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Experiences of Children with Chronic Illness: A Qualitative Evaluation of a Children's Mental Skills Program

Julie Koudys

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Abstract

Children with chronic illness are confronted with a variety of acute and chronic stressors. As a result, they require coping strategies that can be used successfully during extremely stressful situations. Mental skills training programs teach children stress management and relaxation techniques that may be used during stressful encounters. The primary purpose of this multiple case study was to evaluate the effectiveness of Orlick's Feeling Great Program in teaching children with chronic illness to deal successfully with stress and find highlights. Qualitative research methods were used to explore factors related to the process of learning mental skills, including types of skills used most often, the influence of context, and factors that effect skill development. Four children receiving treatment for cancer between the ages of 7 – 9 learned techniques such as muscle relaxation, diaphragm breathing and imagery. Data collection included participant observation, field notes, interview data and highlight journals. Program participants perceived the program to be effective in fostering the development of improved coping skills for use within a variety of situations. During acute stressors, such as painful medical procedures, children and parents reported fewer incidents of reactive coping behaviors, such as crying, and described an increased number of proactive coping responses, such as deep breathing. Furthermore, children learned to cope effectively with chronic stressors, such as feelings of anxiety, nausea and treatment side effects.

This work is dedicated to the memory of my Grandmother;
her courageous spirit inspired my belief in the power of
the human spirit and guided my journey down the path to
living with hope and positivity.

Acknowledgments

This journey was made exceptionally rewarding as a result of the contributions of a number of extraordinary people.

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CHAPTER I

Introduction

Chronic illness, and specifically pediatric cancer, is an overwhelmingly stressful event in the lives of both children and their family members. The initial diagnosis is greeted with feelings of fear, anxiety and uncertainty. Amidst this emotional turmoil, parents must attempt to function in an effective manner. Information must be gathered in an effort to understand the details of an unrelenting disease. Treatment protocols must be explained and decisions made. At the same time, children try desperately to understand what is happening in their body, their life and their family. Every dimension of the child's life will be altered from the moment of diagnosis onward. These children are affected by the addition of invasive medical procedures and treatment regimes, along with the disruption of normal childhood activities. During this period of extreme fear and distress, pediatric cancer patients require effective coping strategies.

Interventions designed to decrease children's distress during invasive treatments are prevalent in the literature examining chronically ill children's stress and coping behaviors (McDonnell & Bowden, 1989; Bachanas & Roberts, 1995; Powers, Blount, Bachanas, Cotter & Swan, 1993). However, far less attention is directed towards the amelioration of more chronic stressors that exist across a variety of environments, such as constant feelings of frustration and uncertainty. Furthermore, the majority of studies employ a quantitative research design, focusing on single episodes of coping within a narrow hospital environment. Therefore, there is limited knowledge about children's actual implementation of stress control strategies and the process of learning to cope within this particular context.

Compounding the stress of a chronic illness are the regular stressors associated with childhood, such as school, performance, and social expectations. Several mental training programs have been designed to help children cope effectively with these daily stressors and

develop a more positive attitude. These programs teach children an assortment of coping skills that may be used across a variety of settings to deal with both acute and chronic stressors. Specifically, children who participate in the Feeling Great program (Orlick, 1998): (a) enjoy the activities, (b) learn to relax at will, (c) successfully implement stress control strategies across a variety of situations, (d) increase their frequency of noticing and experiencing highlights and, (e) increase their ratings of positive feelings about themselves (Cox & Orlick, 1996; Gilbert & Orlick, 1996; Orlick, 1998; St. Denis, Orlick & McCaffrey, 1996). This program was selected for use within a pediatric oncology population at the Children's Hospital of Eastern Ontario in an attempt to answer a number of questions related to the experience of coping with chronic illness. First, are mental skills training programs effective in teaching children with chronic illness to cope more effectively and find more positive experiences? Are children able to successfully implement mental skills in a wide variety of real world situations? What factors influence the development of mental skills and coping skills? Finally, what are the processes children engage in while attempting to learn effective coping skills?

Program participants consisted of 12 children between the ages of 5 - 11. Four of these children, ages 7 - 9, were selected to represent these participants in a multiple case study. Primary sources of data collection were participant observation, field notes, interviews with children and parents, and highlight journal entries. Interviews were audiotaped and transcribed, and field notes made after each session, visit and interview. Data analysis of this information included inductive and content analysis and categorizing strategies. Single case narratives, containing both rich descriptions and explanations, were then created. Interpretations and explanations were discussed with both children and parents to serve as member checks. Moreover, parents were asked to read the final case study narratives in order to ensure report accuracy. Cross-case analysis, identifying themes and patterns across cases, followed the

development of individual case studies. Finally, results were compared to previous research within the fields of mental training and child health care.

The primary purpose of this study was to evaluate the effectiveness of the Feeling Great Program (Orlick, 1998) in teaching chronically ill children to: (a) cope effectively with stressful experiences and (b) identify highlights. However, equally important was the exploration of the individual experience of each child as he/she attempted to develop and implement mental skills and learned to live more positively with his/her illness. This study did not endeavor to simply ascertain a 'yes' or 'no' answer regarding program efficacy; rather, this study sought to understand the 'how' and 'why' of the program experience from both an individual and a group perspective. For this reason, qualitative evaluation methods, and specifically a multiple case study design, were selected. These methods enabled me to explore the primary research purpose, which was relatively outcome oriented, along with several complimentary purposes, which were increasingly process oriented. These complimentary purposes included: discovering if children implement the mental skills taught in the program and in what situations this implementation occurs most frequently, exploring the factors that fostered and/or hindered successful mental skill development, examining the influence of context on mental skill development, and describing the processes chronically ill children engaged in while learning relaxation/stress management strategies and learning to identify highlights. Finally, children's ability to identify highlights through journal and verbal reports was explored, along with factors that influenced this ability. I have chosen to refer to these purposes as complimentary to indicate that they are not above or below the primary research purpose on a scale of importance; rather, these purposes are complimentary to the primary purpose, adding depth and breadth to the understanding of the program's effectiveness and to the experience of being a program participant.

The long-range goal was to add to our knowledge base so that effective interventions will be available to help parents and health care providers assist chronically ill children cope more successfully and adapt a more positive focus. By continuing to discover effective methods for learning mental skills, programs of this nature may be implemented more successfully in the future and children may learn to live more positively with chronic illness.

CHAPTER II

Review of the Literature

Stress in Children With Chronic Illness

Children with chronic illness, and specifically children facing childhood cancer, experience an endless array of illness symptoms, as well as an unrelenting course of treatment and treatment side effects. The experience of living with a serious illness, and its related symptoms and treatments, is extremely stressful for young children. Stressors include receiving the diagnosis, building relationships with health care providers, dealing with symptoms associated with illness and treatment procedures, separation from family and friends, lengthy hospitalizations, and the threat of death (Spirito, Stark & Knapp, 1992).

These stressors have been described as fitting into one of two possible categories: acute or chronic. Acute stressors represent intermittent experiences that children encounter, such as painful procedures and treatment side effects. Procedures may include lumbar punctures and intramuscular injections, and side effects may include nausea, fatigue, hair loss and/or physical scarring. Chronic stressors are more continuous in nature and encompass the daily reality of living with a cancer diagnosis, such as altered activity patterns and life style, and uncertainty towards the future. Chronic stressors interfere with children's ability to engage in regular, day-to-day activities such as going to school or playing with other children (Wallander & Varni, 1992). As a result of these disruptions there is nearly double the rate of adjustment problems in children with chronic illness than that observed in the general population (Haggerty, 1986). Children's ability to cope successfully with both acute and chronic stressors may affect the course of their illness as well as their psychological adjustment (Spirito et al., 1992).

Recent advances in pediatric oncology have enabled greater numbers of children to survive the trauma of childhood cancer. These children experience earlier diagnosis, regular

treatment regimes, and often a return to health within two to five years (Steward, O'Connor, Acredolo & Stewart, 1996). Due to these advances, the literature on childhood cancer has shifted focus from concentrating almost exclusively on preparing for the death of a child, to assisting children and families make the most of life despite having to deal with the complications of cancer and its treatment (Stehbens, 1988). A significant portion of this literature focuses on the types of coping methods used by children in this situation, along with attempts to facilitate development of effective coping skills.

Coping Strategies

In response to frequent stressful experiences children often endure extreme psychological and/or physiological distress. This distress may manifest itself as "dependency, immobility, vulnerability, apprehension, anger and other anxiety states" (Woodgate & McClement, 1998, p. 4). Children with chronic illness, and specifically children with cancer, have little to no control during these stressful situations and are often rendered helpless. At this time children are prevented from employing the most popular coping strategy; escape, whereby children attempt to remove themselves from the distressing situation (Steward et al., 1996). Therefore, school-age children are forced to develop alternative coping skills under extremely stressful conditions. These coping strategies may be described as a continuum, with proactive coping at one end (muscle relaxation, relaxed breathing, imagery), and reactive coping at the other end (crying, screaming, hitting, attempting to escape). At the middle of the continuum is neutral coping behavior (sitting still, being cooperative). Although there are numerous terms describing these various methods of coping (primary and/or secondary coping, cognitive distraction), the majority of these descriptions and definitions can be placed within this continuum.

Numerous studies have examined children's knowledge and use of different coping strategies within medical settings and assessed the interventions designed to assist children with chronic illnesses cope with these stressors (Bachanas & Roberts, 1995; McDonnell & Bowden, 1989; Powers, Blount, Bachanas, Cotter & Swan, 1993). Altshuler, Genevro, Ruble and Bornstein (1995) conducted a study assessing children's knowledge and use of coping strategies upon entering the hospital for elective surgery. It was found that children who were aware of cognitive distraction strategies, a standard proactive coping behavior defined as "manipulation of mental states to focus attention on thoughts" (p. 55), were less likely to use negative coping strategies, such as attempting to escape. Similarly, in a study assessing situational differences in coping approaches, Band and Weisz (1988) found that children reported more use of secondary control approaches during medical procedures. These proactive approaches attempt to control the psychological impact of stressful events without altering the event.

These studies clearly indicate that children are aware of proactive coping responses and are capable of implementing these responses during stressful situations. Furthermore, by teaching children effective alternatives to escape behavior, such as proactive coping techniques, feelings of anxiety, helplessness, and related pain behavior may be replaced by a sense of mastery (McDonnell & Bowden, 1989).

Interventions Designed for use in Medical Settings

In response to the frequency and intensity of stressful experiences in the lives of children with cancer or chronic illness, numerous psychological interventions have been developed to help children cope more effectively with distress during painful medical procedures (Jay, 1988). In a recent meta-analysis of 42 psychological interventions for children with chronic illness, Kibby, Tyc and Mulhern (1998) found that children participating in programs designed to reduce pain and procedure related distress, showed greater benefit than those not receiving intervention.

These benefits were maintained for up to one year. The majority of studies conducted within this population, however, focus on acute stressors related specifically to the disease process, such as reduction of pain, improved management of symptoms, and the management of procedure-related distress (Kibby et al.). Few interventions attempt to teach children how to better manage chronic symptoms of stress within the hospital, school and home environments. This limitation is evident in numerous recent studies.

In a study of pediatric leukemia patients Powers et al. (1993) taught children coping behaviors for use during intravenous injections. The study found that when children engaged in positive coping behaviors during these procedures their behavioral distress decreased. However, these techniques were only designed to address painful events, which are a very narrow component of the pediatric cancer stress experience. The application of these skills was limited to invasive treatments in the hospital setting and did not address the need to enhance coping techniques to deal with more chronic stressors and stressful experiences outside the hospital environment. Given that only 20% of hospitalized children and adolescents identified procedure related pain as the most prevalent stressor in their life (Spirito et al., 1992), the need to broaden interventions to address additional sources of stress is obvious. A fundamental goal of health care is to improve behavioral functioning and quality of life (Kaplan, 1990); therefore interventions must be designed to address the multi-dimensional effects of chronic illness.

In addition to concentrating research efforts solely on the reduction of adverse reactions to specific medical procedures, studies often use only single episode measurements of coping. These studies examine coping simply as an outcome with little regard for the actual process involved with developing coping skills. In a study examining children's attitudes toward health care and responses to medical procedures (Bachanas & Roberts, 1995), children were observed undergoing a single finger-prick blood test. Likewise, Altshuler et al. (1995) observed children's

coping behavior on one occasion, during the waiting period prior to entering the operating room for surgery. These studies illustrate the reliance of current research on single episodes of measurement that concentrate exclusively on the outcome of coping. Studies such as these focus primarily on the result of an intervention, with limited attention directed toward the use of treatment strategies on a repeated basis. Therefore, it is difficult to accurately determine if children actually implement the intended skills on a regular basis, and even more difficult to understand the processes involved in developing these skills (Powers et al., 1993).

The limitation of single episode measurements of coping is also identified by Siegal (1995) who suggests using repeated evaluations and multi-method forms of assessment to reveal the spectrum of emotional responses that may occur during various stressful episodes. This suggestion is paralleled by Glasgow and Anderson (1995), who support the use of multiple observations using a small number of subjects. By assessing children's responses through a variety of methods, on several different occasions, knowledge may move beyond understanding coping as an outcome, to assessing the actual implementation of the program and understanding coping as a process.

Stress in Healthy Populations of Children

In addition to the stress created by the challenge of a chronic illness, children must also face the everyday stress associated with normal childhood activities. Children as young as six years old report conditions and events they find stressful, describe their own attempts to cope, and evaluate the efficacy of these attempts (Band & Weisz, 1988). With increased pressure to excel in school, sport, and performance environments, and an increasingly hectic lifestyle, even healthy children in today's fast-paced society experience feelings of pressure and anxiety (Parrott, 1990). The most common sources of stress identified include: other people, sport/activity/ performance, illness, school, loss of control and not being able to sleep (Orlick,

1998). These common sources of stress, combined with the additional stress of battling a chronic illness, compound the childhood stress experience and make effective coping skills increasingly important within this population.

Mental Training Programs for Use in Healthy Populations of Children

Unlike interventions designed for children with chronic illnesses, programs designed to help healthy children deal with stress are still in their relative infancy. However, with the increasing awareness that children's lives are inundated with stressful experiences, greater numbers of studies are being conducted to assess the effects of stress control programs in teaching children to cope with stress (Cox & Orlick, 1996; DeWolfe & Saunders, 1995; Gilbert & Orlick, 1996; Parrott, 1990; St. Denis, Orlick & McCaffrey, 1996). These programs often incorporate stress reduction techniques similar to the aforementioned proactive coping behaviors, such as cognitive distraction, and emphasize absorption in internal states through attention focusing or mental imagery (Smith & Womack, 1987).

Using a relaxation technique designed specifically for children incorporating muscle relaxation through guided imagery, Parrott (1990) found that children's physiological signs of stress decreased, when measured by skin temperature. Additional benefits of relaxation were: (a) learning to make the transition from physical activity to mental activity, (b) learning to increase body awareness and sensory awareness, (c) learning to cope with physical and mental fatigue, and (d) learning to incorporate new skills for self-control (p. 74).

Decreases in stress levels, as well as increases in social skills, self-esteem and confidence were found in sixth-grade students participating in an 8-week stress management program (DeWolfe & Saunders, 1995). The program involved lessons and practice exercises designed to help children learn more about stress and its effects, and deal positively with these sources of stress.

Cox and Orlick (1996) implemented a 10-week in-school mental training program to teach school aged children mental skills. Results from the study found that children involved in the intervention enjoyed the activities, learned relaxation skills, and implemented these skills across a variety of situations. These results were supported by Gilbert and Orlick's findings (1996) with two-second grade classes. The 10-week mental training program was successful in teaching children to relax at will, implement stress control strategies, and increase their frequency of highlights. Similarly, St. Denis et al. (1996) found that children involved in a 10-week program increased their frequency of highlights as well as their ratings of how positive they felt about themselves.

These results indicate that school-aged children are capable of learning stress control strategies and relaxing at will, and are able to implement these strategies across a variety of situations. Skills such as these are essential to helping children deal with stress, put their worries aside, and focus on the positive within themselves and in their lives (Orlick, 1998).

Benefit of Mental Training Programs for Children with Chronic Illness

Mental training programs, commonly used within healthy populations of children, provide one important advantage over programs typically designed for use within chronically ill populations. Mental training programs teach children a number of relaxation and/or stress management techniques that may be used across a variety of stressful situations, thereby increasing the scope of the intervention beyond the treatment environment. These programs teach children mental skills, which may be used to address the spectrum of acute and chronic stressors involved with chronic illness. Programs of this nature also foster the development of a more positive perspective in children through the use of techniques such as "highlight programs". These programs teach children to focus on the positive experiences in their life and identify the simple pleasures and joys that occur daily.

The value of such program components becomes increasingly obvious when the definition of cancer stressors and adjustment to cancer is examined. Cancer stressors are identified as "those occurrences within the cancer experience that activate a stress response that may be psychosocial, emotional, or physical in nature" (Hockenberry-Eaton, Manteuffel & Bottomley, 1997, p. 179). These stress experiences are not limited to the time immediately during and surrounding painful medical procedures. Therefore, intervention programs need to address the occurrence of cancer stressors beyond these isolated experiences and provide children with the necessary skills to cope with the broader experience of stress. Furthermore, Hockenberry-Eaton et al. (1997) identify children's adjustment to cancer as the ability to adapt to the aspects of their environment that have been altered during the course of their illness and treatment. Cancer-related changes are most certainly not isolated to the hospital environment. Every dimension of a child's life is altered by a cancer diagnosis. Therefore, programs designed for use with these children must equip them with effective tools that respond to a variety of lifestyle and environmental changes.

Mental training programs, and specifically the Feeling Great Program (Orlick, 1998), teach skills that may be used during acutely stressful situations, such as invasive procedures. However, this program also teaches children skills that facilitate improved coping across a variety of situations. These strategies may also be used to help children deal with the numerous chronic stressors associated with this illness.

Qualitative Research Methods

In addition to the gaps in the literature created by the singular focus on reducing treatment and procedural related acute stressors, the use of single episode coping responses to measure coping skill development, and the concentration of work assessing coping solely as an

outcome with minimal attention to the process of coping, there are also gaps created by the prevalence of quantitative research methods.

The use of qualitative research in the field of coping and interventions for children with chronic illness is still in its very early stages. Proof of this fact was established by Krahn, Hohn, and Kime (1995) who, in a manual search of a prominent child psychology journal (Journal of Clinical Child Psychology) from 1990 to early 1993, discovered only one article relying primarily on qualitative approaches, and a minimal number of studies that incorporated even a few qualitative techniques. My own recent search of the literature revealed a similar trend with few predominantly qualitative studies appearing in this area on popular databases. Given the previously stated importance of measuring children's varying emotional reactions on several different occasions (Siegal, 1995), and the necessity of measuring implementation strategies involved in the coping process (Bachanas & Roberts, 1995), the use of qualitative research methods appears to be particularly appropriate for research in this field.

The use of qualitative methods is further supported by Fiese and Bickham (1998) who indicate that the strengths of qualitative modes of inquiry, namely focus on participant meaning and the importance of context, will enrich the understanding of health and illness. In addition, Krahn et al. (1995) identify the strengths that qualitative research provides by suggesting that the scope and flexibility of qualitative inquiry may enable researchers to study a broad range of content areas, without predefined response categories. These techniques have meaningful implications for understanding the experience of stress and coping in pediatric cancer patients. Moreover, the most compelling argument for a qualitative design is the fact that it enables researchers to explore the perspective of the often overlooked consumer of pediatric care, the children themselves (Fiese & Bickham).

Qualitative research methods, and particularly a case study design, will enable the researcher to interact with and observe participating children on numerous occasions for an extended period of time. This design provides the opportunity to discover the methods of coping implemented in different contexts, and at different stages of learning, along with studying the variety of reactions participants may display in these situations. Furthermore, a case study design creates the potential to examine the process involved with the development of coping skills.

Purpose of the Study The primary purpose of this study was to evaluate the effectiveness of the Feeling Great Program (Orlick, 1998) in teaching chronically ill children to: a) cope effectively with stressful experiences and b) identify highlights. Complimentary purposes included: discovering if children implement the mental skills taught in the program and in what situations this implementation occurs most frequently, exploring the factors that fostered and/or hindered successful mental skill development, examining the influence of context on mental skill development, and describing the processes chronically ill children engaged in while learning relaxation/stress management strategies and learning to identify highlights. Finally, children's ability to identify highlights through journal and verbal reports was explored, along with factors that influenced this ability.

Research Questions Research questions were developed prior to initiating the study in order to frame the direction of the inquiry as recommended by Maxwell (1996). These questions remained sensitive to emerging themes and insights and were adapted through out the study in order to address newly emerging understandings. By using research questions in this flexible manner it was possible to preserve "the interactive and inductive nature of qualitative research" (Maxwell, p. 49).

1. Is the research based mental skills training program designed by Orlick (1998) effective in teaching children in this context to cope more effectively and/or find more positive highlights?

2. Are children able to successfully implement the skills learned in the program in a wide variety of real world situations? If so, what are these situations?

3. Which mental skills do children report implementing most frequently and/or most effectively?

4. What factors appear to influence successful mental skill development, i.e., foster development or hinder development?

5. Are there any situations or experiences in which children report an unwillingness or inability to apply mental skills effectively? If so, what are these situations? What might be interfering with its potential effectiveness?

6. How does the specific context of application affect the participant's ability to learn and implement positive mental skills?

7. What processes do children engage in while attempting to learn mental skills from Orlick's Feeling Great Life Skills Program?

CHAPTER III

Methodology

Assumptions and Rationale for a Qualitative Design

Qualitative research is currently lacking an established set of design procedures and there is little agreement between researchers on a precise design protocol (Creswell, 1994). Despite this absence several underlying assumptions of the qualitative paradigm were used to frame this study: (a) the researcher was the primary instrument of data collection and analysis, (b) fieldwork was involved, with the researcher physically going to the research site, (c) participant perspectives were examined, (d) the ensuing qualitative research was descriptive, (e) process was a primary concern, and (f) an inductive process was involved (p. 145). The methods selected for use in this study were based on these assumptions and used in conjunction with principles derived from evaluation research, qualitative methodology and case study design.

Evaluation Research The primary purpose of this study was to evaluate the individual and shared effectiveness of the Feeling Great Program. Therefore, evaluation techniques were the foundation of the research design. The focus of this evaluation was on determining both the process and outcome of program participation. The desire to move beyond understanding coping as an outcome, to understanding coping as a process, necessitated the integration of qualitative research methods and more specifically, a multiple case study design.

Qualitative Methodology and Case Study Design Patton (1987) states that not every evaluation situation is appropriate for the use of qualitative methods. Similarly, not all evaluation questions are adequately answered by qualitative research. This multiple case study had several complimentary purposes, which were process oriented such as, exploring the processes involved in mental skill acquisition and implementation, and examining individual participant experiences

and outcomes. Therefore, qualitative research methods were selected as the most appropriate match between research purposes and methods.

Maxwell (1996) recommends using qualitative methods for studies that explore physical events and behaviors, as well as how the participants make sense of these, and how this understanding affects their conduct. He further supports the use of qualitative methods for the purpose of developing causal explanations. Yin also suggests the use of case study methods in order to explain the links between interventions and outcomes and provide descriptions of topics and events within the program (1994, p. 15). An important area of exploration in this evaluation was the examination of the participant's perspective and the connection between program processes and outcomes. The use of a case study design created the opportunity to provide a comprehensive account of each child's individual experience in the Feeling Great Program, including descriptions of program activities and outcomes. The use of multiple case studies was selected to allow for comparison between cases, creating a broader understanding of both individual and shared program experiences. Qualitative methods also provided another important advantage: they enabled me to develop a personal relationship with program participants. This relationship allowed me to access information and insights unattainable through less personal research techniques.

Definitions

This study placed a high level of priority on individual participant experiences and perspectives. Children perceive, and respond to, events and experiences differently than other children. Accessing these variations was an important part of ensuring individual perspectives were represented. For this reason I chose not to create predetermined response categories or expected behavioral outcomes to indicate stress and coping behaviors. Rather, participants and parents were allowed to define their own perception of stressors, and decide whether coping

attempts were successful or unsuccessful. However, I did identify definitions of stress and coping that were used to frame my own exploration into these phenomena.

The definition of stressors was based, in part, on the definition by Hockenberry-Eaton et al. (1997, p. 179), who described stressors as: "those occurrences within the [child's] experience that activate a stress response that may be psychosocial, emotional, or physical in nature." The definition of coping was based on Lazarus and Folkman's (1984) model of stress and coping. Coping was defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Furthermore, coping behaviors were described as proactive, neutral or reactive based on the continuum of coping created by Peterson, Crowson, Saldane and Holdridge (1999). Although I chose to define these terms, this definition was not imposed on the participant's responses. Rather, these definitions were simply used to help guide my own understanding of these constructs.

Procedural Details

The first step in initiating this study was obtaining ethics approval from the Children's Hospital of Eastern Ontario (Appendix A). After receiving approval, participating children and their families were approached by a familiar health care provider from the oncology/medical day unit (MDU). The health care provider explained that a study was being conducted and supplied basic information regarding the Feeling Great Program and expectations for their involvement. Families were then asked to consider participation and reminded that their involvement was completely voluntary and could be withdrawn at any time. The health care provider then obtained permission for me to meet with the family and discuss further details of the program.

Approximately one week later I met with potential participants and their families. This one-week period was given to the families to ensure they had sufficient time to consider

participation. During this initial meeting detailed program and study information was shared with the family and consent forms presented (Appendix B). Upon obtaining participant and parental consent, individual consultations in the form of initial interviews occurred with both the children and their parents to gain a greater understanding of each child's individual situation and perceived needs.

Children generally participated in individual weekly sessions. However, on some occasions other participants would also be included in program activities. Sessions were conducted during weekly hospital visits, as this was a time that was convenient for both the child and his/her family. Previous studies conducted in elementary schools had implemented the program for a 10-week period. Results indicated that this time frame was sufficient to teach children a variety of effective mental skills. The current study increased the number of sessions from 10 to 12 due to the unique characteristics of the population, such as their health status, and the unusual contextual influences, such as poor room availability. These factors impacted on the quality of children's learning experiences and 12 sessions were used in an attempt to ensure that children had adequate time and appropriate circumstances in order to develop effective mental skills.

At the beginning of the Feeling Great Program, children were taught a variety of relaxation activities along with basic concepts about stress and relaxation. Relaxation activities included locating muscles and learning to relax them, altering breathing rhythms, positive focusing, mental imagery, and relaxing to audiotapes. Children were also involved in a highlight program where they were encouraged to look for daily positive events, experiences and accomplishments. Highlights are defined as simple pleasures, joys, positive feelings or experiences, magic moments or anything that has improved the quality of their day (Orlick, 1998). During these sessions, children engaged in a series of simple activities which taught

mental skills in a fun and relaxing manner. A typical session consisted of a short discussion on relaxation and/or stress control, a relaxation and/or stress control activity through the use of an audio-tape, and follow-up suggestions on how and when to use the mental skills.

Participating children were also asked to keep a highlight journal (Orlick & McCaffrey, 1995a, 1995b) to chart their daily highlights. This journal enabled me to determine the number of highlights children experience, and the areas from which these highlights arise. The journal also asked children to chart their experiences with stress. This created an additional method of accessing children's perceptions of stressful events, the ways in which they deal with these events, and how they feel before and after stressful encounters. The journal also provided an indication of whether children were using the skills learned in the program and how effective they perceived these skills to be.

In order to ensure that the individual rights and preferences of participants were respected, each child was frequently reminded that their participation was voluntary and they could withdraw from activities or discussions at any time. Activities that children enjoyed, and felt comfortable participating in, replaced less desirable activities and sessions were occasionally cut short or rescheduled upon participant requests. For example, if children were feeling tired or nauseous, or wanted to participate in another activity on the unit, sessions would be rescheduled to accommodate these circumstances.

Research Relationship/Role

The goal of the research relationship is "a relationship that enables you to ethically learn the things you need to learn in order to validly answer your research questions" (Maxwell, 1996, p.66). Maxwell further states that in qualitative research the researcher is the primary instrument of research and the relationship with participants is the means by which the research is accomplished. As a result of these unique responsibilities, it is necessary to define the

researcher's role as primary instrument of data collection. It is also important to clarify the dynamics of the relationship between the participating children and myself as the primary researcher. There are three main roles I fulfilled within the current study: primary instrument of data collection, program facilitator, and activity partner/participant.

Researcher as Instrument There are several important characteristics that make the human researcher distinctly capable of acting as the primary research instrument. These qualities are described by Guba (1978) as the ability to respond and adapt to personal and environmental cues, to grasp both the phenomena at hand and the context, to explore feelings and emotions, to process and summarize data on the spot, and provide feedback to participants for clarification (p. 193).

As the primary instrument of data collection, it is necessary that personal values, assumptions, and biases be addressed at the outset of the study (Creswell, 1994). My expectations for the efficacy of the Feeling Great Program within this sample were significantly influenced by my past personal experiences. I approached this evaluation having had experience interacting in both individual and group sessions with children on the oncology/pediatric medical day unit of a typical children's hospital. Personal experiences in this environment included: participation in group medical play, recreational activities, and one-on-one interactions focusing on facilitating coping responses. I have also been involved with numerous program coordination and implementation experiences, including work with both children and adults with special needs, in both recreational and life skill settings. I believe these experiences provided me with a greater understanding of sensitive issues and concerns, as well as enhanced my ability to facilitate the program in an effective manner. I brought both awareness of chronically ill children's needs and programming abilities to this study.

As a result of these previous experiences, I also brought specific biases to the study. I approached this study with the perspective that children with chronic illness experience stress in each realm of their life from home, to school, to the hospital. I also believed that mental training skills, if used consistently and correctly, would help these children cope with stressful situations and develop a more positive perspective. The goal of identifying my own personal expectations was not to create complete researcher objectivity; this was neither feasible nor appropriate for working within this population of children. Rather, every effort was made to ensure an appropriate level of objectivity within my designated roles, while at the same time maintaining my positive attitude toward the program.

Program Facilitator In addition to being the primary research instrument, I also implemented the intervention over a 12-week period, resulting in repeated contact with each participant. These prolonged engagements and persistent observations enabled me to gain insight and understanding that would have been unavailable otherwise (Lincoln & Guba, 1985). As the program facilitator, it was necessary for the children to develop an appropriate level of comfort working with me. Mutual trust, respect, and cooperation were developed at the outset of the study through the use of informal conversations discussing topics children were comfortable sharing, such as sports or favourite activities, and through participation in fun activities related to the mental skills taught in the program. This interaction enabled me to collect detailed data while at the same time enhancing the participants feeling that their participation was worthwhile (Patton, 1987).

Each child's personal preferences and feelings guided activity sessions and their ultimate best interest dictated the types of activities presented, the length and schedule of the sessions, and the extent of the child's and my own participation. As program facilitator, I attempted to clearly convey the purpose of each activity session, as well as the purpose of the research, so that it was clearly understood by the participants and their parents. Permission to audiotape each

session was requested, along with permission to use descriptions of their program involvement, their comments and information contained in their journal.

Activity Partner The close, personal relationship that I developed with these children as a result of my role as activity partner was the most rewarding component of my research experience. This relationship was informal and encouraged fun, creativity and openness of expression. The focus during these sessions was ensuring that children were involved in a positive learning environment where enjoyable activities were offered and learning experiences fostered. Children were encouraged to share stories, jokes and weekly experiences and I often shared my own personal experiences and reflections. Frequently, the most significant insights into participant experiences emerged spontaneously during mutual participation in child-centered and entertaining activities. Within this relationship I was able to interact with children on their own level while at the same time learning more about each child's needs and preferences.

Sampling

Typical case sampling was selected for the purposes of this research. This form of sampling involves selecting cases believed to be capable of providing a typical case profile based on input from key informants such as program staff (Patton, 1987). In selecting a purposive sample I was able to use my own judgment to select a sample that I believed would provide an opportunity to learn and the information needed to answer the research questions (Fraenkel & Wallen, 1996; Stake, 1994). Judgments regarding inclusion criteria for the study were based on recommendations from key informants such as parents and knowledgeable staff members. These individuals recommended participants based on the child's age, stage of illness, treatment protocol and parental support. In accordance with Miles and Huberman (1990) I addressed participant, setting, event, and process sampling decisions.

Research Setting Typical site sampling involves the selection of a site because it is not in any way atypical, extreme or unusual (Patton, 1990). I selected the oncology/MDU patient service unit within the Children's Hospital of Eastern Ontario, as it is a standard hospital unit providing medical care for a population of pediatric cancer patients. Entry to the unit was gained through the Child & Youth Health Network for Eastern Ontario, an organization devoted to developing links between health, education, social and recreational services.

Research Participants "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected ... than with sample size" (Lincoln & Guba, 1985, p. 185). Due to the high level of need expressed in this population the majority of interested children were engaged in the program in some capacity. This resulted in approximately 12 children participating in the program. However, following standard case study protocol I chose to maintain a relatively small sample size. From the original sample four children were selected for the case studies based on several factors.

First, each of the four children had maintained their involvement in the Feeling Great Program for the complete 12 weeks. Some participants were unable to participate in the program for the required 12 weeks due to health or scheduling difficulties. This inability to participate resulted in incomplete data sets. In order to ensure accurate representation of children's experiences, and to enhance validity, I chose to include only children with complete data sets. Second, inclusion criteria necessitated that children be between the ages of 6 - 12 years of age. Several children in the original sample were below this age and therefore their data was not included in the case study narratives. Third, a number of children and parents preferred to communicate in a language other than English. As a result, these families had some difficulty communicating effectively in English and their data was also excluded from the case studies. Finally, the children chosen for case study presentation were selected based on their ability to

accurately represent a variety of possible participant experiences, including positive, negative and neutral experiences.

Inclusion criteria included participant age, type of illness, treatment protocol, stage of illness, and consideration of participant's involvement in additional studies. All program participants were between the ages of 5 - 11. However, the cases presented in this study are from children between the ages of 7 - 9. These age groups were selected as program activities were designed to be appropriate for children within these stages of development. Furthermore, children within this age range are able to effectively communicate their perceptions, feelings and experiences through verbal and written means. This study was confined to children who have any of several different forms of cancer. Treatment protocol and stage of illness were also included as a sampling consideration only as far as they affected children's ability to participate regularly in program activities.

Events The focus of this investigation was the involvement of participants in activities from the Feeling Great program, such as listening to audiotape activities. The program events and activities were observed, and experiences and learning processes explored through informal conversational interviews and highlight journal entries. Occasionally, I observed children during medical procedures and treatment routines. This allowed me to directly witness children's use of mental skills and coping strategies.

Processes Attention was often focused on the manner in which participants attempted to learn program skills, incorporated these skills into their daily lives, and implemented these skills across a variety of situations. In addition, children's understanding of the activities, and how these understandings affected skill use was explored. Contextual influences on such factors as learning, skill implementation, and meaning were also investigated.

Data Collection

Guiding Principles of Case Study Data Collection Yin (1994) suggests following three basic research principles to guide data collection. These principles provide a means of establishing construct validity and reliability in the case study.

1. *Use multiple sources of evidence.* The primary strength of case study design is the opportunity to incorporate numerous methods of data collection (Yin, 1994). By using different sources of evidence, research findings and interpretations become more convincing and accurate, reducing the possibility that conclusions simply reflect the biases and limitations of the methods used to derive them (Maxwell, 1996). Combined method studies, in which the researcher uses multiple methods of data collection, have several strengths (Creswell, 1994). Specifically, multiple methods were used to seek convergence of results through triangulation, to discover complimentary facets of the same phenomenon, to use the first method in a developmental sense informing the second method, and finally to provide breadth and scope to the study (p. 174).

2. *Create a case study database.* Yin (1994) suggests dividing the case study database into two separate sections, one for data and evidence, and the other for the investigator's report. The database created for this study included the following: (a) case study notes - the results of interviews, observations, and document analysis, (b) case study documents - relevant documents collected during the study, i.e., highlight journal entries, and (c) the case study narrative - the results of an analytic process combining available data and converging the facts into preliminary interpretations.

3. *Maintain a chain of evidence.* The reliability of case study data may be increased by maintaining an accurate chain of evidence (Yin, 1994). An external observer should be able to follow the chain from the initiation of the study to the studies conclusion, ensuring that all data collected received appropriate attention and that interpretations and conclusions followed

logically from this data. Data collected for this study was compiled in separate case files. Within each of these files, data was organized chronologically and beginning analyses and interpretations were stored with relevant data sources. This system ensured an effective means of connecting collected data to emerging interpretations and conclusions.

These three principles, triangulation, creating a case study database and maintaining a chain of evidence, were used to provide the framework for the following sources of data collection.

