ADAPTING FILIAL THERAPY FOR FAMILIES WHO HAVE A CHILD WITH A LIFE-THREATENING ILLNESS

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Utilizing a collective case study design, I examined and described the filial therapy (FT) process and adaptations discovered to be necessary and unnecessary in working with families who have a child with a life-threatening illness in the hospital setting. Data from a total of 7 parents was utilized, including those who terminated early, in order to gain a greater understanding of adapting FT for families who have a child with a life-threatening illness and their participation patterns. The parents attended 10 one- to two-hour FT sessions. The data was analyzed to examine for themes, patterns and relationships intrinsically with each case participant, as well as across cases.

Analysis indicated that parents with a child with a life-threatening illness had great difficulty committing to attend FT; and a high rate of attrition occurred for those who did commit. A theme regarding flexibility was found to be of eminent importance in a variety of manifestations including therapeutic methods, session format, location and time of sessions, and intense vs traditional FT. Therapeutic adaptations in flexibility found to be important including openness to cathartic and personal parenting sessions, tolerance of forgetfulness, and lowering typical therapeutic concerns of dependency in the relationship. An inability for parents in this situation to benefit from intense FT methods was also noted.
Changes noted in the child of focus included increased confidence, increased cooperation in the medical setting, increased communication with the parent and with medical staff regarding medical issues, and increased communication with the parent regarding personal feelings and issues. Changes noted in the parents included increased confidence in parenting skills, increased awareness of the child’s perceptions of the environment, increased tolerance in allowing the child to struggle in and out of the medical setting, with both emotional and physical pain in order to gain coping skills, increased ability to allow the child to empower self, and increased abilities in limit setting.
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CHAPTER I
INTRODUCTION

Filial training is a unique form of parent therapy where parents are trained and supervised by professional play therapists to learn the natural medium of expression for children: play. Parents of children who face a life-threatening illness are in a difficult and unique position. Adapting filial therapy (FT) to meet the specific needs of parents and children in this position; will help increase the communication experience between the parents and their children, empower parents and their children, help children gain a sense of control and mastery over their illness, and offer a support outlet for parents.

The Family Experience

The life-threatening illness of a child creates a great amount of stress for the child and the family (Blake & Paulsen, 1981; Jones, 2001; Van Fleet, 1992). Children may experience pain and discomfort, invasive procedures, physical limitations, altered appearance, separation from family in extended hospital visits, confusion, fear, helplessness, guilt and mood changes (Blake & Paulsen, 1981; Frick & Delpo, Goodman, 1999; 1986; Kaplan, 1999; McCandless, 1981; Van Fleet, 1992). The stress of illness and hospitalization can lead to depression which is behaviorally expressed as withdrawal, regression, decreased cooperation, aggression, disruptive behavior and sleep disturbances (Cooper & Blitz, 1985; Lindquist, 1980). Children with a life-threatening illness also experience three major fears: fear of separation, fear of mutilation and fear of death (Adams, 1982; Albee, 1955; McEvoy, Duchon, & Schaefer, 1985).
Parents and siblings of children with a life-threatening illness often experience confusion, fear, anger and guilt (McEvoy et al., 1983; Goodman, 1999; Kaplan, 1999; Shipton, 1995; Van Fleet, 1992). Parents, who have a child with a life-threatening illness, have identified a need to have help in parenting skills (McGrath, 2001; Yiu & Twinn, 2001). Parents have also reported, in hospital interviews, a need for recognition of their own fear of hospitalization (Yiu & Twinn, 2001). The parents reported fear, helplessness, and emotional pain regarding their child’s condition, as well as guilt for leaving the ward for even a few minutes (Yiu & Twinn, 2001).

Knott (1979) identified several common needs of families with children who have chronic and life-threatening illnesses: the need to understand the diagnosis, treatment and prognosis of the child’s illness; the need to experience some relief from the stressful conditions surrounding the illness; and the need to maintain high quality relational experiences in the family (McGrath, 2001; Yui & Twinn, 2001).

Parents are unsure or afraid of how to discuss the illness with their children and often avoid telling their children the truth about the prognosis (Blake and Paulsen, 1981; Goodman, 1999; Gray, 1989; Kaplan, 1999). The children, sensing the hesitancy and confusion in their parents, often attempt to protect their parents by keeping their own fears and experiences regarding the illness to their selves (Webb, 1995).

Filial Therapy

FT is a method, developed by Bernard Guerney, for intervening in the psychosocial development of children using parents as the agents of change (Guerney, 1980). Parents are taught to conduct child-centered play therapy sessions with the
instruction and supervision of professional play therapists (Bratton, 1997; Guerney, 1980; Landreth, 2002).

Guerney, Guerney and Andronico (1970) cite three reasons why parents may potentially be more effective than play therapists in intervening in their child’s emotional health. First, the parent is more emotionally significant to the child. Second, the anxieties learned in the presence of a parent may be more easily extinguished in the presence of the parent. And third, interpersonal expectations and mis-expectations could be delineated clearly by the parent in the context of the play sessions.

In a study of FT as a potential primary preventative process, Payton (1981) found the parents, trained in FT procedures, are statistically significantly more effective agents of change than parents trained in paraprofessional education groups. Oxman (1972) found FT to be statistically significantly effective in improving behavior in children in the experimental group as compared to the control group who did not participate in FT. These results indicate that given the proper tools, the basic skills of play therapy learned in FT, parents are effective agents of change and intervention, in their child’s emotional health.

Children in FT change their perceptions and misperceptions of the parent’s feelings, attitudes and behavior towards themselves. In the special play times, children will also explore thoughts, feelings and needs previously kept from the parent, and often from their selves (Guerney, 1982). In addition, during the special play-time, children have the opportunity to experience their parents differently and begin to
change their perceptions and misperceptions of their parent's feelings, attitudes, and behavior towards them (Bratton & Landreth, 1995).

Parents in FT begin to become more accepting of their child's negative feelings, conveying deeper understanding and empathy to their child in the process (Skinner, 1997; Oxman, 1972). According to Lahti (1993), changes in parents include increases in confidence and feelings of personal power, reduction in degree of parental control and responsibility, and an increased awareness of their child's needs. In addition Lahti (1993) found closer parent/child relationships characterized by enhanced communication, adoption of realistic expectations, and a decrease in friction. Children were found to display an increase in communication, a greater ability to take responsibility for their actions, a decrease in withdrawn and aggressive behavior, and an increase in overall happiness (Lahti, 1993).

FT is conducted individually or in small groups (Guerney, 1976). Parents attend once-a-week, one to two hour training sessions in which they learn the basic skills of play therapy through role-playing, instruction, live demonstrations by the play therapist, and viewing videotapes of parent-child play sessions (Guerney, 1982; Landreth, 2002). Parents are required to conduct one thirty-minute play session per week at home with their child. For supervision purposes, the parents either have live supervised sessions in the play therapist’s play-room or bring videotaped sessions (Landreth, 2002).

The training is both didactic and dynamic in that there is an educational component in conveying the skills by the play therapist; however, there is also a dynamic, therapeutic component. Empathy, support, unconditional positive regard and
understanding are encouraged and conveyed by the therapist and the group when applicable (Andronico, Fidler, Guerney, & Guerney, 1967).

Statement of the Problem

The problem with which this investigation is concerned is that of adapting and determining the effectiveness of FT as a method for intervening with families who have a child with a life-threatening illness. This investigation will evaluate the adaptations necessary for families in this situation to participate and complete the filial process. The effectiveness of FT in reducing stress and anxiety for parents and children while promoting increased levels of overall family functioning will also be considered.

Review of the Literature

The following review is a synthesis of literature and research related to six major areas related to this investigation: (1) play therapy in general, (2) life-threatening illness and challenges to emotional development, (3) how play procedure meets the emotional developmental challenges, (4) relational needs of parents and children, (5) relief from stress, and (6) adapting the toy list.

Play Therapy in General

Play therapy is the most developmentally appropriate intervention for children experiencing emotional stress, trauma, depression, behavioral problems, withdrawal, grief and loss, divorce, etc. (Axline, 1947; Ellis, 2000; Landreth, 2002; Ouellet, 1960). Play therapy is the most developmentally appropriate intervention because play is children’s natural medium of expression (Axline, 1969; Landreth, 2002; Springer, 1974; Ouellet, 1960). Play is their language and toys are their words (Landreth, 2002). Play
therapy, therefore, provides opportunities for feelings and words to be expressed that often cannot be put into words (Butler, Chapman, & Stuible, 1975; Jones, 2001; Le Vieux, 1990).

In child-centered play therapy, children are the leaders of their play. The therapist provides a safe therapeutic environment of acceptance and non-judgment with clear boundaries where the child feels free to express him-or-herself freely. Exploration of self and experiences is natural in unstructured play. In this relationship, the therapist facilitates the child gaining a sense of mastery, a sense of security, an internal locus of control, self-esteem, and confidence (Axline, 1947; Davies, 1992; Frick & Delpo, 1986; Jones, 2001; McEvoy et al., 1985; Kayes, 1991; Landreth, 2002; Van Fleet, 1992).

Kayes (1991) presented several cases of children who had play therapy treatment in the context of extensive hospitalization. In all the cases presented, the child was able to cope with the uncertainty of hospitalization, overcome fears, reduce regressive behavior, and become more cooperative with hospital staff as compared to children who did not have individual play therapy (Kayes, 1991). Bowmer (2002) conducted a study regarding hospitalized children using puppet play to reduce anxiety. The puppet play was shown to reduce anxiety in the experimental group significantly more than children in the control group who did not participate in the puppet play.

*Life-Threatening Illness and Challenges to Emotional Development*

Children who have a life-threatening illness face unique challenges. Blake and Paulsen (1981) cite several cases in which emotional development and independent functioning of terminally ill children are affected by repeated hospitalizations. With each
hospital visit, children’s anxiety level increases. The terminally ill child has increased anticipatory anxiety levels and shows a lower ability to discover adaptation strategies. What this means is that the anticipation of the hospital visit is so anxiety provoking, the children are incapable of creating effective coping strategies in order to have less traumatic hospital visits.

Tyc, Klosky, Kronenberg, Armendi, & Merchant (2002) found 65% of children to experience moderate behavioral stress in anticipation of radiation therapy. High levels of anticipatory distress were displayed by 34%, and 16% exhibited high levels of behavioral stress in conjunction with high heart rates. Children are found to have, at minimum, moderate levels of behavioral anticipatory anxiety before radiation treatment procedures; however, psychological/emotional intervention was not recommended by hospital staff unless the child exhibited significant distress (Tyc et al., 2002).

Tyc et al. (2002) recommend preventative intervention, in advance to distressing medical procedure, would facilitate the children’s ability to cope. Tyc et al. (2002) also recommend that further investigation as to how parent-child interaction styles, and how the parent child relationship may facilitate coping, should be investigated further. In accordance with the Tyc et al. (2002) recommendation; in the Surgeon General’s 2000 Conference on Child Mental Health Conclusions, it is recommended that families must be “essential partners” in delivering mental health services to children and adolescents (DHHS, 2000).

Children who suffer from a life-threatening illness with repeated hospitalizations often exhibit an external locus of control, characterized by feelings of helplessness,
isolation, apathy, and anxiety, and the failure to develop a sense of control or mastery (Battles & Wiener, 2002; Bolig, Fernie, & Klein, 1986; Davies, 1992; Frick & Delpo, 1986; McCandless, 1981). The manifestation of these symptoms is exhibited not only in the hospital setting, but at home, school, socially and every other pervasive life experience.

Perkins (1978) found children with a life-threatening illness to have similar anomalies in their artwork. Human faces are commonly among the first and most frequently produced images to appear in children’s artwork; however, more than half of the children who have a life-threatening illness never drew pictures of persons in their hospital pictures when observed by Perkins (1978). Perkins interpreted this phenomenon as a projection of the children’s experience, in the hospital setting, of isolation, un-relatedness to the outside world, and a wish to avoid confrontation with the experience of an insecure self (Perkins, 1978).

In addition, Key, Brown, Marsh, Spratt, & Recknor (2001) found children with chronic illness to report an increase in symptoms of depression as compared to healthy control group children. Children who perceived their illness to be more severe also reported higher levels of depressive symptoms as compared to the children with chronic illness who perceived their physical symptoms to be less severe (Battles & Wiener, 2002; Key et al., 2001).

Developmentally, children are egocentric and usually attribute occurrences in their lives as related to them in some way (Landreth, 2002). Consequently, children who
have a life-threatening illness often think they are ill as some sort of punishment for past behavior (Le Vieux, 1990; McCandless, 1981; Van Fleet, 1992).

How Play Procedure Meets the Emotional Development Challenges

Play procedures would be the obvious choice of emotional support for children with a life-threatening illness. Using play as the method of expression, dying and life-threatened children are free to safely express their emotions through the symbolism of play (Glazer & Landreth, 1993).

Methodology based on play procedures naturally meets the special needs of this population both developmentally and specifically (Springer, 1974). Child-centered play therapy is useful in helping children regain a sense of control in experiences at a time when they cannot control the experiences in their bodies (Davies, 1992; Ellis, 2000; Frick & Delpo, 1986; Jones, 2001; Landreth, 1988; Lindquist, 1980; McEvoy et al., 1985). In the special play session, children can express anxiety, fear, anger, and possible misinformation regarding why they have developed an illness (McCandless, 1981; McEvoy et al., 1985; Gray, 1987; Springer, 1974). Play provides children opportunities to assimilate experiences, decrease anticipatory anxiety, express feelings regarding their potential of dying, continue to experience growing and learning, and increase their affective adaptation coping strategies (Blake & Paulsen, 1981; Bolig, Fernie, & Klein, 1986; Ellis, 2000; Gray, 1989; Landreth, 1988; Le Vieux, 1990; Rae, Worchel, Upchurch, Sanner, & Daniel, 1989; Van Fleet, 1992; Vilas, 2000).

Cassell (1965) found that children who experienced play in the hospital prior to undergoing invasive medical procedures were statistically significantly less anxious,
more cooperative, and more willing to return to the hospital for further treatment than a control group of children who were not afforded play therapy before the procedure. St. Albert and Daniewicz (1958) reported that children who were treated holistically and included in a pediatric play program while hospitalized were less fearful, more cooperative, more adaptive and relaxed than prior to the institution of the pediatric play program in the hospital.

Bertoia and Allen (1988) presented the case of Rachel who used drawings to process her feelings regarding terminal illness. The child manifested all aspects of grief and loss through the drawings as well as the specific experiences known to accompany terminal illness in children. She conveyed denial, loneliness, fear, acceptance, and spirituality over a several month process of creating spontaneous drawings with a play therapist. She used the drawings to discuss her difficulty in talking openly with family members regarding her illness due to their overwhelming distress.

The increased stress related to relapse and hospitalization makes play, possibly, the most important feature of hospitalization. Even if the child is too sick to get out of bed, toys can be brought to him or her (Azarnoff, 1974; Landreth, 1988; Linquist, 1980). Continuing play sessions when it is most difficult is when it is most important. The play sessions normalize experience, add consistency to inconsistent experience and enhance relational experience in a time of isolation (Adams, 1982; Eisert, Kula, & Moore, 1988; Van Fleet, 1992).
Relational Needs of Parents and Children

FT has been shown to be useful for general relationship enhancement, as well as a positive intervention for children experiencing emotional and psychological problems (Ginsberg, 1996; Jones, 2001; Kraft & Landreth, 1998; Lahti, 1993; Van Fleet, 1992). Parents with a child who has a life-threatening disease have very unique experiences. They often feel anger, resentment, guilt, fear, and confusion (Blake & Paulsen, 1981; Van Fleet, 1992). Sometimes parents exhibit grief in anticipation of the child’s possible death. If prolonged, the anticipatory grief response can disrupt parent-child relations and increase the child’s sense of isolation (Blake & Paulsen, 1981; Van Fleet, 1992).

Parent-child conflicts often increase as the parent of a child with a life-threatening illness attempts to insure that their child adheres to the treatment regimen (Van Fleet, 1992). Many parents choose not to tell their children their prognosis even though children have been shown to be aware of their prognosis as young as four-years-old without being told (Blake & Paulsen, 1981; Le Vieux, 1990). When adults avoid aspects of the relationship, such as the probability of death, the sense of loneliness experienced by the child intensifies (Gray, 1989). Hiding the truth may cause a strain in the relationship, because the child feels betrayed.

Children often misunderstand how they got a life-threatening illness (Ishibashi, 2001; McCandless, 1981). Accurate, age-appropriate information should be given to the child when the child seeks information (Ishibashi, 2001; Kaplan, 1999; Le Vieux, 1990). Accurate information helps children reduce negative feelings and increase cooperation levels. However, children sensitive to their parents’ need to avoid the truth will protect
their parents’ feelings by keeping their own concerns about death and illness to themselves (Bertoia & Allen, 1988; Glazer & Landreth, 1993).

