

Coping with Cancer: Lessons From a Pediatric Cancer Patient and His Family

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Abstract

This case study describes the experiences of a four-year pediatric cancer patient and his primary care giver as they attempt to learn effective skills for coping with cancer. The processes involved in learning and applying appropriate mental skills or positive-living skills in this situation are examined. The child learned a number of different mental skills and applied these skills during stressful experiences both inside and outside the hospital environment. The use of mental skills was also associated with improved behavioral functioning, leading to fewer anger outbursts and decreased aggression. The primary caregiver also learned to deal more effectively with her emotions, such as stress and fear. This enabled her to provide more effective support to her child during stressful situations, decreased her feelings of helplessness, and equipped her with effective parenting techniques to cope with her son's behavioral issues. Results indicate that creative efforts to introduce these skills to children in the early stages of their treatment, with family involvement, may provide an effective means of enhancing children's coping techniques, improving the experience of pediatric cancer treatment and enhancing quality of life during this stressful time.

Introduction

Childhood cancer is an overwhelmingly stressful event in the life of a child and his/her 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 and implications of this unrelenting disease. Treatment protocols must be explained and decisions made.

At the same time, children try desperately to understand what is happening to their body, their life and their family. Normal childhood

activities are curtailed by illness symptoms, lengthy treatment protocols, hospitalizations, painful medical procedures and treatment side effects. These disruptions often make it difficult to engage in regular childhood activities such as attending school and playing with friends (Wallander & Varni, 1992). In addition to these changes in normal daily patterns, children are exposed to a seemingly unending array of new stressors such as receiving the diagnosis and treatment, building relationships with health care providers, separation from family and friends and the threat of death (Spirito, Stark & Knapp, 1992). Some of these stressors may be “intermittent” experiences such as painful medical procedures (i.e., lumbar punctures, intramuscular injections) and treatment side effects. Other stressors, described as “chronic”, are more continuous in nature and encompass the daily reality of living with a cancer diagnosis, such as altered activity patterns and lifestyle, and uncertainty towards the future (Hockenberry - Eaton, Manteuffel & Bottomley, 1997).

Children’s knowledge and use of different coping strategies, and the interventions designed to help children develop coping skills, has been examined in a number of studies. These studies indicate that children are aware of proactive coping responses and are capable of implementing these responses during stressful situations (McDonnell & Bowden, 1989; Bachanas & Roberts, 1995; Powers, Blount, Bachanas, Cotter & Swan, 1993). Furthermore, when children are taught effective coping techniques, their feelings of anxiety, helplessness, and related pain behavior are replaced by a sense of mastery. (McDonnell & Bowden, 1989).

Although there are numerous interventions designed to help children cope effectively with cancer, these interventions focus primarily on acute stressors related specifi-

cally to the child’s disease, such as reduction of pain, improved management of symptoms, and the management of procedure-related distress (Kibby, Tyc & Mulhern, 1998). Few interventions attempted to teach children how to better manage chronic symptoms of stress, within the hospital, school and home 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 evident. The need for broader-based interventions becomes increasingly obvious when cancer stressors and adjustment to cancer are 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 et al, 1997). 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. As stressors are not limited to the time immediately during and surrounding painful medical procedures, and environmental changes are not isolated to the hospital, the need to address the occurrence of cancer stressors beyond these situations and settings is clear. If the primary goal of health care is to improve behavioral functioning and quality of life (Kaplan, 1990), then interventions must be designed to address the multi-dimensional effects of living with a cancer diagnosis.

Mental training and positive-living skills programs provide one important advantage over programs typically designed for use with pediatric cancer patients. These programs teach children an assortment of techniques and perspectives that can be used

in a variety of situations. Skills such as muscle relaxation, positive imagery/focusing, diaphragm breathing and positive perspectives training have been used effectively by healthy children to cope with a number of daily stressors in a number of different situations and environments (Parrott, 1990; DeWolfe & Saunders, 1995; St. Denis, 1994; Cox & Orlick, 1996; Gilbert & Orlick, 1996). These programs often incorporate stress reduction techniques similar to proactive coping behaviors, emphasizing absorption in internal states through attention focusing or mental imagery (Smith & Womack, 1987). Teaching these kinds of skills to children undergoing treatment for cancer might be an effective means of helping them cope with both their painful cancer treatments and related stressors that occur outside the hospital environment.

The remainder of this article describes the individual experiences of one child and his primary care giver (mother) as they attempted to learn effective skills for coping with cancer. The purpose of this intervention was to explore the use of a mental training or positive living skills program, specifically Orlick's "Feeling Great Program" (1998), within one family. The processes involved in learning and applying appropriate mental skills in this situation are examined.

Methods

Participants

One family, consisting of two parents and three children, was involved in this case study. The primary focus of the study was on the experience of the child diagnosed with cancer, Nicholas, and his primary caregiver, his mother. Nicholas was five years old at the beginning of the study.