Observation. The purpose of using observation as a source of data is to describe program activities, the people who participated, and the meaning of what was observed to those people (Patton, 1987). Within the spectrum of observation there are variations of observer involvement, from complete separation to complete participant involvement. The goal of my program involvement, as recommended by Patton, was to combine participation and observation in a manner that enhanced my understanding of the experience of a participant, while enabling me to describe the experience to an outsider.

Participant observation was used in this study as I both implemented and participated in the program activities with the children. However, due to the unique characteristics of the children involved in the study there were factors that limited the extent to which I was able to be a "full" participant, such as my role as program facilitator and my own healthy physical status. Within the role of participant observer Yin (1994) suggests that minor events may be manipulated to produce a greater variety of situations. As a participant observer I was able to select the types of activities children engaged in, conversational topics and highlight activities completed. This situational variety increased the breadth of the study and contributed to a greater understanding of the participant's perspective.

As an observer, I focused my observations on "sensitizing concepts", described by Patton (1987) as concepts that contribute to the basic framework of the study highlighting the importance of certain events, activities and behaviors. Participants were observed during weekly sessions while they participated in program activities, and occasionally during invasive or painful procedures. Key areas of observation paralleled those suggested by Patton (1987); program setting, human/social environment, program activities, participant behaviors, informal interactions and unplanned activities, the language of program participants, nonverbal communication and program documents.

Field Notes. Field notes were drafted after all relevant participant contact, such as program sessions, visits, and interviews. Patton (1987) very simply defines field notes as "the description of what has been observed" (p. 92) and includes four different types of information to include. This protocol provided the framework for my own field notes.

First, field notes were highly descriptive including information such as site, individuals present, types of social interactions, and the types of activities that occurred. Second, field notes included participant comments and responses to activities and questions. The third area recorded were my own feelings, responses to experiences and reflections about events and activities. The final area addressed was my beginning interpretations and analysis of the data.

Key Informants. Qualitative researchers often rely on key informants to provide important insights and direction for study. Patton (1987) describes these individuals as knowledgeable people whose insights facilitate understanding of the participant's experiences and perspectives. Key informants contributed to the study at two stages: during the participant recruitment phase, and throughout the duration of the program on both a formal and informal interview basis.

During the recruitment phase key informants such as, oncologists, child life workers and the clinical nurse specialist provided important information regarding participant background and ability to participate in the study. Recommendations for potential participants were influenced by factors such as the support and consent of the child's family, treatment protocol which affects the frequency and duration of hospital visits, and the duration of time expected to be receiving treatment within the hospital environment. Throughout the study these individuals often provided me with informal and unsolicited feedback regarding participant needs and progress during casual conversations.

Key informants were also used as a source of triangulation. Discussions with parents occurred on both an informal weekly basis and during formal pre and post interviews. The perspectives of key informants were used to help provide information about events I was unable to access through direct observation or personal experience. Parents frequently provided detailed explanations and insights into experiences reported by children, or phenomena I personally observed. These explanations often helped clarify children's comments and provided information necessary to understand their behavior. As recommended by Patton (1987) the perspectives of key informants were clearly separated from actual observed data or participant reports in an attempt to maintain an accurate narration with as little informant or researcher bias as possible.

Highlight Journals. Participating children were also asked to maintain a highlight journal that (Orlick & McCaffrey, 1995a, 1995b) charted their weekly highlights and their experiences with stress. The logbook exercises for junior kindergarten through grade two involved non-verbal pictorial representations of the children's experiences, perceptions, and activities. The logbook exercises designed for grades three through six required children to use their basic reading and writing skills to a greater extent.

Children were asked to draw or write about their highlights, their feelings related to stress and relaxation, and their positive interactions. For each highlight or stressful event they experienced they were asked to complete a logbook entry. If no stressful event occurred that day, or if they tried a relaxation exercise for a reason other than the experience of a stressful event, the children were asked to complete other journal entries. Children were also asked to record positive thoughts and perspectives they had toward them self, others and their environment.

The highlight journal was used as a self-monitoring tool, which provided valuable insight into the child's perspective. The primary purpose of the journal was to provide information about the number and sources of highlights children encounter, the experience of stress for children, and how they deal with these experiences. Furthermore, the journal helped provide an indication of whether children were using the skills learned during the program and how effective they perceived the skills to be.

The secondary purpose of the highlight journals was developmental, as recommended by Yin (1994), wherein the information contained in the journals was used as a catalyst for casual discussion and as a guideline for informal interviews with program participants.

Interviews. Qualitative interviews are directed by three guiding themes: an understanding of the culture, the understanding that interviewers are active participants in the process, and the purpose to hear and understand the participants (Rubin & Rubin, 1995). In this study I attempted to conduct interviews in a manner that encouraged active listening over aggressive questioning, and facilitated the expression of rich description and detailed portrayals by participants. Although different types of interviews were used, with different interview partners at various stages of the study, all interviews adhered to this approach.

Guided Interviews. Initial interviews and final interviews with both children and parents followed an interview guide which Patton (1987) describes as a "framework within which the

interviewer would develop questions, sequence those questions, and make decisions about which information to pursue in greater depth" (p. 112). The use of a guide helped keep the interview focused, without constraining the responses of the participants. (See Appendices C, D, E & F for pre- and post-interview guides with children and parents).

Prior to each interview participants were explicitly informed of their right to refuse to answer any questions, withdraw their answers, or stop the interview at any time. Participants were also asked to respond as accurately and honestly as possible and reminded that the more honest their answers were, the greater benefit there was for both the current research effort and future program implementation.

Informal Conversational Interviews. After the initial guided interviews were completed a more relaxed approach to interviewing occurred throughout the study. Informal conversational interviews were the primary form of interviews conducted with children. This type of interview has several significant strengths appropriate for work within this context and participant population (Patton, 1987). Informal conversational interviews: (a) rely on spontaneous generation of questions in the natural flow of an interaction and from the immediate context, (b) occur as part of ongoing participant observations during fieldwork, (c) are useful when the evaluator has on-going, continuous contact with participants, (d) can build on preceding interviews, developing and changing over time, and (e) are highly responsive to individual participants and situations (p. 110).

Interviews with children occurred weekly with interview questions loosely following suggestions in the Teachers Curriculum Guide (Orlick & McCaffrey, 1995c, 1995d) (See Appendix G) and a general, informal interview guide (See Appendix H). These discussions were often directed by the information and insights emerging from previous contacts and weekly journal entries. As each participant was unique their individual experiences and understandings

could only be accessed through the use of a flexible and adaptive interview format, which was sensitive to individual differences. Therefore the guide was not intended to detract from the spontaneous, flexible and informal nature of conversational interviews. Rather, the guide served as an adaptable catalyst for deeper conversation.

This type of interview was also used, although less frequently, with parents of program participants. During weekly hospital visits parents were often approached to discuss their child's weekly events, along with progressions and regressions. These interviews enabled the researcher to learn greater details of each child's weekly activities and to access parental perceptions of their child's involvement.

Cultural and Topical Approaches. Two primary types of information were accessed during both guided and informal interviews: cultural and topical. Initial interviews were constructed in a manner that elicited primarily cultural information. The purpose of cultural interviews was to probe for "the special and shared meanings that members of a group develop, the kinds of activities that group members typically do, and the reasons why they do them" (Rubin & Rubin, 1995, p. 28). Cultural interviews were conducted following a basic interview guide with participating children (See Appendix C) and parents (See Appendix D). These interviews were conducted at the initiation of the study in order to learn more about relevant health care issues, personal and parental concerns, and daily treatment routines. The style of interviewing in these interviews was relaxed with the interviewer engaging participants in an informal conversation that detailed the experience of living with pediatric cancer.

Following these initial cultural inquiries, topical approaches to interviews were adopted. Topical interviews explored what, when, how and why events occurred, piecing together information from different people to develop a coherent account (Rubin & Rubin, 1995). Inquiries attempting to gather topical information occurred on a weekly basis with children

(Appendix H) and occasionally with parents. Topical data was also an important element during final interviews as the goal of these discussions was to discover explanations for observed and reported events and explore the processes involved with these events.

Each of these interviews and weekly sessions were recorded by audiocassette. Following the interviews, an 'interview log' was created for each tape as recommended by Merriam (1988). Rather than immediately transcribing each tape verbatim, which was not feasible given time and personnel constraints, the tapes were played and important statements or ideas noted. The information acquired from this interview log was used to guide subsequent weekly sessions and conversations. As the Feeling Great Program progressed, however, each of these audiotapes was transcribed verbatim in order to ensure complete and accurate data was collected (See Appendix I for examples of interview transcripts).

Data Analysis

Qualitative data analysis began simultaneously with data collection. This approach is supported by Maxwell (1996), as analyzing data concurrently with data collection enables interviews to be progressively focused on emerging themes and insights, increasing theoretical sensitivity. Data analysis occurred in two segments: individual case study analysis and cross-case analysis. The guiding foundation for this analysis was derived primarily from Patton's (1987) principles of data analysis and interpretation.

Individual Case Study Analysis A case is described as a phenomenon occurring in a bounded context, this phenomenon or case is the unit of analysis (Miles & Huberman, 1984). In the current research the unit of analysis was the child. Therefore, each case study was created as a holistic and unique representation of each child's program experience.

Single case analysis was the first stage in data analysis with all the data collected from each participant included in a comprehensive case file. Patton (1987) describes this process as

developing a case record. The data in the case file were organized chronologically, with weekly field notes, interview transcripts, and journal entries placed together. This information was then edited to remove any redundancies and ensure easy access. In this stage, considerable beginning analysis occurred as I personally transcribed the audiotapes, then reread these transcripts, along with relevant field notes and documents. At this time memos were developed, and filed accordingly, to record beginning interpretations and emerging insights, and indicate what would be done with different parts of the data. Primary coding categories were developed based on initial readings of the data and the purposes of the study as recommended by Rubin and Rubin (1995).

Inductive Analysis Following the development of these individual case records, inductive analysis began. I chose to use inductive analysis as it allowed categories and patterns to emerge from the data rather than fitting the data to a predetermined coding system. Two types of inductive analysis were used: indigenous typologies and analyst-constructed typologies. Indigenous typologies, or emic categories were derived from the conceptual structure and verbal data of participants, while analyst-constructed typologies were developed inductively by the researcher (Patton, 1987). First, categories and themes were identified in the data and coded using the participants' own terms and descriptions. Following this, analyst-constructed typologies were created to code the patterns and themes that were present in the data but lacked specific participant created labels.

Content Analysis Concurrent with inductive analysis, content analysis was used to identify meaningful quotations and themes in the data. The goal of content analysis was data reduction and interpretation (Creswell, 1994). At this time related quotes, examples and patterns were identified and pulled together in a manner that addressed the stated research purposes. These facets of the data were then labeled in order to develop a classification system where

components of the data were organized to increase the meaningfulness and manageability of the data (Patton, 1987).

Categorizing Strategies Overlapping with content analysis was the use of categorizing strategies. Categorizing strategies divide data and rearrange it into categories promoting the comparison of data within and between categories and aiding in the development of theoretical concepts (Maxwell, 1996). Categorizing strategies involve coding and grouping data into categories of related themes, ideas and concepts (Rubin & Rubin, 1995). The use of inductive and content analysis, and categorizing strategies, was conducted simultaneously, with the assignment of inductive codes and content analysis leading to the development of a category system. This system helped facilitate the cross-case analysis as data was organized in a manner that enabled meaningful comparisons between cases.

Case Study Narrative. Following these stages of analysis individual case study narratives were compiled. The case study narrative was guided by Yin's (1989) dominant modes of case study analysis; (a) patterns were identified within the data, (b) explanations about the case were developed ("explanation building"), and (c) changes in patterns or behaviors over time were traced ("time-series"). The case study narrative included two forms of understanding, description and explanation, as suggested by Miles & Huberman (1990). Rich descriptions were used to create a vivid image of program events and activities. These descriptions focused on the context of program implementation, the children's medical experiences, the activities within which children engaged and their response to these activities. Numerous quotes were selected to augment these descriptions and increase the strength of the child's voice in the final narrative.

Explanations were used to justify actions, provide reasons, support claims and make causal statements. Explanations and causal statements were appropriate as repeated contact with participants over an extended period of time enabled me to acquire intimate knowledge of the

program's functioning and effects (Miles & Huberman, 1990; Patton, 1987). These explanations connected program events with their appropriate outcomes, and highlighted the processes that were involved in creating these effects.

Cross-Case Analysis Single-case analysis, and the creation of individual case study narratives, were followed by a variable-oriented strategy of cross-case analysis. This method is described as pattern clarification, identifying and comparing patterns and themes that exist across cases (Miles & Huberman, 1990). During the individual case analysis, the prior development of category systems aided the comparison of data across cases. Relevant patterns and themes were identified, and similarities and differences were noted and analyzed. This cross-case analysis was then coordinated into a comprehensive interpretation of all participant data in order to move beyond the individual program effects to the shared program outcomes.

Validity

Qualitative researchers have no established consensus on the protocol for addressing issues of validity and reliability (Creswell, 1994). However, Maxwell (1996) recommends using validity in a straightforward commonsense way, referring to the correctness or credibility of descriptions, interpretations and conclusions. The following paragraphs address the issue of validity and are used in a manner consistent with that suggested by Maxwell.

Types of Validity There are several unique threats to the validity of the three types of understanding involved in qualitative research: description, interpretation and theory (Maxwell, 1996).

Description. The primary threat to valid descriptions is inaccurate and incomplete data (Maxwell, 1996). The use of audiotapes during weekly sessions and interviews helped ensure that the amount of recording error was decreased and data was accurately retrieved and recorded.

In addition, audiotapes were transcribed verbatim and field notes made as concrete, detailed and chronological as possible.

Interpretation. Imposing one's own biases and expectations, rather than understanding the perceptions and meanings of the participants is a major threat to validity (Maxwell, 1996). In order to address this threat, I chose to use an open-ended interview format during all interviews. Maxwell recommends using this format in order to allow participants and key informants to describe their own experiences in their own words.

I also obtained feedback from participants in the form of member checks. Maxwell (1996) suggests that this is the most important method of preventing misinterpretation of participant perspectives. Member checks were used on an informal basis during data collection through clarification questions and summary statements. Following the data collection period, participants and their parents helped verify the accuracy of evidence and interpretations during the final interviews. Furthermore, parents were asked to read the final case study report and verify the report's accuracy. All of the parents were pleased with both the form and content of the case study narratives and felt they were an extremely accurate representation of their child's experience.

Theory. Ignoring discrepant data and not considering alternative explanations creates the most serious threat to theoretical validity (Maxwell, 1996). Both effective and ineffective program experiences were described in the narratives. In addition, a negative case was included. By including examples of positive, neutral and negative participant experiences an accurate representation of the program's implementation and effects was portrayed.

The final research method used to increase validity was triangulation or the collection of multiple sources of evidence (Creswell, 1994). Although this concept was addressed earlier its profound influence on validity warrants its inclusion in this section. Triangulation reduces the

risk of chance associations and systematic bias that may result from the use of only one type of evidence (Maxwell, 1996). Furthermore, case study conclusions are much more convincing and accurate if they are based on the convergence of evidence from multiple sources of evidence (Yin, 1994). Sources of evidence collected in this study included participant observations, interview data, field notes and journal entries. Therefore, multiple methods of data collection were used to ensure access to a broad variety of data sources and guarantee representation of information from a variety of different perspectives.

CHAPTER IV

Results

The findings from this study are presented in four separate and holistic case study narratives. Each narrative represents the story of one unique and exceptional child. These stories are frequently filled with feelings of fear and anxiety, yet more often they are filled with demonstrations of extraordinary courage and feelings of hope and optimism for the future. The focus of this study is the child, and the child's perspective; therefore the voice of the child guides each story. Along with the child's contributions, parents also contribute to the direction and perspective of each narrative. Their insight is important as they often help express details and emotions difficult for a seven, eight, or nine-year old child to convey. In order to communicate the quality and depth of each child's illness experience, and their experiences within the Feeling Great Program, numerous direct quotes from both children and parents are included in the narratives. Charts overviewing each child's participation by week are also included to describe weekly activities, highlights, and discussion points (See Appendices J, K, L & M). I was granted the privilege of interacting with these children for a four to six month period, as such I am in a unique position to help guide the case studies. Therefore, my own interpretations of events and experiences are interwoven into each case study.

Case Study Narratives

Case Study #1 - Vince

After approximately 78 weeks of treatment for acute lymphocytic leukemia, also known as ALL, 8 year-old Vince is still having difficulty dealing with feelings of fear and anxiety around his treatment. His father describes his response to hospital visits:

> I find when he's coming [to the hospital] he gets more upset now. It's been a year and a half now, over a year and a half, so he's got another 40 some weeks ... and he's getting that he's really upset coming [to the hospital] on a weekly basis.

Vince is currently in the maintenance phase of treatment involving weekly visits to the hospital for chemotherapy and bimonthly visits for lumbar punctures (For procedure descriptions see Appendix N). Standard treatment for ALL requires a lengthy two and a half year treatment course. During this time Vince has experienced "all kinds of problems which gave him a lot of torment." His father explains that these experiences have created a number of "bad memories" making him feel "terrified and nervous about [treatment]."

Treatment days begin like no other day in the week, as his father describes, "He knows he's coming in to the hospital and that's when we find that he acts differently." On these days both Vince and his parents notice a marked decrease in his energy levels. Vince states, "I don't really want to come because I have to get up in the morning early and I want to sleep in." His father notices that "he seems to hold back and he sleeps in longer those days. Usually he's up early but those days he seems to be a little harder to get up 'cause he knows he's coming here." Some days Vince is uncooperative in the mornings, as noted by his father, "He's slow doing his rinses, he has to do his rinses and brush his teeth and he has two rinses to do and he has to eat ... and it's always a rush trying to get here early." On treatment days when Vince really "just doesn't want to come ... he sits quietly in the car."

Arriving at the hospital creates feelings of anxiety and nausea for Vince. His mother describes his customary response: "... walk in to the hospital and start [feeling nauseous]. On the way up on the elevator - he's going [to be sick]... Come up here, run for the bathroom, and

'get me a bowl' ... [Vince] had everybody running as soon as he came into the section." These feelings of anxiety resulted in Vince being "sick even here just doing the regular treatments."

These regular treatments are part of Vince's weekly routine: "I get blood tests, then height and weight, then I go back to playing Nintendo. I get a needle in my leg (intramuscular injection/IM) and then I go home." This description illustrates Vince's experience at the hospital where most of his time is spent between treatment procedures and Nintendo, his favourite activity on the unit. He does not have a specific group of friends that he associates closely with at the hospital, however, he does enjoy engaging in activities with other children when they are arranged.

Compounding Vince's feelings of anxiety is the reality of how difficult routine treatments can be. This difficulty is illustrated by his father:

> Well, they have trouble accessing his veins, he had a Port-o-cath and he had a lot of problems ... they used to put needles and poke him and they had all kinds of problems which gave him a lot more torment. We had that taken out, now they have to poke him in his arm and I know last week when he came in they had to poke him three times before they finally drew blood. So that kind of upset him. I think he got sick then too. So he ... can't just get in, get picked ... they start poking around and veins are going and that gets him upset.

During these procedures Vince's mother often encourages him to take big breaths and relax. Vince believes that "sometimes [he is] relaxed" during treatment procedures. Despite this, Vince continues to report feeling upset and stressed during routine procedures such as "needles in the leg" (intramuscular injections/IM's) and "arm pokes" (blood work). In addition, he is "usually

sicker than a dog" during his lumbar punctures (LP's). Currently, Vince feels as though he does not have any skills to help himself feel better or cope more effectively during these painful and invasive treatments.

Following his weekly hospital visit Vince returns to school, although some days he is "sick when he comes back out" and "drained ... emotionally." Anticipating his return to school Vince states, "Usually I'm really nervous ... about going back to school." "School", is also how Vince describes the feeling of stress.

I (Interviewer) - So how do you sometimes feel when you feel stressed?
V (Vince) - School.

As the start of a new school year approaches his parents have witnessed extreme levels of anxiety in Vince. "He's very frustrated at this point because right now he knows it's another three weeks or so for school [to start] and he's crying and all at night and he's restless in his sleep." There are two situations in which Vince reports experiences of stress within the school environment: academic difficulty and social interactions.

Academic difficulty often results in feelings of frustration for Vince.

> Last year he was taken from some of the classes and then they have special teachers coming in and helping him with different areas and I guess he realizes that he's still not part of [regular classroom activities] ... he sees the other kids doing things in class and he can't and he's frustrated about that. (Vince's father)

Vince's father explains that his academic difficulty is due to the effects of treatment on his memory and learning abilities, "He has trouble printing, he reverses the D's when it should be B's ... he has trouble distinguishing." (For information on cognitive late effects see Appendix O) These difficulties are "affecting his whole attitude about school" and his parents are "concerned about what's going to happen when he starts in September." He is currently being pushed ahead in his studies to maintain his position with his classmates.

The second source of stress for Vince at school involves interactions with classmates. With the exception of his best friend who is "the only one that he chums around with," Vince reports few positive social interactions. In his highlight journal Vince drew a picture of "somebody pushing me down the hill" as a situation in which he experienced feelings of stress (Appendix P). Punching, pushing and beating up are a few of the phrases Vince has used when describing events at school.

These academic and social difficulties create feelings of anxiety and stress for Vince.

> I know it's bothering him about school ... starting. It's really worrying him ... he wasn't really that fussy about school before but now it seems to be worse. I know kids get excited, nervous about it, but it seems to be picked up quite a bit.

Vince's parents connect his feelings of worry and nervousness to his feelings of nausea: "We don't know if he's making himself sick ... I think he can bring it on just like that ... he's had problems with his stomach and getting sick when he'd get upset." This physical manifestation of anxiety has resulted in Vince "miss[ing] a fair amount of school" due to an upset stomach.

Sleep difficulties are another common childhood symptom of stress that Vince exhibits. Bedtime is a time of considerable stress for Vince and he insists on either sleeping with his parents or having one of his parents sleep with him.

> I have to lie down with him, and at one time ... once he's fallen asleep, before he was fine. And it's only been the past few weeks that I'll lie down with him and [then] I'll come to our bed, and he follows me right in there. And he just doesn't want to sleep anymore.

Vince's sleep difficulties compelled his parents to purchase him a "dream catcher" to hang in his bedroom window in the hope that this would aid Vince in establishing a more favourable sleep pattern. To date, Vince continues to be afraid at night, reporting, "Sometimes I just run and go to sleep with them." Vince regularly reports nightmares and trouble falling asleep due to the scary images in his mind and his feelings of fear. Vince depicted these fears in a journal entry illustrating his hands being cut off (Appendix Q). Discussions about these entries led Vince to reveal "I'm scared about my - they might come for me at night [and cut my hands-off]."

Vince was excited to begin participation in the Feeling Great program (See Appendix J for weekly activity chart) and was pleased to receive his highlight journal during our first session. Earlier conversations with his parents revealed that Vince has a very vivid imagination and is an avid drawer: "We go through a ton of paper ... and he's always drawing stuff and stenciling." This imagination and love for drawing was obvious as Vince looked through his highlight journal for the first time; sharing stories of things he had drawn in the past, asking questions about the pages in the journal and indicating things he would draw in the future.

Weekly highlights constituted the majority of journal entries. Vince took a great deal of pride in sharing these highlight drawings introducing them with comments such as, "Wait 'til you see this picture it's really cool." Most of Vince's highlights came from activities at home or with his family, for example, playing on his own or with his sister and going to the movies with his father. He describes one such highlight, "I drew my paper parachute man. You just take a paper bag and you find a guy and you tape it to it and then you throw it up. It has to be a really good, windy day and then they go flying down the street." Only one highlight involved an incident at the hospital (Hot Potato - cooperative game). Similarly, only one highlight was identified at school (playing baseball at recess). Vince consistently identified his weekly highlights and charted them in his journal, often identifying up to four highlights per week, and sometimes as many as seven. Vince learned to identify highlights from the past, present, and future, drawing on prior joyful experiences and current and upcoming events as sources of highlights.

Vince's vivid imagination became most apparent in his journal entries representing sources of stress and relaxation. Vince depicted stress as a large heart with blood pumping in and out of it quickly (Appendix R). He described his picture as, "a heart. Getting stressed. Those are the veins, that's your blood. It's a blood stream." Vince further described the feeling of stress, indicating that his heart pumped rapidly and blood raced around his body. He also used his journal to draw images he was creating while listening to audio activities. He described his image of being strong as:

> He's stronger, he's like half person, half velocoraptor, half stegosaurus ... There's a velocoraptor he has like big guns and then they just jump out of nowhere like this ... stegosaurus, oh my goodness, they're so hard to kill. [They] just break and step on the building. (Appendix S).

In between weekly hospital visits the highlight journal seemed to help Vince remember to use the skills he was learning and look for highlights. His mother felt that the journal increased Vince's awareness of the program, "He was writing in his highlight book and things like that so I think he was more aware, from using the book. If he didn't have the book then he wouldn't have [been as aware of the activities]."

In addition to his highlight journal Vince was also excited to participate in weekly activity sessions where he expressed interest in learning new techniques to help him deal with treatments at the hospital and sleep better at night. It was before bed that Vince first began to use the skills he was learning. The first skill Vince learned was Spaghetti Toes muscle relaxation. He began using this skill following his first session in the program. When asked why he tried using Spaghetti Toes before bed he reported, "I was scared." The relaxation skill was effective and Vince later reported that he was able to fall asleep when he used this skill. Following this initial success, Vince continued to use Spaghetti Toes prior to sleeping, describing his skill use as, "wiggle your toes, like all through your body." As the program progressed and Vince began learning more skills he began using several skills at a time, often combining Spaghetti Toes and Jelly Belly breathing in the following manner, "Wiggle my toes, did Jelly Belly and then I fell asleep."

In addition to relaxation exercises Vince also learned focusing activities, such as Changing Channels. These focusing activities helped Vince foster the ability to focus on positive images and remove negative or scary thoughts. When first attempting the Changing Channels skill Vince responded, "But I can't get rid of the [scary] pictures!" Eventually, Vince learned to adapt these images if he couldn't successfully remove them from his mind. One example of this is the transformation of a ferocious T-rex (tyrannosaurus rex dinosaur): "I could make him into a

clown. And he tried to roar, but he couldn't." Vince altered a frightening image into an image he found to be extremely funny; a dinosaur dressed as a clown that was unable to roar.

During this time Vince began to report that his dream catcher worked and he reported fewer nightmares, "Well, I haven't been having dreams in quite awhile." Session ten ended with Vince stating, "I sleep by myself. Every night. [For] a week, a couple of weeks." Vince's mother confirmed this and added that they had begun an incentive program for him. Vince described this as, "My dad said if I sleep by myself until the week-end he'll give me three dollars and I'll buy my velocoraptor." When asked how he was able to sleep on his own now Vince responded, "My exercises!" He further reported that he uses his skills, "... whenever I try and get to sleep at night." Vince also reported that he was beginning to overcome his fears, which created a decreased need for his newly developed skills.

I - Can you tell me if you ever try anything to help yourself sleep?

V - Not anymore... I'm not scared anymore!

Despite these improvements Vince still found going to sleep stressful, stating, "I would do anything to get to sleep, except sell my soul." There were also nights when Vince was unable to sleep regardless of his new skills: "I tried all the exercises we did. But they didn't work." His mother described his current sleeping pattern, "... you still have to be upstairs with him, there has to be someone up stairs when he does go to sleep. But at least he's in his own room." She was cautious about attributing his improvements to one specific factor and is still uncertain as to "why he wakes up in the night on and off." Nonetheless, it is obvious that in short 12 weeks, Vince has been able to develop skills which enable him to fall asleep more effectively. He has

successfully used techniques such as Spaghetti Toes and Jelly Belly to help him asleep, has reported fewer nightmares, and has learned to sleep on his own.

Vince also began using techniques such as diaphragm breathing (Jelly Belly) and muscle relaxation (Spaghetti Toes) during his weekly treatments at the hospital. Vince's mother noted his preference for certain skills: "Well, we've talked about like the spaghetti, 'like make your toes go like spaghetti'. And the breathing, that's a big one that he seems comfortable with. And those are the two ones that he seems to go for." Indeed diaphragm breathing, or Jelly Belly, became a regular part of Vince's routine during treatment procedures: "Today whenever I got [bloodwork] I used my breathing." Vince's favourite activity, and the skill that he uses most consistently, is Jelly Belly breathing: "Well whenever I get those (intramuscular injections and intravenous lines) I *always* use the breathing." On several occasions Vince demonstrated his breathing technique by taking long, slow breaths. The use of these skills seemed to make treatments less stressful for Vince as he seldom included treatment experiences in his reports of stressful experiences during the week.

Vince also used techniques such as Changing Channels during his procedures, specifically his lumbar punctures (LP's). Following his first lumbar puncture since beginning the program Vince excitedly reported, "I wasn't sick! I thought of something else a lot of the time. I put my mind on something else. Changing Channels to Pokemon!" Vince explained his understanding of Changing Channels, "... different parts of my brain think of Pokemon, other areas think of school, other ones think of being sick, other ones think of being calm. So all the pieces of my brain think about different things." Vince's mother also noted a marked difference in his coping ability during procedures:

> Well, lately he's been a lot better for getting them, well, I told you the second to last time he got [sick to] his stomach, but anyway he's handling them a lot better now I find... He used to cry and scream and carry on. He used to be sick, he used to throw up and different things and he doesn't as much now.

Along with an improvement in his ability to cope effectively with treatments, Vince also began to experience fewer symptoms of general anxiety during his hospital visits. On only one occasion during the program was Vince feeling noticeably sick. At that time Vince asked to listen to a relaxation tape instead of participating in a regular session. Following the tape, Quiet Lake, Vince felt well enough to suggest that I turn on the tape recorder and began to participate in a full session. Taking the time to relax helped Vince decrease his anxiety and he left the session feeling much better. Vince's mother describes this phenomenon, "I think it did work though, 'cause I know a lot of his problems were anxiety, still are anxiety, and that he's not showing the same symptoms of anxiety that he had before. But then again he's getting older, but I think all these things come into play."

During these treatments Vince's mother often offers specific words of encouragement to remind Vince to use his skills:

> Well, I usually, I go for the breathing one all the time ... it's just something that I do myself ... but [Vince] seems to hyperventilate, like he gets all upset and then his breathing gets fast, and that's why I'm trying to slow that one down.

Vince's mother has always encouraged Vince to relax during his treatments. However, his involvement in the Feeling Great Program appears to have helped him develop more effective

skills and he uses these skills more consistently during stressful experiences. In addition to verbal encouragement Vince's mother is also very supportive of Vince's involvement in the program, consistently remembering to bring his journal to hospital visits, encouraging him to complete his journal entries, and ensuring participation in weekly visits even during the most hectic treatment days.

Although Vince was able to use successfully the skills on a regular basis there were still times when he found his treatments difficult to endure. Prior to beginning the program, Vince's father indicated that he had bad memories from bloodwork. At times, this continued to be a difficult procedure, as Vince explained, "I still get mad. I hide my hands. I get nervous. 'Cause sometimes it hurts, sometimes it doesn't." Nonetheless, Vince frequently demonstrated effective coping skills during his treatments such as intramuscular injections and lumbar punctures. In addition, he was able to control his most intolerable symptoms of anxiety, nausea and vomiting, upon coming to the hospital for treatments.

Vince's school attendance also improved this year with his number of sick days decreasing dramatically. His mother attributed this to improved physical health, increased maturity and Vince's ability to apply the new skills he has learned. Vince was able to effectively control feelings of nausea and remain at school during periods of anxiety and stress. One such incident occurred four weeks into the program when Vince called home asking to be picked up as he felt sick: "I didn't feel good at school ... I drank some of my pedialyte and my stomach started getting sore." On the phone his mother encouraged him to "use his skills." Vince used his Jelly Belly breathing, taking slow, deep breaths and was able to remain at school for the rest of the afternoon. Vince also began to develop his own methods of dealing with feelings of nervousness and/or sickness at school, stating, "Sometimes I just put my head down on my desk." During this

time Vince's mother reported that he had only missed three days of school in four weeks, a substantial improvement over his previous attendance record.

Vince continued to identify a number of stressful experiences at school including too much homework, math and negative interactions with other children, i.e., punching and mean comments. "Sometimes I hate school 'cause you have to do so much work, too much work." He says he "gets stressed" during "math" at school and "feel[s] very bad" when tests do not go well. His parents confirm that even though his school attendance has improved Vince is still quite frustrated with his academic progress: "At school where he's ... seeing the other kids are getting ahead and he's not. He's struggling and that's stressful for him." Vince does not specifically report transferring skill use to these situations, however, he has developed more effective methods of dealing with stress at school, for example, "At [one] time I would tell somebody to shut-up. [Now I] say stop first and if they don't stop, go tell my teacher." In addition, his mother feels "that this has helped Vince, the exercises, even if he doesn't tell me that he's doing them. I think something has helped him, because he's not as sick as often."

Vince found the skills to be most useful in three specific situations: prior to sleeping at night, during treatments at the hospital, and during episodes of physical anxiety or illness at school and the hospital. The skills Vince used most frequently and effectively were Jelly Belly, Spaghetti Toes and Changing Channels. Vince greatly enjoyed participating in the Feeling Great program and was disappointed when it ended. "He enjoyed it. When he found out he wasn't going to be doing it, that it was finishing he [said] 'Oh, no.'" Vince's mother was pleased with the program and felt it was an important tool for all children:

> I think it's very important to have some tools to help yourself because there's always anxiety in life and it's good to have these tools because if you don't you could be in

> trouble. I was very pleased with the program, I think it's very good for the kids up here. You know I think it would be good in the schools. I feel it should be mandatory there too. Because it is a learning tool and I mean what's school for?

Case Study #2 - Jacob

Nine-year old Jacob's first experience with medical treatment for acute lymphocytic leukemia 1½ years ago was extremely distressing: "He ran out of the clinic ... crying. And he was not going to have any of this. In fact he was not going to have anything to do with [treatment] at all." His mother describes the impact of these experiences, "The hospital thing, that's been very stressful." She is quick to add, however, that "he's dealt OK" with the frequently unpleasant and painful treatments he has endured since diagnosis. In fact, over the course of the past year and a half Jacob's ability to cope with these treatments has improved considerably. His mother explains:

> And actually it was [a child life worker] that kind of helped him through at first. And once he had his port accessed the first time (indwelling catheter placed under the skin of the chest attached to tubing which goes into the heart, commonly used to administer medication), because he got it so late during induction, then he was fine ... Otherwise he's OK. But I always have to be [with him during procedures] to hold his hand.

Jacob describes his current attitude towards treatment. "Well I don't really feel nervous or anything ... I'm not nervous with everything. I'm nervous for something really scary." Jacob was able to achieve this level of positive adjustment with the continued support of his parents and hospital staff.

It was at this stage in his treatment that Jacob was introduced to the Feeling Great Program. During this introduction Jacob's parents expressed reservations regarding Jacob's involvement. Although highly supportive of the program and related mental skills they were uncertain of the appeal it would have for Jacob and his willingness to complete a highlight journal. Furthermore, Jacob has leukoencephalopathy (See Appendix O for description), a factor they felt might create an additional barrier to successful program participation as it interferes with children's learning abilities. Despite these reservations and low expectations for success they readily agreed to Jacob's participation, conditional upon his consent. At this time Jacob participated in a trial session following which he agreed to participate in the program, with one contingency; he did not want to maintain a highlight journal.

I (Interviewer) - Well do you want to try a [highlight journal] this week and take it home and see how it goes?

J (Jacob) - Umm, no I don't want to take a book...

I - And do you want to try and do activities once a week?

J - OK, but I don't want the book.

Jacob's case presents a unique opportunity for learning, in part due to these alterations in program format (See Appendix K for weekly activity chart). His experience reflects the need for program flexibility within this environment. A child's personality, preferences and prior experiences impact significantly on program implementation and outcome, making a flexible program design essential.

Treatment for ALL requires a seemingly endless number and variety of treatments (See Appendix L for treatment details). Jacob has made substantial advances in his ability to cope

with these treatments, as stated earlier. However, he continues to experience difficulty during intramuscular injections (IM's), stating, "Sometimes it hurts, sometimes it doesn't ... lots of times I get my mom to hold my hand down ... I've only done it two or three times by myself. No holding hands." In addition to identifying difficulties during this procedure Jacob describes situations when thoughts of past negative events make him physically upset, "Sometimes when I think of things I shake ... when I think of something, like what happened to me a long time ago, something that happened to me today, or something and I just think about it again and I shake ... Something like somebody yelled at me." These examples indicate that although Jacob's coping has improved dramatically he continues to experience sources of considerable stress, specifically in relation to his illness and treatment.