Parental fear sometimes leads to excessive overprotection in the face of a life-threatening illness (Blake & Paulsen, 1981; Kaplan, 1999; Le Vieux 1990; Van Fleet 1992). Parents will tend to do simple, menial tasks for the child, not allowing the child to gain a sense of empowerment and accomplishment. Children who are overprotected in this situation tend to become overly dependent, which adds to their sense of helplessness (Blake & Paulsen, 1981).

Parents of children with a life-threatening illness also must gain a sense of mastery (Blake & Paulsen, 1981; Kaplan, 1999). Parents, in this situation, often feel a sense of denial regarding the illness, a loss of control due to lack of information or difficulty understanding the information, and uncertainty as to how to help care for their child (Yiu & Twinn, 2001). Parental mastery derives from the eventual acceptance of the child’s disorder and the uncertainty of the future. They must maintain personal integrity and family cohesion characterized by love and security (Blake & Paulsen, 1981; Kaplan, 1999).

FT facilitates a sense of parental mastery in that parents learn skills that increase sensitivity and empathy to their child (Ginsberg, 1996; Guerney, 1980; Lahti, 1993; Rennie & Landreth, 2000). When children feel understood they build a closer relationship with their parent. A positive relational cycle develops where both participants feel more fulfilled, encouraged and supported (Lahti, 1993).
In FT an overall enhancing effect on the parent and child relationship has been shown to occur (Bratton, 1995; Bratton & Landreth, 1997; Lahti, 1993; Guerney, 1976; Guerney, 1980; Van Fleet, 1992). Rennie and Landreth’s (2000) review of the research literature found the effects of FT to be increased parental empathy and acceptance, decreased parental stress, and positive affects on the family environment in expressiveness, conflict, independence, and control. They reported children experience an increase in adjustment, self-directiveness, and connectedness with the parent, and a decrease in behavioral problems.

In FT parents and children are allowed to gain a new perspective of each other, while the parents are taught valuable parenting skills that can be applied in many different child-rearing situations (Lahti, 1993; Harris & Landreth, 1997; Van Fleet, 1992). A child with a life-threatening illness will benefit from play therapy. Teaching a parent to be the therapeutic agent, allows the parent opportunities to really understand the child’s perceptions of the world and his or her illness.

Children can communicate fears and questions regarding their illness, through play (Brunskill, 1984). The parent has the opportunity to help his or her own child discover constructive coping strategies for the possibility of death. The child is afforded the opportunity to focus on living rather than dying (Glazer & Landreth, 1993) Also, the child, in feeling understood and safe, will feel closer to their parent in a time often characterized by confusion and isolation. Play therapy in the home was described by Moustakes (1959) as

a relationship between a child and his mother or father through which the child discovers himself as an important person, sees that he is valued and loved, and
recognizes his *irreplaceable membership* [italics added] in the family. It is a way through which the child opens himself to emotional expression and in this process releases tension and repressed feelings. Through his play experiences with his parent the child is helped to express “bad feelings” and to move toward a healthy orientation to developmental tasks and problem solving.

Glazer-Waldman, Landreth, and Norton (1992) used FT with five parents of children with chronic illnesses. After 10 two-hour sessions, all of the parents reported positive changes in themselves. Four of the parents reported positive changes in their children. They improved significantly in their abilities to judge their children’s anxiety level, indicating an increase in understanding by the parents. FT was shown to be a useful intervention, characterized by relationship enhancement, with families experiencing the stress of chronic illness of a child.
Relief from Stress

Children who survive pediatric cancer are found to have an increased risk of maladjustment (Ward, 2000). The family can be either a principal source of support, or a source of anxiety. Ward (2000) found that the family functioning prior to the onset of the illness, and the child’s family’s response to the illness, highly influences the survivor’s relationship to his or her family. Children who are responded to empathically and acceptingly by parents are more likely to adjust adaptively to life if they survive the life-threatening disease than children who experience primarily anxiety with their family in the face of the life-threatening disease (Ward, 2000). Through filial training, parents will learn how to respond more empathically to their child, facilitating the process of adapting to the changes incurred due to the illness and increasing familial functioning (Adams, 1992; Van Fleet, 1992).

As the parents learn to respond more empathetically and gain a greater understanding of their child’s perceptions, they (the parents) also gain a sense of mastery and empowerment. As the parent becomes more effective in parenting the child with a life threatening illness, a positive relational cycle develops that is experienced by the parent, child, siblings, and other persons close to the family (Blake & Paulsen, 1989; Van Fleet, 1992).

Adapting the Toy List

Parents are given a list of toys to have available for the special play times they have with their child. The list includes toys and materials that facilitate emotional and creative expression (Landreth, 2002). The list should be expanded in several areas to
accommodate the real life experiences of terminally ill or life-threatened children. First of all, there should be more real medical supplies such as bandages, gauze, syringes, surgical masks, intravenous setups, a stethoscope, and any other supplies specific to the condition of the child (Brunskill, 1984; McCue, 1988; Green, 1974).

Second, there should be many more dollhouse dolls available than the standard five-person family that most filial kits include. Children may want to act out hospital scenes where they create children's wards with several patients. Therefore, nurse and doctor dolls and/or puppets should be included (Green, 1974).

Finally, one or two “spongy” type dolls that are easy to stick a syringe in should be added to the list of toys. These dolls offer children the opportunity to stick needles into “nurses”, “doctors” and “patients” in the play sessions (Rae et al., 1989).

The addition of medical supplies, doctor and nurse dolls, dollhouse dolls, and spongy dolls facilitates the expression of intense feelings children may experience regarding their illness, treatment and hospitalization (Green, 1974; McCue, 1988). Expression of real life experiences in play helps children feel the experiences are manageable (Landreth, 2002). Managing experiences helps children develop tolerance for treatments and medical procedures, as well as a sense of mastery (Brunskill, 1984; Davies, 1992). Children are given the opportunity, through play, to take an active role in hospitalization, an experience where passivity is encouraged (Adams, 1982; McCandless, 1981; McCue, 1988).

Children can create nurses and doctors with clay or play dough; however, it is important to try to meet the special needs of children in this population who may spend
weeks at a time with hospital staff by having real life toys representative of hospital staff and materials they come in contact with (Adams, 1982; Brunskill, 1984; Green, 1974; Webb, 1995).

Summary

FT is the obvious therapeutic intervention for this population. FT outcomes meet the needs of both the parents and the children of this group. Children are offered opportunities to experience true expression of self in the presence of a significant relationship (Guerney & al., 1970). They are given the opportunity to normalize some of their experiences through parental cooperation in maintaining play behavior in and out of the hospital setting (Adams, 1982; Landreth, 2002; Van Fleet, 1992). They can gain a sense of mastery over their environment, enhance self-esteem, increase confidence, assimilate new experiences into self-concept and enjoy living the potential final phase of their life (Blake & Paulsen, 1981; Bolig, Fernie, & Klein, 1986; Gray, 1989; Landreth, 1988; Le Vieux, 1990; Rae, Worchel, Upchurch, Sanner, & Daniel, 1989; Van Fleet, 1992).

Parents are also helped tremendously by FT. They are more capable of establishing a sense of parental mastery in maintaining family cohesion and relational experiences in spite of foreboding possibilities (Blake & Paulsen, 1981). They actively enhance the relationship with their child while therapeutically aiding their child in assimilating life experiences regarding death and hospitalization. Parents are able to foster their child’s growth in the time they have left to live rather than allowing their child to give in to helplessness and stagnate.
Although siblings of children with a life-threatening disease were covered only minimally in the context of this literature review, they are positively affected by FT as well. Parents become more sensitive to siblings’ feelings and needs in the process of FT (Van Fleet, 1992). The increase in parental sensitivity and empathy generates more family cohesion (Bratton, 1997; Van Fleet, 1992).

FT meets the needs of the family experiencing life-threatening illness in a child (Glazer-Waldman et al., 1992; Van Fleet, 1992). The mild adaptations suggested earlier, in this review of the literature, will meet the special needs of this population; however, even traditional FT would be helpful to families in this situation without modification.

**Purpose of the Study**

The purpose of this investigation was to adapt FT to meet the needs of families who have a child with a life-threatening illness. I openly and holistically explored the potential data as it arose in an attempt to modify and adapt FT to meet the needs of this population.
CHAPTER II

METHODS AND PROCEDURES

The nature of this study was qualitative. It was designed to explore the potential effects of filial therapy (FT) with families who have a child with a life threatening illness in an open-ended, holistic manner in order to discover what processes are most advantageous to the families, as well as what adaptations, or types of adaptations are most helpful.

Research Question

This study investigated FT with families who have a child with a life threatening illness through the use of the following exploratory question:

- What adaptations to FT are found to be most beneficial in working with families who have a child with a life threatening illness; and what similarities and differences are there between the different families involved in the study, such as but not limited to: a) the diagnosis of the child of focus; b) the support system the family experiences; c) the type of treatment/ hospital experience the family is undergoing simultaneously with the FT, and how it impacts the FT?

- How does participation in FT impact the following domains: a) verbal and non-verbal communication between the parent(s) and child in both the play session and the home setting; b) Child cooperation in the medical setting as reported by the parent(s); c) experience by the parent(s) of confidence in parenting skills; d) experience of the child in self-confidence and competence in coping as reported by the parent(s)?
Definitions of Terms

*Filial therapy* – Based on the Landreth (1991) model, FT consists of 10 weekly one- to two-hour training sessions where parents are taught to conduct child-centered play therapy sessions with the instruction and supervision of a professional play therapist (Bratton, 1997; Landreth, 2002). FT is a method, developed by Bernard and Louis Guerney for intervening in the psychosocial development of children using parents as the agents of change.

*Life-threatening illness* – For the purpose of the study, a life-threatening illness was defined as a condition, which is terminal or holds an eminent possibility of becoming terminal such as cancer.

Research Design

It was the purpose of this study to use a collective case study design in order to investigate the qualitative research questions over a several month period while the families were involved in FT (Stake, 1998; Strauss, 1987). The qualitative collective case study design enabled me to investigate the unique experiences of families in the difficult situation of having a child with a life threatening illness; and utilized information attained throughout the process to adapt FT to meet their needs, all the while investigating what adaptations are most effective with the families while experiencing the phenomenon of FT intervention (Strauss, 1987). My intention was to create a holistic experience of the data (Guba & Lincoln, 1994).

According to Stake (1998), a collective case study design is useful when the researcher is interested in investigating a number of cases jointly in order to understand
a phenomenon, population, or general condition. I was interested in the particulars of each case, and the intrinsic value of each case, however, the collective phenomenon, in this investigation, adapting FT to fit with families who have a child with a life-threatening illness, was of more interest to me than the individual cases in the investigation (Stake, 1998; Strauss, 1987).

Although a collective case study design was employed for the purposes of this study, I was still highly interested in having an intrinsic understanding of each particular case. Stake (1998) postulates that the uniqueness of a case is one of the most important components of the case. The particulars of the context, history, physical environment, and nature of the case must be recorded. I looked at each case both intrinsically, and collectively in order to gain the most holistic information about how to better adapt FT for families who have a child with a life-threatening illness (Guba & Lincoln, 1994; Stake, 1998; Strauss, 1987). The continuum between intrinsic case study and collective case study is difficult if not impossible to differentiate (Guba & Lincoln, 1994; Stake, 1998; Strauss, 1987). For this purpose, I always made careful notes about the intrinsic components of each case, all the while focusing on the phenomenon being studied, how FT is adapted to fit with the idiosyncratic personalities of persons from the population who were involved in this study. According to Yin (1984) the use of a case study design is supported when it is impossible to separate the phenomenon’s variables from its context. This was the circumstance I experienced with these families.
Subjects

The children whose parents were accepted to the study were between the ages of two and ten. Their prognosis indicated that they had at least six months to live. The subjects were recruited through the pediatric oncology unit of a metropolitan children's hospital in the southwest region of the United States. Due to the new HIPAA regulations and confidentiality within the hospital setting, I relied solely on the pediatric oncology child-life specialists to set up an initial meeting with the parents and myself. I officially underwent volunteer training at the hospital which entailed attending several orientation meetings and learning hospital emergency protocol in order to meet hospital and HIPAA confidentiality standards.

An advertisement was mailed to approximately 70 parents who lived in the area and made regular hospital visits, in May 2003; and again six months later, as determined by the child-life specialists who were aiding me with subject recruitment. Advertisements were also posted in both the pediatric oncology unit of the main hospital, as well as in the specialty clinic for pediatric oncology adjacent to the hospital. Along with the advertisement was a short form the parents could fill in if they were interested in me telephoning them with more information. The short form allowed the parents to put in writing that they were interested in learning more about the FT, and list phone numbers where they could be contacted by me. I was allowed to contact the prospective subjects and ascertain eligibility, convey information regarding FT, and set up an initial interview when applicable once the interest form was completed.
Six families volunteered to participate on a first come, first serve basis. Several other families conveyed interest by completing the card, but failed to respond to the phone call to convey information. Of the six families who volunteered to participate, 2 completed the FT, and 4 terminated early after 3-7 sessions. One other parent conveyed interest and spoke with me on several occasions, but never committed to participate in the study. Families who participated in the study were provided with toy kits containing the materials for the play sessions. The toy kits and adaptations to the toy kits are described more thoroughly later in the chapter.

Participation by both parents was not required, but was encouraged when possible. Case selection is an important component of case study design (Stake, 1998). Researchers try to pick the best case possible when possible. Some case study research, however, is based on a small population sample size, which limits the number of cases available for study (Stake, 1998). That was the situation with which this researcher was faced. Another difficult aspect of case selection, for this investigation, was the difficulty that parents in such a stressful situation had in committing to attending the weekly FT. It was hoped by me that the families who participated would represent many unique aspects within the population of pediatric oncology.

A brief description of each parent who participated, along with general case details is described below. In order to protect confidentiality, the participants have been given fictitious names. The order the participants are listed is according to the number of sessions they attended, with the persons who completed the FT listed first. To contribute to cohesion and comprehension of the description throughout the
manuscript, the participants are placed in alphabetical order. The participants are listed as ANNIE, BARBARA, CINDY, DEBBIE, EMILY, FRANCIS, and GEORGIA. The child will be called child, or child of focus throughout the manuscript, depending on context. In the following descriptions, the subjects will; a) be listed, b) followed by the number of FT completed, c) the number of play sessions completed (they have their first play session after their third FT session), d) the age of the child of focus, e) general date of diagnosis, and f) a brief demographic and historical account of their case. More information is discussed later in chapter III which will give the reader an even greater understanding of the complexity of the subjects.

ANNIE completed all 10 FT sessions, and all 7 play sessions, child: 8 years, diagnosed 2 years earlier. The subject was a 31 year old divorced Hispanic female. She was living with her parents, the child of focus, and her little sister at the time of treatment. She worked part-time outside the home. Her ex-husband was reportedly minimally involved in the child of focus’ life, even though he lived in the same community and attended the same church sometimes.

BARBARA completed all 10 FT sessions and all 7 play sessions, child: 5 years, diagnosed 2 years earlier. The subject was a 48 year old Caucasian widow who is raising her 2 granddaughters after her daughter (their mother) was murdered four years earlier. She lived in an apartment and was actively involved in organizations that place flowers and monuments where people are murdered or die in accidents on the highways. Her husband died in an accident 2 years after her daughter was murdered.
For the purposes of this study, the child of focus is generally referred to as her daughter since she was less than one year of age when her mother was murdered.

CINDY completed 7 FT sessions and 3 play sessions, child: 2 years 6 months, diagnosed one week before commencement of FT. The subject was a 35 year old Caucasian female who lived with her husband, son (5 yr.), and the child of focus, in an affluent suburb. She was a professional but worked only part time. She reported some spousal problems mainly related to disagreements regarding parenting since the diagnosis.

DEBBIE completed 5 FT sessions and 0 play sessions, child: 5 years, diagnosed, one year earlier with cancer. The subject was a 35 year old Caucasian female who lived at home with her husband, and 3 sons (14; 8; 5). The child of focus was born with congenital heart defects and was not expected to live for one year. He underwent a complete heart transplant at the age of 3. He later developed lymphoma, presumably from the heart medication. Due to his precarious heart condition, the cancer treatment was reportedly not aggressive. Her oldest son was reportedly having emotional problems for the last two years. She also reported a disconnected spousal relationship where she believed she was not receiving emotional support. She was an ex school teacher who quit her job to take care of the child of focus full time. She reported the child could not do simple things for himself such as feed himself and dress himself, even though the child could manage to cart the large IV rolling trammel around the hospital and specialty clinic with ease. She appeared to be highly connected to the role of caretaker for the child of focus.
EMILY completed 3 FT sessions and 1 PT session, child: 9 years, diagnosed 4 months earlier. The subject was a 37 year old Caucasian female who lived with her husband and 2 sons (5; 9) in an affluent suburb. She reported that the relationship with her spouse was good. The child was reportedly misbehaving when he was first diagnosed, but she reported that, that behavior had subsided.

