of DIOS is usually not

enough enzymes which results in large and bulky intestinal contents. It is more common in persons who had meconium ileus (Orenstein, 1989).

Orenstein (1989) noted that gastroesophageal reflux may be another complication of cystic fibrosis. Certain medications used in the treatment of cystic fibrosis have the effect of relaxing the sphincter muscle at the bottom of the esophagus. Hard coughing puts pressure on the sphincter muscle and may cause stomach contents to pass back up into the esophagus. As well, persons with cystic fibrosis must be upside down for postural drainage increasing the likelihood of stomach contents returning through the relaxed esophagus.

Liver involvement. CFTR causes damage to the liver in persons with cystic fibrosis. Chloride does not pass through the ductules and osmosis can not occur. The biliary ductules become plugged with the thickened secretions. This may eventually result in obstructive cirrhosis of the liver as well as damage to the spleen (Davis et al., 1996). Malnutrition may cause the liver to store fat. This condition is referred to as fatty liver (Orenstein, 1989). There are secondary complications of liver involvement. In cystic fibrosis, the liver does not metabolize nutrients properly. Fat-soluble and water soluble vitamins as well as some minerals are notably problematic (Shepherd & Cleghorn, 1989). The bile ducts which are supposed to take bile and bile salts from the liver to the duodenum may become blocked. Without bile salts, fat cannot be properly digested and is lost in the stool (Orenstein, 1989). The resulting deficiencies frequently lead to malnutrition, failure to thrive and further liver damage (Shepherd & Cleghorn, 1989).

Reproductive system involvement. Shepherd and Cleghorn (1989) noted that puberty is commonly delayed in persons with cystic fibrosis. This seems to be the result of malnutrition and the severity of pulmonary disease. Carter et al. (1992) reported that 98% of males with cystic fibrosis are sterile. Davis et al. (1996) noted that 95% of males have complete bilateral absence of the vas deferens leaving them azoospermic. One theory suggests that the vas deferens is reabsorbed prenatally because it is plugged with thick secretions.

Carter et al. (1992) also noted that 80% of females are sterile. Davis et al. (1996) explained that the thickened cervical mucus may be the cause of female infertility.

Treatment

Treatment of cystic fibrosis is primarily preventative: it focuses on avoidance of complications and symptoms (Carter et al., 1992). Shepherd and Cleghorn (1989) stated that the goals of therapy are to minimize pulmonary involvement, to encourage normal nutrition and growth, and to encourage a normal lifestyle. After periods of exacerbation, the goal of treatment is to return to the previous level of functioning (Orenstein, 1989).

Persons with cystic fibrosis undergo routine tests to determine the level of functioning. Pulmonary function tests measure lung size as well as presence of an obstruction in the lungs. Exercise tests determine the functioning of the heart and lungs when they are under stress. Chest x-rays provide information about the condition of the lungs. The tests are administered frequently to detect any deterioration of the lungs (Orenstein, 1989).

Heat stroke and salt depletion are avoided by ensuring adequate water intake during times of profuse sweating. Increased salt intake in the diet is usually adequate to compensate for salt depletion, but salt tablets are also an option (Davis et al., 1996).

Treating lung disease adequately is vital for successfully treating cystic fibrosis. Chest physiotherapy and postural drainage are components of airway clearance therapy. Traditional methods include positioning the person with cystic fibrosis so that the openings to the various segments of the lung are facing down and clapping, shaking, or vibrating the mucus loose. There are 10 to 12 positions and each position needs 1 to 2 minutes of treatment. For most persons with cystic fibrosis, these treatments are done 1 to 4 times a day (Orenstein, 1989). New options for airway clearance therapy include devices to increase the amount of mucus cleared and ones that can be administered by the person with cystic fibrosis independently. Bronchodilators are used to dilate small air passages and promote the clearance of mucus. Antibiotics are administered to control infections. Corticosteroids and nonsteroidal anti-inflammatory drugs may be prescribed to reduce the tissue-damaging inflammations. Inevitably, bilateral lung transplantation may be the ultimate treatment for persons with end-stage lung disease (Davis et al., 1996). MacLusky and Levison (1992) reported a 72% survival rate at the end of one year and a 56% survival rate at the end of three years for persons with cystic fibrosis receiving lung transplants. Balfour-Lynn et al. (1997) noted that the lack of available organs is a major limitation to lung transplantation. Lobar transplantation, where a single lobe from a living related adult

donor replaces an entire lung of the person with cystic fibrosis, is becoming an option (Noyes, Kurland, & Orenstein, 1997).