Despite these incidents of stress Jacob has learned to accept his illness and related treatment and make the most of his time spent within the hospital environment. He is a social child and interacts with a number of different children and staff members, enjoying participation in a variety of organized activities such as cooking in the kitchen and pumpkin carving. Jacob's preferred activity at the hospital is Nintendo and he is often found playing in between his various treatments. He has the ability to cope effectively with most disturbing hospital experiences, and identifies few sources of stress outside the hospital environment, as his mother reports, "I don't know that he's got any stress at home to be honest ... At school, I don't think so, he really likes going and he doesn't complain. I don't think there's anything stressful at school." Given Jacob's relatively low levels of stress, which he explains as, "Well [I'm] never *very* stressed," he sees little need to develop strategies for coping with stressful situations, stating, "I don't really need to."

During his introductory session Jacob appeared moderately skeptical of the program activity, Spaghetti Toes. The following week he even expressed amusement toward the activity,

as evidenced by his joking with a fellow participant, saying, "Oooh, Spaghetti Toes." He also appeared doubtful of its efficacy, commenting, "I think I'll never use Spaghetti Toes. I think I'll only use Spaghetti Toes when I'm a grandpa." This reluctance to attempt muscle relaxation continued and Jacob later reported, "Well I don't usually use Spaghetti Toes. I just relax on the couch or in my comfy bed."

Following this session Jacob participated in the breathing activity Jelly Belly, which he describes as, "a bit boring". Jacob quickly learned proper diaphragm breathing stating, "I already know how to breathe, I was doing that for every single millisecond." He also indicated prior use of similar techniques, "I ... use [Jelly Belly] a lot, I use this forever." Jacob's colourful sense of humour and somewhat derisive attitude became apparent during this activity when he repeatedly inquired, "Are we lighting candles? You know, when they light candles and they start to levitate."

Jacob's response to these two mental skill activities, Spaghetti Toes and Jelly Belly, epitomize his initial attitude towards the program. He was moderately skeptical of the mental skills and the manner in which they were presented, he even indicated that he views these skills as being more appropriate for older people such as grandparents, and associated them with more unconventional forms of mental skills such as levitation. In spite of the uncertainty he felt regarding the validity of the skills, Jacob continued to be a diligent and lively participate in the program.

Changing Channels was the next activity Jacob participated in. This activity teaches children to direct their attention, or change their channel, away from negative stimuli to either a positive image or stimulus. Jacob's love of his birthday and birthday parties became obvious during this session: "Do you want to know something that really makes me happy? It's my birthday ... I get to go wherever I want and I get everything first ... and cheese pizza ... my aunt's

going to make a cake and I'm going to eat ... and it's my favourite supper." Although quick to identify a joyful experience, Jacob had little preliminary use for this skill reporting, "I tried [Changing Channels] once, I usually don't try that."

Special Place Relaxation teaches children to imagine themselves relaxing in a Special Place. Selecting the appropriate location for his Special Place proved difficult for Jacob. Consequently, he described several potential images. Among these images was Jacob's description of a ride at a popular theme park, "I'll tell you about a place that I've been to before, Wonderland ... [on the] James Bond ride ... you're thrown around in the seat like James Bond." Despite identifying several potential locations for his Special Place, Jacob expressed uncertainty over actually using these images during treatment experiences or elsewhere, commenting that he would only use imagery, "if I had nothing to think about." Further discussion elicited the following exasperated description of a Special Place: "LaLaLand ... when you're not paying attention to anybody you're in LaLaLand ... it's boring there 'cause all you do is like, 'La, La, La'. Nothing." Jacob's difficulty selecting an image appeared to be a result of his inability to understand the skills' meaning and usefulness.

Jacob's challenging attitude towards skills in the program, although accompanied by an extremely warm personality and a clever sense of humour, presented an initial barrier to successful skill adaptation. A second barrier proved to be his preference for other activities offered in the hospital, namely Nintendo. This preference for Nintendo created difficulty in convincing Jacob to attend weekly sessions. On several occasions Jacob would negotiate session times, pleading to finish "just one more [Nintendo] game" or requesting that other participants go before him, "Has Mark gone yet? Can I go after him?" It was often necessary for Jacob's mother to instruct him to put the Nintendo down and participate in the session. Jacob's creativity in avoiding session time became obvious when he learned the mental skill Changing Channels, as

the following statement indicates, "I'd like to change my channels to Nintendo, playing Nintendo." Often Jacob was less creative and more outright when requesting to participate in other activities in the hospital, often asking, "Can I go carve my pumpkin now?" or "Can we play Nintendo?".

In spite of his initial skepticism towards the program, and his preference for other activities, Jacob turned out to be an animated participant and a receptive learner. Gradually he began to apply the tools he was acquiring in the program to situations he found difficult to cope with successfully, specifically his IM's.

The first skill Jacob began to use on a consistent basis was Jelly Belly, a skill with which he had some previous successful experience. Jacob reported using Jelly Belly "only when I have my leg needles, I hate those needles." Following this initial skill use, Jacob's mother noticed a complete change in Jacob's demeanor during his treatments, "He started using them, as far as I know, the very next week. When he had his bloodwork done, he would do the deep breathing and especially when he gets his needle in his leg, his chemo. I mean the very next week he started to use them and he's been using it ever since." Jacob illustrates his use of Jelly Belly breathing, "I breathe and take a deep breath, sometimes when [the needle] gets in my leg." During Week 10 of the program Jacob indicated further improvements in coping due to more effective use of these breathing techniques, "I did use ... Jelly Belly. *Real* Jelly Belly." In fact, Jacob began to develop a preference for the diaphragm breathing activity Jelly Belly, and would often request it during sessions. In total, Jacob listened to the Jelly Belly audiotape three times during his 12 program sessions.

In addition, Jacob began to use Changing Channels during episodes of pain and stress, reporting, "I started using them when I had that headache thing. When I started having this headache when I was asleep." There were two specific experiences that led Jacob to attempt

these new skills. The first incident occurred at home. Jacob was experiencing a great deal of pain due to an intense headache and pain throughout his bones. Jacob describes his proactive use of mental skills, "I thought of something else when I lied in my parents bed ... lying on the beach ... being in the Tower of Terror ... so I was ... changing from lying on the beach there and then eating pizza." This mental shift in focus, from pain to positive experiences, helped Jacob relax and cope effectively during this unpleasant experience. Jacob's ability to cope effectively during this painful situation enabled him to develop a greater understanding and appreciation of the skills efficacy. Jacob became more receptive to future skill use stating, "Well I'll try it when I go into my bed next time."

Jacob applied similar mental skills in the emergency room while experiencing excruciating stomach pain. His mother reports:

> ... in emergency where he was having a lot of stomach pain, and this went on for a couple of hours, and he didn't say this to me until afterwards that he used the switching channels technique that you had taught him. And he said it really, really worked for him. That he would just lie there and do whatever it was that you had told him and his stomach-ache, he kind of forgot about it.

During this situation Jacob effectively combined two different techniques, Jelly Belly and Changing Channels. Jacob's effective skill use continued until the end of the program. In the final interview he reported using skills during his MRI, "When I had my MRI I used like Changing Channels ... thinking of different things ... the thing I was lying on was moving and I closed my eyes and ... it was fine."

Jacob's mother observed positive changes in this procedure as well:

> Yesterday having his MRI ... he's in that thing for a long time, and it's really, really noisy. I asked him last night, 'Did you use anything that [the program] had taught you while you were in there?' And he said, 'Ya, I did'. He didn't really go into specifics with me but he said that he was thinking about some of the things that you had told him and it really did help ... And I could see a difference from his MRI a couple of months ago where he had to come out a couple of times and just get a breath of fresh air. So it was helpful. He stayed in the whole time and never complained.

It is obvious from these examples that perceived need played a role in Jacob's willingness to attempt using the skills he was learning. In fact, Jacob would often delay attempting new skills until he was undergoing a procedure he found difficult, such as IM's, stating, "I'll try it next week when I have a needle", or during situation's of extreme pain and discomfort, such as stomach aches. Jacob's prior positive experiences using relaxed breathing techniques appeared to make him more trusting and receptive towards these types of skills and he began using Jelly Belly breathing in a more effective and consistent fashion early in the program. However, other less familiar skills, such as Changing Channels, were not implemented until much further in the program, as he reports, "I kind of waited [to start using them]." When asked why he delayed using the skills, Jacob responded, "I thought about them." This reflection appeared to help Jacob develop a greater understanding of the skills and he eventually came to appreciate their usefulness. Despite this increased willingness to implement program skills Jacob continued to resist skill use in other situations, specifically situations where he did not identify a substantial demand, "Well I don't need to think on bloodwork 'cause it doesn't bother [me] that

much." This selective skill use further emphasizes the importance of perceived need to Jacob when it came to using new skills.

Highlights comprise an additional segment of the program that Jacob participated in, albeit in a revised version, "I don't take the book, I don't have to do any work ... I didn't want to take it." Jacob views the journal as additional "work" and verbally recounts his weekly highlight experiences in lieu of journal entries. Jacob's mother describes the characteristic she feels is responsible for this perspective, "He's pretty lazy. Honest. I think he was just too lazy." This led to the exclusion of a highlight journal, an adjustment that pleased Jacob, "Don't worry, my books in here (indicating his head) ... I got it all in here."

Despite Jacob's insistence that he has "got it all in [his head]," he initially experienced difficulty identifying highlights. As his family placed a high priority on maintaining his involvement in joyful activities they were disappointed with his seeming inability to remember these positive experiences. This motivated Jacob's mother to encourage him to use a highlight journal. She felt the use of a journal might help Jacob remember the positive experiences occurring during this difficult period. Jacob was extremely upset by this conversation with his mother, as he truly did not want the additional work a highlight journal represented for him. At the same time, however, he did not want to disappoint his mother. This led to a tearful conversation and in the end a decision was made that Jacob and his mother would discuss his highlights before bed each night in lieu of a journal.

Following this decision Jacob immediately began to recount more highlight experiences, an event he attributed to "my mom told me to tell you some [highlights] this morning ... my mom gave me highlights to tell you." Initially, Jacob's mother helped him identify his weekly highlights; discussing weekly events and helping him recognize and remember his favourite experiences. Over time, Jacob learned to identify highlights independently and would often

spontaneously recount these events prior to the beginning of his sessions, "I had french fries one day ... and then went to a restaurant with my Grandpa and had soup. That's another highlight ... Halloween's coming up. That's a highlight. I'm going to my Grandma's for Thanksgiving and then on Sunday I'm going to my Nanny's for Thanksgiving ... I'm gonna eat bacon for breakfast." Jacob learned to identify a variety of weekly highlights such as going to a movie and getting two new Nintendo games.

Jacob reported a number of upcoming highlights in addition to previously experienced highlights, "Well I have a highlight for tomorrow, playing bingo ... I have another one coming up. It's really close ... it's my birthday ... they have this huge tube thing and they have a whole bunch of video games and you get these tickets for the machine and you win." Jacob had a number of recurring highlights such as weekly bingo and his upcoming birthday. The identification of these future highlights suggests that Jacob was not only able to identify weekly highlights but was also able to develop a positive outlook for future events. Additionally, Jacob learned to recognize the fact that thinking about upcoming enjoyable events also created a positive highlight experience.

These examples indicate that there was a definite improvement from Jacob's ability in Week One to identify highlights. At that time he had difficulty identifying even exciting events as highlights:

I - What about when you go to an Ottawa Senators game? Is that kind of a highlight?

J - Nope, not really. But it was a bit exciting.

In contrast to his earlier difficulty identifying highlights, Jacob eagerly launched into an account of his highlights twice during his final interview, "And I got to go to McDonald's and to the

Christmas party and I got a shirt with a bag and I got a certificate for a free thing of fries." Further into the conversation he again reported these highlights, stating, "I got a highlight for you ... going to McDonald's and the Christmas party and tonight I'm going to Cubs and we're going to see all the [Christmas] lights get turned on."

It is interesting to note that despite this improved ability to communicate highlight experiences Jacob reported that the program did "not really" help him identify more highlights. However, he did indicate that reporting weekly highlights increased his memory of positive events somewhat, "Sometimes I remember some. I remember some of them." Jacob's mother felt he reported highlights out of obligation, "I think he did it because he knew he had to, I'm not so sure that helped him ... that would be my take on it." Nevertheless, Jacob clearly demonstrated an improved ability to identify the positive events in his life as highlights.

Jacob applied two skills consistently: Jelly Belly and Changing Channels. He depicts his use of Jelly Belly as, "[my stomach] always goes up and down, up and down." Changing Channels he describes as, "Well I'm using that Changing Channels and thinking of different things ... like thinking what we're going to do on my birthday ... Well sometimes one of my channels is static, all black. Like the fuzzy channel, it's all black. That's when I'm not thinking of anything." These skills enabled Jacob to decrease his experience of stress during his hospital visits and he reported, "Nothing makes me stressed here." However, he does admit to experiencing the occasional stressful encounter, "Sometimes something's make me stressed, I don't really know what they are." He also reported continuing dislike of his IM's, "my leg needles, I don't like."

In spite of his consistent and effective use of these two skills, Jelly Belly and Changing Channels, Jacob continued to voice a preference for other activities on the unit, specifically Nintendo. He persisted to negotiate for shortened weekly sessions up until the final week,

declaring, "I'll only do it if it's a short one." Furthermore, his final interview was conducted in the hospital hallway in front of a paused Nintendo screen in order to maintain his position in the game. Nevertheless, Jacob was an extremely energetic and pleasant child during sessions and a capable learner, even admitting that he was glad to have participated in the program. His mother supports this statement: "He enjoyed [the program] a lot, and I'd say he got a lot out of it. Honest. He never once said to me, 'Oh, I don't want to see Julie this week', or 'I don't want to [go]'. Never. Except for the workbook. That he didn't want anything to do with. And that was fine."

Jacob's mother was very supportive of the program, facilitating highlight identification, encouraging weekly attendance, and adapting their schedule to ensure consistent participation. This support continued into the treatment environment as well:

> I would ... mostly just talk to him and I'll remind him of the things that you told him. You know, if he's nervous about something, 'Concentrate on your breathing. Do your deep breathing', which he does for his chemo (IM's). That's really about it, just reassure him that I'll be there for him if he's nervous about something.

In addition to being supportive of the program she is "very glad, very glad" that he participated, stating, "I really do think it was very helpful for him."

Jacob's newly acquired skills enabled him to effectively cope with many distressing experiences, a skill essential to any child dealing with the reality of cancer and its treatment. As Jacob's official participation in the Feeling Great Program neared completion he stepped into a new role, the role of teacher. Jacob was asked to demonstrate the techniques that he had learned to a young child on the unit struggling with a procedure only recently mastered by Jacob;

intramuscular injections. The skills Jacob developed gave him the opportunity to finish the program not as a student, but as a teacher, aiding in the development of positive coping skills in another child in need.

Case Study #3 - Karen

One year after diagnosis, eight year old Karen continues to be overwhelmed by extreme levels of fear in the hospital environment; fear of meeting new people, fear of painful procedures and fear of unfamiliar experiences. Her mother describes Karen's current state:

> She's been through a lot in a year so it's understandably so that she's on overload right now. That she's had about enough. She's met so many people in the last year, just the nurses alone must be a few hundred. She's been poked and prodded and everything else. So she's just wanting a little stability probably.

The previous year has indeed been a difficult one for Karen. These difficulties originated with her initial diagnosis of cancer:

> My husband and I knew there was something wrong with her because she was having these horrible sessions, sound asleep at night. Anywhere from midnight to three in the morning she'd start circling in the bed, sound asleep, holding her face, she looked like she was possessed. She had a sharp pain in her left cheek and we had taken her for sinus x-rays and of course, nothing showed until she had the CAT scan and MRI to see the muscle because the tumour is in the muscle - or was in the muscle, it's gone now. But anyway, they finally saw something in an x-ray ... they saw some sort of cloudy mass. After the biopsy they started the radiation right away and the chemo right away.

The cancer they found in Karen's cheek was rhabdomyosarcoma, "... a very rare type that hits the muscle and it's often in the head area but it can be anywhere from the baby toe to all through out the body." Karen's daily life has been transformed by the treatment regime for this cancer, which began with removal of the tumour through surgery, along with radiation, and chemotherapy. Karen's mother explains Karen's remaining treatments: "including this one, starting today, three [chemotherapy] treatments left. Each five days, 21 days apart." In addition to these three treatments Karen undergoes a seemingly endless variety of procedures including bloodwork, mickey checks, mickey changes (feeding tube placed directly in abdomen) and dressing changes (For procedure descriptions see Appendix N). These procedures require frequent hospital admissions and weekly hospital visits which Karen describes, "[I] do crafts. Well, we usually check in, and then I always go to the craft room if my counts are OK ... the only thing I like here are the crafts. And getting out." During these visits Karen has very recently developed her first close friendship with another child on the unit.

These frequent hospital appointments create numerous daily upheavals and have necessitated Karen's removal from the public school system. Currently she is being tutored at home and at the hospital, as her mother explains, "She understands the whole schedule we're going through and she loves the teacher here. [She] helped her last year. She'll have the same tutor [at home] that she had last year, so she knows what to expect."

Although Karen's schedule has developed some measure of consistency, she is still experiencing a great deal of distress within the hospital environment. Specifically, painful and invasive procedures have created considerable physical and mental trauma. Her mother describes these experiences, "If you were to see what they do, it hurts them. I just find that some of her feelings are very warranted, how she's scared to death to have certain things done." As a result of these traumatic experiences Karen has become increasingly anxious, not only during

known painful procedures but also during less invasive weekly routines, such as dressing changes. This increase in anxiety has also transferred to unfamiliar and unknown treatments as "[Karen] doesn't like a lot of change."

Karen currently has a feeding tube placed in her stomach to help increase her caloric intake. She refers to this tube as a 'mickey' (See Appendix N). This is the source of her greatest anxiety; "So right now being put to sleep [for her mickey change] and having this mickey changed are the worst ones." Karen's mother further describes this painful procedure:

> So if you understand that the hole in her stomach is this big (indicates size of a pea) and the [tube that comes out] is the size of almost a large grape, a very large grape, that coming out of the stomach wall and through the skin hurts like hell ... This acid makes the plastic expand and it's not soft, like it doesn't give, it's hard and it pops out [of her stomach] ... It hurts. No parent wants to put a child through that because this is what's scaring her, because these things hurt.

When possible, Karen's mother coordinates these mickey changes with other procedures that require Karen to be put to sleep: "... because Karen was asleep I asked the surgeon, since she had put the mickey in originally, I asked her if she'd change the mickey while Karen was asleep. Perfect." More often though, Karen is given conscious sedation during this procedure which she describes, "They gave me some stuff to feel kind of woozy but I was awake for it ... they give me medicine, like to make me relax, that I wouldn't feel it, but I still did ... it makes me kind of like dizzy and sleepy." Fear of this painful procedure has created significant anxiety for Karen and she has yet to develop an effective method of coping.

This mickey must also be checked on a regular basis to determine if the level of fluid is acceptable. Karen describes the process, "... you've got to hold [the tube] so it doesn't come out [of my stomach], 'cause there's a balloon that holds it in and then [the nurse] checks the water with a syringe and then if there's not enough she takes some out ... of a little cup." Due to the extreme tenderness of the area surrounding her mickey Karen becomes very distressed during any type of contact and insists on controlling the procedure; she tells the hospital staff when they can begin, what they can do and insists on performing a great deal of the work herself.

> Even though I had my mickey, [my mom] had to do it ... I didn't like anyone touching it. The only person that I liked to touch it, my mom, did the cleaning. That was it. And then Nancy (nurse) checked it, and then I was the only one that did the testing and really touched it. I hold it like that ... it's so tender I won't let very many people touch it.

Needles create additional feelings of fear and anxiety, "I don't like the needles ... I kind of feel scared." Sometimes she will cry "when they put the needle in, well maybe just before." One needle in particular is extremely painful for Karen, her GCSF needle. This is a specific type of medication injected into her arm. Karen has developed a very specific physical position that decreases her pain during her GCSF needle, which she describes as, "the scariest needle ... 'cause it stings." This position requires that two people, her mother and a nurse, hold her arms in place while the GCSF is administered. The skill required to manipulate Karen into this position is obvious in her description: "I have ... for the GCSF, there's a position that doesn't hurt me ... and I tell the nurses to do that. I hold right here, the nurse holds like that, and then my mom holds the elbow right here." Karen currently talks to herself during her needles in an attempt to relax, "Well, I just kind of went 'Everything will be all right' and ... I just said 'I'll feel better.'"

Dressing changes are an additional source of stress for Karen as she has yet to develop an effective method of coping with them. These dressing changes, which are required due to her broviac (See Appendix N for descriptions), are extremely stressful, as she explains, "I try [relaxing] with my dressing change and I never can do it ... I'm really scared ... it hurts, it stings." Karen chose the "Stressed Cat" on the cat scale (See Appendix T) to describe her feelings during her dressing change, "I felt like that (indicating stressed cat) this morning [during] my dressing change." Karen's current method of dealing with this procedure is to delay it for as long as possible and she has developed an effective method of stalling that involves repeatedly loosening and reapplying the same portion of her dressing.

In addition to the difficulties Karen experiences during these painful and invasive treatments she is also concerned with her appearance following facial surgery to remove the tumour.

> There are big concerns, I know she's concerned about the way she looks now, the deformity in her left face will be there ... Because when she does go back to school it's going to be tough. Kids are cruel and it's not going to be happy times, I'm sure ... She was looking in the bathroom mirror and she said, 'Mom, you always told me what's important is what's inside, not what you look like right?' ... It will bother her, especially when she gets older. But she knows people look at her and this is what I find I need help with. That even though [her father] and I are reinforcing, it's positivity; we need other people too.

The extreme levels of anxiety resulting from these painful procedures, and accompanying physical scars, have created a sense of desperation in Karen's mother. This

feeling prompted her mother to enroll Karen in the Feeling Great Program. Initial attempts at participation were unsuccessful as the first meetings were characterized by Karen hiding behind her mother's back, crying, whimpering, shaking her head and refusing to speak or meet anyone new. Her distress was obvious. Even with her mother's reassurances that this was not a medical procedure, that she would not be with a nurse or a doctor, Karen continued to refuse to participate. It took three weeks of gradual meetings before Karen agreed to try the program (See Appendix L for weekly activity chart).

Overcoming her initial fear, Karen became very excited to participate. A considerable portion of this excitement was directed towards her highlight journal as she enjoys drawing. "I kind of like painting and drawing... pictures and paint by numbers and all that stuff." Her mother described Karen as "...naturally talented at so many things and she's very artistic which is wonderful, crafts and everything ... she knows she's good and she's trying to teach me now how to draw."

Karen transferred this love for drawing to her journal entries, which were extremely creative. Although she enjoyed her journal, she chose to use it on a relatively intermittent basis. For example, it was approximately five weeks into the program before Karen began making entries. During this time she was admitted into the hospital for 15 days and had difficulty identifying highlights. When Karen did use her journal it was for her most notable highlights, which she described as "your favourite things". Most of these involved her experiences with horses. "Horses are my favourite ... I wish I had a horse ... I like to wash them and brush them." Karen would often verbally recount her highlight experiences:

> I went riding with my cousins on a horse, about that much smaller than a horse. A pony. Like a miniature horse. And I tried lots, and lots, like a full run and it was really fun.

You have to hold on really tight and try to put your weight down so you don't bounce up and down. Oh, it was really fun.

Weekly activities often dictated Karen's journal use and she would select pages based on these events, choosing to enter highlight experiences on the more specific activity pages. For example, she chose to complete the section on My Goals "another week 'cause I know I'm going riding with my dad another week" (See Appendix U). Similarly, she chose to complete the page Being Nice to an Animal after she had been horse back riding (See Appendix V). Karen enjoyed working in her journal and often joked that she was going to fill the entire journal with horse pictures.

Although Karen was able to use her journal to develop a record of positive highlight experiences, there were a number of times that she had great difficulty identifying even small highlights, "I know today wasn't a highlight ... yesterday I didn't have a good day 'cause my dressing was leaking." Karen was sometimes forced to identify highlights based on events she was happy to finish, "I know that I'm glad I'm done with the needle in my leg." She even identified "getting out of the hospital" as a highlight. This preoccupation with hospital experiences reflects the impact these procedures have on Karen, often becoming her central focus of the week. Despite the prevalence of negative hospital experiences in Karen's daily life she did learn to identify more highlights during the 12-week program stating, "I didn't really notice [highlights] before the program."

Karen's mother also felt the journal had enabled her to identify more positive experiences. Prior to beginning the program her mother described the attempts they made as parents to keep Karen's life full of joyful activities, "My husband and I spend a lot of time, we take her to see the RCMP horses, we do a lot of stuff that she loves. We live everyday to the

fullest." Karen's mother felt that Karen's use of the highlight journal helped reinforce their attempts at creating joyful events and happy memories during her treatment course.

> Through out her treatment her dad and I have tried very hard to keep her busy doing activities that she loves to do. And when you look at that book you can see what we were busy doing with her by the week. One thing, we took her pony riding several times ... so I think that she was proud to come in and be able to tell you that she went to a movie, or she went pony riding with her cousins, or went traveling. So it was excitement for her to be able to come in and report to you what she had done the past week. So definitely her drawing about what she was doing sort of reinforced, I think, the happy times on top of all the treatment.

Karen was also an enthusiastic participant in weekly sessions, often physically acting out key concepts she was learning, and dancing or singing during discussions. Karen's expressive nature revealed itself in Week 1 during a discussion relating to stress and relaxation. She described stress verbally as "I get all tensed up. Sometimes I can't even move ... I just feel like all weird." This verbal description was complimented by physical impressions of the stress experience - scared, agitated facial expressions, fast, shallow breathing, tense, stiff leg and arm muscles. She described relaxation as "kind of like calm and tired." This description was accompanied by Karen curling up into a relaxed sleeping position, eyes closed, cheeks resting on folded hands and a peaceful smile on her face.

During this first week Karen learned Spaghetti Toes muscle relaxation. This was the first skill she attempted using immediately following her first session and her mother noted an immediate improvement, "I noticed if you saw her before she had a procedure done it seemed to

help more if it was fresh in her mind. But I think the first thing you taught her was Spaghetti Toes and that first day she used that, I believe to have bloodwork done, and it was helpful." Following Karen's bloodwork that first day, a nurse reported significant improvement in Karen's coping behavior, both prior to and during the needle. Rather than responding fearfully to her needle, Karen told both her mother and the nurse that she was doing her "Spaghetti Toes". Struck by the improvement in Karen's coping, the nurse suggested Karen regularly do Spaghetti Toes before procedures.

This initial success was followed by a difficult couple of weeks where Karen was admitted into the hospital for a 15-day period and was required to be awake during her mickey change. Following this procedure Karen was noticeably subdued. The mickey change had obviously caused her considerable anxiety and physical discomfort:

I (Interviewer) - Today [your mickey change] was kind of painful?

K (Karen) - Ummhmm.

I - Ya, so did you try anything during it to try and make yourself feel better?

K - No.

I - No? It was just pretty upsetting?

K - Ummhmm. 'Cause they give me medicine, to make me relax, that I wouldn't feel it ... but I still did.

Karen found it difficult to use any skills during this procedure due to a combination of her intense feelings of fear and the effects of the conscious sedation. Despite this difficult experience Karen continued to attempt to use her new skills in a number of different situations, namely during dressing changes, mickey checks and needles. When asked if there have been any

improvements since the start of the program Karen is quick to respond, "Changing the mickey, well I mean not changing the thing ... checking the water [in the mickey]. And the dressing change [have improved]."

Midway through the program Karen reported using Changing Channels to her Special Place during her dressing change. She drew her Special Place in her highlight journal and described it as a sunny field, with a lake and a big red barn where she pictured herself riding a horse. Her mother describes her improvements:

> All the methods have made a change. During the dressing changes, probably a quarter of the time they used to take ... she's just naturally become comfortable. In the beginning I know she was using [the skills]. And even today, I believe it was when I was taking the dressing off, she told me she shut her eyes, or told you. But that was something, she is having a few things in her mind that can help her out if need be.

Proud of her enhanced coping, Karen offered to demonstrate these improvements. During this dressing change Karen calmly assisted the nurse in cleaning the area and then allowed the nurse to complete her work without continuous delays and objections. Rather, Karen made the time pass by imitating different animals she heard on the audiotape Animal Sounds, howling like a wolf and growling like a dog.

Karen was equally proud of her improved coping during her mickey checks: "Actually I'm going to have my mickey checked but I'm fine with it now. Because it doesn't hurt anymore." Her mother felt she had displayed remarkable improvement during this procedure by the end of the Feeling Great program, "It's not so bad now, she uses these techniques when they check the level of the fluid that's holding the thing in." Karen continued to play an active role in

this treatment, helping to clean and prepare the area, but was much more comfortable with other people performing this sensitive procedure. The staff responsible for checking her mickey also commented on Karen's newly developed calmness during her procedures. This calmness greatly improved the treatment atmosphere enabling the hospital staff to perform the procedure more quickly and efficiently.

Another major component of Karen's hospital experience were the needles she received for bloodwork, treatment, and intravenous lines. She was also able to develop more consistent coping skills during these, as her mother described:

> Even the bloodwork when it became routine, that became easier as well. So I think her being taught to concentrate on how to relax and to deal with all these things and to focus in on what's being done, and why. I think it's made a great difference. Definitely.

Karen even learned to apply her new skills during injections at home.

> She was having injections in the home after her chemo when her immune system was really low, to get her bone marrow producing the blood cells again. She'd have to use her breathing techniques and just really concentrate and you know go off in her own little world ... she'd refer to changing her channels. So that was really important for when she was having the injections in the home...

Karen also learned to apply her new skills during the scariest needle, her GCSF. Karen continues to maintain her "position" during this needle and insists on doing a large amount of her own preparation, i.e., removing her EMLA patch (topical anesthetic), wiping, and sterilizing the

area. However, she has also learned to implement techniques such as Jelly Belly, Changing Channels and Special Place Relaxation. Karen takes a few deep breaths and instructs the nurse to start, becoming calm and focused. Following the needle Karen reports Changing Channels to her Special Place; horse back riding in a large, sunny field. Karen discusses these gradual improvements:

I - When I first started working with you, you were pretty scared of your needles then ...

K - I'm scared of the one in my arm.

I - So what would you do when they were giving you those needles?

K - (Demonstrates taking quick, ragged breaths)

I - Would you make them wait a long time before they could do the procedure?

K - Umm, ya. I tried not to, but I was really scared.

I - Has that gotten better?

K - Yes. ...

I - How did it make you feel during the needles when you would try [some of the new skills]?

K - Like relaxed. But I didn't really like [the needles]. I just did it, so I did it faster.

I - Now what kind of stuff do you do during any of these situations? What kind of stuff have you tried to make yourself feel better?

K - Umm, taking deep breaths and just telling myself that the quicker you get it over with the quicker it will be done.

Eventually Karen's feelings of fear and anxiety decreased to a point where she actually began to rely less on these newly acquired skills, "Well, I sort of forgot [to use the mental skills]. I'm just not as scared anymore."

In addition to facing numerous obstacles in the hospital environment, Karen has also faced many challenges outside the hospital due to her altered physical appearance. Karen describes these obstacles:

> But sometimes I look at them and then they turn their head, and so I can see ... out of the corner of my eye [that they are looking at me]. So when I turn my head, they look [away] ... I kind of wish they had cancer and know what it's like ... even though I don't want anyone to get cancer ... [just] make them understand how it is to have cancer and all that for years.

Since participating in the Feeling Great Program Karen reports improved confidence in her physical appearance, "...well I'm not as scared of taking my hat off anymore ... 'cause I used to think that people would just stare at me all the time, and sometimes they do." Despite these occasional stares Karen has become more comfortable removing her hat in public.

In spite of Karen's ability to apply these skills in a number of different situations, she still experiences considerable stress and anxiety during unfamiliar or unexpected procedures. Her mother explains, "She's very comfortable with things that are weekly and things that she's used to. But if they suggest they're going to do a new test, or a little extra bloodwork, or you know something that she's [not] expecting about the mickey, and then that could be difficult." Even procedures such as bloodwork, which she has learned to cope with effectively, will still cause excessive distress if performed unexpectedly. Two such incidents occurred near the end of the Feeling Great Program; a flu shot administered in her leg and a needle required prior to her bone scan.

Karen describes her fear prior to the flu shot, "But like I've never really had a needle in my leg before so I was really scared ... I've never had one, hardly ever since I was a baby, and that's a long time away." Karen portrayed this experience in her journal (See Appendix T) and described her reaction to the needle, "[I'm] like shaking. I don't want to do it. 'Uh, just a sec, huh, just a sec, huh, just a sec.' (very agitated, quick, short breaths, almost crying, pushing staff away, refusing help from her mother). And then they'll say, 'OK, can we do it now?', and I'll just say, 'Just a second. Wait!', I'm really scared." During this experience Karen kept attempting to stall the nurse; pleading for more time, pushing her hands away and asking her to use a smaller needle. Even encouragement from her mother to focus on using her mental skills was ignored. Similarly, Karen was equally scared during the needle required prior to her bone scan, "Well, I was really scared and I didn't really remember what it was, so I just couldn't think of what it was that you told me to do 'cause I was so scared of it. I hadn't had it for a long time so I was really scared." These two incidents led Karen to comment, "But [the mental skill] still doesn't really work for me" and "I can't get my mind on [using the mental skills] anymore."

In addition to Karen's fear of new or unfamiliar procedures, she continues to be very fearful during her mickey changes.

K - Well one thing that I'm really distressed about is getting my mickey switched.

I - When you get your mickey changed do you try [using mental skills] or is that one too scary?

K - No, it's too scary. 'Cause they give me medicine to make me feel all dizzy, but not put me to sleep, like I'm still awake but they make me feel kind of drowsy and calm.

I - Well that's good, that probably helps, eh?

K - No, not really.

I - No? Not too much?

K - No, I'm still scared.

Karen believes, "I don't think it will really work 'cause I'm too scared to think about it." Her mother confirms her continuing fear; "Probably the hospital is still the place that would hold the most stress for her. She's still nervous about the mickey in her stomach, the feeding tube."

Despite these areas of continued difficulty Karen's mother felt she displayed significant improvement, "She has learned to use her relaxation methods to help her through a lot. Things are definitely better." The positive life skills Karen uses most often are: Changing Channels and Special Place Relaxation: "But I always think of something. Like I think of horses and ... if I have a nightmare, just think of something that you love", Spaghetti Toes: "No, I don't tell myself [to go like spaghetti], I just make them go soft", and Jelly Belly combined with positive self-talk: "she takes a deep breath before certain things are done ... I think she just does her best to try and relax because she's always saying, 'It'll go better, it won't hurt as much if I relax.'" Karen also encourages her mother to use the skills she has learned, "She's always reflecting to me as well when I get all upset," suggesting her mother "change her channel" when she has a stomach ache, and telling her "Mom, just relax and don't worry about it."

Karen was quite skeptical when she began participating in the Feeling Great Program, "I didn't think it would be this much fun. I don't know what I thought it would be. I kept wondering like how you can make a needle, like you could relax and not make it be so bad, like 'Huh?' I had no idea how you did that. I was kind of scared." As the program came to an end Karen commented, "Well, I'm not as happy anymore, I wish that we could spend more time together [in the program]." When asked if there was anything she would change about the program she responded, "I'd only add that I could have one more day in the program."

Her mother was equally pleased with Karen's experience within the Feeling Great Program and her new skills, "She has always been fearful of many of the things around, and I really find the exercises and just having all the methods ... has definitely made a difference." In addition to helping Karen cope effectively with treatments, participating in the program gave her something to look forward to in the hospital, "She really did look forward to coming in and was hoping to be able to see you ... you've worked wonders with her."

Her mother's final comment on the program addressed the benefits for the parents as well as the children.

> Well I think having you here has made a difference. All of the kids here are faced with major challenges and ... Even the parents get into their own little worlds, trying to handle everything and ... getting stressed as well. It's not always easy for the parents to remember all the things they need to be doing.

Participation in the Feeling Great Program provided concrete techniques parents could encourage their children to use, thereby benefiting both Karen and her parents.

Case Study #4 - Kim

Kim was only five years old when first diagnosed with acute lymphocytic leukemia (ALL), just one week before her sixth birthday, "Celebrated her sixth birthday [in the hospital], alone. Well [with] the family that is. She was in isolation." Like other children undergoing treatment for ALL Kim has a two and a half year treatment protocol. Currently seven years old, she is approximately two years into this treatment. "It'll be two years [in a month] that she was diagnosed. And as of today she has 35 weeks left." The necessity of these hospital visits is clearly understood by Kim. "I come because I have leukemia and I have to go to the hospital to

have the medications." These medications come in a variety of different forms; weekly hospital visits for chemotherapy, bimonthly visits for lumbar punctures, and every four months she receives a much stronger dosage of chemotherapy that results in hair loss (Appendix N). Kim is not only able to describe her treatments but also the exact name of medications, "Well I don't like methotrexate and vincristine (chemotherapy). Sometimes I have a lumbar puncture but I'm asleep so I don't know ... it's a big needle ... when I wake up it hurts in my back."