FRANCIS completed 3 FT sessions, 0 play sessions, child: 2 years, diagnosed 2 months earlier. The subject was a 32 year old African-American female who lived with her husband and the child of focus. She reported the relationship with her spouse to be difficult. The child was reportedly having some difficulty acclimating to the hospital environment, manifested most notably in a regressive language development pattern where a previously talkative 18 month old had regressed to mainly grunting and pointing; but she reported feeling like he was doing better. FRANCIS indicated there were spousal problems at the time of the study.

GEORGIA never committed to the FT and completed 0 play sessions, child: 3 years, diagnosed 2 months before meeting. The subject was a 34 year old Hispanic female from south Texas. She was staying in the Ronald McDonald House while her child was receiving bone marrow aspirations. Her husband and family were mainly in south Texas, but they were visiting every weekend. She reported feeling very stressed and overwhelmed about being away from home, away from family, and the primary caregiver of the child.
Data Collection

Due to the case study design of this research, data was collected in the form of interviews, videotapes, and field notes. I was a participant-observer of the phenomenon which was being studied. I was part of the process, and an observer of the process in both the interviews and the training. I was also a non-participant observer of the play sessions between the parent and child.

I intended to initially collect data on each case as an instrumental case design. In an instrumental case design, each case is examined in depth, scrutinized contextually, and the ordinary aspects detailed in order to help understand a particular theory, or phenomenon more thoroughly (Stake, 1998; Strauss, 1987). As I recorded every aspect of the case according to the aforementioned research questions and any new questions that arose in the context of working with these families, the cases were examined, coded, and re-examined creating data gathered on the collective of the cases (Stake, 1998; Strauss, 1987). Data was then renewed, collected, and coded as a whole, regarding themes, patterns, similarities and differences between each case (Guba & Lincoln, 1994; Stake, 1998). I utilized a step wise process in order to understand the phenomenon of FT with this population as thoroughly as possible considering the limited number of cases examined (Stake, 1998).

Pre-Interview

Before the FT began, each parent who was participating was interviewed regarding the problems they were experiencing in an unstructured format; however the interviewer had several questions in mind before the interview began (see Appendix A).
The unstructured format allowed the parents to convey their story at their own pace and in their own words. I conveyed understanding of the problems, explained play therapy, explained that learning how to have play sessions would be helpful for parent-child communication while using examples from the parent’s experience, and explained the general nature of the research while going over the consent form.

FT Treatment

Following the pre-interview, the parents began the FT training. I utilized the Landreth (2002) ten-week model of FT, consisting of 10 two-hour sessions. The standard format of meeting weekly was first attempted. However, due to the nature of adapting the study to meet the needs of this population, other formats (bi-weekly, extended meetings covering more than one session, etc.) were explored to attempt to meet the needs of the family in a more adaptive way. The families typically met with me individually. The FT was conducted in a confidential setting, such as a parent conference room, or an extra vacant exam room when necessary.

I used child-centered play therapy, and taught the parents the basic principles and skills utilized in child-centered play therapy for use in their home or hospital play sessions. Although the FT sessions were dynamic and didactic, structure evolved according to the task-oriented nature of the process. I used the outline developed by Dr. Garry Landreth, and discussed in his book, Play Therapy: the Art of the Relationship, as the general format for the FT (Landreth, 2002).
The Toy Kits

I included added adaptations to the toy list to meet the specific emotional needs of the population of children with a life-threatening disease (Adams, 1992; Blake et al., 1982; Van Fleet, 1992). Toy kits were provided for the parents. The kits included the following toys, recommended for FT (Landreth, 2002):

(1) play dough  (8) doll family  (15) play money
(2) crayons  (9) toy soldiers  (16) rope
(3) paper  (10) car  (17) cellophane tape
(4) blunt scissors  (11) Lone Ranger™* mask  (18) Bobo doll
(5) nursing bottle  (12) Tinker Toy®† construction set  (19) ring toss game
(6) rubber knife  (13) doctor kit  (20) small box
(7) dart gun  (14) adhesive bandages  (toy container/doll house)

The following toys were added to the toy kit for the purposes of facilitating therapeutic process with children who are experiencing a life-threatening disease (Adams, 1992; Brunskill, 1984; Green, 1974; Rae et al., 1989; Webb, 1995):

- Real medical supplies- bandages, gauze, syringes (with real needles), surgical masks, intravenous setups, a real stethoscope, and any other supplies specific to the condition of the child.
- Nurse and doctor dolls and/or puppets
- 2 “spongy” type dolls - to stick with a syringe

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*Classic Media (http://www.classicmedia.tv)
†Hasbro (http://www.hasbro.com)
Other Adaptations

I anticipated that there would be several adaptations to FT due to the extremely stressful situation the families were experiencing. The critical care of a child while hospitalized and attempting play sessions, siblings and their needs, potential marital problems, how much support the family had from extended family, friends, and church were all factors effecting the adaptations needed in order to facilitate the transfer of information of FT. The case study design was particularly useful in adapting FT because adapting to meet the needs of each case and to use information and data actively while working with each case are methodologically inherent in the case study design.

Field Notes

I took copious notes after each meeting with the parent. I made sure to notice 1) relationship experiences between the parent and child; 2) feelings the parent experienced during the week; 3) feelings the parent experienced the child to experience during the week; 4) communication the parent experienced in the context of the play session; 5) how the parent reported feeling during the special play time; 6) any other experiences the parent conveys as significant in relation to the filial training; 7) any ideas the parent expresses either candidly, or upon questioning, regarding how to make the FT process fit with the lifestyle of the family while coping with the life-threatening illness of a child; and 8) my thoughts, experiences, reflections were recorded. The field notes were analyzed by me and other committee members in an attempt to identify critical incidents, patterns, and themes to be coded.
**Post-Interviews**

At the conclusion of the FT, I interviewed the parent(s) regarding their experience in FT (Appendix C). The interview had a general format, although it was open-ended to allow for the parent(s) to explain their experience in their own words. All post interviews were tape recorded, and field notes were made for investigation of patterns, themes, and critical incidents.

**Data Analysis**

The data was analyzed on a case by case basis. I attempted to find patterns and themes in the individual families. Once the case data was analyzed individually, I used a variable oriented strategy to analyze for themes that cut across cases, and themes that did not cut across cases (Huberman & Miles, 1994). I attempted to make analysis, based on experience as a participant observer and contextual data, regarding the theme or pattern observed and identified in the data. The data was analyzed using a code system. I looked at the field notes, pre-interviews and post-interviews and coded the data according to patterns, themes, and relationships discovered through the process. The codes were developed once the data accrued. Although I was unsure what the codes would be, there was a general method for analyzing the data that was based on the research questions generated at the beginning of the chapter. The introductory method utilized to analyze the data is described as follows:

1) What adaptations to FT are found to be most beneficial in working with families who have a child with a life-threatening disease?

   The primary sources of data needed to answer this question were field notes from the meetings with the parents and the pre and post parent interviews.
2) What similarities and differences are there between the different families involved in the study according to: a) the diagnosis of the child of focus; b) the adaptations found to be helpful and useful; c) the support system of the family experience; d) the type of treatment/hospital experience the family is undergoing simultaneously with the FT, and how it impacts the FT?

The primary sources of data available to answer these questions were the field notes, and the pre and post parent interviews.

3) How does participation in FT impact the following domains: a) verbal and non-verbal communication between the parent(s) and child in both the play session and the home setting; b) child cooperation in the medical setting as reported by the parent(s); c) experience by the parent(s) of confidence in parenting skills; d) experience of the child in self-confidence and competence in coping as reported by the parent(s)?

The primary sources of data needed to answer these questions were the field notes, and the pre and post parent interviews.

Although computers are becoming more and more commonplace in qualitative research, I limited the computer use to Word 2000 for the purpose of field notes. The investigation of different software methods of analysis of qualitative data shows that a huge limitation of software use with qualitative research is the potential to constrain and distort the research (Richards & Richards, 2000). Although, with very large studies with multiple cases the software would be helpful; for the purposes of this study, I determined that the software may be more limiting to the holistic approach in analyzing the data.

Limitations

Several limitations to the investigation are evident. First of all, the study was limited to volunteers. Subjects who volunteer may be more intent on feeling better and facilitating emotional adjustment than those who visit doctor appointments alone.
Secondly, subjects may have been receiving other types of emotional support in the community in the form of support groups, individual therapy, hospice care, etc. The other support they may be receiving could be a confounding variable. Lastly, the subject groups were not demographically balanced. Subjects from a higher or lower socioeconomic background may experience the stress of the illness a little differently. Someone from a lower socioeconomic background would have the added stress of extra bills related to the illness.

Cultural and religious differences in demographics were a potential confounding variable since people from different cultural backgrounds may respond differently to the possible death of a child. Another potential limitation is experimenter bias. I am play therapist who is working toward a doctoral degree in counseling with a specialization in play therapy. I have done extensive literature research on the population; families who have a child with a life threatening illness, and believe that FT will be a therapeutic intervention for both the children involved, and the parents. I am potentially biased in the direction of believing the process will be helpful. I may subconsciously notice and notate only parts of the process that appear to fit with her belief that play therapy, and FT, are effective interventions for families and children.

Another limitation of the study was the Hawthorne Effect. According to the Hawthorne effect, individuals involved in experiments may change their behavior in the experiment in order to please the experimenter. Basically, they are aware of what the experimenter is looking for, either by direct communication, or by perception, and
either, consciously, or subconsciously change their behavior or reports of their experiences to please the experimenter.

In this investigation, I appealed to the parents by honestly explaining both the general process of play therapy and FT, as well as the general reasons that the FT is hypothesized to be an effective intervention with this population. The Hawthorne Effect was, therefore, a limitation to the study that was very difficult to control.

Several limitations to the study have been noted. It was my intent to be both thorough and objective in acknowledging the limitations in an effort to increase objectivity. Although these limitations are important to note, the potential significance of a positive therapeutic intervention with families with a child with a life-threatening disease was worthy of further investigation.
CHAPTER III
RESULTS AND DISCUSSION

Due to the potential redundancy in reporting qualitative results first and then expounding discussion in a later section, the results and discussion sections were merged to create a comprehensive flow. The chapter is divided into; a) results and discussion by each result; followed by b) discussion of implications for practice and future research; c) recommendations, thoughts, and comments; and lastly, d) final conclusions.

I met with a total of 7 parents (see chapter II for an expanded description): one single mother, one grandmother who is a single parent, and five mothers in a traditional nuclear family experience (husband, wife, child of focus, and 2 with other children in the house), over the course of a one-year collective case study investigation of adapting filial therapy (FT) for families who have a child with a life-threatening illness.

FT is a method of parent therapy where parents are taught the basic skills of play therapy and how to have play sessions at home, or in the hospital setting in these cases, to facilitate communication and closeness in the parent-child relationship. The parent begins having play sessions with the child of focus (the child with a life-threatening illness), after the third FT session and is expected to have one play session between each FT session for the remaining FT sessions until 10 FT sessions occur. The parents are encouraged to continue play sessions after the FT is over.
Although every parent I met with did not ultimately become a true subject, every parent who met with me at least twice, will be discussed in order to better understand the unique parenting struggles and needs of members of this population. Parents who expressed interest by completing the interest card, including parents I spoke with on the telephone, but did not meet me in person were not included. I will first report; a) the commitment and attrition difficulties; b) the collective case study findings across cases in the context of the research question; and c) other findings not included in the research question.

Subject Commitment vs Attrition

One apparent finding of the study was the difficulty parents of a child with a life-threatening illness have in committing to participate in FT. Parents, in general, have difficulty committing to parenting classes, in spite of need, however, the level of attrition and difficulty committing in this population, although expected, was much greater than anticipated. As reported in chapter II, the child-life specialists at the participating hospital mailed approximately 70 flyers to the homes of parents in May 2003; and again in December 2003. They reported actively recruiting parents for the study throughout the one-year time frame, and reported to me that they were attempting to convey the helpfulness of the study to parents they had day to day contact with in the hospital and clinic.

Although parents were aware of the opportunity to participate in FT to help them and their child, and several expressed interest to the child life specialists, only seven conveyed true interest over the course of the year. The results of each subject’s ability
to complete the study, number of sessions completed, reason given for terminating, and number of play sessions held, are listed below by subject (see chapter II for an expanded case description of each participant).

ANNIE: Completed the entire training. She reported no problems with committing to the training. She held 7 play sessions during the FT training period.

BARBARA: Completed the entire study. The subject reported difficulty with some of the planned meetings. She held 7 play sessions during the FT period.

CINDY: Completed the pre-interview and 7 filial sessions. The subject reported feeling too overwhelmed to continue the study due to increased stress related to the child of focus, as well as increased stress related to other issues aside from the child of focus, including serious illness of both a close family friend and another family member. The subject completed 3 play sessions with the child before terminating.

DEBBIE: Completed pre-interview and 4 filial sessions. The subject reported feeling too overwhelmed to continue the study due to emotional problems with another child besides the ill child, and overwhelmed with the multiple diagnoses and prognosis of the child of focus. The subject never reported having a play session.

EMILY: Completed the pre-interview and 3 filial sessions. The subject reported feeling too overwhelmed to commit to continue the sessions after the prognosis of the child was reportedly changed for the worse. The subject reported having one play session with the child before terminating the FT.
FRANCIS: Completed the pre-interview and 2 FT sessions. She reported her husband did not want her to complete the training. She reported fear that her husband would be angry if she chose to complete the study. The subject held no play sessions.

GEORGIA: Never committed to complete the study. She conveyed interest in the study and met twice with me to discuss the study. She reported feeling overwhelmed with staying in the Ronald McDonald house with family out of town. She reported feeling too overwhelmed to commit to the study. She also reported feeling like she did not have enough time to complete the study before returning home after the child’s treatment.

**Attrition vs Commitment Discussion**

Several hypotheses regarding the difficulty the subjects encountered with committing were formulated and will be discussed below. The sections are organized by; a) an overall phenomenon I labeled the “plus one factor”; b) a brief discussion of each participant regarding the possible reasons they may have been capable, or incapable, of committing to the course of the study; and c) a discussion of the similarities in the two subjects who were able to commit to the course of the FT, and the differences between them and the subjects who could not commit to completion.

**Plus One Factor**

I noted a phenomenon and labeled it the *plus one factor*. Parents who are experiencing the difficulties related to having a child with a life-threatening illness can sometimes commit to FT. If one other traumatic experience presents itself in their life, they are at their limit and FT is the most likely commitment to be abolished. Although
this phenomenon has been experienced by other populations I have worked with in the past, in those cases it appeared to be a simple case of priorities with FT being at the bottom of the list. In the cases of parents with a child with a life-threatening illness, it was experienced as an issue of concentration. Although the parents were seriously interested in the opportunity, they could not concentrate on maintaining it as a high commitment due to the astounding stress they were experiencing; most particularly if one other stressor presented itself in their life. So parents who have a child with a life-threatening illness can sometimes commit to FT; however, if a grandparent becomes ill, or another child has serious behavior/ emotional problems, or any other traumatizing experience occurs, they appear to be incapable of continuing to commit to FT. Although not anticipated, in retrospect, this phenomenon is not unusual in persons experiencing anticipatory grief reactions and stress related to having a loved one diagnosed with a life-threatening illness (Warden, 1991). It is also hypothesized that FT is regarded by the parents as a completely separate commitment than taking the child for a medical procedure.

When analyzing the data for themes, the plus one factor was coded as a theme. On first analysis, the plus one factor was ambiguous. Closer scrutiny proved that patterns related to spousal support, family environment, other children in the family, extended family support, friendship network, illness of other family members, illness of friends, etc., were all likely to effect the plus one factor in either negating it, or manifesting it at a quicker rate. Although several of the preceding categories will be
discussed later separately, they are noted here when related to the plus one factor since it pervaded coding in all of the families.

Participants who were able to complete the entirety of the FT will be discussed first with hypotheses as to why they were able to commit to FT without early termination. Then each participant who terminated early will be discussed regarding; a) the reasons they reported needing to terminate; b) my hypotheses regarding why they could not continue; and c) notation of the hypothesized plus one factor in attrition where applicable.

ANNIE was able to commit to the entirety. She reported no problems with committing to the study. The child of focus in this case was in the hospital a limited amount of time due to a recession in symptoms. Her hair was fully grown, and she was attending public school again. About halfway through FT, ANNIE reported that the child of focus had officially been diagnosed as in remission.

ANNIE, who is Hispanic, lived with her mom and dad, the child of focus, and a little sister who was still in high school. She also had another sister living a few blocks away. The family reportedly spent a lot of time together, had a cultural community child rearing focus, and tended to lend each other a lot of emotional support. For instance, when ANNIE worked, the child of focus stayed home with a grandparent or aunt, so daycare was unnecessary.