Pancreatic insufficiency is easily treated with pancreatic enzyme supplements that assist in digestion (Davis et al., 1996). These enzymes are specially coated to survive the acidity of the stomach and not break down prematurely (Shepherd & Cleghorn, 1989). Digestive enzymes must be taken with every meal and snack, preferably throughout the meal (Orenstein, 1989).

Shepherd and Cleghorn (1989) noted that there is a link between malnourishment and pulmonary disease. Therefore, it is essential to actively treat nutritional symptoms to increase life expectancy by preventing pulmonary complications. The nutritional deficits for persons with cystic fibrosis are likely caused by a variety of factors (Orenstein, 1989). Shepherd and Cleghorn (1989) listed the factors as increased dietary requirements, inadequate absorption of nutrients, and the losses through sweat and sputum. It is suggested that persons with cystic fibrosis should consume 120 - 150% of the recommended daily allotment of food. Nighttime enteral feeds may assist in calorie intake for those with growth failure (Rosenstein & Zeitlin, 1998). Because of the loss of fat though stooling, about 40% of the calories should be in the form of fat. Fat-soluble vitamins that tend to be malabsorbed can be supplemented. Davis et al. (1996) reported that liver transplantation is an option for severe liver damage.

Whereas the defects of the reproductive tract can not be treated as such, they can be compensated for with artificial insemination. Pregnancy can be achieved in women by

placing the sperm beyond the cervical os. Sperm can be removed from the testes of males and used to inseminate their partners (Davis et al., 1996).

Pulmonary exacerbations occur in 25% of persons with cystic fibrosis. This is an aggravation of lung disease that is usually brought on by an infection. Treatment of pulmonary exacerbation generally requires intravenous antibiotics and a 2 - 3 week hospitalization. This may happen 1 - 3 times a year. Discharge from hospital usually corresponds with a return of pre-hospital lung functioning (Orenstein, 1989).

Current research is aimed at correcting the basic defect. Some options being explored are gene therapy, activating the mutant CFTR, and manipulating the electrolyte transport. These potential cures are still in the preliminary stages of research (Davis et al., 1996).

Cystic fibrosis is a complicated disease that intensely effects the everyday lives of those afflicted. Because cystic fibrosis is a chronic illness, the families of persons with cystic fibrosis are also impacted. Cystic fibrosis is not a disease that can be easily hidden because of the specific treatments required. Whereas research is making momentous strides in the treatment of cystic fibrosis, it is a chronic illness that ultimately results in premature death.

APPENDIX B

My name is Daryl Simourd. I am a student at University of Calgary working on my Master's degree in Counseling Psychology. As a Child Life Therapist at Alberta Children's Hospital, I became interested in families of children with chronic illnesses. In particular, I am interested in how the experience effects healthy siblings. I want to learn more about what concerns them.

My thesis project is Cystic Fibrosis: Issues from the Sibling Perspective. I am preparing to begin my research and am working with Kay Jamieson of the CF Clinic to recruit participants.

I am looking for children between the ages of 6 and 10 years, who have a sibling with CF, to participate in my research. The participants will be asked to make a scene in a sandtray (using figurines including people, animals, vehicles, buildings, structures, scenery and natural items) and then to tell me about the scene. I will photograph the sandtray scene and audiotape the story about it. The participants will make a total of 4 sandtray scenes. Each session will take about 45 minutes to complete. I will provide all of the supplies required. The research will take place in the home of the participant, or in another location away from the hospital.

Participants will benefit by having the opportunity to express themselves regarding having a sibling with cystic fibrosis. Other families with a child with cystic fibrosis may benefit by learning what to expect about the concerns of their healthy children.