Social activities are Kim's favourite part of her hospital visits, which she describes, "Sometimes we go to the coffee shop, then I play with my mom or with Justin, with my friends. Sometimes I make crafts. I do a lot of things. It's never the same thing that I do." Frequent hospital visits have resulted in Kim developing a number of close friendships with other children on the unit. She is "very attached" to these friends which her mother feels has enabled her to deal positively with her numerous hospital visits, "It's just part of her life and she meets people. She loves Justin, she adores him ... they're very good friends." Kim perceives hospital visits as an opportunity to socialize with friends and participate in various activities offered on the unit.

The positive association between hospital visits and social interaction is obvious: "Nothing makes me upset [at the hospital] ... cause [that's] when we play with Justin." In fact, when discussing potentially stressful situations at the hospital Kim does not describe treatments or painful procedures. Instead, she describes situations where a child is excluded from group interactions and she tries to resolve this issue immediately.

> ... we don't say, 'Oh no, you can't play', we say, 'Come, come'. 'Cause he's gonna cry in the corner ... Even one time we're playing a game of four and there was a [fifth] little girl who was coming and ... we didn't say, 'No it's only four', Justin and I take her and she was playing with me.

Kim classifies interactions with her friends as highly important and eagerly anticipates her weekly hospital visits as an opportunity to engage in activities with these friends, as her mother describes, "She's OK to come here. She loves to come to the hospital. She's glad when it's her day to come." Moreover, Kim's mood improves when she is at the hospital.

> She's [in a] much better mood when she comes here. She's always in a good mood [at the hospital]. It's a Wednesday that we come and so she's always in a good mood Wednesday morning. Other mornings I always have trouble [with her complaining and saying], 'I'm going to school' ... Sometimes I say she's always in a bad mood, complaining and that. But ... she loves coming here.

Kim enjoys her time at the hospital immensely and often wants to extend her visit, "[Kim] doesn't want to leave sometimes, we have to wait, [and] she's done chemo and everything". Kim's mother strongly believes that it is her close friendships that are responsible for fostering this positive attitude toward hospital visits.

> I know it's [her friends] because one day she had an exam at school at the end of the year, I told her we had to go on a Thursday instead [of her regular treatment day]. She was crying and screaming. She said 'No. I want to go with my friends' ... She talks about them all the time.

Although these friendships have had an extremely positive effect on Kim, they have also created the opportunity for personal comparison, and Kim often contrasts her own coping skills

and abilities with those of her friends. As Kim continues to experience difficulty during certain procedures these comparisons often leave her feeling less capable and she puts increased pressure on herself to 'meet up' to the standards set by other children. Her mother describes the distress Kim currently experiences during stressful situations:

> Like today ... everyone could hear her screaming, even from the front. She's just trying to cope ... still having trouble, lots of anxiety when it comes to the pokes ... She's still scared with the poking ... And the Port-o-cath ... in there she's still nervous.

In contrast to her own distress Kim describes the ability of her friend, Justin, to sit quietly during injections, often watching as the needle enters his leg. This contrast is also noted by Kim's mother:

> She's got to breathe. She's not the type that will just sit there and be poked ... Some kids just sit there and they have it. She's got to lie down and I [have to] hold her hand and I [have to] be there ... She's got to be relaxed. And when she says she's ready, they have to count to three and then poke.

Recently, however, Kim has developed a more effective method of coping with her IM's. This method was actually discovered accidentally. Her mother describes the encounter, which led to this new coping strategy:

> One day Kim was breathing and the nurse forgot to count to three. And so she just poked and Kim didn't feel anything, and she said, 'OK, I'm ready'. And the nurse said,

> 'I've already done it'. And Kim said, 'You know I didn't feel anything'. So she said, 'Maybe it's better if we don't count'. So that's why we've been trying that. It's only happened twice so far.

This strategy has considerably improved Kim's level of pain and distress during procedures. She describes this technique as making her leg "get all like jello". She also insists that the nurses refrain from counting to three, a common tactic used before needles, as this counting makes her feel more nervous. Kim describes the benefit of this strategy, "I don't count, and I don't feel it, because she didn't [count] to me. But when I look [at the needle] I know that she's gonna put it [in] 'cause I see her [and I get nervous]." Kim's mother agrees with the improvement since they have stopped counting, "Yes, yes. 'Cause if she counts, by the time ... she's counting, 'One, two', you know she's nervous and she knows it's coming." The significant decrease in pain experienced by Kim during this procedure has motivated Kim to continue using this technique and her mother reports, "We'll try it again today."

Coping with treatment procedures is only the beginning for Kim. In addition to dealing with painful treatments she must also cope with side effects, hair loss, fatigue and altered school performance. Her mother describes the impact of these side effects on Kim's mood and energy level, "The treatments are very hard on her. Every kid is different and treatments are very hard on her so she's kind of lazy." After undergoing her weekly procedures Kim is:

> ... not bad. It's just when she gets LP's and that. Like when she comes in on Wednesday she just gets a poke in the thigh (IM). That's OK. But when it's bigger treatments, like every four months she gets this strong chemo that she loses her hair. That's why she doesn't have much hair, every four months she loses it again. So that one is very hard.

Although these side-effects are difficult Kim's mother notes that she does not openly express frustration, "... it's hard for her. You know she doesn't say, 'I don't want to lose my hair'. But you can tell when it starts growing a bit she starts to put little barrettes and things in her hair. But then it falls out." This side effect is a tangible physical reminder of Kim's illness and is also difficult for her mother to witness.

> This time it was worse, she started losing [her hair] in mid-July. So it was harder, because she's getting older, and she knows that I find it very hard. I try not to let it bother me, but it's very hard ... When your kid has cancer they have no hair for a long time, then it starts growing and it falls [out] again. And I don't want her to feel stressed about that and I tell her it's OK. But she's finding it hard when she's losing her hair.

Another side effect of treatment is increased fatigue, which makes, "just getting up in the morning [difficult]." This fatigue has even affected her academic efforts and she is often allowed to complete homework assignments on the weekend, as she is frequently too tired in the evening after school. Her mother describes this condition, "Concentrating all day and then coming home and doing homework was very hard on her ... she's very tired I find."

Despite this fatigue and frequent absences Kim has been able to excel in school, "She misses a day a week. And sometimes two weeks in a row, but still has good grades and does very well." Although she has been able to maintain her grades, she has not been able to maintain her previous level of enthusiasm towards school, as her mother indicates, "I think she liked it more before she was sick." During all of these alterations in her life Kim has complained very little. "She doesn't say much about the disease itself. These kids don't complain very much."

Outside the hospital Kim enjoys spending time with her younger brother, Jeffrey, although her illness has made normal childhood interactions difficult at times; "Sometimes he falls and he don't know that I have a Port-o-cath and he falls on my Port-o-cath. But he don't know. He thinks he's playing, but he's not. He's hurting." Like most siblings, Kim and Jeffrey experience the occasional sibling disagreement, an event she identifies as stressful; "we fight sometimes and [then] I'm crying in my room, ... because he hit me." Kim attempts to diffuse situations like this by talking to Jeffrey, "I try to keep him calm, 'Just calm down, calm down.'" However, she is not always successful in her attempts, "but he don't want to, he yells and he jumps on me." Kim often describes interactions with her brother and obviously enjoys his company, however stressful it may be at times.

Starting the Feeling Great Program Kim was pleased to learn that several of her friends would also be involved. The first skill introduced was Spaghetti Toes muscle relaxation (See Appendix M for weekly activity chart). During this session there was a substantial amount of activity on the unit, such as children crying, staff loudly talking, and equipment beeping. Kim found this level of noise and activity disruptive, making successful relaxation difficult. This led Kim to describe conditions she felt would be more conducive to relaxation, "when you're at home, or when you're outside and there's nobody and you relax in the grass." Despite identifying this potential area of future use Kim was resistant to using this new skill during her hospital procedures such as IM's. Rather, she described her most recent experiences during IM's, which she believes have improved significantly:

> ... but on my leg when they pick me ... they count and they say, 'one - two - three', and when they're [at three] I'm like this (holds her breath and tenses muscles). But when

> [they don't count to] three I'm OK. And one time I said 'OK, I'm ready', and she said, 'We're already done it.'

Kim did not feel Spaghetti Toes was necessary during her LP's either, "I'm not scared 'cause I'm not nervous." Although uncertain of the skills utility Kim did attempt Spaghetti Toes at home and was unsuccessful: "... I tried it, [but] my brother was jumping on me." This interruption made it impossible for Kim to successfully practice relaxing her mind and her body.

Jelly Belly diaphragm breathing was the second activity Kim participated in. She clearly understood the relationship between breathing techniques and emotions. She described situations where she was breathing rapidly and quickly, "Yesterday when my brother hit me in the Port-o-cath, I went like, 'Huh, huh, huh' (quick, shallow breaths) ... it hurts," and situations where she was able to use breathing to help herself relax, "One time I was really, really upset and I did say, 'Kim, relax,' and (takes a deep breath) and I was OK." Kim was currently using breathing techniques during procedures to help her relax, "I breathe like this (deep breath) and when they're first pushing [the needle in], like this (another deep breath)." Once again, however, Kim was somewhat uncertain of using the mental skill Jelly Belly during LP's as she is normally sleeping, "LP's we're sleeping ... sometimes we're sleeping like fast, fast, fast."

Kim's reluctance to apply these mental skills during hospital procedures continued throughout the program. As Kim participated in Changing Channels she described her previously unsuccessful attempts to "change her channels."

I (Interviewer) - If you're kind of scared and you're thinking about scary stuff sometimes, do you sometimes do that?

K (Kim) - It's not me, it's just ...

I - It just comes, right? You don't want to think about it?

K - I try [not to think about scary things], then I do this (gesturing with her hands), then I do this, and another thing but it don't go away.

Kim's previous unsuccessful use of this technique made her reluctant to attempt to use the skill again.

K - I like dancing and I like colouring...

I - Well how about if you thought about yourself dancing? Can you picture yourself doing that?

K - Ya.

I - Ya, you could? Could you, what kind of music would you be listening to?

K - Kool FM.

I - Kool FM? Ya, good. So you can picture, where is your favourite spot to dance or where would your favourite spot be?

K - I dance with my brother.

I - Ya? Around your house?

K - Ya.

I - So could you picture maybe doing that? Would that be more fun?

K - Shakes head 'NO'.

I - No? How about ...

K- Nothing.

I - Well we [should] think of something.

K - No.

I - It works better that way.

K - No.

This refusal to attempt new skills continued during Special Place Relaxation, even though Kim was eager to draw and describe her Special Place, Disney Land: "... [I] ate some ice cream ... go in the pool ... we did go on Dumbo, on the Peter Pan and It's a Small World ... it was really hot." During this session Kim was twice interrupted for treatments and doctor's appointments. Despite these interruptions, she returned excitedly each time to continue drawing her Special Place, an activity she obviously enjoyed. Although she enjoyed this activity she did not yet see the potential utility of the skill:

I - Do you think that imagining your Special Place would help you feel a little bit relaxed?
K - Umm, no.

Although Kim expressed doubt that the skill would enable her to feel more relaxed during procedures, she did admit prior use of a similar technique, "I always do that or [imagine] presents or things like this (indicating her journal drawing of her Special Place)."

Echo Lake proved to be one of Kim's favourite activities. Echo Lake is an activity that provides children with a positive vocabulary to use when talking to themselves. This activity is completed in conjunction with positive and negative thinking exercises in the highlight journal. These exercises enable children to identify negative thoughts they have, change these thoughts to more positive thoughts and learn to recognize their own positive attributes. Kim was an enthusiastic echoer during the tape but had difficulty believing the positive statements she was making later saying, "that's (the positive self-statements) not real." However, with persistence Kim was able to identify a number of her own positive attributes, "I am good in the pool ... and I

do some bombs in the pool ... I'm good at watching [my brother] ... I know how to go on the rollerblades, to go skating, to ride a bike." Kim also learned to alter her negative statements during this session:

I - Instead of saying I can't do this could you say ...

K - I can!

I - What could you say?

K - I'm gonna try.

I - How about I'm not good at this, what could we say instead?

K - I am good at this.

I - How about I don't know how to ride a bike, what could we do?

K - Umm, we could say, I'm gonna help you.

Kim also learned to identify negative statements she made to other people and replace these with more positive or encouraging statements she could say to others such as, "You're my friend."

In the following weeks during the program Kim learned to identify positive aspects of her behavior that contributed to feelings of happiness. One of these events was being nice to other children, "I go to Scouts and I played with some new people ... I play with my friends and ... sometimes there's one person who stays [by themselves], so we go get them and we play [together]." Learning to identify her kind actions made Kim feel "great". Kim enjoyed discussing her own positive thoughts and would put other activities aside in order to describe these positive experiences.

I - Did you have any positive, good or happy thoughts about you yesterday or today?

K - Umm, ya.

I - Ya? And what were the thoughts?

K - Umm, go bowling.

I - Ya, that was a positive thing?

K - Ya.

I - Did you think that you were maybe a good bowler?

K - (Nods 'YES') I win the first one, [Kalie] wins the second one.

I - How did thinking those thoughts make you feel?

K - (referring to Kidscale – See Appendix W) Not like this, not like this, not like this, not like this, like this! ... I did do this! (Selected person jumping for joy).

In addition to increasing her awareness of her positive attributes, Kim also learned to create positive self-statements such as, "I'm going to have a good LP."

During these weekly sessions Kim's level of interest varied greatly from extreme enthusiasm and interest in weekly skills, to indifference and reluctant attendance. This inconsistent level of involvement had considerable impact on the continuity of Kim's participation. Although she did participate in 12 complete sessions, these were widely spaced and her participation was somewhat sporadic, at one time missing three weeks in a row. Kim's absences were a result of several different factors.

First, Kim's mother frequently indicated that Kim experiences "bad moods"; "That's what I was saying 'cause sometimes I say she's always in a bad mood, complaining and that." This is a common side-effect most often related to specific medications. During these stages of treatment Kim would often prefer not to participate in weekly sessions, a situation her mother describes:

> ... she'd say at home, 'I don't want to go with Julie today', and I'd say, 'You don't want to go? You tell her', [and she'd say], 'No, I want you [to]'. [And I'd say] 'Nope, I'm not telling her, you're the one [that should tell her]. ... and then she'd come in ... she'd see you and [say], 'But I don't [want to go]', and I wouldn't say anything and you'd come and get her and she'd go. She went anyway.

Kim's mother was acutely aware of Kim's current need to make her own choices and exert control over activities related to treatment and hospital visits. As a result, Kim was given the freedom to choose whether or not she would like to participate in weekly sessions. Consequently, Kim chose to forego participation on several occasions.

The second reason Kim's participation was somewhat sporadic was due to the difficulties in coordinating Feeling Great session times within her busy treatment schedule. Due to the frequent number of procedures children undergo during their weekly hospital visits it is sometimes difficult to coordinate regular sessions. It was often necessary for parents to remain following their children's treatments in order to ensure regular participation. This proved difficult for Kim and her mother and they would often leave before having the opportunity to engage in weekly sessions.

The third factor influencing Kim's irregular participation was her relationship with other children on the unit and her preference for other activities with these children. Kim's only opportunity to socialize with her close friends at the hospital was in between medical treatments and procedures, the very same time weekly sessions were generally held. Kim associates many positive experiences with these friends and looks forward each week to her interactions with them. Ideally, small group sessions involving these friends would have been arranged. However, due to each child's hectic schedule during treatment days, group sessions including a number of

Kim's friends were difficult to coordinate. As a result, participation in the Feeling Great program often required separation from her friends. This created a conflict for Kim and she would often request inclusion of other children in the activity.

I - So now [the audiotape] we're going to listen to today is a pretty short one.

K - Why can't we listen to it with Kalie in the room?

I - Well, we'll just listen to it quick. How's that?

K - Is Justin gonna do it?

I - He's going to listen to the exact same one.

K - And after it's gonna be all three [of us]? Me, Justin and Kalie?

These three factors, negative mood, busy treatment schedule and separation from friends, combined to create a scattered schedule of involvement in weekly sessions.

During these sessions Kim was also introduced to the concept of highlights which she described as, "when something makes you happy." Highlight discussions during sessions were accompanied by the use of a highlight journal. This portion of the program proved to be extremely challenging for Kim. Specifically, the use of a highlight journal presented a number of difficulties. Although Kim was able to identify highlights on occasion, she did not use her journal to record these highlight experiences. In fact, Kim only made one journal entry on her own during the course of the 12-week program. This journal entry was a detailed picture of her 'Being Relaxed' which she describes as, "... a bath and it's me and it's really hot." Kim offers several explanations as to why she does not complete her journal entries including: writing difficulties, too little time and a preference for using the journal during sessions at the hospital.

The first of these factors, writing difficulties, should not present a barrier to journal use as the journals are designed for use by very young children through drawings and diagrams. Although Kim understood that she could simply draw in the journal she was not satisfied with this level of achievement; particularly when she contrasted her own abilities with the efforts of other program participants, "Her mom [did] it all for her ... it was her mom that was writing so that's not fair ... I don't know how to write things." Kim sets extremely high standards for her own performance as her mother describes, "She's very hard on herself. And ... she shouldn't be." Her mother attributes this quality to Kim's tendency to strive for perfection, "Always a perfectionist. Always. In everything." This internally developed pressure to produce elaborate journal entries, along with expectations of perfection, may have combined to affect Kim's perception of her journal. Rather than viewing the journal as an enjoyable activity, she may have perceived the journal as additional 'work', similar to the work required of her at school. This association was supported by her mother, "I think maybe when there's paper and stuff it's more like school for her. And, 'Nope', she doesn't like that. She used to remember when she started school and she thought she was so bright and now she just hates school." Kim is currently beginning to experience academic difficulty in school as a result of her aggressive cancer treatment. As a result, her attitude toward school, and anything she associates with it is decidedly negative.

Kim also identified lack of time as a barrier to consistent journal use, stating, "Because I have a pool so when it's hot I go swimming in the pool ... and now it's difficult to do [the journal] because I'm at school." Kim viewed the highlight journal as additional work and would only commit to journal use under two conditions; if it required a minimal time commitment, stating, "I have to be quick", or if she had extra time in her week, "I'm gonna make my journal this afternoon 'cause I don't go to school ... it's not a big [treatment] day."

The third factor affecting Kim's journal use was a preference for doing journal activities during weekly sessions at the hospital, "Sometimes ... I don't want to [do the journal at home], sometimes I'm scared [that I'll do it wrong]. I like it better when we make it here than at home". Journal use during sessions was one of Kim's favourite parts of the program and she became extremely excited during sessions whenever we used her journal, "Yeah! We're going to colour!" Kim even identified her favourite part of the program as, "when I was colouring Mickey and Minnie in the picture" for Special Place Relaxation (See Appendix X). Even though Kim enjoyed this form of journal activity these three factors, perception of the journal as 'homework', perceived lack of time, and preference for supervised journal use, combined to decrease Kim's individual journal maintenance.

Nevertheless, Kim did learn to identify highlights on an irregular basis during the program, "I did have some [highlights], I did have some fun with my friends and sometimes there's nobody to play with so this time I had a lot of people to play with me." Identifying highlights was not easy for Kim, it was often necessary for her to pause and reflect on her week in order to remember highlight experiences. Frequently, she would initially claim that she had no highlights, only to remember several highlight experiences later in the session.

I - So can you tell me about this week, did you have any highlights?

K - Uh-uh. (No)

I - If you think for a minute about them?

K - Today.

I - Today? What were your highlights today?

K - (indicates two birthday presents she received)

I - Did you have any other highlights during the week?

K - Ummmm....

I - Can you think of a few?

K - Gymnastics at school ... and play[ing] with my friends ... I did go [to] see Jeffrey at soccer.

This difficulty identifying and remembering highlights persisted until the final three sessions of the program. At this time Kim was given a 'highlight box' as recommended in Feeling Great (Orlick, 1998). Similar to her highlight journal, Kim made no entries into her highlight box, commenting, "I'm forgetting to put them on the little paper." Even though Kim did not complete any highlight drawings she was able to remember and report several highlights for each of her final three sessions, "I had a lot of highlights ... I'm gonna tell some that I did before because ... I didn't tell you ... I went [to] see Buzz and Woody, [Toy Story] Number Two ... it was funny ... went and my Grandfather sleeped at my house ... I went to the Christmas party ... [and] see Santa Claus."

Although Kim began to make improvements in her ability to find and remember highlights, declaring, "When I come I have always a little bit more [highlights]," her mother did not notice similar improvements, "No, no. She never really did [talk about highlights]. And she had that [highlight] box there that she had, I took it out a couple of times and ... I told her maybe you should colour, [she said], 'No, nope. No, I don't want to.'" However, her mother did acknowledge that "... maybe she is thinking about them and I don't know."

Her mother also encouraged Kim to use the skills she was learning in the program. "When I had my IM ... my mom went, 'Spaghetti Toes.'" In addition to declining her mother's encouragement to use her highlight box, Kim would frequently refuse her mother's encouragement to apply the skills she had learned in the program.

> I've told her sometimes, 'Think about what you do with Julie', [and she says], 'No'. She doesn't want to. She just says, 'No'. And, 'No', she doesn't want to hear about it. And I say, 'Well did you want to talk to me about it?'. 'No'.

Kim's mother attributes this reluctance to discuss program activities to problems with her short-term memory resulting from treatment (See Appendix M for details on cognitive late effects), "I ask her ... what you guys talk about sometimes and she doesn't [respond]. Sometimes I wonder, does she remember? And that's part of the short-term memory. So I don't always ask her right away because she doesn't remember." Furthermore, these short-term memory delays might contribute to the difficulty Kim experiences both in school and in remembering highlights. Kim's mother describes the overall impact of these memory delays:

> Sometimes ... she can [remember]. I ask her what she does in school, that was [at] first when I ... was trying to test her, she doesn't know what she did in school just that day. Sometimes, yes, she does [remember]. But then all of a sudden, maybe a week later, she'll talk about something that happened and she'll go in details and then [I think], 'Geez, you should have told me that when it happened'. But it must be hard for her. It must be frustrating.

In addition to declining her mother's encouragement of skill use, Kim began to exert her independence by attending treatment sessions alone, "She told me she didn't want me anymore ... this is about the fifth or sixth time she goes [alone] and she says that I make her nervous. I've been there for two years and all of a sudden she says I make her nervous. She says I talk too much." Her mother feels Kim has made this alteration for several reasons, "... she's seeing other

kids are always going by themselves too, so maybe she's probably watching them or maybe she wants to do your tricks and she doesn't want to tell me about it ... you never know. She's very proud." Kim expands on her newfound independence during procedures, specifically when having her port accessed, "I do it by myself ... when they say go, to just poke, but I don't count ... I just close my eyes." She also undergoes her bimonthly lumbar punctures without her mother:

> I just lie down and they say, 'OK, I'm gonna put [the IV] in your wrist'. They put [me] back to relax and ... they say, "OK, I'm gonna put it [in]', and two minutes after, [I'm asleep] ... [My mom] comes, but when I'm sleeping. When they put [the IV] in she's outside, and when I wake up she's there.

Indeed Kim is using "tricks", such as diaphragm breathing and muscle relaxation, to help herself cope more effectively during treatments: "I have a trick that I do by myself ... I do like this (takes a deep breath) and I say go when they can do it in my leg (IM) and in my arm (bloodwork) and it works pretty good." Sometimes Kim takes several deep breaths, similar to the technique taught in Jelly Belly, "like this (big breath) and then four or five and then I say, 'Go'. ... sometimes I do a lot more [breaths] because I need more ... like when it was the first time I did a lot." Kim also uses muscle relaxation during her IM's, '... when you lie down it's more comfortable. Because it's when you're like this, (sitting with leg bent), it's hard in the muscle. But when you're lying down it's not that hard." However, she is quick to differentiate between how she makes her leg like "jello" and not like "spaghetti" or "macaroni".

I - How, were you making your muscles ... What were you doing?

K - Like jello.

I - Like jello. Exactly. So it's good to be like spaghetti when you're getting your needle right? 'Cause you get softer and your muscles are relaxed, right?

K - Not like macaroni!

I - No, not like macaroni. Exactly.

K - It gets like macaroni, when you're like this, (leg bent), so it's more hard.

I - Yes, you're right about that.

K - But it's because you're like this (leg bent) and then that hurts.

Although Kim applies skills similar to those taught in the program she is quick to assert her ownership of these skills and to point out that she performs these "tricks" by herself.

I – Now, since you and I started working together do you ever try and do anything to try and make yourself feel better during any of your procedures?

K - Umm, no. I don't need to, 'cause I have a trick that I do by myself.

Kim developed her own vocabulary and corresponding imagery to facilitate muscle relaxation. She obviously associates spaghetti with macaroni, which she envisions as being similar to a bent leg. As the bent leg position tends to result in muscle tension this is not an appropriate relaxation image. As a result, Kim continues to rely on her own "trick" to make her leg "like jello."

Kim continues to use the method of coping she developed prior to commencing the Feeling Great Program as it continues to be effective during procedures such as IM's. Specifically, she closes her eyes, takes deep breaths and does not count. She explains why she prefers not to watch during procedures; "When you look, you know if there's blood you're gonna scream. But when ... they put the patch there, and you don't see ... you think that ... there's no

blood." Furthermore, seeing the medical instruments used during the procedures can also be stress inducing; "I don't see what it is ... I think it's a *big* needle ... [Justin] seen one and it was that big." The use of these techniques has enabled Kim to maintain her level of coping during IM's and contributes to continued levels of decreased anxiety during hospital visits.

I - How about at the hospital, are there any things here that sometimes make you feel a little worried?

K - No, not a lot.

I - Nope? A little? Anything that makes you feel a little bit worried?

K - No

I - OK.

K - 'Cause I come here every [week], I come here a lot so I know what it is.

Kim's low anxiety levels are a result of several different factors, namely: knowing what to expect during hospital visits, completing difficult stages of treatment such as lumbar punctures, and knowing how to cope effectively with the remaining procedures such as intramuscular injections. Kim perceives her coping abilities to be sufficient. This perception led her to report, "I didn't really need to [use skills taught in the Feeling Great Program]."

Although Kim insisted that she experienced minimal stress at the hospital, conversations with hospital staff and her mother revealed otherwise. Kim's hesitancy to discuss these difficulties is not uncommon, as she does not easily express her feelings, as pointed out by her mother:

> She's very distant I find. She doesn't want to [talk]. Or she'll cry. You can tell there's something wrong, and you try and ask her to get it out but she has trouble ... You know when your kids are upset but she's not the type to want to talk about what's bothering her, It takes a long time ... She's very reserved.

Despite Kim's insistence that there were no sources of stress at the hospital she did continue to experience anxiety during one procedure in particular, lumbar punctures. This invasive procedure continued to create high levels of anxiety for Kim and she relied heavily on the help of a child life worker during these situations.

I - How about your LP's did they used to make you a little bit worried?

K - But I was hungry a lot.

I - Ya. Now what is the [procedure] that the [child life worker] usually goes in with you for? Is that your LP's?

K - Ya.

I - Ya? And sometimes do you get a little bit upset about those ones?

K - But you come in and it's like you sleep because it's like a magic thing that's doing it (medication).

I - Yes? So you feel OK when you're sleeping for those ones, right?

K - Nods...

I - Now, how would you feel before you would go to sleep for those ones?

K - (Silence)

I - Do you sometimes maybe get a little bit upset?

K - Ya, but I don't like it.

I - Well I wouldn't like it either. I understand that. Sometimes would you maybe cry a little bit?

K - No.

I - No?

K - Just when I was hungry.

I - Just when you were hungry?

K - Because you can't eat breakfast, not even lunch.

Kim is reluctant to discuss her feelings of fear during this procedure and prefers to discuss procedures in which she experiences lower levels of anxiety. However, it is clear from Kim's behavior during LP's that she continues to experience distress. Fortunately, she has now reached a stage in her treatment where lumbar punctures are no longer necessary.

Along with completing her LP's Kim is also nearing completion of her two and a half year treatment protocol as she describes, "No more ... not ever no more vincristine". Kim's mother illustrates Kim's overjoyed response to the end of treatment:

She knows in 14 weeks she's done and she's coming once a month after that. And she thought she was getting chemo once a month and she just realized ... no she's not [getting chemo], it's just bloodwork and that. And she was so happy. Oh my god, to suddenly see her reaction, she was very happy about that.

Even though Kim was overwhelmingly pleased to complete her treatment protocol, she successfully maintained her positive perspective towards hospital visits.

> She loves coming to the hospital. Honestly, she really does ... she doesn't say that it really bothers her. She's never said, 'I'm fed up of being poked at'. Never. So I'm sure it must bother her inside, but maybe it's just part of her life now. It's been over two years...

As Kim neared completion of treatment she also finished her participation in the Feeling Great Program; participation that was marked by numerous contrasting perceptions and reports. Although Kim perceived her coping behaviors to be relatively satisfactory, and perceived improvements in her ability to identify highlights, others did not always report similar improvements. Kim's mother, "didn't mind [Kim being in the program]." However, she did not note a significant improvement in Kim's ability to cope with procedures such as lumbar punctures, stating, "I would have liked for it to help her more, to try the activities. But she didn't want to." Nor did she witness an improvement in Kim's frequently negative perspective outside the hospital environment; "Sometimes I get so depressed. She was such a happy child before [diagnosis]. And she isn't anymore." Although disappointed with Kim's level of skill acquisition, the program did inspire Kim's mother to increase her own knowledge of these techniques.

> I started reading the book you gave me ... Feeling Great. I thought if I read it - 'cause she didn't tell me what was going on - so maybe if I see little things in there I can try and help her. Maybe that's what I should do before she goes to bed, ask her about highlights in her day and stuff.

Although Kim had exhibited a number of different attitudes towards the program, she finished on a positive note and indicated continued interest in participation, "Yesterday she talked about you and she was wondering if she was going to see you." Kim even reported enjoying participation in the program, "[There was] nothing that I didn't like [in the program]. I liked to do it all." There were several days when Kim preferred to participate in other activities on the unit, however she states that this did not occur "lots of times" and she was glad that she participated in the program.

Cross-Case Analysis

The purpose of the cross-case analysis is to compare and contrast the differences and similarities in each individual case study with other case study narratives. Relevant themes and patterns emerged across all four cases. This section presents an integration of the results from the individual case studies to create a comprehensive interpretation of participant experiences. This combined analysis addresses the stated purposes of this study; evaluating the effectiveness of the Feeling Great Program in teaching chronically ill children to cope effectively with stressful experiences and identify more highlights and exploring the processes involved with participation, discovering the types of mental skills used most frequently and in what situations, investigating the factors that foster and/or hinder successful mental skill development, examining the influence of context on mental skill acquisition and implementation, and exploring the processes children engaged in while learning mental skills. This analysis is also presented in chart format (See Appendix Y).

Effectiveness Of The Feeling Great Mental Skills Program

Primary Benefits of Skill Development. The primary purpose of this study was to evaluate the effectiveness of Terry Orlick's mental skills training program (1998) in teaching chronically ill children to use mental skills to cope more effectively with stressful experiences

and find more positive highlights. The experiences of the children in this study suggest that the program shows considerable promise for use with other children living with chronic illness, specifically childhood cancer. Analysis of individual case studies indicate that the majority of program participants perceived the program as being effective in fostering the development of improved coping skills within the hospital environment. Both children and parents reported fewer incidents of reactive coping behaviors, such as crying, screaming or stalling, and described an increased number of proactive coping responses, such as deep breathing and visualization. Participants learned to cope successfully with a variety of treatment related procedures such as intramuscular injections, lumbar punctures, having their port accessed, bloodwork and dressing changes. Below are examples of proactive coping techniques as perceived by the parents.

> Well he's been a lot better for getting [LP's] ... he's handling them a lot better now ... He used to cry and scream and carry on. He used to be sick, he used to throw up and different things and he doesn't as much now. (Mother of Vince)

> ... even the bloodwork when it became routine, that became easier as well. So I think her being taught to concentrate on how to relax and to deal with all these things and to focus in on what's being done, and why, I think its' made a great difference. (Mother of Karen)

> ... in emergency where he was having a lot of stomach pain, and this went on for a couple of hours ... he used the switching channels technique that you had taught him and he said it really, really worked for him. That he would just lie there and do whatever it was that you had told him and his stomachache, he kind of forgot about it. (Mother of Jacob)

In contrast to the dramatic improvements in coping these three children experienced, one participant did not apply the skills on a regular basis. As a result, this participant displayed minimal change from her prior level of coping.

> I didn't mind Kim being in the program. But I would have liked for it to help her more, to try the activities. (Mother of Kim)

Secondary Benefits of Mental Skill Development. In addition to the immediate or primary effects of skill use during painful procedures, children also appeared to experience secondary positive effects from their improved coping abilities. Namely, some children's symptoms of chronic stress decreased, as evidenced through a perceived improvement in attitude toward hospital visits and decreased anxiety during these visits:

> She really did look forward to coming in and was hoping to be able to see you ... you've worked wonders with her. (Mother of Karen)

> ... I know a lot of his problems were anxiety, still are anxiety and that he's not showing the same symptoms of anxiety (nausea) that he had before. (Mother of Vince)

Furthermore, following participation some children began to view a number of their treatments as less scary and painful than previously believed.

> Actually I'm going to have my mickey checked but I'm fine with it now. Because it doesn't hurt anymore. (Karen)

In addition, Karen even reported becoming more comfortable with treatment side-effects, such as hair loss and scarring, and developed improved confidence in her physical appearance, stating, "... well I'm not as scared of taking my hat off anymore."

Mental Skills Most Commonly Used By Participants

A secondary purpose of this study was to discover which mental skills participants most commonly implemented. These mental skills were; Spaghetti Toes (muscle relaxation), Jelly Belly (diaphragm breathing), Changing Channels (refocusing) and Special Place Relaxation (positive imagery), as the following examples illustrate:

> Well we've talked about like the Spaghetti, like make your toes go like Spaghetti. And the breathing, [Jelly Belly] that's a big one that he seems comfortable with. And those are the two ones that he seems to go for. (Mother of Vince)

> I always, think of something like. I think of horses and ... just think of something that you love (Special Place Relaxation). (Karen)

> I did use the Changing Channels [and] Jelly Belly. *Real* Jelly Belly. (Jacob)

Most Common Situations of Skill Implementation

In addition to discovering the types of mental skills most commonly used, this study also attempted to examine the types of situations in which these skills were applied. Children predominantly used these skills during regular hospital experiences which were painful and/or

distressing, such as intramuscular injections, bloodwork, accessing port-o-cath's, dressing changes and lumbar punctures.

> When he had his bloodwork done, he would do the deep breathing (Jelly Belly) and especially when he gets his needle in his leg, his chemo. (Mother of Jacob)

> ... and even today I believe it was when I was taking the dressing off she told me she shut her eyes ... she is having a few things in her mind (Changing Channels) that can help her out if need be. (Mother of Karen)

> Well whenever I get [intramuscular injections and intravenous lines] I always use the breathing (Jelly Belly). (Vince)

Children also applied mental skills during hospital procedures which were less distressing, such as MRI's and CAT scans.

> Yesterday having his MRI ... he's in that thing for a long time and it's really, really noisy and I asked him last night, 'Did you use anything that the program had taught you while you were in there?'. And he said, 'Ya, I did.' (Mother of Jacob)

Furthermore, children used these mental skills in their home environment during stressful situations related to their health, such as medical procedures and episodes of sickness and pain.

> She was having injections in the home after her chemo ... she'd have to use her breathing techniques (Jelly Belly). (Mother of Karen)

> I thought of something else (Changed Channels) when I lied in my parents bed [with a headache] ... lying on the beach ... being in the Tower of Terror ... so I was ... changing from lying on the beach there and then eating pizza. (Jacob)

Moreover, one participant used the skills prior to sleeping at night to help reduce feelings of fear and anxiety and fall asleep more quickly without the presence of a parent.

> Wiggle my toes (Spaghetti Toes), did Jelly Belly, and then I fell asleep. (Vince)

Outside the hospital environment children found additional uses for the skills they were learning. At school Vince would use these mental skills to decrease his feelings of anxiety and related sickness, "I drank some of my pedialyte and my stomach started getting sore." During this incident verbal encouragement from his mother to use the skills he was learning, such as Jelly Belly, enabled him to remain at school and he proudly reported, "I didn't go home though."