The only reported major stressor in the participant’s life outside of the hospital was a somewhat strained relationship with the child of focus’ father and ex-husband, and new wife of the ex-husband. Due to the family support and less stressful hospital
experience, experienced by ANNIE, I hypothesize that the strained relationship with her ex-husband was either balanced by the positive, or not negative enough for the plus one factor to be a factor with this family. In fact, this parent experienced so much support, and less stress in the hospital at the time of FT, she was the only participant who was able to commit and follow through to meet me at the hospital on days she was not scheduled to be at the hospital.

BARBARA was able to commit to completing the FT. She lived alone with the child of focus and the child’s sister. In the hospital experience, the child was originally diagnosed two years earlier and had gone in remission for several months before the tumor returned a few months before she began FT. BARBARA had a lot of family support. Her daughter, mother, and brother all lived in the same part of town and helped each other with the children on a regular basis. When she was in the hospital with the child of focus, for example, her daughter or mother would take the child’s sister. Her brother reportedly paid her rent and bills so she could stay home with the children, and with the child of focus in the hospital.

I postulate that BARBARA was able to commit to the FT due to acclimation to the hospital experience, and a high level of family support. Although they were in the hospital or the specialty clinic at least weekly, the participant had been attending regular hospital appointments for two years and appeared to not be so overwhelmed by the schedule.

Although BARBARA completed the 10 FT sessions easily, at the end of the ten sessions, I had a difficult time connecting with BARBARA for the post-interview.
BARBARA’s daughter went into very early labor (9 weeks), and was hospitalized.

BARBARA reported the problem, but although previously very attentive to responding to my calls, she became very difficult to contact. I hypothesize that this difficulty is a manifestation of the plus on factor. The subject, who previously had been very reliable, suddenly became very unreliable, difficult to get in touch with, and even failed to cancel an appointment after this other stressor presented itself in her life.

CINDY committed to FT and completed the pre-interview and 7 sessions before terminating. She reported an enthusiastic interest in FT and appeared very interested and engaged for the first several sessions. After the fourth FT session, CINDY reported a very difficult week because her other child was ill, and due to the child of focus’ reduced immune system functioning, she had to work very hard all week to keep the two children apart. Although she participated in three more FT sessions, she appeared as less and less engaged after the fourth difficult week.

I experienced the child as more and more demanding of the parent each time the parent attended a FT session. Because the parent began the FT so soon after diagnosis, she reported no behavioral problems when the FT started. She actually reported the child to be very cooperative in the medical setting in the pre-interview. I felt some of the behavior problems were typical of children experiencing repeated hospitalization, but the parent was reporting concern that the child’s actual personality was changing. Attempts to normalize the behavioral changes by the child for the parent were rebuffed by the parent who consistently looked for a medical cause for the change in behavior. Although there is an American Psychology Association Diagnostic and Statistical Manual
for Mental Health Disorders (2000) text revision diagnosis for personality change due to a general medical condition, I experienced the changes the parent was reporting to be typical of the research literature for children undergoing invasive medical procedures and hospitalization (Blake & Paulsen, 1981; Cooper & Blitz, 1985; Knott, 1979; Le Vieux, 1990; Lindquist, 1980).

CINDY completed her first two play sessions, then reporting she had stopped the play sessions. She reported her last play session in the hospital felt significant, since the child engaged in medical play; however the child became very agitated when the play session ended. She reported the child's blood pressure had risen because she had become so frustrated that the play session had ended. Although the parent met with me two more times after the hospital play session, she refused to have another play session.

Ironically as the child became more demanding and resistant with the parent, I experienced the parent as becoming more resistant to FT. The parent's oppositional behavior increased right after the fourth week, and continued throughout the remaining FT experience. The last week, the parent reported that her mother and best friend had both recently become ill. The following week, CINDY left a phone message terminating the FT. The transcript of the message is below. It would appear that the parent could not continue FT once other stressful factors, such as illness of her best friend and mother, and reported difficulties with her husband, entered into the dynamics of her life circumstances. The message left on my voicemail transcribed below is an example of the plus one phenomenon:
Hey LeAnne, its CINDY...I got your message. We are actually in the hospital right now. CHILD had a couple of procedures done and then my husband is going to come by and take over this afternoon. Uhm, the last message I left you, I basically decided I’m not going to continue with the play sessions for right now. I’ve just got too much going on. It’s not only CHILD, there’s just a lot of other things going on. At some point, I am going to have to fly up north. I don’t know if it is going to be this week or next week. Uhm, so at this point, uhm, I am choosing not to meet basically, at this point for right now. I think the play sessions are a good idea; it’s just that CHILD not adapting to them well. And I am spent with everything. Not only with her, but with everything else going on. So, you know, that’s just what I’ve decided to do at this point. So, thanks for everything. And if you’re at the clinic at some point meeting with somebody, I’ll just, you know, I may see you there.

As evidenced in the voicemail, she repeatedly reports that with everything “else,” she cannot remain committed to the FT. Her difficult experience, when the child became upset over ending a play session in the hospital, in combination with the illness of her mother and best friend were too much. Therefore, FT was cut from the parent’s commitments at that time.

DEBBIE committed to FT but terminated after the pre-interview and four FT sessions. The child of focus had several serious diagnoses aside from lymphoma, including extensive cardiology problems that required a complete heart transplant two years earlier, before he developed lymphoma. She reported a strained spousal relationship, and her older son (14) was having severe emotional problems; was reportedly depressed, angry, aggressive, and experiencing suicidal ideation. She also reported that her mother who lived nearby was diagnosed with advanced hepatitis and was often hospitalized.

Several hypotheses are presented as to why DEBBIE could not commit to continue FT. The plus one factor is hypothesized because the client attempted to participate, but
was unable to have her home play sessions, or ultimately continue FT due to feeling overwhelmed with having a child with multiple life threatening diseases, plus lack of support at home, plus illness of her own parent, plus emotional disturbance of her older son.

Second, the child was born with a severely defective heart and the nature of the relationship between the parent and child had always been one of great dependency on the parent. I experienced this parent as attached to the role of taking care of the child of focus; and resistant to helping the child gain more independence in areas where he could be independent. For example, the child was five years old and was still unable to dress himself even though he was developmentally coordinated in his motor skills and capable of rolling around the IV cart throughout the specialty clinic and hospital.

Third, due to the difficulty reported in parenting with the older child who was having emotional problems, I hypothesize that the parent was focusing all her energy on taking care of the child of focus. She was incongruent in that she would ask for help, but any help offered was either dismissed, or she did not follow through with the instructions in order for change to ultimately occur. For example, I offered to help with the older child and was dismissed without serious consideration on several occasions. In another example, the parent took the child of focus to a specialist so he could learn how to feed himself. She participated in the procedures; however, she did not continue the regimen at home and the child did not maintain the ability to feed himself.

Ultimately, the parent was experienced as so overwhelmed that she could not commit to anything. In the previous paragraph examples, the primary manifestation of
each is hypothetically due to the stress she is experiencing. She appeared, to be in a stagnated state of existence where change was almost impossible to occur on an emotional or relational level. She could not see beyond her most present experience to comprehend how committing to some of the aid she sought would help her life feel less chaotic in the long run. She also reported harboring a lot of resentment to medical and social services for not being able to help her enough.

EMILY terminated after the third FT session. She reported having one play session, but I was unable to review it. EMILY telephoned after the third FT session and cancelled her next FT session citing a change in the child of focus’ prognosis. She was very upset when she called. I waited 5 days and called EMILY to see if she wanted to reschedule. The child-life specialist from the hospital who had been working with me called the next day and informed me that EMILY had decided to drop out of the FT.

In the case of EMILY, the plus one factor manifested in the subject’s inability to continue when one more traumatizing factor occurred in her life. Having a child with a life-threatening illness, plus having the prognosis change, overwhelmed the subject and FT was the thing that she removed in order to feel she had control over her life-experiences at that time. She reported having lots of family and friend support and a good spousal relationship, so she was able to commit to the FT in the beginning before the child of focus’ health began to deteriorate. Although I saw her several times in the hospital after she terminated and had an opportunity to acclimate somewhat to the new circumstances, she never showed interest in continuing FT again.
FRANCIS was initially excited about the prospect of FT as evidenced by reporting to me that she thought it could be very helpful for her and her son. In her case, her son had been diagnosed a few months earlier and had just completed his major hospitalization and bone marrow procedures. He was still admitted for high fever, and was scheduled for regular specialty clinic appointments, but the parent reported feeling like the majority of the hospitalization experience was over.

The parent reported that she lived with her husband and that they had had some marital problems before the diagnosis of their child with a life-threatening illness. She reported her husband was not supportive of her participating in the FT because he felt the hospital experience was complete and the child would recover on his own. She reported that the only family nearby were all related to her husband and were also not supportive of her participating in FT since her husband was not supportive.

After the second session, FRANCIS reported that she needed to terminate the FT. She stated that her husband stated an ultimatum to end the FT or end the relationship, and she was going to succumb for fear of losing her relationship. This may be a manifestation of the plus one factor, being the troubled relationship, plus the child’s illness was too much to commit to FT; however, the fact that the FT was actually used as an ultimatum in the relationship confounds the hypotheses so the plus one factor was not considered the hypothesis as to why the client could not commit at this time, but the fear of loss instead.

GEORGIA never could commit to the FT. GEORGIA was alone during the week for the most part, with visits from family on the weekends. She was staying at the Ronald
McDonald House while her son received bone marrow replacement therapy. Once he was complete with the hospitalization portion of his treatment, he moved to the RMH with his mom while he had specialty clinic appointments every other day for several weeks.

Although the mom was highly interested in the FT, dealing with the serious illness and hospitalization, plus not having local family or a support system, plus living at the RMH, plus being a single parent with the child throughout the hospital and specialty clinic experience, the FT was hypothetically too much to commit to at that time. She reported feeling overwhelmed and unable to concentrate on committing to meetings at the hospital, specialty clinic, or even RMH. In this case, the plus one factor appears to be a possible explanation for her inability to participate.

*Commitment Similarities between Subjects*

The most notable similarity between the two parents who were able to commit to the FT is family support. Both had extended family in the area who offered both emotional as well and financial assistance to them as parents. It is obvious how having family support would increase one’s ability to participate in FT while undergoing the stress of having a child with a life-threatening illness.

Another notable similarity in the two participants is they both had been coming to the hospital for over six months. The original diagnosis occurred for both participants at least 2 years earlier. One was in remission, and the other had recently been in remission but was re-diagnosed approximately four months before beginning the FT. Regardless of this difference, the acclimation to the hospital experience seems to
increase the likelihood of a parent’s ability to commit to FT in the cases of these two families.

One interesting similarity to note is that both of the parents who did commit to the entirety of the FT are single parents. ANNIE is divorced and BARBARA is a widow who is actually the grandparent and raising the child. Perhaps because they are single parents, they have made sure to put themselves in a situation where they have a higher level of family and friend support than other parents. Or perhaps the family members have made themselves more available for supporting the parent due to her status as a single parent with a child with a life-threatening illness. Another possible conclusion is that the single parents were not also dealing with spousal problems typical of this population, and therefore were more capable of committing to the FT.

Collective Case Results and Discussion

The results across cases, both similarities and differences, will be reviewed in the context of the research question. Each section of the question is restated and followed by the concurring findings, and a discussion of the findings. Subjects will again be referred to as ANNIE, BARBARA, CINDY, DEBBIE, EMILY, FRANCIS, and GEORGIA to preserve confidentiality. Underlined quotations were made by the subjects.

Research Question: What adaptations to FT are found to be most beneficial in working with families who have a child with a life-threatening illness?

Although the research question asks what adaptations were found to be most beneficial when using FT with families who have a child with a life-threatening illness; it is my opinion that conveying adaptations which were attempted and found to be
unsuccessful are as important for further research, and therapeutic intervention attempts. Therefore, adaptations found to be least beneficial and negated from utilization are discussed as well. The primary adaptations were flexibility and toys. Several sub-categories are listed with each primary adaptation.

**Flexibility**

Flexibility on the part of the therapist when working with families who have a child with a life threatening illness was found a significant theme upon analyzing the data, and to be of eminent importance. Although this finding was expected, the manifestation of flexibility as a key component in multiple facets was somewhat surprising. Flexibility will be discussed in the context of; a) therapeutic methods (parent cathartic session, dependency versus independence, and homework); b) individual versus group; c) intense filial training; d) non-traditional weekly sessions; e) hospital versus other setting; and f) location of sessions in the hospital.

**Therapeutic Methods**

Several adaptations were found to be useful regarding traditional therapeutic beliefs when working with parents with a child with a life-threatening illness in FT. One important adaptation to FT was related to a phenomenon experienced with parents who participated in four or more FT sessions. I labeled the phenomenon the parent cathartic session. Other adaptations to traditional therapeutic methods in FT relate to dependency versus independence, homework, and tolerance for cancellations and forgetfulness. Each finding will be discussed separately in the following paragraphs.
Parent cathartic session.

Parents who participated in four or more sessions had a session where an important cathartic release occurred. The therapist disregarded the didactic component of the session that day and focused solely on the parent’s need to express feelings. Parents regularly discussed personal issues in FT, but each parent who continued FT for 4 or more sessions discussed at length, and with feeling, the experience of having a child with cancer. Although a cathartic type experience occurs often with parents in FT, it is usually related to guilt over feeling ineffective as a parent. In these sessions, it was related to the therapeutic need to process feelings around cancer, death, grief, loss, and less related to parenting. Most parents, however, did still include some discussion regarding guilt over feeling powerless and overwhelmed in attempting to parent their child through a life-threatening illness during the cathartic session.

ANNIE’s cathartic session occurred in the ninth meeting. She reported that when her daughter was first diagnosed, she felt an overwhelming desire to appear strong by the difficult news. She reported she drove her car to the country and cried and prayed because she didn’t want her daughter, or anyone to see her cry. She reported that everyone told her how strong she was all the time, and that she felt completely different inside. She discussed how her daughter started to shut down next and she felt so lost and unsure, she had no idea what to do. She cried most of the session, but reported that now she feels she has taken some control over her feelings and has helped her daughter open up.
BARBARA had a cathartic ninth session as well. Her daughter had been rushed to the hospital a few days earlier in severe pain and it took a couple of days for the doctors to figure out what was wrong with her. BARBARA took charge of the session in the beginning and began processing the previous days. In an excerpt from my notes:

She then moved on and told a story of how child said, when she wasn’t looking at her, and it wasn’t typically prompted in their relationship, “I love you, nana” Monday night. When she told this story, she cried. Her eyes watered up and she said she didn’t cry at the time it just caught her off-guard. I responded that it felt special and real. She responded yes. I also responded that it felt like she was acknowledging her for everything she does for her, and acknowledging her own mortality in a way since she is realizing the importance of her nana and the relationship. BARBARA acknowledged that response and said she felt like it might have been the first time that anyone had ever acknowledged her for all she does and her sacrifices.

BARBARA went on to share the story of her daughter’s death, the death of her husband in an accident, when her child was first diagnosed with cancer, her grief response, and her anger with her husband for getting into an accident when she needed him. I experienced the entire session as a talk therapy session rather than a FT session.

It is common when people are in a state of severe bereavement to continue in life as if nothing ever went wrong. BARBARA reported that no one was allowed (because she would not allow it) to cry or convey sadness about the losses for several months
after the loss of her husband. She reported a state of denial and a need to control the environment by not letting the sadness into their lives. She reported a fear that the children would feel scared if she released the façade and allowed the waves of grief to roll in.

DEBBIE’s cathartic session occurred in the fourth meeting. Although DEBBIE was experienced as less capable of communicating what she was feeling and thinking in the FT, I had put many of the pieces together over the last several sessions and phone conversations between sessions. I had experienced DEBBIE as incongruent most of the time, smiling while discussing her son’s serious illness and other grave stresses in the family.

In session IV, DEBBIE began the session by disclosing her lack of support. She conveyed she had no friends, family was far away, her mother was very ill too, and the relationship between her and her husband was reportedly incohesive. She appeared to be very sad, cried, and conveyed congruence between her internal and external feeling experiences. She also appeared to be relieved and surprised by my ability to convey understanding of her experiences. From the notes:

*Investigator: “things seen really chaotic and hectic in life and at home right now. You are overwhelmed, frustrated, pulled in many directions, busy, tired, scared, maybe feeling guilty, fearful for your son, and you and your husband have a strain in your relationship that feels like one more problem a lot of the time, rather than as a support outlet, or something else it might have been in the past.”*

*DEBBIE: “I think you understand.”*

Although the agenda for the day was put aside in order to allow the parent to have the cathartic session, it is my opinion that the parent knew what she needed that day and chose to use the session in her best interest. Due to the didactic component,
and the therapeutic agenda to convey information each session, the filial therapist typically attempts to contain the dynamic component of FT in order to transmit the information. Flexibility regarding the didactic agenda when working with this population appears to be important for the parents to utilize some of the time for their own significant agenda as well.