APPENDIX C

Consent Form

Cystic Fibrosis: Issues from the Sibling Perspective

Investigators:
Dr. Nancy Marlett
Daryl Simourd

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The purpose of this study is to use a non-verbal medium to gather information from healthy siblings about their concerns about having a sibling with cystic fibrosis. The investigators are interested in determining if there are common themes among healthy siblings. Additionally, the investigators are interested to determine the effectiveness of sandplay as a means of gathering information from children.

As part of the study, your child will be asked to make a sandtray scene and then tell me about the scene. I will provide the sandtray and the miniature figures that your child will arrange in the sandtray. Your child will make sandtray scenes on 4 separate occasions. These procedures will take approximately 45 minutes. You should be aware that even if you give your permission, your child is free to withdraw at any time for any reason without penalty.

Benefits to your child may include having the opportunity to express him/her self regarding the experience of having a sibling with cystic fibrosis. This research may be of benefit to other parents and siblings by providing them with information regarding common concerns for siblings of children with cystic fibrosis.

Participation in this study will involve no greater risks than those ordinarily experienced in daily life.

Data will be gathered in such a way as to ensure confidentiality. All the data will be collected by Daryl Simourd. No one else will have access to the identity of your child. The sandtray scenes will be photographed and identified with a number. The explanations of the sandplay scene will be audiotaped and identified with the corresponding number. Once your child has completed the 4 sessions, his/her name will be removed from the audiotapes and photographs and the data will be identified only by the number. Once collected, responses will be kept in strictest confidence; only group results will be reported in any published reports. The raw data will be kept in a locked filing cabinet in my office at home only accessible to the researcher. All files will be destroyed two years after completion of the study.

It is anticipated that participation in this research will not involve any financial costs for you or your child.

In the event that you suffer injury as a result of participating in this research, no compensation (or treatment) will be provided for you by the University of Calgary, the Calgary Hospital Regional Authority or the researchers, Daryl Simourd or Nancy Marlett.

You still have all your legal rights. Nothing said here about treatment or compensation in anyway alters your rights to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions, please contact Daryl Simourd at 228-2457, my supervisor at Dr. Marlett 220-2985, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626, or the Office of the Vice-President (Research) at 220-3381.

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, the University of Calgary, at 220-7990.

_____ _____

(Name) (Date)

_____ _____

(Signature of subject, or responsible proxy, if applicable) (Date)

_____ _____

(Name of Witness) (Date)

A copy of this consent form has been given to you to keep for your records and reference.

The researcher has explained to your child the research and his or her involvement, and has sought the child's ongoing cooperation throughout the project.

_____

(Researcher)

APPENDIX D

SANDTRAY CATEGORICAL CHECKLIST (SCC)
Personal use only - may not be copied for others

CREATOR: _____ DATE: _____ TRAY: _____of _____

DIRECT OBSERVATION AND OBJECTIVE ANALYSIS

1. STORY (briefly worded)

_____
_____
_____
_____
_____

2. FIGURES (and meanings if verbalized)

Animals:_____
_____
_____
_____

People:_____
_____
_____
_____

Structures (buildings, barriers, connectors, etc.): _____
_____
_____
_____

Objects (furniture, jewelry, weapons, food, etc.): _____
_____
_____
_____

Vehicles: _____
_____
_____
_____

Natural Elements and Vegetation: _____
_____
_____
_____

Other: _____
_____
_____

3. SETTING

___disorganized ___animal/vegetative ___war ___Oriental
___primitive ___people/animal ___community/city/village ___symbolic/mythical
___bizarre (explain) ___home/family ___party/celebration ___spiritual/Self tray
___wound tray

Oriented as: ____Content _____Theme

4. CREATION PROCESS/DRAMATIC PLAY

___scene made intact with few changes ___dramatic play as scene is made (describe)
___major changes as scene is made (describe) ___scene made first - then change of any kind or resolution
___scene made - then destroyed (describe below)

---

5. USE OF HUMAN AND ANIMAL FIGURES

___used appropriately ___no human or animal figures used ___people killing people
___used realistically ___animals in place of people ___penned or crowded into a tight mass
___used symbolically ___broken and/or dismembered body parts ___buried or hidden from others
___implied but not used ___animals devouring animals/people ___intentionally knocked down and left