Experiences that Continue to Create Significant Feelings of Stress for Participants

Despite improvements in coping, there continued to be several stressful experiences where children were either unable to use their newly acquired skills effectively or did not attempt to transfer skill use.

Karen continued to express difficulty with unfamiliar and unexpected procedures, and with procedures involving her mickey. Her mother explained:

> She's very comfortable with things that are weekly and things that she's used to. But if they suggest they're going to do a new test, or a little extra bloodwork, or something that she's [not] expecting about the mickey ... then that could be difficult. (Mother of Karen)

Similarly, Vince continued to experience difficulty at times during his bloodwork, stating, "I still get mad. I hide my hands. I get nervous. 'Cause sometimes it hurts, sometimes it doesn't."

Likewise, Kim continued to experience significant stress during lumbar punctures. She relied heavily on the support of a child life worker during these procedures despite continued reinforcement of skill use during weekly sessions.

Factors Affecting Successful Mental Skill Development

An important purpose of this study was the investigation of factors that foster and/or hinder successful mental skill development. Results from this study indicate that the development of improved coping skills is a complex process influenced by a number of interrelated factors. These factors include: children's perceived level of need and/or competence, level of participant readiness, receptivity or resistance, program enjoyment, parental support, and the context within which the program operates.

Perceived Need and Perceived Competence. The first factor affecting skill use is the child's level of perceived competence or need in regard to their current coping abilities, and the meaning children ascribe to the mental skills as a result of this perception. Meaning is used in the most general sense described by Maxwell, "the perspective on events and actions held by the people involved in them" and "how the participants in your study make sense of this and how their understandings influence their behavior" (1996, p. 17).

Several children exhibited distress during procedures and had not developed effective methods of dealing with this distress. The following quotes illustrate these difficulties.

> I try [relaxing] with my dressing change and I never can do it ... I'm really scared ... it hurts, it stings. (Karen)

> ... they used to put needles and poke him and they had all kinds of problems which gave him a lot more torment. We had [his Port-o-cath] taken out, now they have to poke him in his arm and I know last week when he came in they had to poke him three times before they finally drew blood. So that kind of upset him. I think he got sick then too. (Father of Vince)

In contrast, other participants displayed a far greater level of calmness surrounding hospital visits and treatment procedures and have developed effective coping strategies.

> It really was [stressful], especially at first. But he's learned to cope very well. (Mother of Jacob)

> Nothing makes me upset [at the hospital] ... [that's] when we play with Justin. (Kim)

These examples illustrate the variations in coping skill development found within this small group of participants. Children who experienced greater distress, such as Karen and Vince, perceived a greater need to learn effective coping strategies. These children also ascribed greater meaning to the skills taught in the Feeling Great Program. This understanding then influenced

their level of commitment to learning and using new coping techniques. In contrast, children who were coping relatively effectively, such as Kim and Jacob, perceived themselves to be more competent and felt they required less assistance. These children initially attached less importance to these skills and were less committed to the program as a result.

Further support for the influence of perceived need on the use of mental skills was later observed in the case reports of both Karen and Jacob. During the 12-week mental skills program these children began to effectively apply the skills they were learning during stressful experiences. This successful skill use led these participants to view procedures as less distressing, and consequently, to perceive a decreased need to apply coping skills during procedures, as they report:

Interviewer - Can you tell me if you ever try anything to help yourself sleep?
Vince - Not anymore ... I'm not scared anymore!

> Well I sort of forgot [to use mental skills]. I'm just not as scared anymore [during procedures]. (Karen)

These examples illustrate the importance of perceived need on mental skill implementation. As children increased their competence in dealing with painful and distressing procedures their perceived need to use coping strategies decreased, along with their actual skill implementation.

Readiness: Receptiveness and Resistance to Implementing Mental Skills. Varying levels of coping ability appear to influence children's readiness to learn and apply mental skills. These differences create either increased receptivity or increased resistance toward mental skill development. Children reporting lower levels of coping appear to be more receptive to learning

and adapting new skills, while children expressing higher levels of coping appear to be more resistant to learning and adapting new skills. Both Vince and Karen reported difficulty coping with distressing procedures and were immediately enthusiastic about learning and applying new skills, as the following quotes suggest:

> Well whenever I get those (IM's, IV's) I *always* use the breathing. (Vince)

> But I think the first thing you taught her was Spaghetti Toes and that first day she used that... (Mother of Karen)

In contrast to the enthusiasm of these participants, other children displayed less interest in the new skills and initially resisted adapting these skills, as the following quote illustrates:

> I think I'll never use Spaghetti Toes. I think I'll only use Spaghetti Toes when I'm a Grandpa. (Jacob)

Karen and Vince's increased need to develop more effective coping skills made them more receptive to learning new skills and enhanced their early skill acquisition. In contrast, Jacob's and Kim's initial skepticism made them more resistant to developing new skills. Both of these participants indicated little need for developing new coping techniques as they felt they were currently dealing effectively with treatments and identified few other sources of stress within their life. However, Jacob eventually became more receptive to implementing skills he believed to be effective, such as Jelly Belly. This receptiveness further increased during situations of

need where he had no currently effective methods of coping. There were two specific situations, which led to his increased skill use:

> I started using [mental skills] when I had that headache thing. When I started having this headache when I was asleep. (Jacob)

> ... in emergency where he was having a lot of stomach pain, and this went on for a couple of hours, and he didn't say this to me until afterwards that he used the switching channels technique that you had taught him and he said it really, really worked for him. (Mother of Jacob)

Jacob recognized the inefficacy of his current coping methods during these painful situations. As a result, he became more receptive to using the mental skills he was learning during these experiences.

Parental Support. Parental support had an obvious impact on skill acquisition and implementation. All parents in the program were supportive of their children's attempts to learn new and more effective coping techniques. Moreover, parental reports indicate that all parents provided verbal support to their children during difficult procedures.

> Normally I try and talk with her and remind her that she should try to think about what you had taught her and try to relax. (Mother of Karen)

> Well, I usually go for the breathing one all the time ... it's just something that I do myself ... but he seems to hyperventilate, like he gets all upset and then his breathing gets fast, and that's why I'm trying to slow that one down. (Mother of Vince)

> I would mostly just talk to him and I'll remind him of the things that you told him. You know, if he's nervous about something, 'Concentrate on your breathing. Do your deep breathing', which he does for his chemo. (Mother of Jacob)

> I've told her sometimes, 'Think about what you do with Julie'. (Mother of Kim)

Despite the similarities in verbal encouragement, there were differences in the type and consistency of support parents provided. Some parents appeared to place a higher priority on their child's regular involvement in the Feeling Great Program. This priority was demonstrated by several specific behaviors. First, these parents encouraged their child's participation in the program over competing activities and events offered on the unit, often prompting their child to interrupt other activities, such as crafts or Nintendo, to attend sessions. A second observed act that indicated high level of priority was parental insistence on weekly involvement. These parents had explicit expectations for their child's regular participation and made attendance part of their child's weekly routine during hospital visits. A third behavior indicating priority was parental willingness to arrange their schedule in order to accommodate weekly participation. Parents of children with cancer juggle a hectic schedule, including various treatment procedures, doctor's appointments and sessions with physiotherapists, teachers and neuropsychologists. Parents who placed a high priority on program involvement would adapt their already full schedules in order to ensure weekly involvement, often staying after treatments were completed

in order to participate. Furthermore, these parents consistently informed me of any changes in their weekly schedule, reporting alterations in treatment days or additional doctor's appointments, in order to ensure consistent participation.

Based on these behavioral indicators of commitment and/or priority, some parents were 'more committed' to the program than others. The different level of priority placed on the program appears related to several variations in program experience, such as consistency of participation and skill acquisition. Children of 'more committed' parents appeared to benefit the most from program involvement.

Program Enjoyment. An additional factor influencing skill acquisition appears to be children's level of program enjoyment. This enjoyment appears to be related to two factors: children's previous perceptions of hospital visits and the children's current perception of the Feeling Great Program.

Several participants indicated significant anxiety and minimal enjoyment during hospital visits prior to beginning the Feeling Great Program. These feelings are illustrated in the following statements:

> I find when he's coming here he gets more upset now. Like it's been a year and a half now, over a year and a half, so he's got another 40 some weeks, he's coming and he's getting ... really upset coming on a weekly basis. (Father of Vince)

> The only thing I like here are the crafts. And getting out. (Karen)

Involvement in the Feeling Great Program was viewed by these two participants as a welcome addition to a relatively joyless occasion. These children looked forward to their weekly sessions

and perceived the program to be an opportunity for fun and excitement. Weekly sessions were one of few enjoyable distractions during their hospital visits and they were disappointed when they ended.

> Well I'm not as happy anymore [now that the program is ending]. I would only add that I could have one more day [in the program]. (Karen)

> He enjoyed it. When he found out he wasn't going to be doing it, that it was finishing he [said], 'Oh, no'. (Mother of Vince)

Alternatively, other participants had accepted hospital visits as part of their life and had developed an enjoyable pattern of activities and social interactions. Jacob was able to identify activities he enjoyed on the unit, such as Nintendo, and made the best of his time spent there. Furthermore, Kim had learned to associate the hospital with her friends and the opportunity it presented for social interaction, as her mother describes, "It's just part of her life and she meets people. She loves Justin, she adores him ... they're very good friends." These participants initially viewed program involvement as an imposition on their currently satisfying pattern of activity and often preferred other activities, such as socializing with friends and playing Nintendo. The following quotes demonstrate these preferences:

> I'd like to Change my Channels to Nintendo, playing Nintendo. (Jacob)

Kim - Why can't we listen to [the audiotape] with Kalie in the room?

Interviewer - Well, we'll just listen to it quick. How's that?

Kim - Is Justin gonna do it?

Interviewer - He's going to listen to the exact same one.

Kim - And after it's gonna be all three [of us]? Me, Justin and Kalie?

These two participants did not display an equivalent amount of mental skill acquisition early in the program. However, this preference did alter over time, specifically for Jacob. Despite his frequent requests to participate in other activities he did eventually learn to enjoy his involvement in the program, as indicated by his mother, "He enjoyed [the program] a lot, and I'd say he got a lot out of it. Honest. He never once said to me, 'Oh, I don't want to see Julie this week', or 'I don't want to [go]'. Never."

Kim had greater difficulty learning to enjoy her time in the Feeling Great program. Although she made indications that she was enjoying participation towards the completion of the program, there was a long history of preference for other activities, "... she'd say at home, 'I don't want to go with Julie today.'"

Ultimately, the children who expressed greater program enjoyment, and perceived the program to be a pleasurable pastime, were more enthusiastic and consistent participants. This enthusiasm toward the program appeared to effect not only their program participation, but also seemed to enhance their learning experience.

The Influence of Context. Another purpose of this study was to examine the influence of context on mental skill acquisition and implementation. The context within which a program operates, including the physical setting, social climate, and available activities, significantly impacts the structure and function of the program, as well as each participant's program experience (Patton, 1990). There are four important contextual influences, which must be

considered when analyzing the function of this program: physical environment, cancer treatment schedule, competing child life activities, and social culture.

Physical Environment. The Feeling Great Program operated on the oncology unit of a busy children's hospital. This created an extremely varied, and sometimes distracting, physical environment. Each week children attended sessions in different environments including empty conference rooms, empty hospital rooms, isolation rooms, physiotherapy rooms off the oncology unit, offices belonging to floor staff and sometimes even busy hallways. This ever changing environment created frequent distractions for participants as each new room presented opportunity for exploration and discovery, with new toys, games, computer screens and medical equipment to be examined, and room characteristics to be investigated. Sessions in new or unfamiliar rooms often began with children wandering around the room, commenting on its features and contents, and then attempting to play with novel toys and/or objects.

In addition to the inconsistency in session location, sessions often took place against a back-drop of hospital noise and activity such as crying or screaming children, beeping machines and frequent intercom announcements. These distractions often occurred at inopportune moments, for example during an audiotape encouraging muscle relaxation or relaxed imagery. Some children found these exterior distractions difficult to "tune out" and would sometimes display difficulty focusing on the audio activity. This created a barrier to complete relaxation.

Cancer Treatment Schedule. In addition to the influence of the unique physical characteristics of the hospital environment, this program was also deeply affected by the actual pediatric cancer treatment schedule. Pediatric oncology patients undergo a lengthy and intensive treatment protocol and their participation in the Feeling Great Program was substantially influenced by this rigorous treatment regime.

In addition to creating frequent noise distractions, the intercom system also created mental and emotional distractions as these announcements were used to inform patients of their turn for treatment. As a result, each intercom announcement created apprehension in children as they listened in anticipation of their treatment turn.

Treatment schedules were an ever present interruption in program implementation. Children were frequently called away from weekly sessions over the intercom, or were retrieved by parents or hospital staff in order to receive weekly treatments. Weekly sessions were commonly interrupted as many as three times in one day. These interruptions inevitably changed the tone of the child's session either by disrupting relaxation activities or by disrupting conversations, both of which were difficult to "pick up from where we left off" upon the child's return.

A great deal of inconsistency in weekly participation occurred as a result of the children's busy agenda of doctor's appointments and treatments. Weekly Feeling Great sessions were constantly being arranged and rearranged to adapt to this busy schedule. As a result, children never had a consistent schedule of weekly involvement. Rather, sessions occurred on different days of the week, at different times during the day - sometimes before treatments, sometimes after treatments - and sometimes, weekly sessions would not occur at all. These varied session times impacted on children's mental and physical state during participation. Children attending sessions prior to receiving treatment were frequently anxious to complete their treatment and hungry due to fasting. These factors affected children both mentally and physically, creating feelings of anticipation, preoccupation with upcoming treatments, and decreased ability to concentrate. Children who participated in sessions following treatments were relieved to be finished and were looking forward to leaving the hospital, or were fatigued due to the length of the hospital visit or treatment side-effects. This full treatment schedule

required both parents and children to adapt their weekly schedule in order to accommodate participation. Participants or parents who were either unable or unwilling to adapt their schedule accordingly often engaged in less consistent, more sporadic participation.

Competing Child Life Activities. An integral component of the oncology unit is the child life program and the activities associated with this program. The oncology unit is an extremely busy atmosphere with a number of available distractions, including painting, drawing, arts and crafts, Nintendo and board games. In addition, special events are planned on a regular basis such as trick or treating at Halloween, constructing gingerbread houses at Christmas, and making pancake breakfasts and fudge in the kitchen. These events are identified as an important part of each child's weekly hospital visit by parents, staff and myself. As a result, weekly Feeling Great sessions often revolved around these activities. By maintaining a flexible schedule for participants, it was possible for children to participate weekly in a number of enjoyable activities. However, this full activity schedule also contributed to increased irregularity in program participation and created substantial disruptions and distractions during sessions, as children attempted to ensure participation in all events.

Social Culture. This program was introduced into an environment where there were established social patterns. These relationships form the social culture of the hospital unit and influence children's involvement and learning experience. The most significant interactions involved parents, peers, hospital personnel and myself as the program implementer and activity partner.

The interactions between parents and children impact significantly on skill acquisition, as described in the previous section on parental support. This parental support helps children understand the importance of participation, maintains interest and motivation, ensures consistent involvement, and creates an enriched learning experience.

Peer relationships also influence children's program experience, as children occasionally participate in activities with friends, inquire about other children's involvement, and express interest in not only their own development but also that of their peers. This environment of peer involvement appeared to support children's continued participation, as children frequently asked for assurance that other children were engaging in similar activities. However, these relationships also created some difficulty as children compared their own progress with that of other participants. This practice was also displayed by involved parents. This social comparison sometimes created feelings of inadequacy. In addition to their supportive value, peer relationships sometimes created a barrier to involvement as participants would occasionally prefer to remain with friends rather than attend weekly sessions.

Hospital personnel form an integral part of this social culture. These staff members function alternatively as friend, parent, nurse, doctor and counselor. These individuals, although not formally part of the Feeling Great program, were aware of the program, understood the strategies being taught, and reinforced these and other positive methods of coping.

Finally, the relationship between the participating children and myself represented an opportunity for social interaction, sharing, support, and friendship. These factors contribute to the overall program experience and are inextricably connected to the child's learning experience.

This program operated within a system of natural relationships and communication between parents, children, hospital staff and myself. This social culture is an integral part of each child's hospital and program experience and cannot be overlooked as an important contextual influence.

Processes Involved with Successful Mental Skill Acquisition

Few studies have been directed toward understanding the processes children engage in while attempting to develop and apply new skills to enhance coping. A fundamental purpose of

this study was the exploration of these processes. Repeated contact with participants as they engaged in mental skill activities provided a unique opportunity to identify several factors related to this process such as regular practice, overcoming negative treatment memories and skepticism towards mental skills, developing trust in the efficacy of mental skills, and fostering children's confidence in their ability to apply these skills.

Consistent Practice in a Relatively Stress-free Environment. When first starting the Feeling Great Program, most participants indicated prior awareness and/or use of techniques similar to the mental skills taught in the program. Several participants indicated that these skills were effective, as in the case of Kim, "... my legs get all like jello ... and I don't count, and I don't feel [the needle]." Another participant, Jacob, indicated the skills were satisfactory, "I use [deep breathing/Jelly Belly] a lot. I use this forever." Other participants reported less effective experiences, as in the case of Karen, "I try relaxing with my dressing change and I never can do it." Vince also reported ineffective ability to cope despite his reports that "sometimes I am relaxed". Although participants reported prior awareness of these techniques they were not always able to apply these strategies consistently and effectively. This resulted in continued distress.

During the 12-week program children were given the opportunity to practice a number of these mental skills such as muscle relaxation, diaphragm breathing, refocusing and positive imagery. This practice took place in a relatively stress-free environment. Although there were distractions, as described earlier, participants were not confronted with the immediate stress of painful and invasive medical procedures. During this time, children learned to apply these skills more effectively and were thus able to cope successfully and experienced less stress during treatments.

The most striking example of the effect of practice on proper skill development can be seen in the case of Jacob. At the beginning of the Feeling Great Program Jacob indicated prior use of deep breathing techniques, such as Jelly Belly, during painful hospital procedures. He found this technique to be relatively effective and his coping had improved. However, extensive practice of this technique in weekly sessions resulted in a noticeable improvement in his skill use. His mother observed a dramatic physical difference in Jacob as he began applying true diaphragm breathing techniques during his intramuscular injections. Jacob himself was also aware of improved technique and he reported that he was now using "*real*" Jelly Belly during physically painful experiences. Although Jacob had been using these skills prior to participation in the program, regular practice of these skills gave him the opportunity to refine his technique and apply these skills more effectively.

Overcoming Prior Negative Experiences. Many children began the Feeling Great Program having experienced a number of extremely painful procedures, which created considerable physical and emotional distress. These experiences led to the development of a number of disturbing memories, as Vince's father describes, "Well they have trouble accessing his veins ... they used to put needles and poke him and they had all kinds of problems which gave him a lot more torment ... so he has bad memories." These disturbing and painful experiences resulted in considerable anxiety, nausea, and fear, even before treatments began. Ultimately, this led to a number of avoidance behaviors such as stalling, bargaining or physical escape. Karen described her use of these behaviors, "[I'm] like shaking. I don't want to do it. 'Huh, just a sec. Just a sec, huh, just a sec'. And then they'll say, 'OK, can we do it now?', and I'll just say, 'Just a second! Wait!'"

Many of these negative experiences were deeply ingrained in children's memories and greatly influenced their approach to hospital visits and treatments, creating an expectation of

continued pain and trauma. An important part of the process of learning mental skills appeared to be replacing these fearful memories and expectations of pain, with positive treatment experiences and expectations for decreased pain and enhanced personal control. The case of Karen provides a clear example of this process.

Karen had developed an overwhelming fear of medical procedures, even procedures identified as relatively pain-free, such as mickey checks and dressing changes. These experiences were perceived by Karen to be both extremely stressful and painful. She had no effective methods of coping with these scary experiences and often reacted with intense fear. She became increasingly agitated and frequently interfered with hospital personnel as they attempted to perform these procedures. As a result, treatments were often prolonged; the experience of pain increased, and the event became extremely distressing for all involved, Karen, her mother and the hospital personnel. Overcoming the belief that these treatments were both scary and painful was an essential component of developing effective coping habits. Although frequently frightened, Karen was able to apply the skills she was learning in the Feeling Great Program during numerous stressful situations. Her consistent and effective application of these techniques enabled her to overcome her expectations of fear and pain, as she describes, "Actually I'm going to have my mickey checked but I'm fine with it now. Because it doesn't hurt anymore." Experiencing less pain and trauma during stressful events helps children develop a new understanding of these events; an understanding that by applying mental skills to enhance relaxation the event will be performed more quickly and efficiently, and result in less pain and distress.

Overcoming Skepticism Toward New Coping Strategies. A fundamental part of the process of learning new methods of coping involves overcoming feelings of doubt or skepticism toward new skills. Prior to beginning the program several children displayed some uncertainty as

to the skills effectiveness, as Karen describes, "I don't know what I thought [the program] would be. I kept wondering how you can make a needle, like you could relax and not make it be so bad. [I was thinking], 'Huh?'. I had no idea how you did that. I was kind of scared." Feelings such as these interfere with skill development as they increase children's resistance to learning and applying new skills. Jacob's experiences accurately illustrate the relationship between feelings of skepticism and resistance to trying new skills.

On several occasions Jacob expressed skepticism toward the activities and skills presented in the program. He suggested that these techniques were more appropriate for grandparents and likened them to unconventional activities such as levitation. Despite the skepticism Jacob expressed towards the manner in which the skills were presented, he was able to draw on past experiences using similar techniques, such as relaxed breathing, to overcome his skepticism. Jacob had previously used breathing techniques successfully during stressful experiences. Therefore, although he was originally skeptical of Jelly Belly he was able to make the association between this skill and successful coping. His effective use of Jelly Belly then helped him become more trusting of other strategies taught in the Feeling Great Program, and he began implementing additional skills, such as Changing Channels. However, there were skills of which he remained skeptical, such as Spaghetti Toes, and he never reported using these skills.

Developing Trust in Mental Skills to Enhance Coping. Related to overcoming skepticism is the development of a firm belief in the ability of these skills to improve feelings of fear, anxiety and pain. This belief developed as part of the process of learning as children begin to experience decreased levels of stress and fear and associate these changes with the use of mental skills. An example of how strongly this belief affects children's skill development and application can be seen in the case of Karen.

Karen's first attempt at using the mental skills was extremely successful, as her mother describes, "I think the first thing you taught her was Spaghetti Toes and that first day she used that, I believe to have bloodwork done, and it was helpful." This initial success strengthened the belief that the use of these skills would decrease feelings of fear and pain, and fostered a positive expectation for repeated success. Karen trusted these skills to be effective and continued to use them during procedures such as dressing changes, mickey checks and bloodwork. However, Karen did not experience a similar level of improvement during her most difficult procedure, mickey changes. Karen was so frightened during this procedure, and groggy due to medication, that she was unable to use her newly developed skills; "No, it's too scary 'cause they give me medicine to make me feel all dizzy, but not put me to sleep, I'm still awake but they make me feel kind of drowsy and calm." Karen even reported that she did not believe the skills would be effective in this situation, "I don't think it will really work 'cause I'm too scared to think about it." Karen was unable to believe in the ability of these skills to help during this distressing procedure. As a result, she did not attempt to use these techniques during this event and continued to experience substantial distress.

Similarly, children who viewed the skills as inferior to their current skills were less likely to adapt these new skills and continued to rely on their current coping methods. For example, Kim reported little need to learn new methods of coping, stating, "I don't need to, 'cause I have a trick that I do by myself." She continued to rely on this "trick" during intramuscular injections as she found this to be an effective method of dealing with this painful procedure and did not trust the mental skills presented in the program to be equally effective.

Fostering Confidence in Ability to Effectively Use Mental Skills. Although it is important that children overcome their skepticism of mental skills and develop trust in the ability of these techniques to improve their coping efforts, it is equally important that children develop

confidence in their own ability to use these skills effectively. This confidence appears to develop as a consequence of consistent and effective use of mental skills. As participants learned to apply mental skills on a regular basis they became more confident in their ability to deal with distressing experiences. Confident in their coping abilities, children begin to feel less threatened by stressful events and even begin to perceive these encounters as less frightening. This improved confidence in ability to cope with both anticipated and unanticipated stressful events significantly affected the attitude with which children approached hospital visits. Children initially approached treatment with feelings of extreme fear and anxiety, often feeling overwhelmed by their inability to meet the demands of these situations. As their ability to cope with treatment procedures improved, children approached treatment with greater confidence.

This enhanced confidence led to decreased physical and emotional anxiety for one participant in particular, as Vince's mother reports, "... I know a lot of his problems were anxiety, still are anxiety, and that he's not showing the same symptoms of anxiety that he had before." Overtime, Vince became more confident in his coping abilities and experienced significantly less anxiety both prior to and during hospital visits. Moreover, both Karen and Vince became so confident in their coping abilities that they even reported using mental skills less frequently as they no longer felt the same level of need.

I - Can you tell me if you ever try anything to help yourself sleep?

V - Not anymore ... I'm not scared anymore! (Interview with Vince)

> Well I sort of forgot [to use the mental skills]. I'm just not as scared anymore [during procedures]. (Karen)

Effectiveness of the Highlight Program

Highlight Journals. In addition to assessing the effectiveness of the Feeling Great program to teach children to cope effectively with stressful experiences, this study also examined the use of a highlight program to help children identify more positive experiences, or highlights (For results in chart format see Appendix Z). Children were asked to maintain a highlight journal and report weekly highlights for the duration of their participation in the program.

Only two children in the program, Karen and Vince, consistently used their journal to chart weekly highlights. These children enjoyed drawing and spent a great deal of time involved in creative activities, as indicated by their parents:

> She's naturally talented at so many things and she's very artistic which is wonderful, crafts and everything ... she knows she's good and she's trying to teach me now how to draw. (Mother of Karen)

> We go through a ton of paper ... he's always drawing stuff and stenciling. (Father of Vince)

These children were excited to receive a highlight journal and viewed it as an opportunity to draw and colour, as Karen's mother describes, "... she enjoyed working in that booklet and she really did look forward to coming in." Both Karen and Vince displayed considerable creativity in their journal entries, using it to record weekly highlights, happy and stressful events, and to reinforce skills they were learning in weekly sessions, such as drawing their Special Place. Journal entries were a source of pride and they enjoyed sharing their weekly creations.

> Wait 'til you see this picture, it's really cool. (Vince)

> So I think that she was proud to come in and be able to tell you that she went to a movie, or she went pony riding with her cousins, or went traveling. So it was excitement for her to be able to come in and report to you what she had done the past week. (Mother of Karen)

Parents of these children felt the journal made important contributions to the program by creating a record of joyful events and by increasing awareness of program activities and highlight experiences.

> I think throughout her treatment her dad and I have tried very hard to keep her busy doing activities that she loves to do. And when you look at that book you can see what we were busy doing with her by the week .... (Mother of Karen)

> He was writing in his highlight book and things like that so I think he was more aware, from using the book. If he didn't have the book then he wouldn't have [been as aware of the program]. (Mother of Vince)

In contrast to the pleasure Vince and Karen derived from their journals, Jacob and Kim displayed less enthusiasm toward journal use. In fact, Jacob boldly refused to maintain a highlight journal, equating journal use with additional "work", stating, "I don't take the book, I don't have to do any work." Jacob's mother explains why she believes Jacob refused to use a journal, "He's pretty lazy. Honest. I think he was just too lazy ... if you had of told him that he

had to do it he probably would have done it ... but there was nobody forcing him to do it, so it was like, 'Oh, if I don't have to, I'm not going to.'" Throughout the program Jacob maintained his resistance to journal use and never completed any journal entries.

Kim was equally unenthusiastic about her journal, completing only one entry over the 12-week period. Despite this lack of interest in independently completing journal entries, Kim did complete several journal activities during weekly sessions. Kim perceived the journal as additional "work". This association had negative consequences, as her mother explains, "I think maybe when there's paper and stuff it's more like school for her and, 'Nope', she doesn't like that." Additionally, Kim's mother describes her as, "Always a perfectionist. Always. In everything... As a result of this perfectionism Kim was concerned that her journal entries needed to be flawless and she did not want to use her journal on her own, for fear of doing it incorrectly. These two factors, association of the journal to homework and her internally developed pressure to achieve perfection, created a negative attitude towards journal use and ultimately resulted in poor journal maintenance. Despite this lack of independent interest, Kim enjoyed using her journal during weekly sessions, commenting, "I ... like it better when we make it here than at home." In fact, Kim selected drawing her Special Place in her journal as her favourite part of the Feeling Great program.

These examples reflect the variations in journal use. It appears that the use of a journal may be an enjoyable and effective method of recording highlights for some children. However, as the following results indicate, the highlight journal is only one method of reporting highlights. Children were also asked to verbally report weekly highlights.

Verbal Highlight Reports. Vince was the only participant to consistently report highlights throughout his 12-week participation. Other participants displayed greater difficulty learning to identify and recount highlights. Karen experienced considerable difficulty

identifying highlights during the initial weeks in the program due to a number of overwhelmingly negative hospital experiences. Despite these initial problems, Karen's parents worked diligently to create highlight experiences for her and helped her maintain her focus on these positive events. This support, along with consistent journal use, helped reinforce Karen's ability to identify and report highlights. Similar to Karen, Jacob also experienced difficulty remembering and reporting highlights on a weekly basis. This difficulty greatly concerned his mother and she became increasingly proactive, offering guidance and support while learning to identify highlight experiences. This support led to gradual improvements in his ability to locate highlights and eventually led to spontaneous highlight reports at the beginning of each session. Kim also struggled to locate highlights during the 12-week program. However, her ability to recognize highlights did not improve until the final three program sessions. At this time Kim began recounting a greater number of spontaneous highlights from both past and present encounters.

These examples provide evidence that children are capable of learning to identify highlights. However, this is not an immediate process. Children appeared to require substantial guidance from me during weekly sessions and from their parents in the home environment. This assistance was necessary in order to demonstrate to children what events and experiences may qualify as highlights, and to help them remember the positive events of their past week. However, once children learned to identify highlights they were capable of locating their own past, present and upcoming highlight experiences.

Three of the participants, Vince, Kim and Karen, felt that the program had indeed helped them locate more highlights, stating:

> When I come I always have a little bit more [highlights]. (Kim)

> I didn't really notice [highlights] before the program. (Karen)

However, Jacob did not report similar improvements and even reported that the program did "not really" help him find more highlights. Furthermore, several parents felt uncertain of the benefits of the highlight program.

> I think he [reported highlights] because he knew he had to, I'm not so sure that helped him. I don't know what you think but that would be my take on it. (Mother of Jacob)

> It's hard to tell [if he noticed more highlights]. Maybe I should mention it to him more what good things happen. (Mother of Vince)

In contrast, Karen's mother felt certain that the program and the journal had made a positive difference in Karen's ability to identify highlights, "Definitely her drawing about what she was doing sort of reinforced, I think, the happy times on top of all the treatment."

These differences may be attributable to the fact that few children discussed their highlights with their parents on a regular basis for the duration of the 12-week program. The only participant that indicated sharing highlight experiences with her mother on a continuous basis was Karen, who explained, "I draw them so sometimes she knows." This may account for the differences in parental awareness of highlight experiences.

The overall evidence supporting the increased ability of children to identify highlights is mixed. Children did report an increased number of highlights during the course of the 12-week program. However, their parents did not report an obvious or significant improvement in their child's ability to focus on the positive aspects of their life. This lends support to the notion that

highlight experiences are internal and cannot be viewed externally. Therefore, in order for parents to become aware of their children's highlights their children must openly share these experiences.

Despite the somewhat conflicting data regarding highlight identification, there is evidence that suggests that the children were able to learn to identify more highlight experiences. Perhaps the clearest indication of enhanced ability to locate highlights is observed in the final interviews with Karen and Jacob. When asked if they felt the program had helped them identify more highlights neither child directly answered the question; rather, both children responded by sharing highlight experiences.

> One highlight I liked was playing that game with you, you know that we would draw something and flip it over. (Karen)

> ... going to McDonald's and the Christmas party and tonight I'm going to Cubs and we're going to see all the lights get turned on. (Jacob)

The fact that children responded to this question by relaying highlight experiences provides support for children's improved abilities to identify highlights.

Factors Affecting The Highlight Program

There were two main influences that appeared to effect children's ability to identify highlights and consistently use their highlight journal: perception of the journal as either an activity book or homework, and parental support.

Perception of Highlight Journal. Two children indicated prior to the program that drawing and colouring were a few of their favourite activities. These same two children were

eager to receive their journal and perceived it as an opportunity to participate in an enjoyable pastime, drawing. This perception increased the enjoyment children found in maintaining a journal, and also increased the consistency with which they made journal entries. In contrast, children who viewed the journal as "work" were less likely to use the journal, and even refused to accept a journal. This indicates the importance of personal perceptions and preferences on journal use, as children who perceive the journal as an activity book and enjoy colouring and drawing are more likely to complete regular journal entries. However, for children who do not enjoy drawing it is essential to be flexible and develop an alternative method of identifying and reporting highlights, such as informal discussions with parents or verbal reports to the program implementer.

Parental Involvement in the Highlight Program. The second factor affecting children's ability to locate and report highlights was parental support and involvement. Parental support was evidenced by: parents reminding children to complete journal entries, helping children locate the correct pages or activities to use, and remembering to bring the journal to the hospital on a weekly basis. This support was essential for those children maintaining a highlight journal. Furthermore, children did not immediately learn to identify highlights. This was a learned process that took time and practice. Parents who played an active role by helping their children locate highlights and discussing highlights on a regular basis, reinforced their child's learning experience.

Discussion

Results from this study indicate that Orlick's (1998) mental skills program is perceived by most participants as being effective in teaching chronically ill children practical methods for dealing with stress in a variety of situations. Participants also learned to identify a greater number of weekly highlights. These results support findings of previous studies that found the

Feeling Great Program to be successful in teaching a school based population of children relaxation skills and stress control strategies, as well as helping them identify more highlights (Cox & Orlick, 1996; Gilbert & Orlick, 1996; St.Denis et al., 1996). In the current study, mental skills training proved to be effective in helping children deal with painful and/or distressing medical procedures, as well as stressful experiences outside the hospital environment. These findings support previous work within this population, suggesting that pediatric patients are able to learn effective coping strategies, and that the use of these strategies decreases their behavioral distress during medical procedures (Blount, Powers, Cotter, Swan & Free, 1994; Hockenberry-Eaton, DiLorio & Kemp, 1995; LaMontagne, Wells, Hepworth, Johnson & Manes, 1999; Powers et al., 1993).

The use of mental skills such as positive imagery, refocusing, relaxed breathing and muscle relaxation, helped children deal with both acute and chronic sources of stress. Acute sources of stress include "intermittent episodes", such as painful procedures and/or treatment side effects, such as nausea and vomiting (Hockenberry-Eaton et al., 1997). Participants in this study reported improvements in their level of distress in both of these areas: procedural and treatment distress. After participating in the Feeling Great Program children displayed more proactive coping responses including deep breathing, muscle relaxation, positive imagery and positive self-talk, during medical procedures. Furthermore, children also reported decreases in some treatment side effects, such as nausea, and improved acceptance of other side effects, such as hair loss.

Chronic sources of stress are "continuous" and include: the daily reality of living with a cancer diagnosis, uncertainty about the future, adjustments in daily routines and activities, and continuous fear of both procedures and side effects (Hockenberry-Eaton et al., 1997). Participating children displayed less adjustment-related distress following involvement in the

program. These children exhibited fewer signs of overall physical and emotional anxiety, such as anticipatory nausea and sleep disturbances, and developed a more positive attitude toward treatment and hospital visits.

Implications for Practice

From a practical perspective the results of this study have several implications that may improve the treatment experience for both pediatric patients and their parents. These implications include the need for early intervention to decrease the development of traumatic treatment memories and foster confidence in children's ability to apply effective coping methods, the need for repeated practice of coping skills in a relatively stress-free or procedure-free environment, the importance of increased motivation and support from both parents and peers, and the need to maintain flexibility and fun within the mental skills program.

Overcoming negative memories of prior procedure experiences was an important step in helping children develop positive coping behaviors. Chen, Zeltzer, Craske and Katz (2000) found that once children develop bad memories, which are often exaggerated in the child's mind, these memories become a significant predictor of future distress behaviors. These findings reinforce the importance of helping children develop effective strategies at an early stage of treatment in an effort to prevent the development of traumatic memories and increased behavioral distress during treatments. This suggestion is also supported by Sawyer, Antoniou, Toogood and Rice (1997) who recommend that efforts should be directed at decreasing distress experienced by children and parents early in the treatment process. An additional benefit of early intervention is the opportunity to foster children's belief in the ability of mental skills to decrease pain and distress during procedures, as well as the opportunity to foster children's confidence in their own ability to apply these techniques effectively. The current study identified both of these factors as being important components of the coping process.