Due to the individual nature of the FT sessions in this study, the parents were accruing the material at such a fast rate that sacrificing a session to the needs of the parent was not a significant issue. The parents were able to process feelings regarding the illness and their own response to it very well, in a genuine and congruent fashion. The parent coming to more realistic and comfortable terms with the illness will ultimately help the child and help in child/parent communication as well.

Because the parents had all been reporting a need to be a pillar of strength, and none had reported seeking therapy in this process, it would appear the therapeutic relationship created an opportunity for them to utilize the moment and take advantage of the relationship to help themselves I believe this session to have been a significant factor in the growth of the parent and a useful part of the time spent with the parent.

Dependency vs independence.

Another result noted to be different with this population compared to other therapeutic populations is the concern of creating dependency in clients. With most populations, therapists are ethically concerned about creating dependency in their clients. Clients who are forgetful are not called to remind them of appointments in order
to create a relationship based on the client’s ability to take care of their self, and not become dependent on the therapist.

When working with the population of parents who have a child with a life-threatening illness; I believe that parents are forgetful because it is the nature of persons under such great stress and grief to be forgetful (Cook & Oltjembruns, 1998; Corr, Nabe, & Corr, 2003; Worden, 1991). I found that almost every parent in the study forgot about a FT session at least one time. Because the goal of the therapy was not to foster independence for the parent personally, I found it useful to give the parent a reminder call the night before the scheduled session to make sure they still wanted to meet. Occasionally the parent had changed the hospital specialty clinic appointment and forgot I was intending to meet them there the next morning. Interestingly, I found that parents who stayed in the study began to remember to call me when things had changed.

Due to the nature of the population and high level of stress, it would appear that the probability of creating dependency with the parents, based on a courtesy call the night before a meeting to be slim. In fact the parents were not called until they missed a session without calling one time. The fact that they did not show signs of dependency indicates that the forgetfulness of the client was not intended to create a dependent relationship with me, but simply due to forgetfulness related to stress. In the case of this population, it is reasonable to check in more often than with a client coming for therapeutic growth.
Homework.

Although homework in FT is typical on a week to week basis, due to the stress level of the parents, I found homework was difficult for the parents to remember, much less complete. The homework is typically minimally difficult and consists of a simple task, such as identifying four feelings to the child between FT sessions. Homework was discussed in the context of the session whenever possible to adapt to the specific life circumstances of the parents. This difficulty may also be a related phenomenon to the plus one factor. Because they are in such a stressful lifestyle and have so much chaos in their lives, they cannot commit to more than just the play session as a homework assignment.

Tolerance.

When working with parents who have a child with a life-threatening illness, I adapted a higher level of tolerance for cancellations, forgetfulness, and missed appointments. Typically, the filial therapist would confront the parent's cancellation or forgetfulness as a parenting concern related to commitment to their relationship with their child (Guerney, 1980). The parents already feel some guilt regarding the illness of their child (Blake & Paulsen, 1981; Mack & Berman, 1988; Van Fleet, 1992). Even though the guilt is irrational, to confront them with their forgetfulness and not display tolerance, would confront their parenting in general, to a point they would more than likely terminate.

The forgetfulness and high stress create a different dynamic where the parent is more likely to cancel regardless of their commitment level to helping their child. I would call the parent and let them know when they had forgotten a session, but would not
confront them with other issues related to forgetfulness. The parents who continued FT were able to self-correct this problem after approximately 5 FT sessions.

**Individual vs Group**

FT is traditionally conducted in the group format. The group format for parents who have a child with a life-threatening illness is ideal since parents have an opportunity to share feelings with other persons who truly understand what they are experiencing. However, due to the high level of flexibility needed in order to meet with each parent, coordinating with a group of two or more parents was found to be almost impossible. I was able to have 2 group sessions, and the findings are reported below.

**Individual.**

The findings indicate that the benefits of meeting individually included; a) a faster pace of conveying the didactic elements of FT, b) the relationship between the therapist/ investigator and parent was enhanced, and c) the probability of the parent’s ability to come to the FT was enhanced. I experienced meeting with parents individually increased the pace of information attainment, particularly for parents who continued beyond five FT sessions. The role plays, individual attention, and discussion allowed the parents the ability to learn the information very quickly, which left more time in the sessions for therapeutic flexibility.

ANNIE completely understood the play sessions as evidenced by ability to identify communication, themes, and personal feelings; and reported using many of the skills, including reflective listening by session 7; both outside and inside the play session.

BARBARA completely understood the play sessions, was able to identify themes and
personal feelings, and reported using the skills outside of play sessions by session 8. CINDY understood the importance of play, reported noticing the child’s play and relevance of play outside of play sessions (when she overheard her play in the next room), and reported using reflective listening skills outside of the play session by session 5.

Another advantage to individual FT sessions was the enhancement of the therapist/parent relationship. I found that due to the increase pace of information attainment, the extra time was utilized by most parents as an opportunity to process personal feelings regarding the hospital experience with the therapist. Most parents spent anywhere from fifteen minutes, to one hour processing personal feelings regarding their experiences per session. ANNIE, BARBARA, CINDY and DEBBIE processed personal feelings related to guilt, grief, fear, sadness, anger, spousal difficulty with communication; and need to be perceived as a pillar of strength. Although the therapist was unable to have enough group sessions to be sure the same benefits would not have occurred in the group setting, the findings do indicate that it occurred in the individual setting.

The last finding regarding meeting individually was the convenience to the parent. As mentioned before, the low rate of response also left me, and parents with no choice as other parents were usually not available. At one point, however, three different parents were meeting with me at the same time and on the same session. Although a couple of sessions were completed with a group of 2 or more of these parents, the parents were unable to sustain scheduling sessions together due to; lack of
commitment to be at the hospital on non-hospital visit days, different specialty clinic
days, and overall stress manifesting in a need for personal accommodation by me.

*Group.*

I had the opportunity to have 2 group sessions with three of the subjects. The
subjects used the time to learn the skills and immediately created a feeling of rapport
within the group due to the similarities of experience. Although the group was not
heterogeneous since all three children had different diagnoses, different amount of time
spent in the hospital setting, and different prognoses, the parents all conveyed empathy
and support to one another in this setting. Due to the limited number of sessions, I am
unable to ascertain how beneficial the group setting might have been, however, the
subjects maintained friendships and support alliances in the hospital setting after the
two sessions as reported to me by BARBARA and CINDY, indicating that even a minimal
number of group FT sessions capitulated helpful alliances and support for the parents in
the hospital. If available, or if more persons are willing to commit to FT, the group
environment would probably be the best format for the population considering how
quickly they aligned with a minimal number of groups.

*Non-Traditional Weekly Sessions*

Traditional weekly sessions were found to be the most beneficial across the cases
that participated in this study. This finding was surprising due to the flexibility issue. I
believed the parents might prefer daily, or bi-weekly sessions as an alternate, but the
parents preferred the more traditional weekly sessions. One adaptation to traditional
weekly sessions found to be useful was to make each appointment on a weekly basis.
The results indicate that the parents can not commit to a weekly time where they can always meet (for example, Wednesdays at 5:30). The weekly sessions may also move from the hospital, to the specialty clinic, to maybe even the house of the participant depending on their hospital schedule that week.

**Intense Training**

Prior to beginning the study, I anticipated that condensing FT into an intensive training format would potential meet the treatment needs of this population due to extensive hospital visits, stress, potential to complete long sessions while waiting for lab results, etc. When working with several of the subjects, I attempted to use the methods utilized with intense FT (Harris & Landreth, 1997; Smith, 2002). I attempted presenting the idea of having daily sessions with parent while the child was hospitalized, and “power sessions” where the parent may cover the topics normally covered in two sessions in just one long session. The child-life specialists involved in the study also suggested the power session format for parents staying in the hospital with their children receiving bone marrow transplants. Even the parents were responsive initially, when presented with the idea of completing the FT at a faster rate while they were staying in the hospital; however, neither type of intense FT adaptation was found to be effective with this population. Examples of the attempts made to use power sessions and the results are listed below:

CINDY had one intense session initially. Although she reported no problems with the session, she was not available for further long sessions. She did continue normal
length sessions for several more weeks before dropping out due to reported overstress related to other problems in life at the time.

In the case of EMILY, whose child was hospitalized at the time, I attempted to meet with the parent for an intense 2 part power session the first day (covering session 1 and 2) and she appeared very interested. The next day, I met with the parent for session 3 and she attempted to have her first play session that night in the hospital. She reported feeling a sense of urgency to have the session that night due to a potential meeting with me the next day. She reported the child was exhausted and the play session was very difficult. She excused herself from further FT sessions for a week or so, eventually dropping out of FT when the prognosis of the child changed.

In the case of GEORGIA, the family was from out of town and stayed at the Ronald McDonald House. The medical treatment was to last only 3-4 weeks, so the traditional Landreth model was not possible, and the only possibility to meet with the subject was in some form of intense FT. The mother reported being interested in the FT, and spoke with me on several occasions. I suggested a willingness to adapt the FT to meet this parents needs by trying intense FT, where the subject could meet with me daily at the hospital or at the RMH while undergoing treatment. The subject was unable to commit.

In the actual circumstances, my self, parents and child-life specialists, all discovered that the intense FT procedures would not work with this population.

Several possible reasons are plausible as to why it was so difficult. First, the hospital setting is intensive and chaotic. It is difficult to determine when a procedure
may actually occur, or when the nurse or a doctor may come to the room to meet with the parent. To meet one time every few days is feasible. But daily or for power sessions appears to take the parent away from the child of focus for too long. There are also extended family and friends who come to the hospital for visits. The parent feels obligated to stay near them when they visit. Second, the child of focus was more deprived of parental attention and comfort while staying in the hospital and becomes agitated with the parent for abandoning them every day, or for power sessions while they are in the hospital. Third, the parent is not sleeping very well in the hospital usually and tends to become somewhat exhausted after a day or two. Fourth, the commitment to have a play session between each FT session in the hospital, while both the parent and child are exhausted, appears to be overwhelming. Several parents were able to have a play session in the hospital and reported it to be a nice break, and a good experience, but to try to have more than one every few days, is stressful on both the parent and child in the hospital environment.

The last problem, which is related to the previous problem, is the hospital activities. The hospital staff had many activities on a day to day basis for the child and parent to participate. Sometimes the activities exhausted the child so much during the day, that trying to have a play session that evening, in the middle of a chemo treatment, was both stressful and ineffective.

In retrospect, many of the problems experienced in utilizing intense FT with this population were indicated in the preliminary research literature. Apparently I overlooked the foreshadowing that children would feel abandoned, exhausted and overwhelmed at
having their parent removed for several hours at a time on a daily basis (Blake & Paulsen, 1981; Glazer-Waldman et al., 1993; Le Vieux, 1990; Van Fleet, 1992). Another indicator of the difficulty in intense FT with this population was the literature related to parental guilt and a need to be with the child as much as possible in the hospital (Knott, 1979; Van Fleet, 1992).

Location of Sessions

I found that being flexible to move from location to location so parents can be close to their child was of eminent importance. I found that adapting the FT to meet most settings was highly necessary. Since this hospital did not have play therapy rooms available for use, the actual meeting place changed according to the schedule of the parent, and the schedule of the hospital. When available, a parent conference room was ideal; other options were examination rooms, hallways, even a balcony in the case of this study (internal balcony). The flexibility and ability to use imagination to discover a private place to meet in a hospital or specialty clinic was a clearly important adaptation experienced regularly.

Another way that flexibility was found to be important was when the family had a reprieve from the hospital one week. Parents reported not wanting to make a special trip to the hospital, that the emotional stress of being in the hospital was sometimes overwhelming, and that they preferred to not be there unless absolutely necessary. Most parents parallel absolute necessity to medical procedures only. One parent met several times at the hospital on days she did not have to be there (ANNIE); however,
most parents were reluctant to even try to make an appointment with me at the hospital when there was not already an appointment scheduled to be there.

In the case of BARBARA, several sessions occurred in the home of the subject between hospital visits. The subject preferred the home environment and was open to allowing me into her home for FT meetings. In the case of DEBBIE, for example, the child had specialty clinic appointments once a month. The parent would commit to meeting me at other times, between hospital visits, but was unable to attend those appointments. She regularly cancelled or no showed appointments that were not coinciding with specialty clinic appointments. In her case, she was also unwilling to allow me to come to her home for a meeting between appointments.

Most of the parents who did commit to make a special trip were found to cancel, or miss the appointment due to forgetting the meeting. The findings indicate that parents are more willing to meet in the home, or take the week off from FT when they do not have to be at the hospital, than to make a special trip for the FT. The best possible solution is to meet in the hospital, and be prepared to take a week off it they do not have a hospital or specialty clinic appointment that week.

**Toys**

The toys were adapted to fit the special needs of families who have a child with a life-threatening illness. The toy adaptations included; a) using real medical supplies, b) having spongy type dolls for performing procedures (injections) with, c) extra dollhouse dolls for creating hospital children wards, and d) doctor and nurse dolls or puppets. The findings for the cases included in this study will be listed according to the toys adapted.
Real Medical Supplies and Spongy Dolls

The idea to use real medical supplies with hospitalized children is not novel in the context of play therapy research of chronically ill children (Adams, 1982; Azarnoff, 1974; Bowmer, 2002; Eisert et al., 1988; Glazer-Waldman et al., 1992; Kayes, 1991; Le Vieux, 1990; McCue, 1988; Shipton, 1995; Van Fleet, 1992; Vilas, 2000; Webb, 1995). The research with parents and FT with chronically ill children is limited, but there are other studies that also used real medical supplies and found them to be helpful (Glazer-Waldman et al., 1992; Van Fleet, 1992).

In the instance of this study, the real medical supplies were used by two of the five children who had play sessions with their parent, and two out of three who had more than three sessions with their parent indicating the use of medical play may increase as the parent has more sessions with the child; or the child may become more comfortable exploring and communicating more stress inducing play as the number of play sessions increases. In one example:

In the video of the play session with ANNIE and her daughter a week before an MRI, the child played out the entire procedure with the spongy doll and the real medical supplies (gown, gloves, stethoscope, set ups). The parent reported surprise at the detail the child used because, “usually, she is so uncooperative in the room and moving around so much, I didn’t think she was paying attention to the preliminary procedures.” The parent reported that when they arrived for the MRI, the child was very calm and relaxed. When the doctor queried to her lack of nervousness, the child reportedly commented, “I was nervous, but I am not anymore.”

This finding indicates that the use of real medical supplies helped the child to process feelings regarding a procedure, that was normally very difficult for her and ultimately she was able to help herself increase cooperation during the MRI.
spontaneously took the initiative to use the medical supplies in the play session to cope. The parent reported that the doctor asked the parent what was different and the parent reported telling the doctor it was the play sessions.

This communication is interesting because not only did the doctor recognize a significant change in the child’s cooperation, the parent directly reported attributing the change to the play sessions she was having with the child of focus between doctors appointments. The communication indicates that both the parent and child are feeling a sense of mastery in the world directly related to gaining a sense of mastery through the use of parent child play sessions.

The discussion point of spontaneity is also relevant. Typically, in the hospital setting, the child-life specialists will use medical and anatomically correct dolls to help children perform procedures, and this has been shown to be helpful in decreasing anxiety and increasing cooperation (Vilas, 2000)). This child had assistance such as this in the medical setting, and although it may have been helpful in decreasing her anxiety, she still conveyed enough anxiety to be considered very uncooperative by her parent and medical staff; however, given the opportunity to play out the experience spontaneously, and without assistance, or guidance from an adult, she was able to find a way to decrease her anxiety to the point of cooperation noted by the medical staff, doctor, parent and even the child. It would appear in this case, that although the therapeutic play used by child-life specialists was helpful, the FT play sessions with parent and child, where the child has control over her choice of play materials, was
more helpful in increasing cooperation and decreasing anxiety of the child than the directive type play used by the child-life specialists.

In the case of BARBARA, the child was hospitalized one to three times per month for chemotherapy or complications related to high fever. She never used the medical supplies in her play. She solely focused on mastery and control related toys such as the cards, and never mastery and control/ reality based toys such as the real medical supplies. The parent reported increased cooperation, and increased communication between her daughter and medical personnel, indicating the child was processing feelings regarding hospitalization in her own way to increase cooperation, without the use of the medical toys. Mastery and control play is very important to most children, but for children in the hospital setting it is of particular importance due to the lack of control they have over most of the hospital experience (Gray, 1989).

Again, this child had been exposed to medical play many times with the child-life specialists in order to prepare for a procedure. Although she was not experienced as dramatically uncooperative by medical staff and parent, she was experienced as more verbal, cooperative, and active in her treatment after beginning the FT play sessions with her parent. It would appear that she has developed her own method of coping with the stress of the medical situation, and including her parent in that process is helpful.