Program

In addition to being the primary investigator in this study, the first author also had the opportunity to be closely involved with Nicholas and his mother as the Feeling Great Program facilitator at the Children's Hospital of Eastern Ontario. Nicholas was involved in weekly or biweekly sessions for 4 months in the Feeling Great Program. In these sessions he participated in activities such as Spaghetti Toes (muscle relaxation), Jelly Belly (diaphragm breathing), Changing Channels and Umbalakiki (focusing/refocusing) and Star Trek and Floating on Clouds (Positive Imagery). A typical weekly session involved a discussion of the past weeks events, listening to a Feeling Great activity on audiocassette and brainstorming ideas for using the skills. This role gave the first author a unique understanding of Nicholas and his family, the Feeling Great Program and the context within which it operated.

Data Collection

A number of different sources of data were collected during the initial 4-month intervention period and for a two-year period following the intervention. First, field notes were collected during the course of the child's participation in the Feeling Great Program. These field notes included information gathered on site visits to the hospital during the child's participation in weekly sessions of the Feeling Great program, conversations with key informants such as the child's mother and hospital staff, and observation of the child during mental training sessions and treatment situations. The first author continued to follow the progress of the family for two-years after the initial intervention period. Two primary forms of communication during this time were included as data; electronic mail between key informant (mother) and the first author, and a treatment log created by the

child's mother that was posted on the child's internet web site. Finally, a retrospective interview was conducted with the mother and child using a semi-structured interview guide.

Data Analysis

Data analysis included both “data reduction” and “data interpretation” (Creswell, 1994). The documents and interview data were analyzed, and “segmented” into relevant codes and categories. Emergent themes were examined and categorized to develop coding themes and coding category relationships. The analysis 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”).

Results

Pre-Intervention: Reactive Coping Behavior

Four-year old Nicholas is extremely frightened and angry during visits to the hospital for treatment for acute lymphoblastic leukemia (ALL). His coping style is reactive and involves screaming, running away, hiding and physically striking out at parents and hospital staff. This behavior has forced his parents and staff members to restrain Nicholas regularly, as his mother explains.

For Nicholas to have bloodwork I needed to sit on his pillow, put my legs around him and wrap my arms around him and hold him there to get the sample. For chemo we used to have anywhere from three nurses to five nurses to hold him down to administer his chemo. He was very tense and afraid and constantly screamed and fought making the needles hurt all the more. It re-

minded me of physical and emotional abuse ... I have never caused so much pain in my child.

This aggressive behavior often begins long before the actual treatment procedure. Nicholas frequently resists entering the hospital by running away and/or grabbing onto doorframes and walls. Once in the hospital, even routine procedures, such as removing tape or bandages, require his parents to physically restrain him. More invasive procedures, such as needles, are the most traumatic for Nicholas and often result in the reactive coping described above.

Treatment for acute lymphoblastic leukemia (ALL) requires a lengthy 2 ½ year protocol which is split into three phases; induction, maintenance and consolidation. Nicholas, who is only 10-months into treatment, is currently in the maintenance phase. This phase requires weekly hospital visits for bloodwork and chemotherapy, bimonthly visits for lumbar punctures, and countless other procedures, such as MRI's and CAT scans. Months of unrelenting cancer treatment and hospital visits have only increased Nicholas' fear and aggressive behavior, while his coping abilities during painful and distressing procedures remain ineffective. This experience is not only stressful for Nicholas, it is also extremely stressful for his entire family, especially his parents.

We didn't know what we were going to do with Nicholas' built up anger and aggression and ever growing fears ... At this point I was willing to do and try anything if it would help Nicholas learn to deal with what was being done to him ... and get him through treatment for leukemia. He was constantly very angry and while he was having these anger outbursts he would hit me (mom) and deliber-

ately hurt me. He was very abusive with his words and also constantly frustrated. His fear with needles was way out of control and we physically had to hold him down to give him his treatment.

These anger outbursts often extended into the home environment where Nicholas was becoming increasingly frustrated and aggressive, often refusing to comply with his parents and verbally and physically striking out at them and his sisters.

I was beginning to get very angry and it got to the point where something had to be done to help me deal with him like that. Because no matter what I did he got angrier and angrier, he would literally throw all of his mattresses off of his bed ... And then as soon as it was over, as soon as that anger was out, it was like he was a totally different child. Like two personalities. But he was so angry and he was getting physical with me, so I thought it's only a matter of time before he becomes physical with the girls.

Participating in the Feeling Great Program

It was at this point that Nicholas began to participate in the Feeling Great Program attending weekly or biweekly sessions for a four-month period. These sessions involved listening to audiotapes teaching positive mental skills, discussing stressful experiences and brainstorming effective methods of coping with these experiences. Nicholas enjoyed participation in the Feeling Great Program, as his mother describes, “when he went with you it was fun, and it was even more fun than sitting in the play room ... He thought it was fun because ... you were doing imaginary things”. During these

sessions Nicholas was energetic and enthusiastic, displaying considerable creativity in his use of imagination, as the following quote indicates, “I am fishing with the man in the moon and we are catching sharks, baby ones. And I am going to put it in a bowl. Then the sun comes out and fishes with us too”. During these sessions Nicholas also identified a number of experiences that caused him stress, such as “chemo”, and described how these experiences make him feel, which is “mad”.