Several prior studies indicate that children are often aware of a number of proactive coping techniques, however, do not always apply these techniques and often continue to engage in ineffective coping behaviors during stressful situations (Altshuler et al., 1995; Peterson et al., 1999). This discrepancy is attributed to a motivational deficit. Peterson et al. (1999) suggest that children perceive proactive coping skills as being more difficult to perform, and believe that the use of these skills will draw less attention to their distress. Children in the current study also indicated prior awareness of a variety of positive coping strategies. However, these participants were either unable or unwilling to apply these skills effectively. Following participation in the Feeling Great Program these children displayed substantial increases in the use of proactive coping responses, a finding attributed mainly to repeated practice in a stress-free environment. As children engaged in regular practice of mental skills they became more familiar with, and more capable of, implementing these skills. Their enhanced coping behavior empowered them to use these skills regularly. This regular use also helped alter their perception of mental skills, and coping skills in general. They no longer viewed coping skills as being difficult or ineffective, and improved both their confidence in the skills and in their ability to implement these skills. Increased emphasis on consistent practice in a relatively stress-free environment will help children learn to develop more positive coping methods. Ideally, this practice should be encouraged by: parents, caregivers, teachers and health care practitioners.

Parental support was identified in this study as an important requirement for high quality mental skill acquisition. Peterson et al. (1999) suggest that children need both encouragement and motivation in order to engage in proactive coping behaviors during stressful events. Parental support, both during specific stressful experiences and throughout the course of treatment, is perhaps the most influential form of encouragement. Therefore, every effort should be made to facilitate parental involvement. Increased parental involvement has also been found to reduce

feelings of helplessness in parents and decrease feelings of distress in both the participating parent and the child (Blount et al., 1994; LaMontagne et al., 1999; Powers et al., 1993). Helping parents and caregivers develop more effective coping skills along with their children, is also recommended by Thoma, Hockenberry-Eaton and Kemp (1993). These findings emphasize the value of increasing parental involvement in interventions of this nature, perhaps by including parents in weekly sessions, by creating a coaching role for parents or by increasing skill use in the home environment.

In addition to parental support, children also identify support from friends as being extremely important, specifically support from peers with cancer as they "provide information, understanding, empathy and acceptance" (Woodgate, 1999, p. 204). Research supports the notion that perceived social support lessens the impact of stressful experiences (Varni, Katz, Colegrove & Dolgin, 1993; Woodgate, 1999). Such things as "being like my friends" and "fitting in with the group" are believed to contribute to a positive self-perception in pediatric cancer patients (Hockenberry-Eaton et al., 1995). In the current study, separation from peers occasionally presented a barrier to participation for participants. Moreover, inclusion of peers enhanced children's program enjoyment and motivation. Therefore, small group sessions including other children receiving treatment for cancer, would provide a unique learning environment; an environment where children could reap the benefits of enhanced coping skills and increased social support.

Finally, this study clearly indicated the importance of maintaining a flexible level of involvement for participants. This flexibility should address children's personal preferences, past experiences and contextual factors, such as concurrently offered activities, treatment schedules and peer relations. A flexible program design enables children to participate on their

own terms, thereby enhancing feelings of control and program enjoyment, and increasing the opportunity to match program activities with participant preferences.

Limitations and Future Research Recommendations

When interpreting these results it is important to remember several research limitations. The participants in this study were selected using purposive sampling methods and comprise a relatively small sample size (four participants). Moreover, the participants are relatively homogenous in nature, with respect to similar ages and stages of treatment, and attending the same medical facility. These factors limit the generalizability of these findings.

In addition, the experience of stress and coping is complex and multidetermined. A number of factors influence children's coping and stress responses, such as length of time in treatment, prior experiences, medication side effects and support from family and hospital personnel. The goal of this study was not to control these variables, rather to determine how this mental skills program would function in conjunction with these influences. However, these external factors do impact on the coping process and cannot be separated from the child's program experience. Therefore, they must be considered when interpreting these results.

Similarly, the process involved in acquiring and implementing coping skills is extremely complex. This study endeavored to identify several key components involved in this process. However, further research that attempts to understand coping as a process, for different populations of children within various contexts, is necessary. A comprehensive understanding of this phenomenon may be used to provide enhanced support to children and their families.

Summary

School-aged children with chronic illness are capable of learning a number of different mental skills and applying these skills during distressing hospital experiences and in stressful situations outside the hospital environment. The use of relevant mental skills is associated with

proactive coping responses during painful procedures and an increasingly positive attitude toward hospital visits and treatment procedures. These skills also provide an effective means of dealing with both acute and chronic stressors associated with childhood cancer. Creative efforts to introduce these skills to children in the early stages of their treatment, with both parental and peer involvement, may provide an effective means of enhancing children's coping skills and improving the experience of pediatric cancer.

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Appendix A

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH. OTTAWA. ONT. K1H 8L1 TELEPHONE (613) 737-7600

July 19, 1999

Ms. Julie Koudys
169 Lees Avenue
Apartment 501
Ottawa, Ontario
K1S 5M2

Re: Proposal 99/35E - Qualities for Living: Skills for Children Living with Chronic Illness

Dear Ms. Koudys:

Thank you for your revised Consent in the above-mentioned proposal received today.

Please accept this letter as written approval from CHEO's Research Ethics Committee for the Consent dated July, 1999.

It is your obligation to notify the REC prior to the institution of any modifications to this study, or any adverse events which may occur during the course of this study.

To ensure that the REC is kept informed of the progress of clinical studies, *we request a yearly progress report* from each investigator.

Kindly refer to the ***Proposal Number*** in any future correspondence.

Sincerely,

D. Palframan, M. D., F.R.C.P. (C)
Chair
Research Ethics Committee

/rw

Appendix B

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
A University of Ottawa Teaching Hospital / Un Hôpital d'enseignement affillié a l'Université d'Ottawa
401 SMYTH, OTTAWA, ONT. K1H 8L1 TELEPHONE (613) 737-7600

QUALITIES FOR LIVING: LIFE SKILLS FOR CHILDREN LIVING WITH CHRONIC ILLNESS

STUDY DESCRIPTION & CONSENT FORM

Currently we are attempting to determine if the research based quality of life skills program developed by Orlick (1998) is useful in helping children with chronic illnesses cope more effectively or find more positive highlights in their lives both within the hospital environment and in school or home settings. In addition, we are examining the processes involved in helping children cope successfully and carry a positive perspective as well as the factors that may interfere with the efficacy of the program. We are also examining how children's understanding of the activities involved with the program, and the specific context of its application, affect their ability to successfully implement positive mental skills. Your child is currently receiving treatment for a chronic illness at the Children's Hospital of Eastern Ontario and may be able to help us find answers for some of our questions as well as gain positive benefits from participation in the mental skills program.

The Feeling Great Life Skills program is designed to teach children positive life skills, including how to relax, deal with stress effectively, and look for positive things within themselves, others and their environment. Results of previous studies with school populations, have shown that children who participate in the Feeling Great program: a) enjoy the activities, b) learn to relax at will, c) successfully implement stress control strategies across a variety of situations, d) increase their frequency of noticing and experiencing highlights and, e) increase their ratings of positive feelings about themselves.

This research project is comprised of a series of simple games and activities which teach quality of life skills and concepts in a fun and exciting manner. Children will participate once or twice weekly in sessions that teach a variety of relaxation activities along with basic concepts about stress and relaxation. Relaxation activities may include locating muscles and learning to relax them, altering breathing rhythms, positive focusing, mental imagery, looking for highlights and relaxing to audiotapes. A typical session will consist of a short discussion on relaxation and/or stress control, a relaxation and/or stress control activity through the use of an audio-tape, and follow-up suggestions on how and when to use the skills they are learning.

In addition to individual sessions with each child, group sessions involving cooperative games will also be conducted once a week. Cooperative games are games of acceptance, cooperation and sharing that allow everyone to win. These games instill confidence in children and provide them with the opportunity for challenge, stimulation, self-validation and success. These group sessions will contain an activity that reinforces the concepts and skills taught in the individual sessions. The program will run for a period of 10 weeks with individual activity sessions and cooperative game sessions being held once weekly. Your child will participate in the activities with the researcher and other children involved with the study at the most convenient times for your family, i.e., when they come in for treatments.

Children will be asked to comment on each activity and keep a simple highlight logbook to assess their progress in learning and using these skills. This will enable us to determine the number of highlights children experience, and the areas from which highlights arise. The book will also ask children to chart their experiences with stress. This will allow us to understand what children perceive to be stressful events, the ways in which children deal with stress, and how they feel before and after stressful events. The logbook will also provide an indication of whether or not children are using the exercises learned during the program and how effective they perceive the exercises to be.

Children will also be tested with a DT 1000 heart rate monitor before the program and after the program to measure the physiological effects of the relaxation training. The DT 1000 heart rate monitor is a simple, non-invasive, lightweight monitor which clips to the ear lobe.

I will participate in the activities, observe the children engaged in the activities, and talk with the children to gain their views of its effectiveness. I will also talk with you as a parent as well as other relevant health care providers to help supply more information regarding the efficacy of the program and its activities. Some of the sessions will be audiotaped to enable me to keep accurate data. However, the use of an audio-tape is not compulsory and you may decide not to have any of the sessions or interviews taped. The information gained from this study will be used to evaluate the program in terms of its capacity to teach children important life skills as well as to improve upon the program for future use with larger numbers of children. Study results will be reported in ways that ensure complete confidentiality with only the investigators having access to the data. The findings will be used for both research and future program implementation purposes. Before quotations and data are integrated into a final report you will be furnished with a copy to ensure that both your own child's experiences and perspectives are accurately represented.

Participation in this study is voluntary and you may decide not to participate or decide to withdraw your child from the study at any time. We feel it will be a very worthwhile and uplifting experience for your child. An overview of the philosophy of the program activities is available upon request.

I acknowledge that research questions that I have asked have been answered to my satisfaction. In addition, I know that I may contact Julie Koudys, Dr. Terry Orlick or Denise Albrecht if I have further questions either now or in the future. I have been informed of the procedures involved with the program and the potentials effects of involvement with the program. I have been provided with sufficient time to consider my decision to participate.

I have been assured that personal records relating to this study will be kept confidential. I understand that I am free to withdraw my child from the study at any time.

"You may contact the Chair of the Research Ethics Committee, for information regarding patient's rights in research studies at (tel. # 1-613-738-3272); however, this person cannot provide any medical information with regard to this study."

_____

Signature of the participant/child

_____

Signature of person authorized to sign on behalf of participant, e.g., parent or legal guardian

_____

Signature of Witness

I HAVE EXPLAINED THIS STUDY TO THE PERSON AUTHORIZED TO SIGN ABOVE AND I AM SATISFIED THAT IT IS UNDERSTOOD.

_____

Signature of investigators or designees

If you should have any concerns or questions regarding this study, please contact Julie Koudys (613-260-9837), Dr. Terry Orlick (613-562-5800, ex. 4272) or Dennise Albrecht, Child & Youth Health Service Network (613-737-2220). If you have any concerns about the ethics or conduct of this project you may contact the chairperson of the Ethics Committee at 613-738-3272.

Dated July, 1999.

Appendix C

Children's Initial Interview Guide (Cultural)

Demographic Information

1. Age of child, grade of child, ability of child to attend school

2. What types of things do you like to do for fun?

Functioning Information

3. Can you tell me a little bit about why you come to the hospital?

4. Since you got sick have there been a lot of changes in your life?
   Probes and follow-ups will attempt to elicit information on changes at home, in school, in daily activities, with family/friends

5. How would you describe; a typical trip to the hospital/day/week?
   Probes and follow-ups will focus on eliciting information from the following areas;
   - travel time, accommodations (if appropriate), duration of visit, treatment
   - child's schedule, i.e. activities, daily schedule, health care routines

6. When you're at home/school/hospital/other related setting what types of things happen? Are there ever any things that make you feel worried, upset or stressed?

7. How do these (identified things) make you feel?

8. What do you do when these (identified things) happen? Do you ever do anything to try and make yourself feel better or happier?

9. If they describe coping attempts, Do you think these (coping attempts) work?
   If no coping attempts described, go to question 10.

10. Do you think there are things you could do to make yourself feel better or happier?

11. If yes, what do you think you could do?

12. Would you like to try and learn some things you could do that might make you feel happier or better at home, in the hospital or anywhere else?

Appendix D

Key Informant Initial Interview Guide (Cultural)

Interview guide for cultural interviews with parents and health care providers.

Demographic Information

1. Age of child, gender of child, grade of child, ability of child to attend school

2. Can you tell me a few of the things your child enjoys doing? Their interests and activities?

Medical Information

3. Can you tell me a little bit about your child's illness?

Specific form of cancer, when diagnosed, when began treatment, how long receiving treatment, type of treatment and schedule

Functioning Information

3. How would you describe a typical trip to the hospital/day/week?
   - travel time, accommodations (if appropriate), duration of visit, treatment
   - child's schedule, i.e. activities, daily schedule, health care routines
   - *families schedule, i.e. activities, daily schedule, part in health care routines

4. Within these time periods, and in various situations (i.e., home, hospital, school) can you identify and describe any particular events or experiences that you feel are especially stressful for your child?

5. How does your child most often respond in these situations?

6. What, if anything, do you/the child/ do to make your child feel better?

7. If attempts are made to comfort child, how effective do you feel these efforts are?

8. Can you think of any activities or skills that you feel would be beneficial for this/your child in these situations/settings?

Appendix E

Children's Final Interview Guide

1. We talk a lot about stress and worry, can you tell me some of the things that make you feel stressed or upset either in the hospital, at home, at school or anywhere else?

2. How do you feel/act in these situations?

3. Since we started working together do you ever try to do anything to make yourself feel better/more relaxed/less stressed in these situations? If so, what do you do? How do you feel after you do that?

4. Does your mom/dad ever do anything to help you at these times? Does your mom or dad ever encourage you to try the skills we do together? Do they ever talk to you about your highlights?

5. We talked a lot about highlights together, do you think that talking about or drawing your highlights helped you find more happy or positive things each day? Do you think if helped you remember all the good things you do?

6. We did quite a few different activities together, i.e., tapes, journals, what was your favourite part? Could you pick your favourite activity? Were there any thing you didn't like as well? What were the things or parts you like least?

7. Did you start using the activities right away or did it take awhile before you started using the activities? Why did you try or start to use the skills we did together? Why didn't you try or use any of the skills we did together?

8. Are you glad you participated in the program? Is there anything you would like to say about the program or about yourself now?

Appendix F

Key Informant Final Interview Guide

1. Within either your home, the hospital or your child's school can you identify and describe any particular events or experiences that you feel are especially stressful or upsetting for you child? What comments, behaviours or responses made you think your child felt this way?

2. Since taking part in the Feeling Great Program how does your child most often respond in situations like these? Do they ever try to do anything to make themselves feel better? If so, what do they try? Does this seem to be effective?

3. During these situations what, if anything, do you do to help make your child feel better? Do you encourage your child to try anything during these situations?

4. Were there any situations or experiences outside the hospital environment when your child used these skills? If so, when and how effective did this appear to be?

5. Your child was involved in a highlight program over the past couple of months, do you feel this helped them to look for the positive in each day or to notice more of the happy highlights during their week?

6. Did your child indicate that they enjoyed partaking in activities in the Feeling Great Program, either the tapes and sessions or the journal?

7. Do you feel that your child immediately like and used the program activities or did it take some time before your child learned to use the activities? What do you think made your child start using these skills on a regular basis?

8. Are you glad your child participated in the Feeling Great Program? Is there anything you would like to say about the program or add to our discussion?

*** This interview guide was adapted for each interviewee based on prior knowledge of participant experiences and prior conversations with parents and children. This ensured that questions were relevant and specific to each individual participant.

Appendix G

FEELING GREAT LIFE SKILLS PROGRAM
DAY-BY-DAY
KINDERGARTEN TO GRADE 2

DAY #1

Questions:

Does anyone know what it feels like to be scared, or tense, or afraid or worried?

Do you know what it feels like to relax?

What's the difference between feeling worried and feeling relaxed?

Teaching Point:

Present the concept of stress and relaxation through uncooked and cooked spaghetti. Stress or tension is like hard, stiff, uncooked spaghetti and relaxation is like warm, soft, cooked spaghetti, curling up on your plate. Reference: Free to Feel Great Book, pages 50-54.

ACTIVITY

1. Audio-tape<u>Spaghetti Toes</u> (Tape 1 Side A #1).
Reference: Free to Feel Great Book, pages 51-52.

Post-Activity Questions:

How did you feel doing Spaghetti Toes?

When could you use Spaghetti Toes?

Reminders

For children:

Practice Spaghetti Toes on your own after school, or at home in bed tonight.

For teacher:

If possible bring in a piece of uncooked and cooked spaghetti for each child to explore. A microwave oven in the staff room can add a last touch of warmth (for the cooked spaghetti).

Smile. You have taken the first step on what will be a very meaningful journey for these children.

<u>Notes/Comments</u>

Appendix H

Children's Informal Conversational Interview Guide

1. Did anything happen to you in the past couple of days, yesterday or today, that made you feel sad, mad or worried?

2. Do you want to share what happened?

3. How did that (stressful event) make you feel?

4. Did you do anything to try to make yourself feel better, less stressed or more relaxed?

5. If yes, what did you try? Did it help you feel better?

6. If no, what could you have tried?

*** The above questions were adapted to address the following areas when appropriate.

- sharing highlights
-sharing stressful events and related feelings, along with coping strategy attempted and how it worked
- sharing relaxation activities attempted and related feelings/experiences
- sharing experiences in using positive thinking with oneself and positive interaction with others
- sharing attempts at using positive imagery or effective focusing, and related feelings/experiences

Appendix I

Initial Interview - Kim

Italics - Kim, CAPITALS - JULIE

I'M GOING TO ASK YOU SOME QUESTIONS, AND SOME OF THEM WE'VE PROBABLY ALREADY TALKED ABOUT, BUT I'M GOING TO ASK YOU AGAIN. IS THAT OK?

Ok.

HOW OLD ARE YOU KIM?

7 ½.

7 ½.? DO YOU LIKE BEING 7 ½.?

I'll like better being 8.

YA? WHEN YOU GO TO CAMP NEXT WEEK HAVE YOU DECIDED WHICH AGE GROUP YOU'RE GOING TO GO IN YET? (Referring to Camp Trillium, Kim had explained during our first meeting that she was trying to decide which age group to go into at Camp)

I don't know, I can go in 6 and 7, or 8 and 9.

YA?

Maybe 8 and 9 will be better, 'cause I think 6 and 7 is more baby things like for little kids.

YA?

Last year I did go to camp and I was in 6 and 7 and I loved it. But maybe 8 and 9 will be better.

YA, YOU MAY HAVE MORE FUN DOING DIFFERENT THINGS THIS TIME.

Ya, I did some things - a little bit like for big kids not for little kids.

YA, THAT MAKES SENSE [THAT YOU WOULD DO BOTH]. SO WHAT STUFF DO YOU LIKE TO DO?

I like to, I like everything. I love one time we did make cookies and we did go to a kayak.

KAYAK?

Ya, and we did go everywhere it was fun.

GOOD. DO YOU PLAY, DO YOU LIKE PLAYING ANY GAMES?

Ya, when it rains we stay in. But we were up (in bunk beds), so we didn't have nobody, we just had Maureen to look in the other room. And where we were all sleeping. It was hot, 'cause it was really hot.

WAS THAT AT CAMP?

Ya, and there was barely any room at top 'cause it has a lot of people. But the parents, they were not there. Cause they was talking. But me and Jonathan we just had to talk all by ourselves so it wasn't really too fun.

NO?

But it was hot too, and there was spiders there.

OH, SPIDERS?

Ya.

YOU DON'T LIKE SPIDERS?

No, but I was up so that I can see those spiders.

I SEE. YOU WERE NEAR THE CEILING, WERE YOU?

Yes.

GOTCHA. NO, I DON'T LIKE SPIDERS EITHER. SO WHEN YOU'RE NOT AT CAMP, WHEN YOU'RE AT HOME WHAT STUFF DO YOU LIKE TO DO THERE?

Umm, I like to watch TV when it rains, I like to do roller blade and do bike and ... (pauses)

SO WHEN YOU ROLLERBLADE HAVE YOU EVER FALLEN DOWN?

Sometimes. 'Cause my brothers in the bicycle back (indicating behind her). So when I'm there, and he's there, but we can - And one time he just hang on me, and so I fall, and I hurt my head. But I do have protection.

GOOD, GOOD. I FELL ONCE WHEN I FIRST STARTED ROLLERBLADING AND I SCRAPED MY HANDS UP ...

Oh, my mom don't have things to protect her and she was doing some rollerblades and she said, "Oh, it's just a small thing I'm gonna jump on", and she falls. She hurt her hand and she hurt her bum.

OWW.

And she whacked a big thing there (indicating she hit her bum) and she said it was little but it was big.

OH, GOTCHA.

I'm better than my mom.

ARE YOU?

Yes.

WOULD SHE AGREE WITH THAT?

Yes. Probably. We have a big rock so when I just step on it like this I fall.

YA?

I put my hands down and I fall like this.

SO YOU KINDOF PROTECT YOURSELF?

Yes.

IT LOOKS LIKE YOU HAVE A SUN TAN.

Where?

RIGHT THERE. ARE YOU OUT IN THE SUN SOMETIMES, HAVE YOU BEEN PLAYING OUTSIDE?

Ya, but I put cream on.

I DO TOO.

My mom's skin is white, and she don't put cream on. And I put cream, and I'm burnt.

SO YOU TAN BETTER?

I'm like my father. My father's brown, my mothers white, like milk.

DO YOU TEASE HER ABOUT THAT?

Ya.

SOUNDED LIKE YOU MIGHT. SO CAN YOU TELL ME A LITTLE BIT ABOUT WHAT GRADE YOU'RE IN AT SCHOOL?

I was in 2 but I'm going in 3. My mom doesn't want to tell me who is my teacher. And I know who is it 'cause when she talks to my grandma she says, and I always do hear and she doesn't' know.

SO YOU KNOW WHO YOUR TEACHER IS?

Ya, I wanted her.

OH, GOOD. THAT'S GOOD. SO CAN YOU TELL ME A LITTLE BIT ABOUT WHY YOU COME TO THE HOSPITAL?

Ya, I come because I have leukemia and I have to go to the hospital to have the medications and all this.

YEP, YEP. SO YOU COME FOR TREATMENT?

Ya.

SO WHAT ARE YOUR TREATMENTS USUALLY LIKE?

Well I don't like the methotrexate and the vincristine. Sometimes I have a lumbar puncture, but I'm asleep so I don't know.

YA, THAT'S PROBABLY GOOD THAT YOU'RE ASLEEP.

Ya, 'cause it's a big needle but it just a little bit (indicating with hands that they only put part of the big needle into her back) and it hurts. When I wake up it hurts in my back.

YA, SO WHEN YOU COME HERE SOME DAYS, WHAT IS IT USUALLY LIKE? CAN YOU KIND OF DESCRIBE YOUR WHOLE DAY TO ME? WHAT USUALLY HAPPENS? LIKE WHEN YOU FIRST GET HERE, WHAT DO YOU USUALLY DO?

Sometimes we go to the coffee shop, then I play with my mom or with Derick, with my friends. Sometimes I make crafts (inaudible). I do a lot of things. It's never the same thing that I do.

NO? ALWAYS DIFFERENT?

Ya.

THAT'S NEAT. SO YOU USUALLY COME IN, AND THEN DO YOU GET BLOODWORK FIRST THING IN THE MORNING?

Yep. And then ... I did have to get two bloodwork 'cause one it went in and that one it worked but it hurt. (Kim is explaining that they were unable to draw blood on the first attempt and they had to do it twice)

GOTCHA, SO THEY HAD TO DO TWO.

Ya.

YUCK.

And when we did two, I have two stickers. And one day I did get three 'cause one for my brother.

DO YOU GET ALONG WITH YOUR BROTHER?

Huh?

DO YOU LIKE YOUR BROTHER?

Ya, but sometimes he falls, and he don't know that I have a Port-o-cath, and he falls on my Port-o-cath. But he don't know. He thinks he's playing, but he's not, he's hurting.

YA.

He don't know how to play. Like when I was playing with Justin and my other friend, we were sitting on, he was pretending that we hurt him. And not Jeffrey started to yell and wanted to, he did that and my friend said we we're playing, we're not hurting you.

SO SOMETIMES IT'S MORE BY ACCIDENT USUALLY ...

Ya, he thinks that we're really hitting him, but we're like this ...

PRETENDING?

Ya, he don't know he's too small.

YA, I HAVE A BROTHER TOO. BUT HE'S OLDER THAN ME AND WHEN WE WERE LITTLE WE USED TO FIGHT SOMETIMES BUT NOW WE GET ALONG PRETTY GOOD.

We fight sometimes and when I'm crying in my room, sometimes because he did hit me. I cry sometimes 'cause he hits hard and sometimes he hits something, and he goes to my room, and jump on me again.

OUCH.

Jump again and again and again. I try to play with him, sometimes do something like we're going to mini-putt and I try to say, "Come Jeffrey, we're going to mini-putt" and he hits hard. And we go and I try to keep him calm, "Just calm down, calm down", but he don't want to. He yells, and he jumps on me.

PROBABLY 'CAUSE HE'S LITTLER.

Ya. I hope he was my age.

WELL SOMEDAY HE'LL BE A LITTLE BIT OLDER AND YOU WON'T KNOW, IT WON'T FEEL LIKE HE'S SO MUCH YOUNGER, THE OLDER THE TWO OF YOU GET. WHEN YOU'RE AT THE HOSPITAL ARE THERE EVER ANYTHING'S THAT MAKE YOU UPSET?

No, nothing makes me upset.

WELL THAT'S GOOD.

'Cause when we play with Justin we're all, we don't say "Oh no, you can't play", we say, 'Come, come'. Cause he's gonna cry in the corner. 'Cause we're all friends we're not gonna say, "Oh no, you can't play".

EXACTLY, WELL THAT'S VERY NICE OF YOU.

Even one time we're playing a game of four and there was another little girl who was coming and we know her and we didn't say, "No, it's only four". Justin and I take her and she was playing with me.

OH, GOOD. THAT'S VERY NICE OF YOU, KIM. WHEN YOU GET TREATMENTS AND STUFF DO YOU EVER, WHAT DO YOU DO TO MAKE YOURSELF FEEL BETTER?

Sometimes, I stay like this and my legs getting all like jello (indicates a slumped, relaxed position). And I don't count because once she say one and when she says three I'm like this (demonstrates, very stiff, tense, scared posture, goes from relaxed at one to terrified at three)

YOU'RE TENSE?

And my leg it gets hard. And so I don't count and I don't feel it because she didn't say it to me. But when I look, I know that she's gonna put it 'cause I see her.

YA, SO IT'S BETTER IF YOU DON'T COUNT. WELL, THAT'S INTERESTING. WELL I THINK THAT'S PROBABLY ALL THE QUESTIONS I HAD FOR YOU. YOU ANSWERED EVERYTHING REALLY GREAT, THANK-YOU!

Karen - September 2 – Weekly Session #1

Italics - Karen, CAPITALS - JULIE

Why do you put this on?

DO YOU WANT ME TO TELL YOU?

Ok.

BECAUSE WHEN I GO HOME AND I GO ON MY COMPUTER AND I TYPE UP, KIND OF LIKE A STORY ABOUT WHAT WE DID. AND WHETHER OR NOT YOU LEARNED STUFF, WHETHER YOU LIKED AN ACTIVITY OR DIDN'T LIKE IT, AND THAT WAY I KNOW, LIKE WHAT STUFF YOU LIKED AND WHAT STUFF YOU DIDN'T LIKE. IT HELPS ME KEEP TRACK, MAKE SENSE? AND THEN I'LL KNOW SO IF I EVER WORK WITH OTHER CHILDREN ...

I thought rec was something like record, like the tape, like... (Referring to buttons on the tape recorder)

UMM, IT'S RECORD. SHORT FOR RECORD. MAKE SENSE?

Cause the VCR and stuff it's another one.

OH, IS IT? OH, I'VE NEVER NOTICED. YOU'RE OBSERVANT, KAREN. I HAVE SOMETHING FOR YOU.

That book?

AND GUESS WHAT COLOUR I MADE IT FOR YOU?

Blue?

YES. I HAD THEM MAKE IT BLUE ESPECIALLY FOR YOU JUST CAUSE I KNEW YOU LIKED IT. I'LL SHOW YOU WHERE THE FRONT IS. AND THERE'S THE FRONT. SO THIS IS YOUR HIGHLIGHT BOOK, AND IT HAS ALL KINDS OF DIFFERENT SPOTS IN IT FOR YOU TO DRAW THINGS IN. NOW HAVE WE EVER TALKED ABOUT HIGHLIGHTS TOGETHER, YOU AND I?

Ummm, like one of your favourite things, like favourite things are highlights.

EXACTLY. YEP. LIKE ALL THE HAPPY THINGS. NOW WITH THIS BOOK THE ONLY THING THAT I ASK IS THAT WHEN YOU COME HERE TO THE HOSPITAL, WHENEVER YOU COME, THAT YOU BRING IT WITH YOU IS THAT OK?

Ok.

AND YOU'LL SHOW ME WHAT STUFF YOU PUT IN IT AND WE CAN TALK ABOUT MAYBE WHAT STUFF YOU WANT TO PUT IN IT FOR NEXT WEEK. IS THAT COOL?

Uh-huh. Unless I have too much stuff to bring.

UMMHMM, WELL HOPEFULLY YOU'LL BE ABLE TO FIND ROOM, CAUSE I'D LIKE TO BE ABLE TO SEE WHAT YOU'RE DOING. SO HOW ABOUT I TELL YOU ABOUT ALL THE DIFFERENT STUFF THAT'S IN THE BOOK. IS THAT OK? (UMMHMM) OK. SO THIS IS ALL THE HIGHLIGHTS, THIS IS ALL THE GOOD STUFF THAT HAPPENS. AND IT GOES ON FOR AWHILE.

Oh?

UMMHMM. YES, THOSE ARE HIGHLIGHTS AND YOU CAN KIND OF WRITE OR DRAW OR YOU CAN DO BOTH IF YOU WANT. NOW THESE ARE, AND THEN IT GETS INTO STUFF LIKE FEELING BEST, WHERE YOU DRAW ABOUT THE THINGS THAT MAKE YOU FEEL BEST, LIKE IF YOU GET TO LEARN SOMETHING...

Can I draw a kitten?

YES, THAT WOULD DEFINITELY COUNT.

A little one like that?

UMMHMM, DID YOU GET A NEW KITTEN?

No, no. I got one that's two. I'm not really allowed to have anymore cause they say you're supposed to get two of them at the same time. Because if you get two at different times, cause my kitten is 2, and if I wanted a smaller one, that one...

THEY MIGHT FIGHT.

Ummhmm. Ya, cause one of them might think it has to give up it's house and one will pea all over the place.

YA.

Are we listening to music?

WELL WE'RE GOING TO LISTEN TO A TAPE ACTUALLY, SO, AND NOW THIS - ABOUT DRAWING SOMETHING THAT MAKES YOU LAUGH, LIKE SOMETHING FUNNY, OR SOMETHING THAT YOU SAW OR DID. NOW THIS IS ALSO FOR YOUR HAPPY HIGHLIGHT STUFF. AND NOW THIS SECTION IS RELAXATION, SO THIS TALKS ABOUT...

Oh, I felt like that this morning when my dressing change.

DID YOU?

Yep, yep. But then I felt like that.

AFTERWARDS? WELL THAT'S GOOD. THAT'S EXACTLY WHAT I WANT YOU TO DO WITH THAT, WITH THESE SCALES. IS TO TELL ME HOW YOU FELT BEFORE YOU TRIED, BEFORE SOMETHING, AND YOU CAN TELL ME, "OH, BEFORE MY DRESSING CHANGE I FELT LIKE THIS..."

Well, I have to circle it, right?

YOU CAN TELL ME, OR YOU CAN CIRCLE IT. OR YOU KNOW WHAT YOU CAN DO? YOU CAN COLOR IT.

Umm, no.

YOU DON'T WANT TO COLOR IT?

I'll just do, like point to it.

YOU'RE GONNA POINT TO THEM? OK, THAT'S FINE. CAUSE THEN, SO WHAT YOU AND I ARE GOING TO DO TOGETHER IS LISTEN TO SOME TAPES AND WHAT THE TAPES DO IS TALK ABOUT WAYS THAT YOU CAN TRY AND MAKE YOURSELF FEEL MORE LIKE THIS AND MORE RELAXED AND EVERYTHING.

I'm getting a needle today.

ARE YOU? (INAUDIBLE) OH, WELL THAT'S MAYBE (INAUDIBLE) THAT STUFF HELPS THEN.

I was pretty relaxed, not yesterday, the day before though.

YA?

Ummhmm.

GOOD, GOOD. HOW DID YOU MAKE YOURSELF FEEL PRETTY RELAXED?

Well I just like kind of went "Everything will be all right." And then... (Ya) Well, I just said, "I'll feel better."

AND DID IT WORK PRETTY GOOD?

Ummhmm.

THAT'S GOOD.

It hurt a little bit. Not as much as I thought. That's not my medicine that kind of stings.

YA, IS THAT THE ONE THAT YOUR MOM SAYS THAT SOMETIMES IT HELPS IF YOU KIND OF MAKE YOUR ARM HARDER AND YOU KIND OF GO LIKE THAT?

Ya, ya. I only do that for my needle in my arm, or bloodwork.

GOTCHA.

I don't get bloodwork from my arm.

OK, (INAUDIBLE). THIS IS YOUR SPECIAL PLACE, SO SOME PLACE THAT YOU GO THAT YOU REALLY LIKE OR THAT YOU THINK ABOUT THAT MAKES YOU HAPPY.

Actually when my counts are high I might even go riding on a horse.

YOU ARE? THAT'LL BE GREAT!

When my dad has the time off.

GOOD, YOU'LL LOVE THAT! NOW THIS IS ABOUT BEING RELAXED, AND THEN THIS GOES INTO ALL THESE LITTLE PICTURES HERE? (UMMHMM) THESE ARE PICTURES OF ALL THE LITTLE ACTIVITIES THAT WE DO. AND THIS ONE IS CALLED SPAGHETTI TOES AND THAT'S WHAT WE'RE GOING TO DO TODAY, IS WE'RE GOING TO TALK ABOUT SPAGHETTI. NOW BEFORE WE TALK ABOUT SPAGHETTI TOES, AND BEFORE WE LISTEN TO THE TAPE I'M GOING TO TALK TO YOU A LITTLE BIT ABOUT STRESS AND RELAXATION.

(Karen points to furthest cat on cat scale in highlight journal)
THAT CAT LOOKS PRETTY STRESSED OUT, EH?

Uh-huh. (Nodding head in agreement)

HOW DO YOU USUALLY, DO YOU EVER FEEL STRESSED?

Ya, sometimes.

YA? HOW DO YOU FEEL INSIDE, HOW'S YOUR BODY FEEL?

Ummm, right now I kind of feel like around here. (indicating middle cat on cat scale)

LIKE THE IN-BETWEEN ONE?

Well, kind of in between those.

IN BETWEEN, AND A LITTLE RELAXED. SO YOU'RE FEELING PRETTY OK TODAY?

Ya.

GOOD. WELL, WHEN YOU ARE STRESSED, HOW DO YOU FEEL WHEN YOU ARE STRESSED?

Umm, kind of like, umm (points to end cat on cat scale).

YA, LIKE THAT CAT. DO YOU GET KINDOF LIKE...

Like I get all tensed up.

ALL TENSED UP, THAT'S A GOOD WAY TO PUT IT. AND DOES YOUR STOMACH SOMETIMES FEEL LIKE IT'S IN KNOTS SOME DAYS?

Not really. I kind of feel like, (makes agitated face, wrinkles it up, tenses body, sticks legs and arms out straight, tenses muscles)

YA (LAUGHING).

(Inaudible) Sometimes... I can't even move.

ALL RIGHT, AND DO YOU FEEL GOOD WHEN YOU FEEL LIKE THAT?

Umm, not really. Not really.

NOT REALLY? NO?

I just feel like all weird.

AND DO YOU FEEL BETTER WHEN YOU'RE A LITTLE BIT RELAXED?

Ya.

YA, HOW DO YOU FEEL WHEN YOU'RE RELAXED?