The only child to have reportedly, or on videotape used the spongy type doll was the daughter of ANNIE. The parent reported the use of the doll and I observed the play on a videotape of the play session. I am unaware of any other children from the study
playing with the spongy doll. The omission of the spongy type dolls in most of the play is interesting because they are commonly used in the hospital by child life specialists to help children understand about the procedures they are undergoing. The low level may be due to familiarity; the toy is not new so the child has less interest, or perhaps the children in the study had not needed the spongy type doll yet to communicate and process their internal feelings, or the dolls are not as important, as reported in the literature, as child life specialists believe them to be (Vilas, 2000). It may be that having a variety of toys, even for the child-life specialists, and allowing the children to choose which toys they need on which days and at which times, would benefit the children more than choosing for them according to adult standards and protocol.

*Extra Dollhouse Dolls*

Although extra dollhouse dolls were available for the children in case they wanted to make hospital wards, none of the children reportedly, or on videotapes, ever used the extra dolls for that purpose. One child used the extra dolls to create a scene from school, however all the other children who chose to use the dollhouse dolls only used the dolls for the purpose of playing out family scenes and fantasies.

The reasons the children did not use the dolls for hospital play are inconclusive, however a few hypotheses will be discusses here. One possibility is that there is a “dollhouse” included in the FT toys in the form of the lid of the box being made into a house, but there is no hospital, or hospital ward. Perhaps if a hospital or ward were available, the children would have played out a hospital scene using the dolls.
Another reason may be that they simply didn’t have a chance. Sometimes children will not use significant toys in a playroom for months. For example, I have personally worked with several children who chose not to use the Bobo punching doll for a long time, then one day beat it up the entire session. The importance of the Bobo doll was still there, and it was important to have it available, regardless of whether the child used it in the first five sessions.

*Nurse and Doctor Dolls*

The nurse and doctor dolls were not played with by the children in the study. ANNIE’s child played with the doctor doll for a few minutes one week, but the play did not appear to be particularly significant. She picked up the doctor doll, looked at it, said something offhand, “hi, Mr. Doctor,” and put it back. The findings regarding the significance of doctor and nurse dolls are inconclusive.

The same discussion applies to the doctor and nurse dolls as the extra dollhouse dolls. Due to the circumstances of the children in this environment, I believe the dolls to be important to have available. It may be that the nurse and doctor dolls were not novel and less interesting at that time. It may be that the nurse and doctor dolls were provoking anxiety in the children and were disregarded. Regardless, having them available for future play is still important.

*Research Questions and Analysis*

What similarities and differences are there between the different families involved in the study according to (a) the diagnosis of the child of focus?

The child of focus in each family had unique diagnoses. I was less concerned with getting the particulars of the diagnoses, as much as the prognosis of each specific
diagnosis. Several had a form of leukemia, but all had different prognoses. An indication of the stress level of each parent is apparent by the prognosis of each child. Each subject is listed along with the diagnosis and prognosis of the child at the time of FT.

ANNIE’s child: Brain cancer in remission, chemotherapy abandoned for 6 months, prognosis fair to good.

DEBBIE’s child: Lymphoma induced from medication due to heart anomalies which resulted in a full heart transplant 3 years earlier, prognosis, poor.

BARBARA’s child: Wills tumor on lung, prognosis, fair to good. BARBARA’s child was in remission for one-and-a-half years, but recently the tumor returned.

CINDY’s child: ?- prognosis, good. I did not write down the diagnosis at the time it was conveyed, but did write down the prognosis.

FRANCIS’ child: Leukemia- new diagnosis, prognosis good. FRANCIS’ child was finishing first phase of bone marrow treatment upon beginning the FT.

EMILY’s child: Leukemia- very aggressive type, prognosis, poor to fair. EMILY reported that if the cancer returned in less than one year then the prognosis would be very bad. The cancer returned and she terminated FT immediately. This child died 2 months after FT was terminated.

GEORGIA’s child: Leukemia- New diagnosis, prognosis questionable. GEORGIA never committed fully to beginning the FT.

The similarities and differences are more evident in relation to prognoses. In most cases, the parents of the child with the more severe prognosis were more likely to terminate FT. The exception is the case of CINDY whose child had a good prognosis but
terminated after 7 sessions. CINDY’s case was confounded by multiple other life issues, including a serious illness of her mother, and best friend, which caused her stress level to reach a point where she determined she could not participate in FT any longer. It is my opinion that CINDY would have completed the FT had she not experienced the other outside stress.

This finding regarding prognosis, is related to stress and overwhelming grief. It would appear evident that stress related to the illness would have to be correlated on some level with likelihood of survival. As indicated in the review of the literature, parents who have a child with a poor prognosis often go into a dual state of denial and anticipatory grief, where they begin to detach from the reality of the child (Blake & Paulsen, 1981; Cooper & Blitz, 1983; Core et al., 2003; Van Fleet, 1992). It is not surprising that parents with a child with a more severe diagnosis would have more difficulty maintaining the FT and ultimately the play sessions because the reality of the situation, and ability to maintain a state of denial, would be almost impossible while conducting home or hospital play sessions. The stress is perceived as beyond overwhelming and the maintaining the status quo is the coping strategy experienced as most viable by most parents in this state in life.

What similarities and differences are there between families involved in the study according to the support system the family experienced?

Each family was in a unique situation regarding the level of support they experienced from outside sources such as extended family, friends, social services, and in the case of spouses, each other. The reported level of support received and sought out in each family is listed below.
ANNIE reported high level of support. ANNIE and her child lived with the subject’s parents and little sister. Her other sister reportedly also lived near. The subject reported that the family all helped each other with child care on a regular basis. The subject was the primary caregiver of her child in relation to hospital stays; however she worked outside the home and always had a family member with the child outside of school.

ANNIE was divorced from the child of focus’ father. She reported very little support from him regarding the hospital visits and stays. She also reported a lot of animosity with her ex-husband’s new wife and that this animosity was a source of sadness for the child of focus. Although the subject had little support from her ex-husband, overall, she had a lot of support from her family.

ANNIE also reported that she sought out many of the services offered through the hospital and social services and child-life specialists. She reported using many of the resources available to help her with her acclimation to the hospital setting and to help the child of focus. She was the very first parent to respond to the offer of FT in the hospital and was experienced as highly motivated to seek support for herself, her daughter, and her family.

BARBARA reported having extensive family support. She reported her mother, daughter, and brother were very helpful in dealing with her situation and the hospital experience. Her daughter often helped with childcare, and her brother financially supported the family since BARBARA’s husband died 3 years earlier so she could stay home to take care of the child of focus and her sister.
She reported that one of her family members was less supportive, and sometimes caused more stress in the family due to problems with alcohol, housing, and emotional health. Although she reported the problems with one family member as sometimes raising the stress in the family; she reported the overall family support level to be very high and functioning as a unit.

BARBARA also reported seeking other hospital services through the social workers, and child life specialists. She reported the services had been helpful in acclimating to the hospital environment. BARBARA completed the FT.

CINDY reported a high level of support with friends and family initially. Most of the extended family lived out of state, so friends were reportedly more able to be supportive with childcare, etc. She reported some difficulties in her relationship with her spouse related to taking care of the child of focus and her other child; however I observed that the parents split time at the hospital and each took responsibility for allowing the other breaks and time away.

CINDY reported her mother and best friend became ill after several FT sessions. She reported the change to be very stressful. She reported at that time feeling very overwhelmed and much less extended support in the acclimation to the hospital. CINDY did not report seeking out other hospital social services outside of the FT. CINDY discontinued the FT after seven sessions.

DEBBIE reported very little support in her family. She reported her relationship with her spouse was strained. She also reported her mother lives nearby; however she had come down with Hepatitis and was seriously ill and hospitalized herself a lot of the
time. She reported one of her other children, a 14 year old male child, was having severe behavioral and emotional problems. She reported having very few friends.

DEBBIE also reported seeking some social support from the hospital social workers. She reported it to not be very helpful because she reported the hospital social worker would only help with the child of focus and not the entire family problem. I offered to work with the family and older child separately while she continued FT. DEBBIE refused the extra help and discontinued FT after 4 sessions.

EMILY reported a high level of family and friend support. She also reported a high level of support with her spouse. EMILY terminated the FT when the prognosis of her child changed after the third FT session.

FRANCIS reported very little family support. She reported she and her husband had been having problems before the child was diagnosed with leukemia. The extended family in the area was her husband’s mother. It was reported that the mother-in-law helped with childcare; however, she was reportedly not experienced by the parent (FRANCIS) as an outlet of emotional support. FRANCIS dropped FT after two sessions. She reported her husband did not want her to continue the FT and she reported fear he would leave her if she continued.

GEORGIA stayed in the Ronald McDonald house while the child of focus was undergoing treatment for leukemia. Her spouse and extended family visited during the weekends. She had very little support in the hospital from friends or family. Friends were not available at the hospital at all since she did not live in the area. She was never able to commit to FT.
It would appear that parents who experience more family and friend support are more likely to continue FT. ANNIE and BARBARA both reported the most support and both completed the entire FT. CINDY reported a high level of support in the beginning and discontinued FT soon after her reported support system changed due to the illness of two other persons in that support system. CINDY also had reported some problems in the spousal relationship. FRANCIS, GEORGIA, and DEBBIE all had reported the least amount of social and family support at the time of FT and none were able to commit to FT for an extended period of time, if at all.

The finding that individuals with higher levels of support are more likely to continue FT was not surprising. Their stress level was positively affected. Also, they were able to have a family member spend time with the child of focus in the hospital while they met with me, instead of leaving the child alone in the room, or in the play room with a volunteer. Also, in the case of ANNIE, she met me at the hospital on days when she didn’t have hospital appointments. She could do this because family members were able to respond to the child of focus’s needs at home, or if she became ill or hurt at school. The parents who had less support from family and friends appeared to have more trepidations regarding being further than a few miles, or even yards of the child of focus in school, hospital, or home setting.

What similarities and differences are there between the different families involved in the study according to the type of treatment/hospital experience the family is undergoing simultaneously with the FT?

Each family was in a very different situation according to the type of treatment/hospital experience they were experiencing; however, several similarities in experiences
were shown in the findings to increase the likelihood the parents would be able to participate in the study to completion. Each subject will be listed separately with a brief description of their hospital experience, followed by conclusions regarding their similarities and how those may have impacted the participant’s ability to complete FT.

ANNIE: The child of focus was visiting the hospital regularly to check blood counts and verify recovery; however in session VI; ANNIE reported that the doctors indicated that the MRI showed the brain tumor continued to remain under control, so she was officially in remission. The child of focus had re-grown all of her hair and it was beyond shoulder length when they began FT indicating it had been several months since she had radiation or chemotherapy. ANNIE completed the FT and came to sessions many times on days when no other hospital or specialty clinic appointment was necessary.

BARBARA: The child of focus was currently undergoing intensive chemotherapy. They had specialty clinic appointments weekly and underwent rounds of chemotherapy about every three weeks where they would stay in the hospital for approximately four days straight. The child had been diagnosed originally when she was three, had gone into remission, and about 4 months before beginning FT, the cancer had returned. BARBARA completed the FT.

CINDY: The child of focus was diagnosed one week before agreeing to begin FT. The child was undergoing regular specialty clinic appointments and was hospitalized several times over the course of FT, which occurred over a two-and-a-half month period. The parent terminated the FT after 8 sessions total, including the pre-interview.
DEBBIE: The child of focus was never hospitalized while we were meeting. However, due to the child’s severe medical condition, they had appointments with several different doctors, in several hospitals, several times a week on most weeks. Reportedly a minimum of one doctor’s appointment occurred each week. DEBBIE had been involved with the hospital since birth. Reportedly, the child of focus was born with a major heart defect and later developed lymphoma. DEBBIE terminated FT after 5 FT sessions including the pre-interview.

EMILY: The child of focus was diagnosed 4 months before FT began. His treatment was reportedly very aggressive and he was hospitalized regularly. The parent terminated FT after four sessions total, including the pre-interview.

FRANCIS: The child of focus was in the hospital on a very regular basis. The child was diagnosed 3 months before she began FT and the child had completed an extensive bone marrow procedure immediately proceeding the FT. The parent attended 3 FT sessions including the pre-interview.

GEORGIA and the child of focus stayed at the Ronald McDonald house because her son was undergoing a bone marrow transplant when we first discussed her interest in the FT. They spent several days in the hospital, then would come every other day to the specialty clinic for follow-up treatments. She was unable to commit to starting the FT.

The similarities noted between the hospital experiences of the participants, are that ANNIE, DEBBIE, and BARBARA were involved in the hospital, with their child, for a
much longer period covering a minimum of 2 years. ANNIE and BARBARA both completed the FT.

DEBBIE’s hospital experience was notably different than ANNIE and BARBARA because her child had several diagnoses and had several doctors in several different hospitals. Her child was also much less likely to survive due to multiple and serious diagnoses.

FRANCIS, GEORGIA, EMILY, and CINDY were all relatively new to the hospital experience with a maximum of 4 months since diagnosis. None of these parents were able to complete the FT. CINDY’s child had the most recent diagnosis of anyone in the study upon commencement (1 week). Her child was also the youngest involved in the study (2 yrs).

It would appear that the most important similarity in projecting probability of completing FT regarding the treatment and hospital experience was time to acclimate to the hospital experience in general. Parents who are new to the hospital environment and feeling anxious about their child’s health may be overly needy in the first few months and easily commit to different services, groups, and organizations that they hope will help them gain a sense of control and empowerment over the experience. It appears they found the hospital experience to be more stressful and burdensome than they were previously able to ascertain, and felt a need to discard some of they committed to in the beginning.

Another point is that parents who have experienced the hospital environment for longer and parented throughout that environment and treatment changes, are more
able to qualify which behaviors and parenting needs they have to work on, and which
are a symptom of a medication, or other medical problem. Parents who are new are still
trying to understand the changes they are experiencing in their self and their child, and
may not be capable of enough self awareness in this new hospital environment, for
final therapy to be really helpful, since they cannot distinguish what is medical versus
what is behavioral at that point in time. It might be useful to allow parents to acclimate
before attempting to involve them in FT when they first begin the hospital regimen.

How does participation in the FT impact the following domains: (a) verbal and non-
verbal communication of parent and child in both the play session and the home
setting; (b) child cooperation in the medical setting as reported by the parents; (c)
experience by the parents of confidence in parenting skills; and (d) experience of the
child in confidence and self coping skills as reported by the parents?

(a) verbal and non-verbal communication of parent and child in both the play session
and the home setting? - Parents who completed the FT reported a dramatic increase in
both verbal and non-verbal communication in the home setting and the play session.
One parent reported overt play communication in her child’s play sessions while other
parents reported more subtle communication in the play sessions, and more verbal and
overt communication in the home setting. The findings of each of the three parents
who had the most play sessions, ANNIE, BARBARA, and CINDY will each be addressed
below regarding communication.

ANNIE reported her very first play session was a dramatic display of
communication through the medium of play. She did not videotape this session, so the
play session was discussed verbally in FT. She reported that her child had a very
difficult week. From my notes:
ANNIE reported that the child had vacation bible school this week where she saw her half-brother and step mom several times. ANNIE reported that when the child attempted to approach her brother, her step mom would pull him back and say, “Don’t talk to her.” ANNIE reported that the child had asked several times why her step mom would not allow her to give her brother a hug. ANNIE reported telling her daughter to, “not worry about it.” At the end of the third day, they were scheduled to have their first play session. ANNIE reported that the child immediately hit the bop bag for several minutes then got the puppets and the aggressive puppet ate the nurturing puppet being very “mean.” Later she got the dog family and said, “This is a family” and put the mommy, daddy, and small dog together. Then she reportedly said, “something’s missing...oh yeah, it’s the baby brother” and put the baby brother with the rest of the family. She went back to the bop bag and hit it for several minutes and had the shark eat the head off the little girl doll. In the end, she kneaded the play dough for several minutes saying “soft” over and over.

The child obviously communicated her anger, frustration, confusion, and hurt from the previous three days. She communicated a wish that her family consisted of her mom, dad, half brother and self while leaving out the step-mother. She also arguably communicated feeling like she was getting her head bit off by her step mother with the shark play.

On the sixth FT session, after the third play session, ANNIE came to FT reporting a very important communication by the child in the play session. This session was videotaped, so the play session was viewed together in FT and discussed verbally. ANNIE reported that the child had an impending MRI the week before and was typically very nervous. She reported that the child would typically become very uncooperative during MRI procedures in the past. She had a play session two days before the MRI.

The results of the play session and MRI are listed below:

*She moved to the medical play area (first time). She put on the gown, gloves, mask, and began to perform the procedure. She showed close attention to detail. She spent most of the play session doing the medical play in a meticulous fashion, setting up, performing the procedure and breaking it down. She appeared to be*
very engrossed in the play and did not even notice when the cat wandered into the play area (normally she would notice the cat). At the MRI, the child was reportedly very calm. When the doctor asked if she was nervous, she reportedly said, “I was before, but I’m not anymore.” ANNIE reported she was calm, relaxed, and cooperative. In another appointment that week with a different doctor ANNIE reported that the child was very verbal and expressed how she was feeling directly to the doctor (normally she reportedly just sat quietly while her doctors and mother talked around her).