Observer (if used): _____

6. USE OF SAND

_____Damp _____Dry

___figures placed on top, sand untouched ___intentionally thrown and splashed
___sand firmly packed down ___used destructively by pouring and/or burying
___some movement of the sand with finger tips ___heavily wetted down
___diligently molded or shaped ___half to whole of tray flooded
___sand used to bury _____

7. USE OF TRAY

___very empty ___sparse ___well used ___full ___very full ___overflowing __ 2 trays together

Areas of focus _____
Empty areas _____
Figures placed in center _____

8. CREATOR'S RESPONSE TO SCENE

___indifferent or no response ___apologetic ___relieved ___deeply moved
___pushes it away ___emotional (sad angry excited) ___energized
___sadistic toward it ___satisfied (somewhat very) ___trancelike

SUBJECTIVE IMPRESSION AND IMPLIED MEANINGS

9. MAIN PSYCHOLOGICAL EXPRESSIONS:

___destruction/violence ___alienation/loneliness ___organizing/structuring ___worship
___aggression ___self-protection ___construction/building ___uniting of opposites
___opposing forces ___self-nurturance ___happiness/celebration ___integration
___competition/challenge ___working/playing

Other: _____

Portrayed as Reality __ __ __ __ __ Fantasy

10. COGNITIVE DEVELOPMENT AND SCENE PROGRESS

Cognition: ___age appropriate
___regressive to approx. age ___
___advanced for age

Scene progress: ___continuous
___regressive (explain)
___progressive (explain)
___resolution of conflict
(restructuring or previous scene #___)

_____
_____
_____

11. COORDINATION OR WHOLE AND PARTS OF THE SCENE

___chaotic of no coordination of figures or scene ___empty
___partial attempts to coordinate ___overemphasis of rows
___some coordination in small groupings ___chaotic destruction of scene during process
___appears equally coordinated and chaotic ___destruction of scene at completion only
___mostly coordinated with minimum chaos
___scene coordinated as a whole

12. STRUCTURING OF RELATIONSHIPS (human and animal)

___no relationships represented ___opposing groups and/or individuals ___dyadic relationships
___a distinct separation or figures from others ___individual's relating to self or environment ___family unit/s
___one or more communities/groupings

Interactions portrayed between them:

___destructive/sadistic ___self-protective/assertive ___cooperative/constructive

13. BOUNDARIES

___entire scene runs together ___some groupings with no clear boundaries
___boundary formulation
___groupings ___use of space ___natural/man-made dividers ___containment ___dramatic play

___very fenced and/or rigid world ___figures sit or spills over sides of the tray
___figures and objects sink into the sand ___boundaries invaded

14. MOVEMENT/OBSTACLES

___static scene with no sense of movement
___chaotic and undirected movement
___movement blocked (describe)
___parts of scene blocked, other parts not (describe)
___some blockage, but movement can progress or go around (describe)
___destructive movement
___movement with appropriate obstacles
___free-flow of movement with no obstacles
___movement inward toward the center

_____
_____

15. RELATIONSHIP OF PARTS AND OPPOSITES

Parts/opposites represented: _____

___opposites kept separate
___negative interaction of opposites
___positive interaction of opposites
___attempt to unify opposites through: ___roads, rivers, etc., ___bridges ___figure placement ___dramatic play (describe)
___no attempt to unify opposites
___opposites unified
___opposites integrated

_____

16. THERAPISTS IMPRESSION OF THE SCENE

___confusing/conflicting (exp.)
___peaceful/calm
___disruptive (explain)
___disconnected
___no feeling or connection
___lacking color, depressive
___self-destructive
___colorful, happy
___positive and moving
___angry/fearful/sad/painful
___spiritual

_____
_____

17. SIGNIFICANT SYMBOLIC REPRESENTATIONS AND THEMATIC PLAY

_____
_____
_____
_____

18. SIGNIFICANT REPETITIVE THEME AND FIGURES USED

_____
_____
_____

19. QUESTIONS RAISED

_____
_____
_____

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