Kind of like calm and tired and you know like (shows sleepy face, eyes closed, relaxed body, slouches over, and relaxes limbs).
YES, THAT WAS A GOOD WAY TO SHOW IT. UMM, WELL HAVE YOU EVER SEEN SPAGHETTI BEFORE IT'S COOKED?

Ya.

WHAT'S IT LIKE?

Ya, ummm, they look like yellow things and they're long and thin.

AND WHAT DO THEY FEEL LIKE?

Umm, I haven't really felt them, but I think it's kind of hard.

YA, IT'S REALLY HARD.

And you can break it!

EXACTLY! YOU ARE EXACTLY RIGHT. NOW HOW ABOUT WHEN IT'S COOKED?

It looks like all soft and stringy and ...

WIGGLY.

And longer and a little bit thicker..

YES, YOU'RE RIGHT. SO NOW THE HARD SPAGHETTI IS KIND OF LIKE HOW YOU FEEL WHEN YOU'RE STRESSED, EH? IT'S LIKE THAT...

(Karen makes stressed face and physical postures, demonstrating being stressed)

AND THEN WHEN YOU RELAX, YOU FEEL A LITTLE BIT MORE LIKE THE SOFT SPAGHETTI LIKE YOU FEEL WIGGLY AND FLOPPY.

(Karen goes floppy, wiggly, demonstrating being relaxed)

EXACTLY. SO WHAT THE TAPE WE'RE GOING TO DO TODAY, IT HAS YOU WIGGLE YOUR TOES; IT HAS YOU WIGGLE YOUR FINGERS AND STUFF.

Like this? (Wiggling her fingers)

EXACTLY. YOU ARE EXACTLY RIGHT.

Hey, someone's standing out there. (Looking out window, at workman)

I THINK THEY'RE DOING WORK OUT THERE.

I saw someone go through the building and down there and ...

OH, REALLY? YA THEY MUST BE.

See? (Karen is still wiggling her fingers)

THAT'S PERFECT. YOU'RE DOING VERY WELL. AND THEN IT HAS YOU MAKE THEM FEEL RELAXED. IT HAS YOU WIGGLE THEM AND THEN IT HAS YOU MAKE THEM JUST FEEL KIND OF SOFT AND RELAXED AND JUST KIND OF SIT THERE.

Like this?

YA, AND IT TRIES TO MAKE YOU...

But not like, like this... (Demonstrating the difference between the two types of muscles: tense and relaxed)

EXACTLY AND THEN YOU GET ALL TENSED UP. YOU'RE EXACTLY RIGHT. NOW HOW ABOUT WE LISTEN TO THE TAPE NOW?

Ok.

NOW SOME PEOPLE LIKE TO SIT DOWN AND SOME PEOPLE LIKE TO LAY DOWN SO IT'S UP TO YOU.

I think I like to sit down.

OK, I'M A 'LYER' SO I'M GOING TO LAY DOWN, WELL I'M NOT A 'LYER' BUT I LIKE TO LAY DOWN, SO I'LL PROBABLY LYE.

Can you do this?

IF YOU'RE COMFORTABLE YOU CAN, THAT'S QUITE IMPRESSIVE YOU'RE VERY FLEXIBLE.

Audiotape activity - Spaghetti toes.

DID YOU WIGGLE?

Uh-huh, but it was kind of hard to keep my eyes closed.

WAS IT? THAT'S OK, THAT'S ALL RIGHT. WAS IT, WERE YOU ABLE TO, HOW ABOUT TRYING TO MAKE YOURSELF GO SOFT AND SLEEPY? WERE YOU ABLE TO DO THAT OR WAS IT A LITTLE BIT HARDER?

Umm ...

A LITTLE BIT HARDER, EH? IT TAKES, IT'S ONE OF THOSE THINGS, YOU KNOW HOW WHEN YOU, IF YOU'RE DOING GYMNASTICS OR SOMETHING, AND YOU'RE JUST LEARNING IT, AND YOU KIND OF HAVE TO PRACTICE IT. THIS IS ONE OF THOSE THINGS THAT YOU KIND OF HAVE TO PRACTICE TO GET GOOD AT. IT'S A SKILL, BUT IT'S A MENTAL SKILL, SO YOU HAVE TO PRACTICE TRYING TO MAKE - IF YOU THINK INTO YOUR FINGERS AND YOU THINK INTO YOUR FINGERS 'GO WARM AND SOFT', YOU CAN USUALLY GET THEM TO DO IT. BUT SOMETIMES IT TAKES A LITTLE PRACTICE. CAN YOU THINK OF ANY TIMES WHEN IT MIGHT BE GOOD TO KIND OF MAKE YOUR BODY GO SOFT AND WARM AND SLEEPY?

Umm, like having a needle or a dressing change.

YA, THAT'S GOOD. DO YOU THINK MAYBE, HOW ABOUT THIS WEEK IF YOU, FOR THIS WEEK AND NEXT WEEK BEFORE WE SEE EACH OTHER, WHENEVER YOU'RE HAVING A PROCEDURE IF YOU TRY IT? DOES THAT SOUND OK? (NO RESPONSE) NOT SO MUCH?

Well, I try it with my dressing change and I never can do it.

YOU NEVER CAN DO IT? NO?

I'm really scared.

YA, I BET. CAUSE IT HURTS?

It hurts. It stings.

WELL, WHAT IF THIS WEEK YOU TRY IT, EVEN FOR JUST A LITTLE BIT? AND MAYBE EVERY WEEK YOU'LL BE ABLE TO DO IT A LITTLE BIT MORE. EVEN IF BEFORE HAND WHEN YOU KNOW YOU'VE GOT TO DO IT, EVEN IF BEFORE HAND WHEN YOU START, YOU KNOW HOW SOMETIMES YOU START TO GET UPSET BEFORE? AND YOU HAVEN'T EVEN STARTED YET AND YOU'RE ALREADY SO UPSET, I DO THAT SOMETIMES. SOMETIMES I KNOW WHEN, I HAVE TO DO SOMETHING I DON'T LIKE, I'M NOT EVEN DOING IT YET AND I'M ALREADY UPSET. I DO THAT. DO YOU SOMETIMES DO THAT?

Sometimes.

YA. YOU THINK ABOUT IT BEFOREHAND AND IT MAKES YOU KIND OF UPSET. WELL HOW ABOUT WHEN YOU'RE JUST THINKING ABOUT IT BEFORE, WHEN YOU'RE COMING HERE IN THE MORNING, BEFORE THIS STARTS, JUST TRY AND MAKE YOURSELF FEEL A LITTLE BIT BETTER AND YOU CAN TRY AND THINK, "OK, KAREN ..."

My dad got a cavity yesterday.

YOUR DAD DID?

He went to the dentist.

OH, NO. DID THEY HAVE TO GRIND IT AND CLEAN IT?

Umm, I think they had to break it or something.

YA? AND LET THEM FILL IT? AND THEN I BET HE WAS PRETTY TENSED THEN TOO, WHEN THEY DID IT. WELL HE COULD HAVE USED SPAGHETTI TOES. HE COULD HAVE LEARNED HOW TO MAKE HIMSELF RELAX. BUT HOW ABOUT THIS WEEK IF YOU MAYBE GIVE IT A SHOT, AND THEN NEXT WEEK YOU CAN LET ME KNOW HOW IT WENT? *(Ok)* DOES THAT WORK? *(Nods)* AND YOU KNOW WHEN ELSE IS A GOOD TIME? SOMETIMES RIGHT BEFORE YOU GO TO SLEEP IT HELPS YOU GET TO SLEEP AT NIGHT IF YOU'RE LAYING IN BED AND YOU JUST LIKE...

I almost fell asleep on that tape.

THAT'S WHEN I DO IT USUALLY, IS TO TRY AND SLEEP AT NIGHT, AND TO MAKE MYSELF RELAX. SO MAYBE DURING THIS WEEK WHENEVER YOU FEEL ANY (INAUDIBLE) SO, HOW'S THAT SOUND MAYBE DURING THIS WEEK, WHENEVER YOU FEEL A LITTLE STRESSED, EVEN IF YOU'RE AT HOME AND YOU GET FRUSTRATED FOR ANY REASON AT ALL.

Ok.

OH, DON'T STOP IT YET. (Referring to tape recorder)

Ok.

IF YOU GET FRUSTRATED FOR ANY REASON AT ALL YOU CAN TRY AND MAKE YOURSELF GO ALL SOFT AND RELAXED. SOUND GOOD? JUST LIKE THAT. (Karen is demonstrating relaxed pose) EXACTLY. OK, NOW HOW ABOUT YOU GET YOUR BOOK HERE, NOW WHAT I DID WITH [ANOTHER PARTICIPANT] WAS I FOUND SOME PAGES I WANTED HER TO DO. I HAVE TO FIND A HIGHLIGHTER.

Crayons are kind of hard to color with.

I AGREE. WELL SEE I'M GONNA GET YOU TO COLOR THEM RIGHT NOW, I'M JUST GONNA ...

Are you gonna check which ones I should do?

YA, YOU CAN DO MORE THAN THE ONE'S THAT I CHECK, BUT IF YOU CAN AT LEAST DO THE ONES THAT I CHECK, THAT'D BE GOOD.

How about this one?

YEP. AND YOU KNOW WHAT? IF YOU EVER WANT TO COLOR THESE LITTLE GUYS YOU CAN COLOR THEM TO. HOW ABOUT THIS PAGE? AND SINCE I THINK YOU'RE GONNA HAVE SUCH A - DO YOU THINK YOU HAVE A HAPPY THING HAPPEN AT LEAST ONCE A DAY?

Probably.

SO WE SHOULD PROBABLY COLOR A FEW OF THESE SO THAT YOU CAN DRAW ME AS MANY AS YOU WANT, OK? OF ALL THE HAPPY STUFF THAT HAPPENS.

I have something like everyday that happens.

THAT'S AWESOME!

I know that everyday.

YA? GOOD. *(Ummhmm)* SO THEN NEXT WEEK YOU CAN TELL ME ABOUT THEM. HIGHLIGHTS FOR EVERYDAY, SO HOW ABOUT THIS ONE?

Maybe not (inaudible).

THINK SO? WELL HOW ABOUT IF I PICK A FEW MORE AND IF YOU GET A CHANCE TO DO THEM YOU CAN DO THEM...

Ok! My goals?

UMMHMM. DRAW OR WRITE SOMETHING YOU WILL DO THIS WEEK. DO YOU WANT TO DO THAT? OR DO YOU WANT TO SAVE THAT FOR ANOTHER WEEK?

Um, maybe another week cause I know I'm going riding with my dad another week.

OH, OK.

And my mom and I - I have a cousin that ... I'm close to ... (inaudible)

HOW ABOUT THIS? CAN YOU DO THESE ONES FOR ME? THESE ONES ARE ABOUT STRESS SO YOU CAN TELL ME.

Now can I turn this off yet?

YA, I THINK SO ... YA.

Final Interview – Karen's Mother

Italics - Karen's Mother, CAPITALS - JULIE

EITHER IN YOUR HOME, OR IN THE HOSPITAL, OR ANYWHERE ELSE, OR ANY OTHER ENVIRONMENTS THAT KAREN IS IN, CAN YOU IDENTIFY SOME OF THE THINGS, AND KIND OF DESCRIBE THE EVENTS THAT YOU FEEL ARE MOST STRESSFUL FOR HER?

Probably the hospital is still the place that would hold the most stress for her. She's still nervous about the mickey in her stomach, the feeding tube. It's not so bad now, she uses these techniques when they check the level of the fluid that's holding the thing in. But she knows it's upcoming when they have to change the whole device, so she actually asked me this morning she said, "Don't tell me, but the next time they check my...".
(Karen enters room)
"... balloon is that when they're going to change it?". Covering her ears. But I told her they're going to hold onto this one as long as they could. So that was more relaxing. But that, I think might be a little troublesome.

SHERYL SAID THAT TOO.

As for school, she visited last week for the first time. She hasn't been to school for a couple of years, so she was very nervous. I was there at the time, there was a pizza party and a movie afterword, and I was at the back of the class for maybe the first hour and then she stayed on her own for maybe a couple of hours. That went very well. She was, as I said, nervous at first but by the end she was very comfortable in that atmosphere. And then the environment at home I think it's a good one. She's, you know we're a very close family and we like to do all kinds of things together. [Her father] reads to her at night when I'm getting her feeding bottle together, so I don't think that there's any stress at home, unless... but you know I think it's pretty happy when you compare it to some. But I think all in all, like I said, some of the things she has difficulty with happen here.

YA, SOME OF THEM, FROM MY OWN OBSERVATIONS, A LOT OF THEM I THINK ARE THEY NEW ONES OR UNKNOWN PROCEDURES SOMETIMES?

Yes. Usually, yes. She's very comfortable with things that are weekly, and things that she's used to. But if they suggest they're going to do a new test or a little extra bloodwork, or you know something that she's not expecting about the mickey, and then that could be difficult. But she has learned to use her relaxation methods to help her through a lot. Things are definitely better.

ARE THERE TIMES THAT YOU THINK THAT SHE, OR CERTAIN THINGS THAT YOU FIND THAT SHE USES THEM [MENTAL SKILLS] MORE OFTEN THAN OTHERS, LIKE CERTAIN PROCEDURES OR ANYTHING?

I THINK WITH HER DRESSING CHANGE SHE'S JUST NATURALLY BECOME COMFORTABLE. IN THE BEGINNING I KNOW SHE WAS USING THEM, AND EVEN TODAY I BELIEVE IT WAS WHEN I WAS TAKING THE DRESSING OFF SHE TOLD ME SHE SHUT HER EYES, OR TOLD YOU. BUT THAT WAS SOMETHING, SHE IS HAVING A FEW THING IN HER MIND THAT CAN HELP HER OUT IF NEED BE. AND SHE HASN'T HAD BLOODWORK OUT OF HER ARM FOR AWHILE. SO IF SHE HEARD LATER ON THAT SHE HAD TO HAVE BLOODWORK OUT OF HER ARM, OR IF WE CAME IN NEXT WEDNESDAY AND THEY SAID YOU KNOW IT'S PERIPHERALLY TODAY, SHE PROBABLY WOULDN'T BE VERY HAPPY.

YA.

And so we just have to take it as it comes.

ALL RIGHT, AND WHAT ARE THE THINGS THAT YOU FIND THAT SHE TRIES TO USE DURING PROCEDURES, OR WHAT HAVE YOU NOTICED, ANY SPECIFIC THINGS THAT SHE DOES TO TRY AND MAKE HERSELF FEEL BETTER?

Well, I find she talks a lot and convinces herself, "You know this is to make me better and it's all part of it." And I find she breathes a bit to relax. She takes a deep breath before certain things are done and I find that probably is what's most noticeable that she uses. But I think she just does her best to try and relax because she's always saying you know, "It'll go better. It won't hurt as much if I relax." So she knows that she says that out loud.

GOOD, AND DO YOU FEEL THAT THIS, WE'VE KIND OF TALKED ABOUT, BUT I GUESS IT'S A SUMMARY QUESTION. DO YOU FEEL THAT IT HAS HELPED SHERYL DOING THE ACTIVITIES AND OVER THE COURSE OF THE PROGRAM THAT SHE HAS IMPROVED WITH THINGS?

Oh definitely. She has always been fearful of many of the things around and I really find the exercises and just having all the methods that you've taught her has definitely made a change during, you know, the dressing changes, probably a quarter of the time they used to take. And even the bloodwork when it became routine that became easier as well. So I think her being taught to concentrate on how to relax and to deal with all these things, and to focus in on what's being done and why, I think it's made a great difference. Definitely.

GOOD, NOW DURING THESE SITUATIONS IF THERE ARE EVER TIMES WHEN SHE WAS UPSET, DID YOU EVER TRY ANYTHING TO HELP HER FEEL BETTER? AND IF SO, WHAT THINGS WOULD YOU DO OR ENCOURAGE HER - WHAT KIND OF THINGS WOULD YOU SAY?

Normally I try and talk with her and remind her that she should try to think about what you had taught her and try to relax. I must admit that sometimes it can be, how do I say this? A little stressful on myself. And I must admit that sometimes, "Come on Karen. You can do this. You've done it many times." And then after I feel badly for getting after her and I try to remind myself to focus in and sort of reflect, if it were me in the bed and to remind myself how much Karen has been through. So I try my darndest, but it's hard you know, being human, 'cause you get well, "This isn't any big deal." Because sometimes it's not. If it's something that it doesn't hurt, it's just the fact that she has to go through with it, if she doesn't want to do it right then, sometimes. But normally when it is something that I know is painful I just try and coax her along, and be very understanding, and be a mom.

Karen (in the background) - Ya, right!

Julie to Karen - SHE JUST STRAPS YOU DOWN DOESN'T SHE?

Mother - *Ya, I hold her down. Have I ever held you down?*

Karen - Ya.

Mother - *Oh? When? The first time the mickey was changed that was along time ago, but I don't do that anymore. I don't have to. 'Cause you do it on your own.*

Karen - Well, ya.

Mother - *Well, once. That was a year ago my sweets.*

WERE THERE ANY SITUATIONS OUTSIDE THE HOSPITAL WHERE YOU EVER SAW SHERYL USE ANY OF THE SKILLS?

She was having injections in the home after her chemo, when her immune system was really low, to get her bone marrow producing the blood cells again. She'd have to use her breathing techniques and just really concentrate and you know go off in her own little world. And she'd refer to changing her channels on the TV. And, so definitely...
(Karen makes a face in the background)
Mother to Karen - *You told mom that your mind was a television, you could change the channels. So that was really important for when she was having the injections in the home. And whenever I get upset she always tells me, "Mom". And it's cute, because that shows me what she's doing. Because she'll pat me on the back and she'll say, "Mom can I give you a hug?", and "Mom, just relax and don't worry about it." So she's always reflecting to me as well when I get all upset.*

SHE'S ENCOURAGING YOU.

Ya, exactly. So what she's learned is shown that way too.

GOOD. ALL RIGHT. AND NOW WE DID HIGHLIGHTS IN THE PROGRAM OVER THE PAST COUPLE OF MONTHS. AND DO YOU THINK BY HAVING SHERYL COLOR HER HIGHLIGHTS, OR HAVING HER EVERY WEEK COMING AND TALKING TO ME, DO YOU THINK THAT IT HELPED HER AT ALL TO NOTICE MORE OF HER HIGHLIGHTS OR IDENTIFY MORE OF THEM SINCE THE PROGRAM STARTED?

I think, through out her treatment her dad and I have tried very hard to keep her busy doing activities that she loves to do. And when you look at that book you can see what we were busy doing with her by the week. One thing, we took her pony riding several times and there was a time there ... So I think that she was proud to come in and be able to tell you, you know, that she went to a movie, or she went pony riding with her cousins, or went traveling, so it was excitement for her to be able to come in and report to you what she had done the past week. So definitely her drawing about what she was doing sort of reinforced, I think, the happy times on top of all the treatment. Definitely seeing you was an asset.

AND DID SHERYL INDICATE THAT SHE ENJOYED THE PROGRAM AND DOING SESSIONS?

Ummhmm. Yes, she enjoyed working in that booklet and she really did look forward to coming in and was hoping to, you know, be able to see you and enjoyed being with [her friend in the program] as well. As a threesome. And so definitely, you've worked wonders with her.

SHE'S BEEN FUN TO WORK WITH. BECAUSE YOU'RE A CHARACTER, THAT'S WHY YOU'RE FUN TO WORK WITH. (Comment directed toward Karen)

Well she's talked about you often and I think she knows that it's been very helpful, what you've taught her.

GOOD, I HOPE SO. DO YOU THINK THAT SHERYL IMMEDIATELY STARTED USING ACTIVITIES AND LIKED IT? OR DID IT TAKE SOME TIME BEFORE SHE STARTED USING THEM?

Well, I think if she had, I noticed if you saw her before she had a procedure done, it seemed to help more if it was fresh in her mind. But I think the first thing you taught her was Spaghetti Toes and that first day she used that, I believe to have bloodwork done and it was helpful.

GOOD, SO IS THERE ANYTHING THAT YOU WOULD LIKE TO ADD TO OUR DISCUSSION ABOUT THE PROGRAM, THIS IS MY OPEN-ENDED...

Well I think having you here has made a difference. All of the kids here are faced with major challenges and I think with even the parents getting into their own little worlds, trying to handle everything and them getting stressed as well it's not always easy for the parents to remember all the things they need to be doing...

TAPE CUTS OUT.

Karen's mother finished her sentence by saying that it's difficult for parents to remember how to help their kids, and what their kids can do. So this program reinforces what they can do to help. She found it very important for all the kids on the unit and hoped they would find a way to continue offering the program to children on the oncology unit.

Appendix J

Overview: Weekly Activity Record - Case Study #1 Vince

1	Explanation of highlights, small joys, things that make you happy, things you like, things that make you laugh.	**Spaghetti Toes** Muscle relaxation exercise.	**Relaxation** - "Like relaxing in the pool on a rubber chair." **Stress** - "School.", "Needles in the leg" **Highlight Journal** - Described journal activities and concept of highlights. **Muscle Relaxation** - Described difference between tense/stiff muscles and soft/relaxed muscles, learned how to make muscles like soft spaghetti "Not so cracky it's all wobbly."	Learned first skill, **Spaghetti Toes.**
2	1. Watching Go-Go Gadget movie with dad 2. Cannonball in the pool **Sources of Fear** - drew in journal, "Hands cut-off", "Nightmares" **Feeling Stressed** - drew in journal, heart beating, blood rushing around.	**Jelly Belly** Diaphragm breathing exercise. **Happy Highlights**, explains concept of highlights	**Relaxed Breathing** - Breathing slowly and deeply, all the way into your tummy. - discussed Vince's sources of fear (nightmares - "I'm scared ... they might come for me at night") and how he feels when stressed (heart beats rapidly, blood rushing around body)	- used **Spaghetti Toes** prior to sleep. "I fell asleep."
3	1. Pokemon 2. Funny dream about pencils. 3. Kite race with his sister. 4. Watching TV on new TV.	**Changing Channels** Positive focusing/ refocusing exercise.	**Changing Channels** - Changing scary channels to happy channels and changing scary images to funny images, "I could make him [T-rex] into a clown."	- used **Spaghetti Toes** and **Jelly Belly** prior to sleep. "Wiggle my toes, did Jelly Belly and then I fell asleep."
4	1. Playing with a friend 2. Swimming 3. Going to the Coliseum in future.	**Animal Sounds** Sound listening activity, auditory focusing.	**Focusing** - Concept of paying attention with ears and eyes, "Focus on your work." **Highlights** - Trying to think of highlights before sleep, "things that you like to do."	- Didn't feel well at school, used **Jelly Belly** breathing. - Used **Changing Channels** to focus on school, "My channel was channeled on school.."
5	1. Rescuing a lost dog. 2. Making paper airplanes. 3. Remembering going on a house boat. 4. Going to the Coliseum in the future. 5. Watching Jurassic Park.	**Rainbows** Imagery activity, imagining the bodies healing powers.	**Rainbow Imagery/Being Strong**- (Bodies healing powers) "Wherever they're hurt they just rush more blood than the rest of my body. It goes to help and get rid of the infections and stuff."	- Used **Spaghetti Toes** and **Jelly Belly** prior to sleep. - Thought about his highlight before sleeping, "Jurassic Park."
6	1. Parachute man. 2. Winning a prize in the 'Claw Game'. **Laughing** - Jughead Joe, drew in journal **Experience with Stress** - being pushed down a hill, in journal	**Special Place Relaxation** Imagery activity, imagining a place where you feel safe, calm, happy	**Being Strong** - "... velocoraptor he has like big guns ... stegosaurus, they're so hard to kill..." (highlight journal drawing) **Special Place Relaxation** - Imagining being in a special place, "A special place called Injun, a dinosaur reservation, only plant eaters ... you can feed them." **Sources of Stress** - "Somebody pushed me."	- Used skills prior to treatment procedures, i.e. bloodwork, "**Jelly Belly**". - pictured himself **Being Strong**
7	1. Walking his dog. 2. Doing school work with mom. 3. Playing detective with detective glasses	**Standing Muscle Relaxation** Muscle relaxation activity you do while standing	- **General Skill Use**, situations currently applying skills in, situations he feels skills would be useful in (Did not initially have a room, session took place in hallway, eventually found an available room)	- **Changing Channels** during LP, "I wasn't sick... I thought of something else a lot of the time." - "Today whenever I got [treatment] I used my breathing." (**Jelly Belly**) - "Whenever I try and get to sleep at night".
8	1. Thanksgiving (upcoming) 2. Playing baseball at recess	**Star Trac** Imagery activity, imagining a space journey	**Imagery** - Using positive images, i.e., Star Trac, space voyage imagery during stressful/negative experiences, "[The star] kept changing colours ... red, that's the last colour until I crashed it."	- Used **Jelly Belly**, after having a nightmare, "Taking a deep breath. I tried to breathe."
9	1. Eating turkey at Thanksgiving 2. Renting a video game 3. Collecting Beanie Babies (something that makes him feel good)	**Echo Lake** Positive Self-Talk Activity	**Positive Self-Talk** - Positive statements children can make to themselves to feel good, confident, and ready to do anything. **Negative Self-Talk** - Discussed methods to alter negative self-statements to positive statements, i.e., "I'm gonna fail" ▸ "Try, Try, Try!"	- Used **Spaghetti Toes** and **Jelly Belly** when trying to get to sleep, "Wiggle your toes like all through your whole body." - Suggested he could use skills, when he "gets stressed in math.."

10	1. Hot Potato - cooperative game at hospital 2. Hiking in cubs 3. Saw a flying saucer 4. Doing a card trick 5. Locked out of his house with his sister 6. Playing clue with his sister	Unbelievable Activity teaching how to focus on the positive and put aside worries	**Positive Thinking** - Worked on positive thinking sheets in journal, identifying positive and negative statements, learning to adapt negative statements, "I could do this", "I feel good by petting my dog, giving him a bath..." **Treeing It** - putting worries aside in your mind, i.e. focusing on positive during stressful experiences, leaving worries at the door, Vince "thought it was weird a little."	- Used "all of them ... in the middle of the day ... I got worried." - "I sleep by myself ... [I use] my exercises." (Jelly Belly)
11	1. Dressing up as Zoro 2. Staying home from school when sick 3. Going on a trip 4. Getting two new video games	**Quiet Lake** Relaxing imagery tape of lying beside a calm, quiet lake	- Vince was feeling sick this week and initially requested we not have a regular session, asked to listen to a calm activity. - Listening to tape helped Vince feel much better, discussed his weekly highlights and upcoming treatments, i.e., the dentist.	- Used relaxation skills while listening to **Quiet Lake** to overcome feelings of nausea.
12	1. Trick or Treating 2. Sword fight with a friend 3. Sleep-over at a friend's house 4. Upcoming - getting a Pokemon poster	Unable to do activity today, interrupted for treatment	**Positive Thoughts** - "Not thinking of monsters, not thinking of ghosts..." **General Improvements** - sleep patterns and school attendance	- Improvements in level of fear and stress before sleep, "I'm not scared anymore!"
13	1. Got a Pokemon poster 2. Had pizza *** difficulty identifying highlights this week	**Laughing** Listening activity, tape of child laughing	**Sleep Patterns** - Difficulty sleeping, discussed techniques used prior to sleeping	- Used skills prior to sleeping night before when couldn't get to sleep, "I tried all the exercises, but they didn't work."

***NOTE - Vince had 13 weeks in the program as we were unable to do an activity tape during Week 12

Appendix K

Overview: Weekly Activity Record - Case Study #2 Jacob

1 (Trial)	Explanation of highlights, small joys, things that make you happy, things you like, things that make you laugh.	**Spaghetti Toes** Muscle relaxation exercise.	**Relaxation** - "That you're going to rest, like in the middle of the day." **Stress** - Jacob states that he has little stress, "Well, [I'm] never VERY stressed." **Highlight Journal** - "I don't want to take a book." **Muscle Relaxation** - Describes difference between tense muscles and relaxed muscles, using spaghetti, "they're like hard sticks and you can break them and then you put them in the pot ... then they start to melt."	Learned first skill **Spaghetti Toes**, learned how to make muscles like soft spaghetti.
2	1. Going to a birthday party, eating cake 2. Going to a hockey game 3. Upcoming camping trip with family - expresses difficulty remembering without a journal, "Well I don't take the book usually so that's all I can think of."	**Jelly Belly** Diaphragm breathing exercise.	**Jelly Belly** (Diaphragm Breathing) - Breathing slowly and deeply, all the way into your tummy. - Jacob learns proper breathing technique quickly and understands difference between relaxed breathing, "when you're breathing in air your stomach will go up," and upset breathing, which he describes as "hyperventilating." - continues to reject book, "I didn't want to take it", describes book as "work."	- Did not use **Spaghetti Toes**, "I think I'll never use **Spaghetti Toes**, I think I'll only use **Spaghetti Toes** when I'm a grandpa." - Asks if we can "light candles and ... start to levitate" during **Jelly Belly**.
3	1. Going to North Bay 2. Having a friend over	**Changing Channels** Positive focusing/ refocusing exercise.	**Changing Channels** - Describes event that makes him happy, "it's my birthday ... I get to go wherever I want and I get everything first." - Asks, "Can we play Nintendo now? ... I'd like to change my channel to Nintendo."	- Describes **Jelly Belly** as "a bit boring though." - Indicates prior use, "I already know how to breathe." - Uses **Jelly Belly** "only when I have my leg needles, I hate those needles." - Does not attempt Spaghetti Toes, "I don't usually use **Spaghetti Toes**."
4	- Describes his week as "boring ... I didn't have any highlights." - "Went to school but that wasn't a highlight." - "I didn't have any highlights when I got home." - "No highlights yet today."	**Animal Sounds** Sound listening activity, auditory focusing.	**Focusing** - Discussed concept of paying attention with ears and eyes. **Highlights** - Discussed concept of highlights being small, positive events in each day, not BIG events.	- No report of skill use during the week. - Jacob is extremely distracted today and having difficulty focusing on skills and conversation.
5	1. Identifies painful highlight experience, later states, "Well that wasn't really a highlight, discussed concept of "lowlights." 2. Sleeping in 3. Upcoming highlight, playing bingo at school * ends with, "I don't have any highlights."	**Jelly Belly** Diaphragm breathing exercise. (by request)	**Jelly Belly** - Jacob describes himself as having a "*Real* Jelly Belly." - Discussed importance of highlight journal with Jacob's mother, agreed to let her try and encourage journal use with Jacob.	- Requests "**Jelly Belly, Jelly Belly, Jelly Belly!**". - Did not use any skills at home this week, "I don't really need to."
6	- spontaneously recounts highlights before session 1. Seeing a movie 2. Getting two new Nintendo games	**One Breath Relaxation** - diaphragm breathing and positive thinking activity, teaches quick relaxation	**Relaxed Breathing** - Use of breathing for relaxation, specifically during treatments such as IM's, described his use, "it [my stomach] always goes up and down, up and down." **Sources of stress** - "I'm not nervous for everything, I'm nervous for something really scary." - Asks to end session, "Can I go now?".	- Used **Jelly Belly** prior to treatment, "I did Jelly Belly that's the best part." - States, "I use this a lot" and demonstrates deep breathing technique.

7	- recounts highlights spontaneously before session again 1. Won two chocolate bars in bingo at school 2. Had a friend over for a visit on the week-end 3. Started Cub's last week, going to Cub's tonight * Mother encouraged highlights, "My mom told me to tell you some this morning."	**Special Place Relaxation** Imagery activity, imagining a place where you feel safe, calm, happy	- Discussed his least favourite procedures, IM's, "I don't like getting it 'cause it hurts a lot." **Special Place Relaxation** - Jacob had a great deal of difficulty deciding on an image he would like to use, discussed Disney Land, rides at Wonderland, being on a boat, and "LaLa Land." - Agreed to try **Special Place Relaxation** but not until next week, "I'll try it next week when I have a needle." - Discusses how emotions affect him physically, "Sometimes when I think of things I shake."	- Uses **Jelly Belly** during leg needles, stating, "Well I always do the **Jelly Belly** breathing, but I always do that forever." - Does not really use **Changing Channels**, "I tried it once, I usually don't try that." - States, "I don't need to think [use skills] on bloodwork 'cause it doesn't bother me that much at all."
8	- continues spontaneous highlight recollections 1. Had french fries 2. Driving with dad & friend 3. Went to a restaurant with grandfather 4. Upcoming, Halloween 5. Upcoming, Thanksgiving 6. Upcoming, eating bacon at breakfast	**Muscle Relaxation** Activity encouraging muscle relaxation.	- Jacob reveals that he does not mind coming to the hospital and sometimes has fun when he is here. - Jacob selects relaxation activity, "I think I'd rather do the relaxation one", over imagery activity. - Understands intent of the audiotapes, "to help me relax my body."	- Jacob was sick during the week, "I got a headache ... my bones are sore", used **Changing Channels** during this situation, "I thought of something else when I lied in my parents bed ... lying on the beach, the Tower of Terror, eating pizza." - Indicates potential future use, "Well I'll try it when I go into my bed next time."
9	Did not look for any highlights this week, identified only one; 1. Upcoming, "My birthday ... my mom's gonna bake a cake."	**Jelly Belly** Diaphragm breathing exercise. (by request)	- Jacob describes a number of positive events in his week, "I went to my Nanny's Friday, I went to my Grandma's, we had to have supper at my Godmother's house", does not identify these as highlights. - Discussed concept that in order to find highlights you have to look for them.	- States, "Well I hardly used [mental skills]." -Later states, "Well I always do the **Jelly Belly**, everyone does it" and "I always, sometimes, use my **Changing Channels**."
10	- States, "I didn't have any highlights this week ... but I have lowlights with that stomachache." - Later states, "OK, I think I had some highlights." 1. Not going to school 2. Upcoming, bingo 3. Won a chocolate bar 4. Watched a movie	**Quiet Lake** Relaxing imagery tape of lying beside a calm, quiet lake	- Discussed use of **Special Place Relaxation** and how **Quiet Lake** can be used in the same manner, imagining yourself being calm during procedures such as LP's. - Jacob describes how he feels before LP's, "I get really hungry ... I don't get worried." - Discussed concept of highlights being small joys.	- During a terrible stomach ache which brought him to Emergency Jacob reports, "I used the **Changing Channels**, **Jelly Belly**. *Real* **Jelly Belly**."
11	1. Won 10 stickers 2. Got something at the Royal Canadian Mint 3. Upcoming, bingo * started a game at this point to encourage Jacob to identify more highlights: 4. Had a friend sleep-over 5. Upcoming, birthday 6. Upcoming, Trick-or-Treating on Halloween 7. Upcoming, going to a Halloween party	**Umbalakiki** Activity teaching how to focus on the positive and put aside worries	- Discussed concept of worry, "sometimes I worry about stuff." **Treeing It** - putting worries aside in your mind, i.e. focusing on positive during stressful experiences, leaving worries at the door, Jacob's response to activity, "Well it's kind of weird touching a tree and getting your bad feeling to go away." - Asked, "Can I go carve my pumpkin now?". - Jacob is learning not only to identify highlights but also to help increase the number of highlights he experiences, "I make them highlights."	- Jacob describes continued skill use, "Well I'm using that **Changing Channels** and thinking of different things ... like thinking what we're going to do on my birthday."
12	1. Went to a hockey game 2. Upcoming, going to another hockey game 3. Upcoming, going to the Deifenbunker 4. Going to several Halloween parties 5. Upcoming, his birthday	**Relaxed Breathing,** activity that encourages use of relaxed breathing skills and positive self-talk	- Jacob was very excited for his upcoming birthday and wanted to continue his plans with his mother, therefore he was resistant to participating today, "I'll only do it if it's a short one." - Requested either Jelly Belly or Umbalakiki.	- Jacob declares, "I hardly need to use [mental skills]." - H was extremely distracted today by his upcoming birthday and birthday presents.