The results indicate that the child was communicating clearly her anxiety and fear related to hospital procedures and gaining a sense of mastery over those experiences. It is also clear that the results indicate that the increase in communication through the play sessions is having a positive effect on the parent/child relationship. ANNIE reported feeling “astonished” at how clear the communication was in the play session and how the child knew much more about her medical experiences that the parent previously thought. For example, ANNIE reported that she did not even know that the child was aware that she was having an MRI that week. The child was able to communicate that she is more aware of her situation and impending procedures than previously believed by the parent.

In the home setting, an increase in verbal and non-verbal communication was reported by ANNIE as well. Toward the end of the FT, the child’s pet guinea pig died. ANNIE reported that her family wanted to buy another one and try to trick the child into believing it was the same guinea pig. ANNIE reported she did not want to do that. She was concerned because one of the goals of FT was to help the child verbalize when something upsets her versus shutting down as she had in the past.

ANNIE reported that she told the child the guinea pig had died and the child cried for a long time. She reported that she did not try to make it better or tell her it was OK,
instead she communicated understanding and conveyed that she felt very sad too. The child decided she wanted to have a funeral and all the family and cousins were invited and everyone made eulogies and memorialized the pet. The results indicate that both the parent and child are communicating more effectively, clearly, and honestly since the beginning of FT.

BARBARA reported having a greater experience of an increase in communication in the home and medical setting than in the play sessions. The communication in the play sessions was more subtle; however the communication change outside the play sessions was experienced as more overt.

In the play sessions, the child continued to have the same play pattern every week. She is 5 years old and was diagnosed at 3; right after her grandfather died in an accident. The play was mastery oriented and developmentally similar to that of a three year old.

For example, she always took the toys next to BARBARA, but she never included BARBARA in a parallel play type of behavior pattern. She only played with the cards (matching the Winnie the Pooh cards), the cell phone, the farm animals, and the play dough. She chose to not speak during the play sessions at all. The only apparent communication was a need for mastery in her environment, anxiety in general, and a developmental regression in play indicating a need to resolve the play issues from a time of trauma when she may not have played as often as another child her age would have.
In the home and hospital setting however, the child began to communicate much more freely. One of the goals set in the beginning was for the child to become more open and expressive with how she was feeling, and to communicate more freely with medical staff. Below is an excerpt from my notes as reported by the parent in the fourth FT session:

*She reported an exchange with child where child was upset she couldn’t go to a birthday party, due to her immune system right now, and BARBARA responded that child was sad and disappointed she couldn’t go. BARBARA reported that the child said, “I hate cancer,” and that BARBARA responded, “I hate cancer too.” Then the child said, “When I don’t have cancer, I am going to all the birthday parties that I want to.” BARBARA reported that she responded that sometimes child feels lonely because of cancer. Then the child said suddenly, “I miss my mommy, I want my mommy to hold me” (her mother died when she was less than a year old, BARBARA is her grandmother). BARBARA reported she responded, “It’s hard to grow up without your mommy.” Then BARBARA reported she (child) just cried for a few minutes, hugged BARBARA, asked for pictures of her mom to look at, then, after about five minutes went to play.*

The results indicated that the child was communicating her anger about her cancer and grief over the loss of her mother clearly since the FT started considering the child was reported to shut down regarding her mother and her cancer before the FT. In another conversation reported in the seventh FT session:

*BARBARA shared that she had also been using the reflective listening pretty much all the time lately. She shared that child had informed her in the car the day before that she was ready to go to the hospital and that she didn’t need to bring a picture of her mom this time. BARBARA reported reflecting that she didn’t feel like she needed a picture of her mom and said, “are you sure?”, and child said, “yes, I am sure. I used to worry about her, but now I know she is just fine.” BARBARA said it really made her wonder what the girls wonder about their mom and it was surprising to think of them worrying about her.*

These results show a continuation in the process of resolving her grief over the loss of her mother and how that relates to hospitalization. BARBARA also reported in the ninth session that the nurses had noted that the child was much more verbal
regarding her illness and her needs. BARBARA also reported that the child was more
talkative in general with persons in her environment who she previously avoided
interacting with such as apartment staff in their complex, child-life specialists, and
medical staff who she comes in contact with on a regular basis.

CINDY had only two play sessions even though she completed seven FT
sessions. She reported understanding how the play session increases communication
and also reported having a greater understanding of communication in the home
setting. A play session which occurred in the hospital, as reported in my notes, is
reported below:

*She reported that during the play session the child had performed all of the
medical procedures, in detail, on her dolls. She reported that she had also fed
CINDY and that she had taken care to feed the baby.*

The child was on steroids and had been eating constantly over the last few weeks.
Her focus on feeding and food is apparently an attempt to process, and gain mastery
over her need to eat constantly. Her medical play indicative of attempting to gain
mastery and understanding of the experiences she was having in the hospital
environment. The results indicate that the child was communicating her need to
understand the medical procedures, her understanding of them at this point, and that
food was predominate part of her life right now.

CINDY also reported realizing how often children communicate using the medium
of play. She reported in the third FT session that she had begun to listen to her
daughter while she played in her room. She reported hearing her play out many things
that had happened in the previous days both at home and in the medical setting. These
results indicated that the parent understood the medium of play as a form of communication, and was using it to understand her daughter more accurately.

ANNIE and BARBARA both reported a drastic change in the communication of their child both in and out of the play sessions. ANNIE’s child used the play session from the beginning, where with BARBARA’s child the play session communication was more subtle and the day to day communication outside the play session became much more overt. In both cases, the end point in the same. The child and parent were both; understanding each other more effectively, and both were using the communication and increased understanding to process, cope, and grow. CINDY’s results were limited, but it appeared the child was trying to communicate her feelings and perceptions in her play with her mom. Although the results with CINDY are limited due to early termination and limited play sessions, they are still valuable to the research and were therefore included.

(b) child cooperation in the medical setting as reported by the parents? – Parents experienced the cooperation by the children in the medical setting to increase as they continued with FT overall. One parent held only two play sessions with her child and the data is inconclusive regarding cooperation. The two parents who conducted several play sessions with their child reported the child to be more cooperative in many of the medical situations presented to them once the play sessions were underway. Each participant and the results regarding cooperation are discussed.

ANNIE reported a significant increase in cooperation in the medical setting. She reported three different doctors asked what was different with the child after she began
FT, in response to noticing the child was much more cooperative in the office. ANNIE also reported the child became more verbal with the doctors, expressing her own feelings regarding her treatment. The child also conveyed feeling, “not nervous anymore” in regard to one of the medical procedures she was undergoing where she typically was reportedly experienced by the parent as “very uncooperative.”

BARBARA reported that her child also became more cooperative in the medical setting. She had previously been reported as fairly cooperative with procedures; however she would shut down when doctors or nurses attempted to talk to her about her treatment and condition. The parent reported that over a two to three week period, several different doctors and nurses conveyed to her that they were experiencing the child as much more open and cooperative with medical procedures, as well as less physically resistant, because she was more able to verbalize what she wanted, needed, and was thinking about the procedure.

CINDY’s results regarding cooperation were inconclusive. Cindy reported the child was using the play sessions for medical play, however she was becoming less cooperative with medical procedures in the medical setting, and with medical procedures at home in general. The results are inconclusive because the parent chose to stop conducting the play sessions before the child had a used the play sessions to internally process the hospitalization experience. Because the child was initiating medical play in her play sessions, I believe she was attempting to gain a sense of mastery over her experience, and ultimately may have been more cooperative in the medical setting.
(c) experience by the parents of confidence in parenting skills? - Parents who continued the FT and the play sessions reported a great increase in confidence in parenting skills. Parents who terminated early reported less change in their experience of themselves as confident in their parenting. In one example, ANNIE initially reported she often allowed the child to have extended privileges, despite behavioral problems, because the child was sick. During FT, ANNIE reported that she began to set limits with her child, recognizing that it is important to continue setting limits on behavior during an illness to help the child feel safe in the consistent structure the child understood before her illness (Van Fleet, 1992). She reported that her family encouraged her to “give in” to the child when the child chose a behavior ANNIE had set as a limit for privileges. ANNIE reportedly began parenting more confidently, despite what her family urged, and followed through with the consequences for misbehavior.

In the medical setting, both parents and children experience a loss of control over the experience in general (Knott, 1979). The FT sessions, and the play sessions, help parents gain a sense of control over the experience because they are creating more cohesiveness in the relationship and ultimately helping their child cope. This sense of control adds greatly to their sense of confidence in their parenting in a time that people are not prepared to parent through.

Having more ability to understand their child dovetails with their ability to know what kind of limits and what type of freedom the child needs to facilitate growth (Guerney, 1982; Van Fleet, 1992). The FT process manifested like a positive cycle; the opposite of a vicious cycle, where the more the parent understood the child, the more
the child understood the parent, which allowed the child to communicate, grow and become confident, therefore empowering the parent and allowing the parent to gain a sense of mastery and control in parenting in general.

(d) experience of the child in confidence and self coping skills as reported by the parents? - Parents who completed the FT reported the child of focus to display an increase in confidence and self coping skills. The increase on confidence and coping was demonstrated by the children in the home, and hospital (and the school setting in the case of ANNIE). Each family who completed at least five filial sessions and two play sessions will be reported below. The families who did not complete the study or terminated before they had at least two play sessions did not report a change in confidence or coping in either direction.

ANNIE reported her child increased in confidence and coping in the home, hospital, and school setting. She reported this manifested in the home in an increase in communication with the parent and other adults, expressing both positive and negative experiences and coping strategies. She reported in the school the child reported coping with problem solving strategies related to school friends, disagreements, and communicating effectively with her teacher. In the hospital experience, the parent reported that the child became much more vocal in her treatment and chose to be a more active participant in the discourse with various doctors.

BARBARA reported the child of focus became more confident and exhibited more coping skills in the home and the hospital. The child was not attending school at the time of treatment due to extensive hospital visits with chemotherapy and, consequently,
a lowered immune system. In the home the child was experienced by BARBARA as more likely to express her discomfort and irritability, both emotionally and physically. Barbara also reported the child was more open with dealing with the loss of her real mom to death several years earlier.

In the hospital, the child was reportedly more open with the nurses, sharing when she felt uncomfortable more readily than had been previously reported by both the parent and the nurses. She also shared negative feelings regarding the hospital experience and cancer with her parent, indicating positive coping strategies were occurring at that time.

CINDY had mixed results again. The child engaged in medical play in the hospital setting, indicating that she was attempting to process and ultimately cope with the hospital experience; however the parent terminated the study early at a time when the child was becoming less cooperative, and appeared to be coping less effectively with the hospital experience the parent reportedly previously experienced her to be coping.

Again, this finding was expected in the families who completed the FT sessions. Evidently as these children were able to communicate their feelings and needs, and gain a sense of mastery, they began to literally master their environment in the real world more effectively as experienced by significant adults in their life.

Other Findings

I noted other findings not specifically covered in the research questions. Due to the qualitative, collective case study design, the exploratory component of the study addresses allowed for findings outside of the research questions. The other findings are
listed below according to play themes, the pillar of strength phenomenon, parental involvement in the hospital experience, and goal setting.

*Play Themes*

I noted similar patterns of play indicated in earlier research discussed in the literature review; mastery and reality play were the most common themes observed (Gray, 1993; Van Fleet, 1992). Mastery play was observed in all the children in many different manifestations. ANNIE’s child played out family difficulties and appeared to make the scene end how she wanted it to end. BARBARA’s child played repeated matching games with the playing cards every week which is indicative of mastery play.

Reality play, or playing out real life experiences, including medical play was the second most common play theme reported and observed. CINDY’s child performed specific medical play with her dolls during the second and third session. CINDY’s child also played out real life nurturance themes related to food and eating. She was on steroids and eating constantly and played out feeding her dolls during a large portion of her three play sessions. ANNIE’s child conducted medical/reality play throughout many sessions with the most poignant being the medical play session where she performed an MRI on her doll, in great detail, the same week she was to have an MRI. She also used reality play to convey many other experiences she was having at home, school, church, and in the medical setting including doll play regarding her perceptions of the family and family environment.
Pillar of Strength Phenomenon

One of the themes in the data was the parent’s need, in all cases, to be a “pillar of strength” in the relationship with their child. The parents all reported a coping strategy where they would pretend that everything was normal. For example, earlier in the dissertation, this phenomenon was mentioned when discussing ANNIE’s need to drive to the country to cry so the child, and other relatives, would not realize how worried and scared she was.

Considering that all the parents who participated in FT reported this need, and I observed it in others, and it is reported in the literature, the need to appear to be a pillar of strength must be the most natural, immediate reaction to learning that your child has a life-threatening illness (Blake & Paulsen, 1981; Ishabasha, 2001; Knott, 1979; Le Vieux, 1990; Van Fleet, 1992). The consequence of this reaction, as observed by me and reported by the parents, is that the parent is experienced as disingenuous by the child. The child perceiving the parents need to avoid the truth, begins to isolate and joins the parent as a disingenuous pillar of strength. The child, in isolating him or herself from the reality of illness, will not communicate emotional or physical pain to the parent, or doctor, regarding the illness. A vicious cycle develops where the parent, feeling frustrated, becomes more determined to model to the child a sense of safety and security through the disingenuous strength, therefore the child isolates and pretends to be strong and continuous to join the parent’s state of avoidance.

The play sessions allowed the child to communicate, perhaps subconsciously, his or her understanding of the reality of the situation, and to experience the parent as real
and genuine again. The parent was able to realize that the immediate reaction to the
disease was irrational, through the process of FT. Together, the parent and child were
then able to recreate the positive cycle of communication and understanding where
relational cohesiveness occurs.

*FT Parent*

In all seven cases, the parent who participated in FT was the mother. I found that
is was more likely for the mother to be in charge of the hospital and specialty clinic
visits. Although one of the fathers expressed interest in participating in the FT, he was
unable to attend the sessions due to his work schedule. I offered to schedule the visits
whenever would be most convenient for them, either including or not including both
parents, and they chose to go by the hospital and specialty clinic appointments.

*Goal Setting*

The FT investigator included an opportunity for each parent to set three goals for
self as parent, and three goals for the child for the FT experience. I set the goals the
very first week, and checked in with each parent regarding the goals, each week, after
the first play session was held. The parents reported liking this aspect of the FT. Each
parent had different goals set for self and child, but each goal fit with the specifics of
their experience. Some of the goals set included helping the child to be less “adult like”,
increase in spousal communication, increase in experience of self as effective, ability for
child to dress and feed self, decrease in parental guilt, and decrease in experience of
child demanding-ness of parent.
The parents reported that both the parent and child were attaining the goals set. For example, ANNIE set a goal for the child to communicate more clearly how she was feeling and not shut down. The results indicate she was communicating more clearly how she felt both physically and emotionally, and not shutting down. BARBARA set a goal to be more able to discriminate between problems related to cancer with her child, and problems related to grief over the loss of her biological mother. The results indicate that the child became much more verbal regarding her feelings related to cancer and the loss of her mother after she began having play sessions. The distinction was much clearer at that point.

Implications for Practice and Future Research

Practice

Many of my findings could be useful for a practitioner who would like to provide intervention in the hospital setting. The following section is a stepwise discussion of the hospital, and gaining access to the families for practical purposes. Researchers should also read this section to understand the stepwise process. Further discussion of details specific to researchers are also discussed in the following section.

Hospital and the Families

In the hospital where the study was conducted, the staff was protective of the patients and their families. As a practitioner and a researcher, it was important to convey a great understanding for the population of families who have a child with a life-threatening illness, in order to gain the trust of the staff as someone who would potentially have access to the parents. I assumed the role of primarily practitioner to
convey the empathy and regard for the families, rather than the researcher who needs to collect data, although the secondary role of researcher was discussed with the staff as well.

I requested a meeting with the director of child-life in order to begin the process of gaining access to the hospital. I conveyed respect for the population in the meeting, in the form of a power point, which highlighted all of the researched problems families have when dealing with the life-threatening illness of a child, discussed in the literature review. The power point was effective because the child-life specialists recognized many of the problems inherent in the population, and respected that a significant amount of research was performed in order to gain an understanding of the population.

The next step was educating the child-life director on the nature of FT and how FT could potentially be adapted as a therapeutic intervention with families who have a child with a life-threatening illness. Using the literature related to the population and the literature regarding the benefits of FT with similar populations, I was able to educate the child-life director, and ultimately gain acceptance to begin the process of working with these families.

Once the child-life director agreed to allow access to the population, the next step was to become a volunteer in the hospital. To become a volunteer, I was immunized for hepatitis, tested for other latent diseases, and attended several volunteer training seminars. Once officially a volunteer, recruitment materials were submitted to the hospital for permission to distribute. Due to the HIPAA regulations, the child-life specialists in the pediatric oncology ward and specialty clinic had first contact with the
parents and mailed out the flyers to the parents who they thought would be interested in participating in FT. Flyers were also left in the ward and specialty clinic waiting and break areas. A card, was sent with the recruitment flyer, and left with the flyer, that parents could fill out if they were interested in more information regarding FT, so I could telephone the parent without breaching HIPAA regulations.