Appendix L

Weekly Feeling Great Program Activity Record - Case Study #3 Karen

Week	Handout	Activity	Key Discussion Points	Comments
1	Explanation of highlights, small joys, things that make you happy, things you like, things that make you laugh, "Like your favourite things." **Highlight Journal** - Described journal activities and concept of highlights.	**Spaghetti Toes** Muscle relaxation exercise.	**Relaxation** - description, "Kindof like calm & tired." "I try it with my dressing change, I never can do it." **Stress** - "I get all tensed up", feels like 'stressed cat' during dressing change **Muscle Relaxation** - Described difference between tense/stiff muscles and soft/relaxed muscles, learned how to make muscles like soft spaghetti.	Learned first skill, **Spaghetti Toes.**
2	1. Going to a friend's party. 2. Walking a dog. 3. Only having one MRI.	**Animal Sounds** Sound listening activity, auditory focusing. **Magic Wands** Healing imagery.	**Focusing** - Concept of paying attention with ears and eyes, Karen imitated horse sounds. **Healing Imagery** - Concept of bodies "magic powers" to heal itself, Karen used imaginary wand during tape.	- Used first skill, **Spaghetti Toes** immediately following first session during blood work, procedure went much more smoothly.
3	• difficulty identifying highlights, "Today wasn't a highlight ... or yesterday...." 1. Taught a child to make a craft.	**Jelly Belly** Diaphragm breathing exercise.	**Relaxed Breathing** - Breathing slowly and deeply, all the way into your tummy, "I think I like **Spaghetti Toes** ... 'cause **Jelly Belly's** kind of hard for me."	- Unable to use skills during mickey change, combination of being too scared and effect of waking sedation.
4	• still no journal use, "I had a lot of homework" 1. Getting out of the hospital after 15 day admission 2. Told lots of people how brave she was during mickey change	**Changing Channels** Positive focusing/ refocusing exercise.	**Changing Channels** - Changing scary/worried channels to happy channels, "Like if I have a nightmare, like just think of something that you love."	- currently uses **Changing Channels**, "I always like, think of something, like I think of horses."
5	Drew horse on cover of highlight journal (described it as her **Special Place**)	**Quiet Lake** Relaxing imagery of a quiet lake **Special Place Relaxation** Imagery activity, imagining a safe, calm, happy place	**Special Place Relaxation** - Imagining being in a special place, Karen described her Special Place as a sunny field, riding a horse, with a lake and a big red barn.	- Used **Changing Channels** during her dressing change to help her calm down. - Told her mother to **Change her Channels** when she had a stomach ache. - Used **Jelly Belly** breathing and **Changing Channels** during her GCSF needle to stay calm. - Used **Quiet Lake** relaxation to fall asleep after GCSF needle. - Mom states, "She's come along way," nurse agrees.
6	1 & 2. Horse back riding on a horse ranch - **My Goal** in journal, walking two horses - **Being Nice to an Animal** in journal, drew herself feeding a horse - **My Special Place** in journal, riding a horse	**Butterfly Flutterby** Imagery activity, imaging the flight of a butterfly	**Imagery** - Use of imagery during stressful procedures, times when she has bad thoughts. **Being Strong** - using images to make yourself feel strong, Karen described her image as when she is pulling a horse by its reigns - asked "Why don't we learn this when we start coming here for treatment?".	- Reported using skills less as she isn't scared anymore and doesn't feel like she needs them as much as she used to. - Imagined a purple butterfly with pink spots landing on a blue flower during **Butterfly Flutterby.** - Mom reports program is "Fantastic."

7	* difficulty finding highlights while in isolation 1. Visit from NHL hockey player while in isolation 2. Upcoming, horseback riding at cousins	**Echo Lake,** Positive Self-Talk Activity	**Positive Self-Talk/Thinking** - "I know you can do it", "Think a happy thought." **Highlights** - Importance of looking for highlights even in difficult situations.	- changing negative thoughts and statements to positive thoughts - "I was really scared today because last time is when [I] bruised", was able to feel a little calmer and procedure was "Not so bad."
8	1. Spending time with cousins 2. Playing with kittens on her cousins farm 3. Trick-or-treating at the hospital	**Relaxed Breathing,** Diaphragm breathing activity	**Relaxed Breathing** - importance of taking slow, deep breaths during upcoming difficult procedures - very nervous for flu shot in leg, discussed potential skills she could use, i.e., **Changing Channels, Spaghetti Toes, Relaxed Breathing**	- Relaxes during mickey checks, "I'm fine with that now, because it doesn't' hurt anymore."
9	1. Horse back riding. 2. Playing with her cousins 3. Sleep over with cousins **Stress Control,** in journal, drew experience during flu shot in leg	**Laughing/Sound Listening,** Listening activity, child laughing, tape of different sounds	- Karen had difficulty with previous weeks treatment, flu shot in leg, discussed how could have coped better. **Imagery** - Imagined images corresponding to sounds on the tape, "Like my cat going, like getting fur all over me..."	- Unable to use skills during flu shot, "I've never really had a needle in my leg before so I was really scared." - Large improvements in coping during mickey checks noted by health care provider.
10	1. Backstreet Boys concert 2. Horseback riding. 3. Past highlight, visit from an NHL hockey player 4. Being done with needle in leg 5. Hair is growing - drew pictures of her **Favourite Things/ Things that Make You Feel Good**	**Focusing Through Distraction (Umbelaklid)** Activity teaching how to focus on the positive and put aside worries	**Umbelaklid** - putting worries aside, freeing them, "flushing them", especially with regard to the death of another child, "I had one that I didn't really have a highlight of because one of the little cancer patients was very, very, very sick and they tried everything they could but he died."	- Used **focusing** when horse back riding, "like you have to hold on tight, like even if you put pressure on the horse, like you still bounce ... it's really hard."
11	1. Doing well in school work.	**Rainbows,** Activity discussing bodies healing powers, using imagery to feel stronger and healthier	**Rainbows/Being Strong** - importance of focusing on bodies strength and believing in ability to get well - Discussed upcoming tests that were creating stress, bone scan, MRI, cat scan.	- Used **Animal Sounds** and **Changing Channels** during dressing change, thinks about different animals, growls like a dog and howls like a wolf.
12	(Too distracted to report highlights)	**Spaghetti Toes** Muscle relaxation exercise.	**Muscle Relaxation** - Importance of practicing skills, attempting to relax muscles during stressful procedures.	- Difficulty during bone scan needle, very nervous, couldn't remember what to do, "It doesn't really work for me anymore ... I can't get my mind on it." - Did **Spaghetti Toes,** "I don't tell myself, but I just like make them go soft."

Appendix M

Overview: Weekly Activity Record - Case Study #4 Kim

Week	Highlights	Activity	Key Discussion Points	Skills Learned
1	Explanation of highlights, small joys, things that make you happy, things you like, things that make you laugh.	**Spaghetti Toes** Muscle relaxation exercise.	**Relaxation** - "To relax, to sleep and relax and look at TV. To relax on the couch and you can watch TV." **Stress** - "When there's somebody I don't know in the [medical] clinic and they don't know how it can be done [without hurting]. And it hurts [when they give me treatment]." **Highlight Journal** - Described journal activities and concept of highlights. **Muscle Relaxation** - Described difference between tense/stiff muscles and soft/relaxed muscles, learned how to make muscles like soft spaghetti.	Learned first skill, **Spaghetti Toes.**
2	No highlight journal entries 1. Played with a lot of friends this week	**Jelly Belly** Diaphragm breathing exercise. **Happy Highlights**, explains concept of highlights	**Relaxed Breathing** - Breathing slowly and deeply, all the way into your tummy, Kim understood this concept quickly. - Described a stressful experience when her brother hit her in the portocath, she started breathing really shallow and fast, said, "It doesn't feel good when you breathe like that ... it hurts." - Described a time when she used relaxed breathing, "One time I was really upset and I did say, 'Kim, relax'. And I was OK."	- Tried **Spaghetti Toes**, "a little bit", but it was unsuccessful as, "my brother was jumping on me."
3	- No journal use, mom said they were very busy this week. - Kim explained why she did not use her journal, "Because I have a pool so when it's hot I go swimming ... and now it's difficult to do some because I'm at school." - No highlights	**Changing Channels** Positive focusing/ refocusing exercise.	**Changing Channels** - Changing scary channels to happy channels and changing scary images to funny images. - Kim explained how she doesn't want to think of scary things but sometimes they just come into her mind and she can't get them out, "It's not me". - Described highlights as, "Highlight is when something makes you happy."	- During her IM her mom encouraged her to use **Spaghetti Toes**, "Today ... when I had my IM ... my mom went '**Spaghetti Toes.**'"
4	Drew a journal entry of **Being Relaxed** - "It's a bath, and it's me, and it's really hot ... All warm." 1. Playing baseball and hockey with her brother	**Rainbows** Imagery activity, imagining the bodies healing powers.	**Rainbow Imagery/Being Strong**- (Bodies healing powers) Discussed the concept of healing and being strong. - Described herself as being strong when she carries her brother, "I can put him on my [arms] in the pool, I can take him on my back."	- Did not use any skills from the program, however, explained that she is, "Good at relaxing," and described how she relaxes during IM's, "I close my eyes and then I relax."
5	- No highlights, "Cause I was in bed all day [sick]." - was excited to colour in journal during session	**Animal Sounds** Sound listening activity, auditory focusing. **Echo Lake** Positive Self-Talk Activity	**Focusing** - Concept of paying attention with ears and eyes, enjoyed Animal Sounds, "I got to say, Bark, Bark, Moo!" **Positive Self-Talk** - Positive statements children can make to themselves to feel good, confident, and ready to do anything. **Negative Self-Talk** - Discussed methods to alter negative self-statements to positive statements. - Had difficulty at first, saying the positive statements were "not real", later described several positive characteristics, i.e., "I am good in the pool."	- Pictured herself **Being Strong**, carrying her brother on her back. - She suggested she could make herself feel better before tests by "doing **Spaghetti [Toes].**"
6	1. Birthday gifts 2. Gymnastics at school 3. Playing with friends 4. Watching her brothers soccer game 5. Found an early birthday present	Continued doing **Positive Thinking** and **Positive Self-Talk** activities in journal.	**Positive Thoughts/Self-Talk** - Felt "great", when she included an extra little girl in her game, so the girl was not left alone. - decided to say something positive to her friend, "You're my friend." - was extremely happy today, "That's really happy ... When it's your birthday you feel like this", indicated a child jumping for joy on the kidscale.	- improved her ability to find positive events in her environment and positive feelings towards herself and others

Week	Highlights	Activity	Key Points and Issues	Skills Used
7	1. Bowling with friends for her birthday 2. Ice cream cake 3. Had turkey on Thanksgiving 4. Played with a little cousin	**Special Place Relaxation** Imagery activity, imagining a safe, calm, happy place	**Special Place** - Described her **Special Place** and drew it in her journal, Disneyland, "Ate some ice cream ... go in the pool ... we did go on Dumbo, Peter Pan, and it's a Small World." - continued with **Positive Thinking** sheets, said she was a good bowler, this made her feel like the happiest child on the kidscale.	- identified a positive statement she could make to herself, "I'm gonna have a good LP." - Thinks of positive things during LP's, such as "presents."
8	No highlights	**Laughing** Listening activity, tape of child laughing	- discussed the methods/skills she uses during invasive procedures - suggested times she could use mental skills from the program	- relaxes during IM's, "When you lie down it's more comfortable [If you sit] it's hard in the muscle". - Described how he makes her leg like "jello", not like "macaroni" during needles.
9	Had no highlights, gave her a "highlight box"	**Umbalakiki** Activity teaching positive focus and putting aside worries, **Positive Thinking** sheets	**Treeing It** - Putting worries aside in your mind, i.e. focusing on positive during stressful experiences, leaving worries at the door. - asked to colour in her journal today	- Explained why she doesn't do weekly journal entries, "Sometimes I'm scared because I like it better when we make it here than at home."
10	1. Eating donuts 2. Played outside with her brother	**Sound Listening** - Listening activity tape of different sounds	- enthusiastic today about cooperating, asked for a fun tape, "A fun one! Like **Animal Sounds!**" - Discussed use of relaxation techniques and ideas for use of mental skills. - **Auditory Focusing**, listening with your ears and focusing on the sounds.	- Goes for treatment all by herself, without her mother. - Described how she prefers to receive treatment, "When they say go, they don't count, they just put [the needle] in."
11	"I had a lot of highlights." 1. Movies 2. Visited grandfather 3. Visited a teacher 4. Christmas party 5. Went to see Santa 6. Got a reindeer 7. Slept at Grandma's house	Unable to do an audiotape activity today. Did not have a room. Session took place in the hospital hallway.	- Discussed all her different treatments, IM's, LP's, accessing her port. - Described how she does most procedures on her own, uses her own skills during these procedures.	- Described how she continues to cope during treatments, "I do it by myself. When they say go, to just poke, but I don't count. I just close my eyes."
12	1. Played a game at the hospital 2. Visited her grandma 3. Played with her brother 4. Received a gift	**Sound Listening 2** - Listening activity tape of different sounds	- Very brief session as she was finished treatment and mom was ready to leave.	- Said she had no stress this week and was not nervous for her treatments.

Appendix N

Definitions of Relevant Medical Terms

ALL - Acute Lymphoblastic Leukemia - An acute form of leukemia occurring predominantly in children, characterized by the unrestrained production of immature lymphoblasts (a type of white cell) in the blood forming tissues, particularly the bone marrow, spleen and lymph nodes.

Bloodwork (Blood Draws) - Blood is usually drawn from the large vein on the inside of the elbow. First, a constricting band is put above the site to make the veins larger and easier to see and feel. The vein is felt by the technician, the areas is cleaned, and the needle is inserted.

Broviac (Hickman Catheter) - An indwelling catheter that has one end of the tubing in the heart and the other end outside the body. (See indwelling catheter)

Chemotherapy - Treatment of disease with drugs. The term usually refers to cytotoxic drugs given to treat cancer.

Dressing Changes - External catheters (i.e., broviacs) require careful maintenance to prevent infection or the formation of clots. The site where the catheter exits the body must be cleaned every other day and a fresh, sterile dressing needs to be applied and taped in place.

Finger Poke - When a laboratory technician (or nurse) pricks the finger tip to obtain a small sample of blood.

Indwelling Catheter - Surgically implanted catheter used to eliminate the difficulty of finding veins for IV's and allow drugs to be put directly into a large vessel of the heart where they are rapidly diluted and spread throughout the body.

Intramuscular Injections - Drugs that need to seep slowly into the bloodstream are injected into a large muscle such as the thigh or buttocks.

Intravenous-access Line (IV) - A hollow metal or plastic tube which is inserted into a vein and attached to tubing, allowing various solutions or medicines to be directly infused into the blood.

Lumbar Puncture (Spinal Tap) - Procedure in which a needle is inserted between the vertebrae of the back to obtain a sample of cerebrospinal fluid and/or inject medication.

Maintenance - Part of leukemia protocol for treating ALL. It follows the intensive induction and consolidation phases and helps to destroy any remaining cancer cells.

"Mickey"/Feeding Tube (Enteral Nutrition) - If a child requires supplemental feeding, enteral nutrition may be recommended. This is feeding via a tube placed through the nose, mouth, or directly into the stomach through the abdominal wall (Karen has her tube in her stomach). Nutritionally complete liquid formulas are fed through the tube.

Port-a-cath - Indwelling catheter which has a small portal under the skin of the chest attached to tubing which goes into the heart. (See indwelling catheter)

Protocol - The "recipe" for a child's cancer treatment. Outlines the drugs that will be taken, when they will be taken, and in what dosages. Also includes the dates for procedures (e.g., bone marrow aspiration schedule).

Adapted From: Keene, Nancy. (1997) Childhood Leukemia: A Guide for Families, Friends and Caregivers. CA: O'Reilly & Associates.

Appendix O

Cognitive Late Effects

Some childhood cancer survivors suffer neurotoxic effects, which cause subtle changes in their learning style, as well as social behaviour. These changes may result in learning difficulties or significant intellectual loss. Signs and symptoms of possible cognitive late effects are:

- handwriting, spelling, reading, or reading comprehension difficulties

- attention deficits, children may become either inattentive or hyperactive

- short-term memory and information retrieval problems

- difficulties understanding math concepts, processing auditory or visual language

- children's grades drop from A's to C's, yet they are working just as hard

- difficulties remembering stories, or events, and repeating things frequently

- feelings of frustration around school work

Adapted From: Keene, Nancy. (1997) Childhood Leukemia: A Guide for Families, Friends and Caregivers. CA: O'Reilly & Associates.

Leukoencephalopathy: CNS Toxicity

Leukoencephalopathy is characterized pathologically by multifocal demyelination. Patients with this syndrome may present with a variety of clinical findings ranging from poor school performance and mild confusion, to lethargy, dysarthria, dysphasia, ataxia, spasticity or progressive dementia.

Jacob is currently in need of a full-time teachers aid in school and his coordination is poor.

Adapted From: Philip A. Pizzo & David G. Poplock. (1996) Principles and Practices of Pediatric Oncology. PA: Lippincott-Raven Publishers. As quoted in personal correspondance with Jacob's mother.

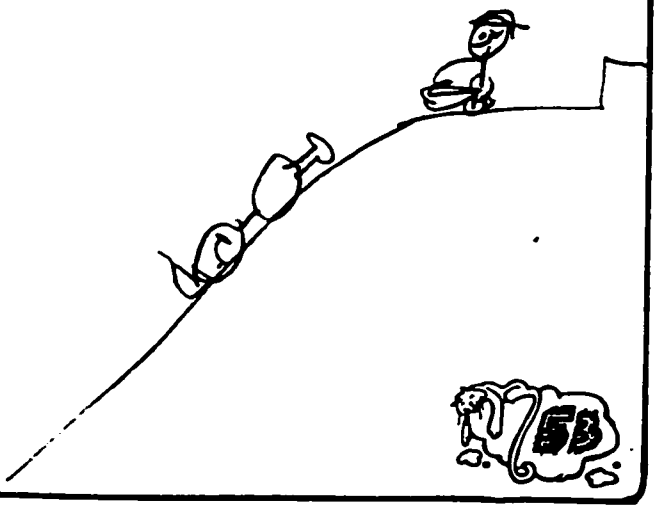
Appendix P

Stress Control

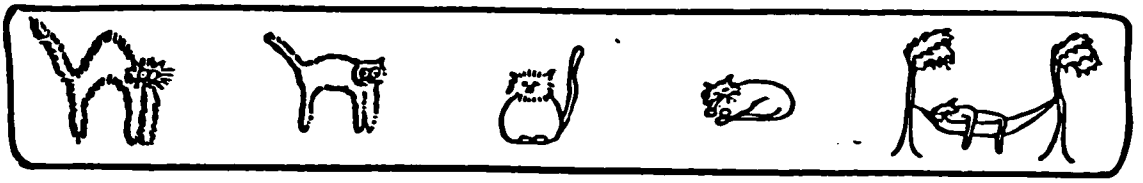
Did anything scary or stressful happen?

Yes

Draw (or write about) what happened?



Which cat did you feel like when this happened?



Appendix Q

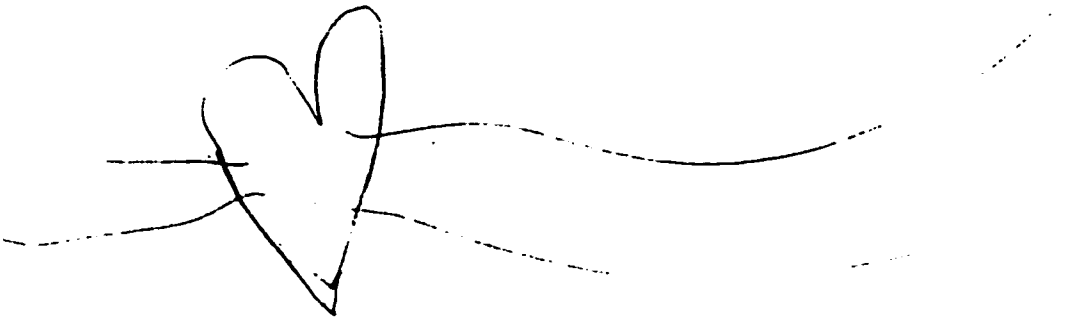
Stresssss

Draw (or write about) some things that make you feel stressed, tense, worried or scared.

Appendix R

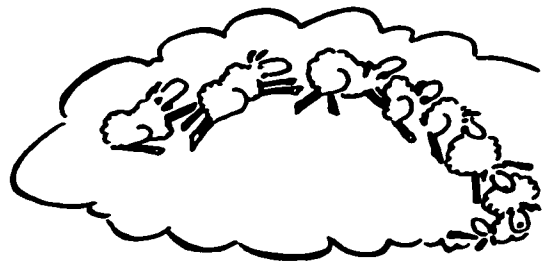
Signals of Stresss.

Draw (or write about) how you feel "inside you" when you are stressed, tense or scared.

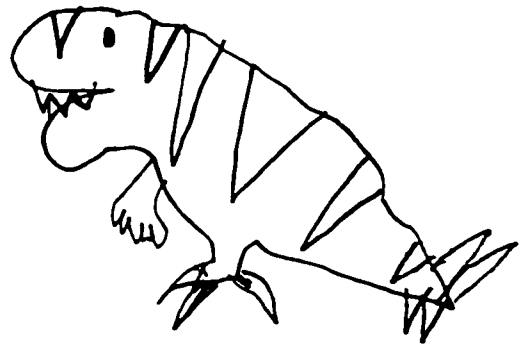


Appendix S

Being Strong

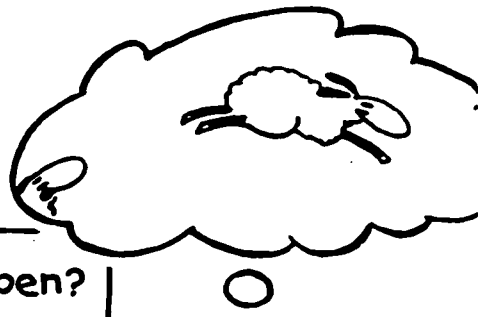


Draw a picture of YOU Being Strong



Appendix T

Stress Control

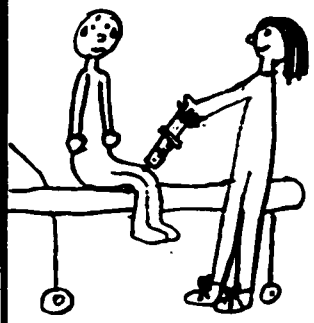


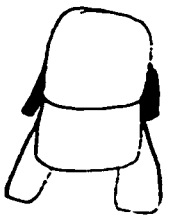
Did anything scary or stressful happen?

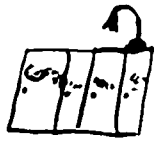
Yes

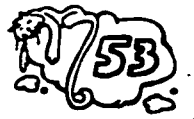
((😮))No

Draw (or write about) what happened?

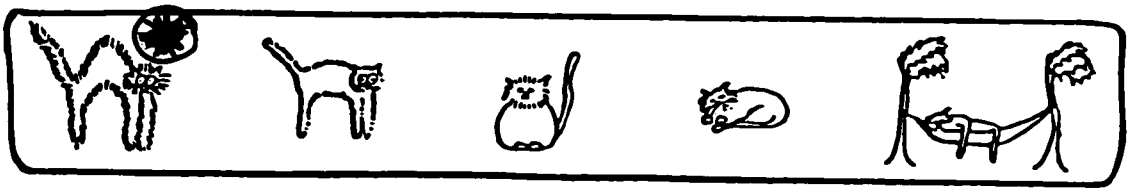








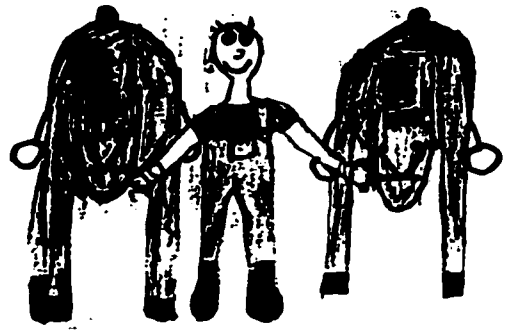
Which cat did you feel like when this happened?

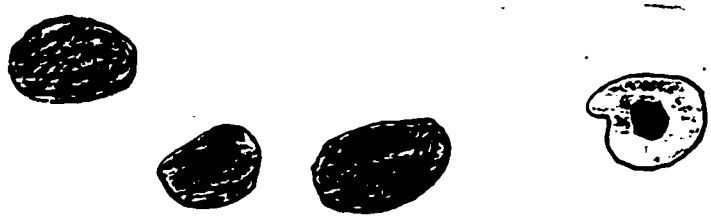


Appendix U

My Goals

Draw or write some things
you will do this week

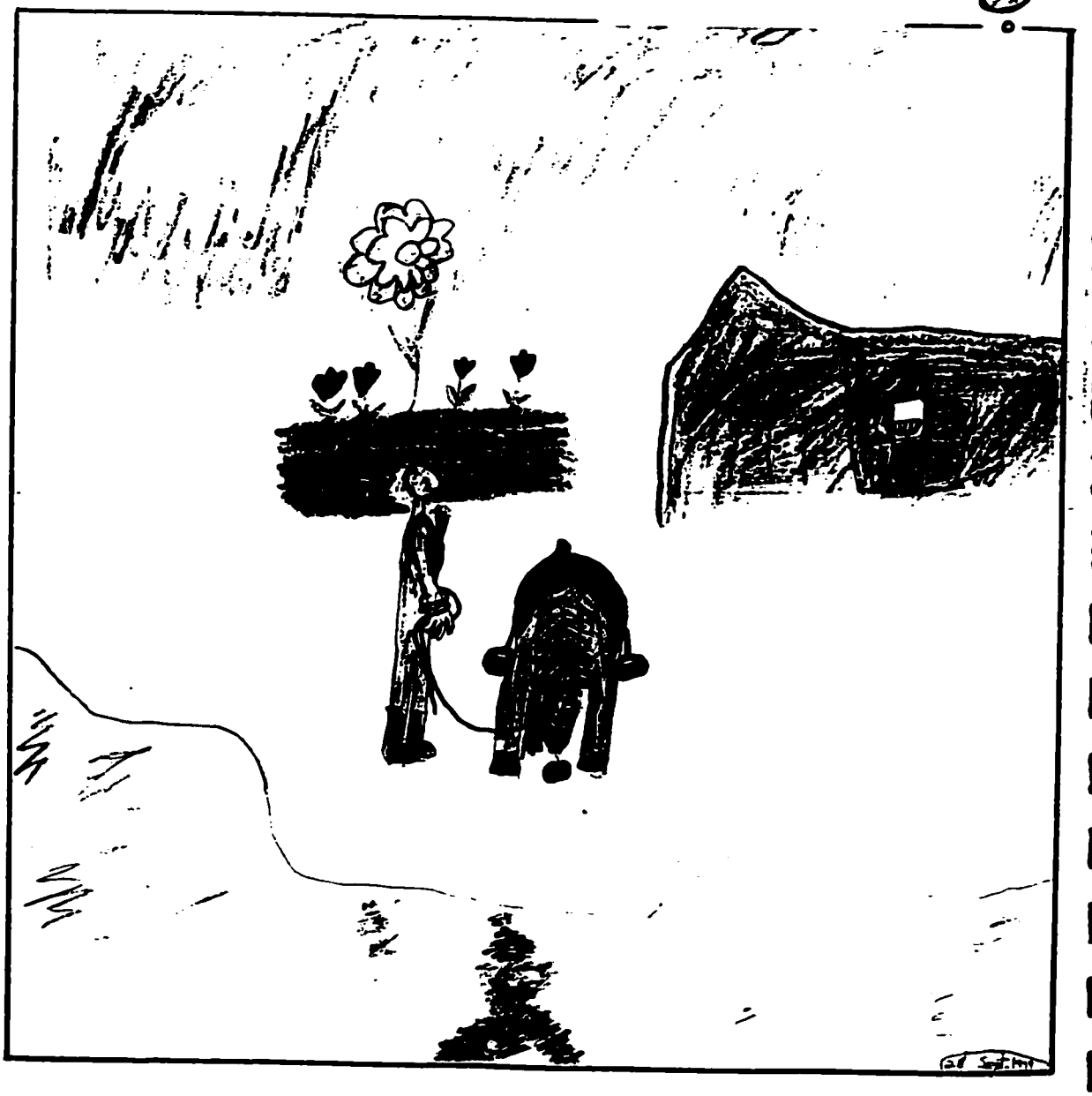




Appendix V

Being Nice

Draw (or write about) you Being Nice
to an Animal



Appendix W

Positive Thinking

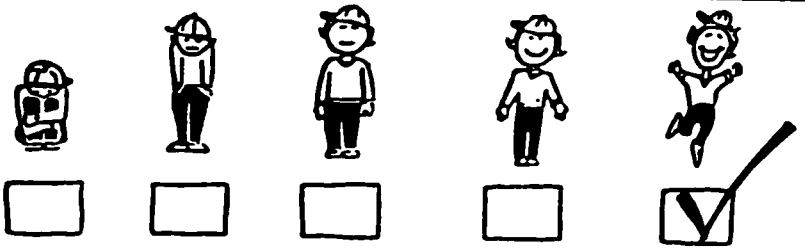
Did you have any positive, good or happy ☺ thoughts about you yesterday or today?

YES No

What thoughts did you have?

Go bowling, thought she was a good bowler.

How did your thoughts make you feel?

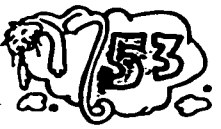


Try to be positive with yourself today.
Write one good thing you will say to yourself today.

I'm gonna have a good LP!

Try to be positive with others today.
Write one good thing you will say to someone else today.

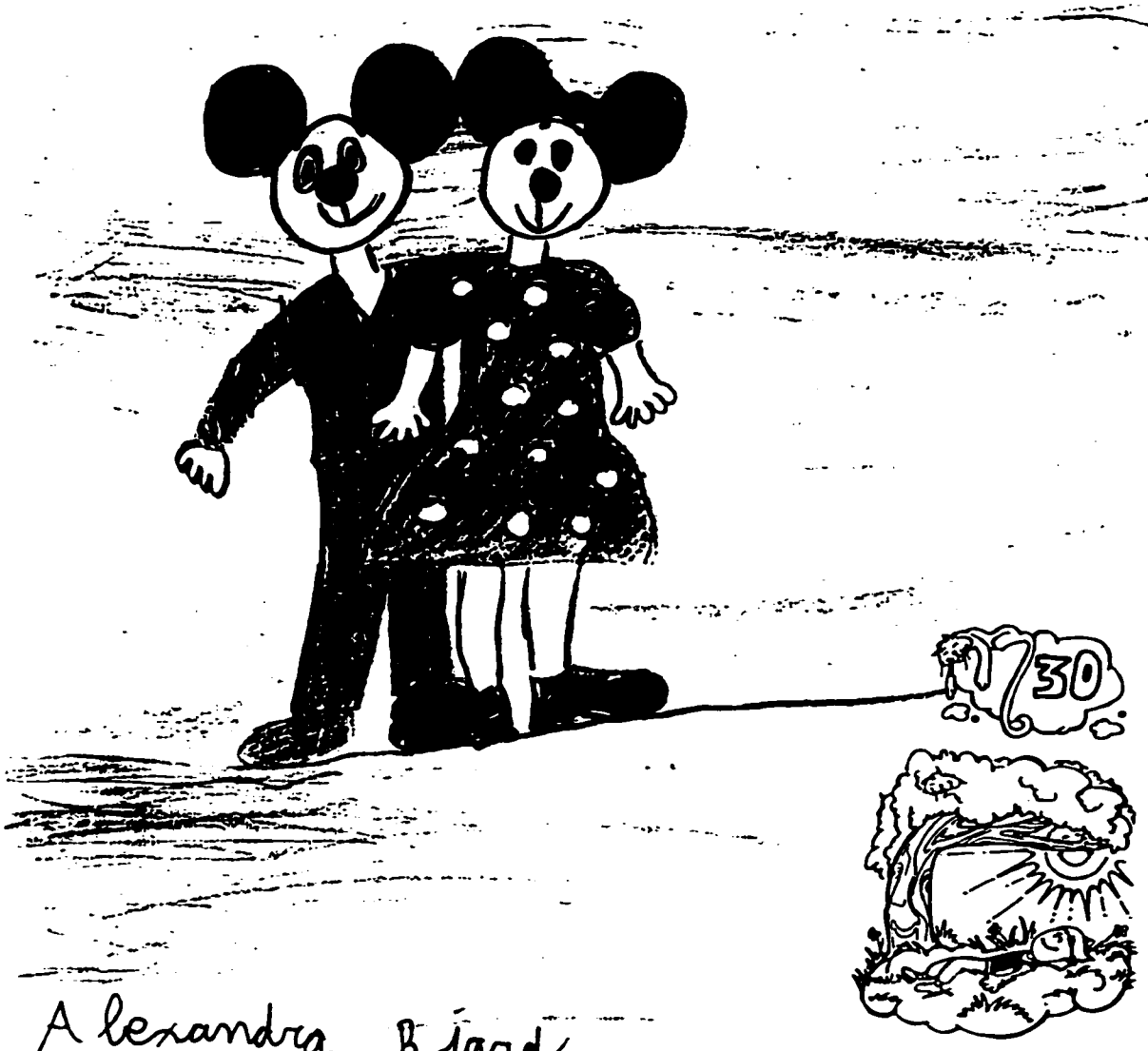
Val- You're my friend!



Appendix X

Special Place Relaxation

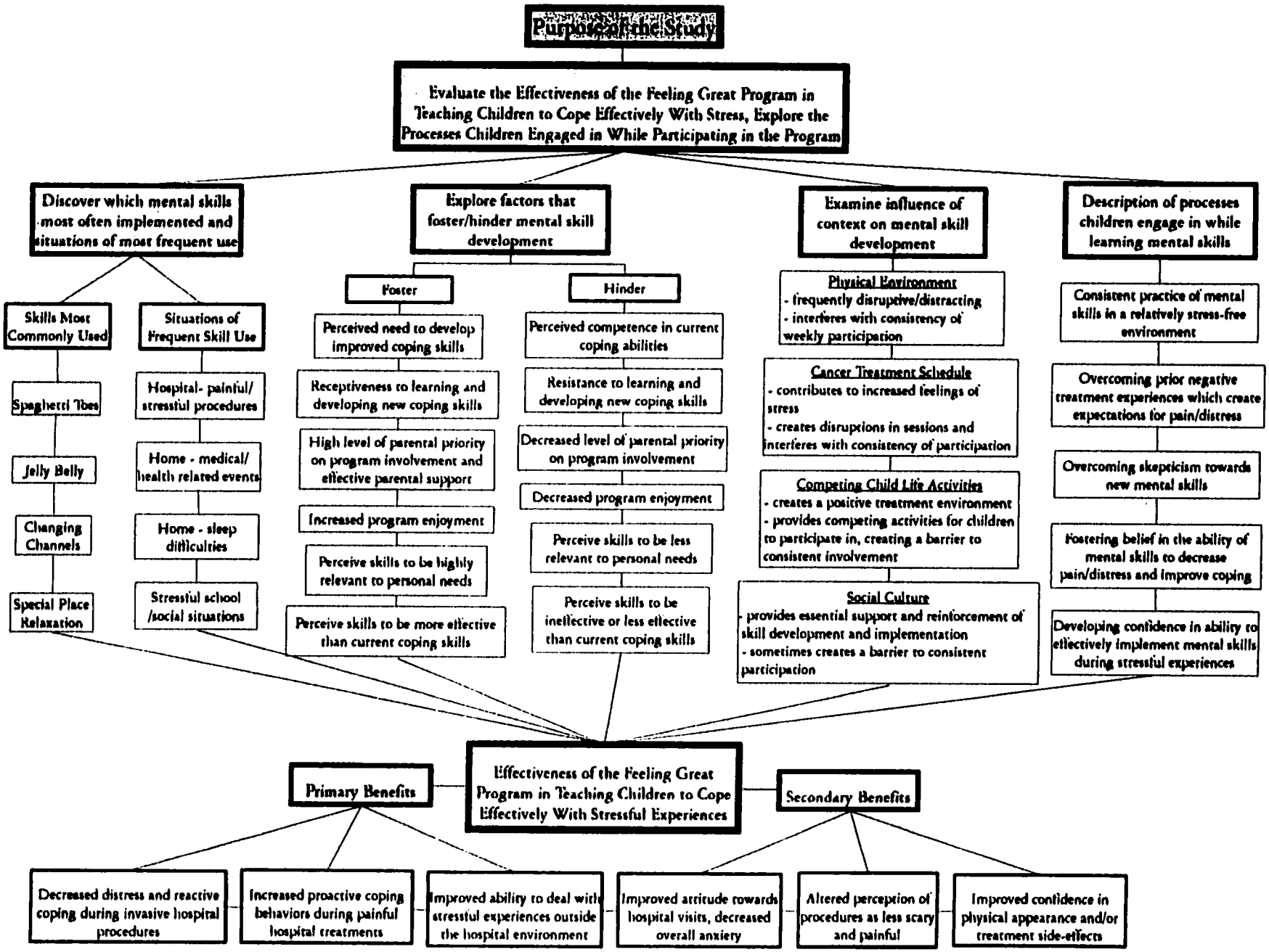
Draw or write about your own special place.



Alexandra Baird

Appendix Y

Evaluation of the Feeling Great Program - Mental Skills



Appendix Z

Evaluation of the Feeling Great Program - Highlight Program