On the recruitment flyer, FT was labeled Child Parent Relationship Training because FT is a difficult word to say and understand. I chose to use the word training rather than therapy because training does not have the stereotypical implications that some people apply to therapy. I chose the words “life-threatening” rather than terminal for two reasons. First of all, life-threatening allowed for more families to be eligible for the study. Second, other organizations (such as charities) who work with this population use the word life-threatening because parents are more capable of accepting themselves and their family as part of that population, than part of the population of parents of a child with a terminal illness.

Therapist self care when working with this population is another important factor. As mentioned, one of the children of a family died. The death of a child is very difficult to deal with, and therapists working in the hospital setting need to prepare themselves for this possibility both emotionally and professionally. The other parents were upset by the loss of this child and grief counseling was necessary to help them begin to process the experience and determine what, and how they wanted to tell their own children. Because of proximity to the parents who had lost their child, preparation to assist them in grief counseling, if sought, was important as well. It is important to recognize that as
a therapist, a relationship has been forged, and it is likely that a parent may return to you for assistance through such a difficult time because of their familiarity with the relationship.

**Future Research**

In the previous section, a stepwise discussion of the process of gaining access to the families was entailed. For the purposes of research in a hospital setting, it is important to note here that the researcher must also have permission to access the families from the hospital’s Internal Review Board. The process to have a study reviewed and accepted in a large hospital may take several months. Allocation of time for this process to occur is important for researchers to note. If working in a university setting, the researcher must also have permission to conduct the study from the University Internal Review Board which entails that each time one review board requests a change in the application, the other board must be notified of the change. All materials, including consent forms, and recruitment flyers must be completely agreed upon and accepted by both the university and hospital IRB, which again could take several months.

**Quantitative Experimental Research**

First of all, in the hospital setting, it would better to open up the study to all children who have a life-threatening illness, around certain parameters, rather than just pulling from one specific disease, such as oncology in the case of this study. This would have been helpful in accruing a large subject sample. The biggest difficulty would be managing several more child-life specialists and several hospital wards. For example, in
this study the second floor of the specialty clinic and the third floor of the hospital were allocated for pediatric oncology. Expanding beyond oncology would have entailed creating relationships with child life specialists who worked on various floors in order to gain access to potential participants.

Having a larger subject sample, however, would facilitate the use of groups in FT. As noted in the results section, even a minimal number of groups allowed the parents to use that experience to create a support outlet in the hospital setting. Although the parents would be experiencing some differences in the hospital setting, and the groups would be heterogeneous, I think the hospital setting in general is traumatic enough for parents of children with different types of life-threatening illnesses, to be able to connect with one another in FT in a homogeneous manner.

A large hospital study showing statistically the effectiveness of FT in working with the parents on the cooperation, anxiety, and communication of both the parent and child could ultimately facilitate hospitals hiring staff that specialize in play and FT in order to offer it as a service at an expanded level. The benefits of a hospital offering FT to an expanded group could facilitate a great change in the way parents and children experience hospitalization in the future. The quantitative studies of FT with similar populations have shown statistically significant evidence that FT is an effective intervention (Glazer-Waldman et. al, 1992; Glazer-Waldman & Landreth, 1993; Van Fleet, 1992). To have a larger study would benefit the population and the recognition by hospital doctors, staff, and administrators the importance of play and FT.
In order to accrue more participants, it is necessary to gain the assistance of the child-life specialists. It may be effective to have the child-life specialists sit in on the first several FT trainings in the pilot study, so they can see first hand how helpful it is. Although the child life specialists were helpful, I experienced them as having difficulty understanding how to help parents realize that the training could help them. I believe if they were sitting in the FT, they would have seen it first hand and had a more passionate approach to helping parents realize the value of trying to commit to the training.

It was my experience that parents who came weekly to the hospital generally came on the same day. Wednesday people usually came on Wednesdays. I believe it would be possible to have FT every week on the same day, with the same parents, if the therapist has an opportunity to meet with the parents and explain the benefits. Some parents may have to come early, and some may have to stay late, but it is potentially possible. The findings do suggest that parents are resistant to staying longer than necessary, but if a group could be created; they may feel more responsibility to the group and find a way to continue.

Qualitative Research

The ability for the parents to commit to 10 sessions appeared to be one of the factors they found overwhelming. For the purpose of future research where participants are seen individually in a case study design, it is recommended the FT be shortened to 8 sessions. As mentioned in the results and discussions section, the parents learned the FT skills at a faster pace than parents in the group setting normally do. Even though
the parents used extra time to discuss their own issues, the FT could easily be cut down to 8 sessions when working one on one. This may help parents commit to the FT training since it is less overwhelming.

Goal setting was used for the parents to set personal goals for self as a parent and for the child of focus and was found to be very helpful and useful. It was interesting that the children were manifesting behaviors, verbalizations, and coping skills directly related to the goals set by the parent. It would be interesting to use this technique and to look at how the goals are manifested more specifically, or how that parental intuition is predicative of what will happen in FT aside from what the research shows will happen in FT.

Recommendations, Thoughts, and Comments

Ideally, hospitals must begin to recognize that an emotional intervention for the child, which includes the parents and the family, is necessary in order for the child to have the greatest amount of success in the hospital environment. The literature indicates parental involvement in the emotional health of the child is eminent, and the conclusions of this study parallel the literature. The problems inherent in the population related to attrition and commitment are related to stress and a great difficulty in understanding how FT is going to be helpful. If the hospitals began to institute play therapy and FT into the hospital culture, and the doctors and nurses included play therapy and FT as part of the treatment plan of the children fighting life-threatening illness, parents would be more committed, and attrition and early termination would diminish significantly.
Due to the difficulty parents of children who are newly diagnosed have in acclimating to the hospital environment and the changes in their child, as reported in the results, play therapy is recommended for the emotional treatment plan of children ten years of age and under for a minimum of six months to a year. The therapist would have an opportunity to assess the parental stress level and ascertain when the parent is ready to begin the FT phase of the emotional treatment plan. Once ready, one or both parents could begin the FT and begin to gain a sense of mastery over parenting a child who has a life-threatening illness. Until play and FT are a part of the hospital culture and included in the treatment plan for children with a life-threatening illness, the children will not be treated holistically, and emotional dynamic beings, in the hospital environment.

Another recommendation regarding the ideal hospital environment and the future is to have child-life specialists who are trained in play therapy. The knowledge and empathy child-life specialists can convey in the hospital setting with the parents and children because of their knowledge regarding the specific illnesses would be exceptionally useful for a therapist in the hospital setting. Many counseling programs offer minors, or opportunities for specializations. If the counseling and child-life departments, at universities where both graduate degrees are available, could work together to offer a minor or specialization in child-life for play therapy counselors, the hospitals could hire the counselors with child-life specializations for the sole purpose of creating and maintaining the play and FT treatment plan program in the hospital setting.
The two parents who completed the training to the end were phenomenal in their determination to understand the process and help their child. The transformation in them and their child was overt and, as one parent put it, “astonishing.” They were much more aware of their child’s abilities and used the hospital time to empower them, rather than to let them escape from reality. They were resourceful and capable and definitely showed the effectiveness of FT with parents in this population who can find a way to maintain their commitment to the training. The fact that FT and the play sessions was able to help a few children cope more effectively made the entire study worthwhile.

Conclusion

FT with families who have a child with a life-threatening illness has the potential to be a dramatic and positive intervention. All the families experiencing coping with having a child in this condition are good candidates for being helped by the intervention; however, the data show that people have difficulty attending the FT during such a stressful time, particularly if they have not acclimated to the hospital environment at onset.

The benefits of increased communication between parent and child where the child feels understood and has an opportunity to gain a sense of mastery over the hospital experiences was shown to increase the cooperation and activeness in treatment of the children who had play sessions. That one finding helps families and children in the hospital setting reduce trauma and anxiety by a huge factor. Generally, when children choose to be uncooperative in the medical setting in order to attempt to
gain control over their bodies, they are held down or anesthetized and forced to accommodate the procedure.

For the child to choose to be cooperative in medical settings and use the play session as an outlet for mastery instead, decreased unnecessary trauma in the hospital setting by a profound amount, being that some children have to be held down every single time they come in contact with a nurse for even simple procedures that do not hurt.

Again, I will state, it is my hope that more people will continue to do research on play therapy, and more specifically FT in the hospital setting. Hopefully more quantifiable studies will be attained in the near future such as those conducted by Glazer-Walman and Landreth (1993), and Van Fleet (1992). The more research that is out there, the more likely the doctors and administrative hospital personnel will notice that FT is a viable intervention to increase cooperation of children in the hospital setting.

Ultimately, the only way that FT will become something that parents participate in actively on a regular basis in that stressful of a situation, is if it becomes an integrated part of the culture. Hopefully, FT will eventually become a part of the hospital culture where doctors recommend it to parents and parents talk to other parents who have completed FT and eventually, entire staff of people who lead FT will be needed in the hospital to help the parents help their children. But for now, we have to slowly integrate ourselves and continue to recognize the importance and hope to slowly spread the methods and benefits of FT with this population one study (and hospital) at a time.
APPENDIX A

PRE-INTERVIEW SEMI-STRUCTURED QUESTIONS
CPR-Pre-Interview General Outline- OPEN

1) Tell me how things are going at home and with your child’s illness.

2) What are some concerns you have regarding your child’s illness and emotional health?

3) What are some of the goals you have in participating in the CPR training here at the hospital?

4) How would you describe your experience of the communication between you and your child? Does your child communicate how he or she is feeling physically and emotionally to you?

5) Describe how you experience medical procedures here with your child?
   Cooperation? Trauma?

6) Do you experience your child to be developed in motor skills at the same rate of other children his or her age?

7) Are you married? What kind of familial support are you receiving? Social support?

8) How have you experienced yourself as a parent through this process? Do you feel effective?
APPENDIX B

POST-INTERVIEW
CPR-Post-Interview General Outline- OPEN

1) Tell me about your experience with the CPR training? What was it like to undertake this new role with your child?

2) What did you like best in this new role? The least?

3) What, if any, difficulties did you have while doing the training and the play sessions?

4) What did you find the most helpful in the training? How was this helpful? What was the least helpful? What was unhelpful about it?

5) In what ways was your behavior affected by the CPR training? Your attitudes? Your feelings? Your perceptions?

6) How has CPR training affected your relationship with your child?

7) In what ways, if any, are you different as a result of CPR training? What do you do differently now?

8) In what ways, if any, is your child different as a result of CPR training? What does he/she do differently now?

9) In what ways, if any, has CPR affected your other relationships?

10) Were the hopes you had before the training realized? How?
APPENDIX C

CONSENT FORM
University of North Texas  
Cook Children’s Health Care System  
RESEARCH CONSENT FORM

<table>
<thead>
<tr>
<th>Subject Name:</th>
<th>Date:</th>
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<tbody>
<tr>
<td>Title of Study: Adapting Filial Training for Use With Families Who Have a Child With a Life-Threatening Disease</td>
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<tr>
<td>Principal Investigator: Rheta LeAnne Steen (telephone 469-441-1215; 940-565-4407)</td>
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<tr>
<td>Co-investigators: Dr. Sue Bratton</td>
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Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the proposed procedures. It describes the procedures, benefits, risks, and discomforts of the study. It also describes the alternative treatments that are available to you and your right to withdraw from the study at any time.

**Purpose of the study and how long it will last:**
Parents who have a child with a life-threatening illness are invited to participate in a ten-session filial/family play therapy training program. Participants will be expected to attend ten weekly two-hour training sessions. The sessions will be held in small groups, or individually according to availability. The purpose of the study is to investigate if filial training effects familial communication, parent and child communication levels, and parental and child stress and anxiety levels, as well as gain understanding as to how to best adapt filial/family play therapy to meet the needs of families who have a child with a life-threatening illness.

**Description of the study including the procedures to be used:**
The study consists of filling out three psychometric measures, the Child Behavior Checklist, the Parent Stress Index and the Family Environment Scale, before and after attending either a ten-week filial/family play therapy training program at Cook Children’s Hospital. Parents who attend the sessions will be expected to come weekly for one to one and a half-hour sessions, for a period of ten weeks. When possible, due to hospitalization or other life events making the parent more available, the investigator might meet with a parent multiple times in one week. The minimum requirement, however, is meeting one time per week. The three measures to be filled out at the beginning and end of the ten-week period take about 20 minutes each (approximately one hour total each time). Parents who participate in the training will be expected to have a weekly thirty-minute play session with the child who has a life-threatening illness, beginning the third training session. The parents will be expected to videotape their play session at least two times, so the leader can give the parents feedback. If the parent does not have a video camera, one will be provided.
The investigator will be also be taking extensive notes regarding the process and experiences of the researcher and the participants over the ten sessions in order to better understand the process that occurs and potential adaptations that may be needed when using filial/family play therapy with families who have a child with a life-threatening illness. Information the parent reports regarding the experience personally, emotionally, relationally, psychologically, etc., may be included in the data and analyzed. Confidentiality of the subject identity will be observed at all times.

**Description of procedures/elements that may result in discomfort or inconvenience:**
Every effort will be made to schedule the filial/family play therapy training sessions around pre-existing doctors appointments; however, there may be some inconvenience occurred if participants need to make an extra trip to the hospital to attend the training session.

**Description of the procedures/elements that are associated with foreseeable risks:**
The risks involved in participating in the treatment group are minimal. Many people in counseling report increased levels of anxiety initially, then an overall anxiety levels due to a possible increase of familial communication and an expansion of insight related to the child’s world experience.

**Benefits to the subjects or others:**
FT has been shown to be beneficial in most populations examined. Play therapy has been shown to be very beneficial to children who are hospitalized and chronically ill. The potential benefits in stress and anxiety alleviation for the child and parents who participate, as well as the potential increase in familial communication is great.

The benefits of the filial training should exceed the risks. The parent-child relationship and potential increase in familial communication should ultimately aid in overall coping behavior and help decrease the levels of anxiety and stress experienced by the parents and the child.

This study is investigating how to adapt traditional FT for families who have a child with a life-threatening illness. Benefits of participating in the study for self and others include the potential that more hospitals will begin to use the adapted FT to aide families who have a child with a life-threatening illness.
Costs:
Parents who participate in the filial training will receive filial kits of toys, for use with their child.

Parents may check out the video camera to record play sessions if one is not already available. The video camera will be checked out to the parent using an honor system where the parent is expected to return the video camera at the next session so others may use it. If the video camera is damaged or lost, the parent will not be held responsible.

Confidentiality of research records:
In order to protect confidentiality, the names of participants will not be used. The measures given will be coded and kept locked in the primary investigator’s office. Data will be used to show the effectiveness of filial/ family play therapy with families who have a child with a life-threatening illness. All names will be kept confidential. Any notes taken by the investigator will be coded to insure confidentiality and kept with the locked measures. If results are published, the families’ names will be kept confidential, and not disclosed in the publication and identifying information will not be given. The videotapes will not be used for research and parents may keep tapes of their play sessions to review later. All tangible records will be shredded at the completion of the study.

Alternatives:
Alternative procedures or courses of treatment which may be advantageous to parents who have a child with a life-threatening illness and their child are listed as follows:
- Support group (such as the candle lighters), individual play therapy for the child, family FT with a private practitioner or at a local clinic (referrals available on request), Effective Parenting classes, family therapy, individual therapy for any individual in the family.

This is not an exclusive list, There may be many other alternatives that the researcher is unaware of which could be helpful to the parents of a child with a life-threatening illness and their child.

Participation in this research study is voluntary and refusal to participate will involve no penalty or loss of benefits to which a participant is otherwise entitled.
Review for protection of participants:
This research study has been reviewed and approved by the CCHCS Committee for the Protection of Human Subjects (682) 885-6471 and the UNT Committee for the Protection of Human Subjects (940) 565-3940.

RESEARCH SUBJECTS’ RIGHTS: I have read or have had read to me all of the above.

LeAnne Steen has explained the study to me and answered all of my questions. I have been told the risks or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate or to withdraw will involve no penalty or loss of rights or benefits or legal recourse to which I am entitled. The study personnel may choose to stop my participation at any time.

In case there are problems or questions, I have been told I can call _LeAnne Steen at telephone number 940-565-4407. Also, I can contact Terry Sutton at CCHCS 682-885-2582 , or Katie Carter at CCHCS 682-885-4047. Also, I can contact Dr. Sue Bratton at the University of North Texas Department of Counseling 940-565-2062.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I have been told I will receive a signed copy of this consent form.

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<th>Subject's Signature</th>
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For the Investigator or Designee:

I certify that I have reviewed the contents of this form with the person signing above, who, in my opinion, understood the explanation. I have explained the known benefits and risks of the research.

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Research Consent Form - Page 4 of 4
REFERENCES