Nicholas' involvement in the mental skills program also extended into the home environment as his mother often helped him practice the skills he was learning.

I'd take him to bed and he'd lay down and I'd tell him ... 'Now take some deep breaths'. And we were going to relax his body, put it to sleep, from his toes to the top of his head. So he would do a little wiggling of his toes, move his legs, his knees, his hips, his butt. Like all the way up, right to his head and the hair, and then take another deep breath, and then [I'd say], 'Close your eyes'. And sometimes we'd talk about imagination and then I'd tell him, he'd have to do some deep breathing and keep his eyes closed and go to sleep.

Developing Mental Skills

The combination of learning environments in the hospital and in the home, helped Nicholas develop mental skills and changes were obvious, in both environments, very early into the program.

I saw changes in Nicholas' behavior almost immediately upon beginning the program. We started to use his imagination right from the begin-

ning, he would imagine he was on a cloud and he would use my face to concentrate on so he could make it through the needles. He also began to use Jelly Belly and Spaghetti Toes to relax his body. When it was bedtime he would relax his body, bit by bit, taking deep breaths until he was relaxed to go to sleep. He would do this at chemo time too.

The skills Nicholas was learning to use during these procedures immediately helped decrease reactive coping behaviors, such as screaming and hitting, and enhanced proactive coping behaviors, such as focus on positive stimuli, use of imagination and relaxation techniques. These skills had a profoundly positive effect on the level of pain and distress experienced by Nicholas, and at times he was able to get through intramuscular injections without ever feeling the needle. Moreover, the skills decreased the feelings of helplessness and anxiety experienced by Nicholas' parents during procedures. Nicholas' ability to implement these skills helped decrease both the duration of the procedure, as he allowed hospital staff to perform their jobs more efficiently, and the pain involved with the procedure, as he was able to relax his muscles and maintain physical control during painful events. These changes are described by his mother,

The largest impact of the program on Nicholas was the ability to be able to control his fears. He learned to get over his fear of needles and to not react to something that may not cause him pain until he actually experiences that pain. And he has learned to say 'Ouch' instead of screaming his head off. Nicholas has learned self-control, mind over matter, to be able to place his thoughts somewhere else when something that

does, or may, cause him pain is happening to him. He has [progressed] from a little boy who needed four or five people to hold him down for chemo, to being able to go for bloodwork on his own, take off his tegaderm patch (topical anaesthetic), and to watch the needle being prepared and injected into his leg. All willingly.

Along with drastic improvements in Nicholas' behavior during invasive medical procedures, his parents also reported significant decreases in his level of frustration and anger, and in his aggressive behavior, in the home. Nicholas' parents felt that the skills taught in the Feeling Great program provided instant help in this situation, "I found almost immediate relief with that. Like almost immediately [it improved]". His mother attributes these improvements to enhanced self-control in Nicholas. "I really think he himself has learned control. He's learned how to control himself because he's been on prednizone (medication that often alters mood) the last three times and has controlled himself every single time. And he literally will walk out of the room [when he is angry], and go to his room, and sit on his bed on his own".

Nicholas also learned to identify simple joys and "highlights" and would often focus on these happy experiences during this difficult period.

For highlights, a lot of the times he used things that made him happy. Happy thoughts. So what he would do, is if something was scaring him, he would close his eyes, using his imagination, he would replace it with that happy thought. And there were all kinds of things - at the end of the day there were scary things, but

those things he didn't like to talk about. But he did like to talk about his highlights. So we would ask him, 'What was one of your highlights today?' And sometimes he'd turn around to me and say, 'Mommy you're my highlight'. So I'd say, 'Oh, okay. That's good'. Or [he'd say], 'Daddy's my highlight'. Or the girl that was helping with his relaxation she was one of his highlights because she helped him cope through all of those scary times.

Nicholas' mother was extremely consistent in her approach to parenting Nicholas with the use of these skills. She describes how she would foster the use of these skills in the home environment.

We say [to Nicholas], 'You're angry inside your head ... inside your body. You're not allowed to [just] let it out. You've got to let it out without hurting anyone else. So you have to calm down and take it out of your head'. So he will physically take it out of his head and put it into his little worry box. Like he could put his hand on the table now and stand up taller and just go (takes a big breath), 'It's gone!'. And he'll leave it, like he'll leave [his anger] on the table. He can do that. And I notice him practicing it".

Improving Family Function

Although Nicholas was the only one with cancer, his experience was affecting the entire family. His explosive temper, and anger outbursts, had begun to seriously impair his relationship with his siblings and were making normal family interactions extremely difficult. This behavior was vividly described by his mother.

You almost feel like you're a unique family, different from anyone else in the community and there's almost this big sore spot right in the middle. Because everybody's lives have changed because of it (Nicholas' cancer). We do a lot of positive things around his cancer, and there are a lot of positive things that have come out of it. But I find the girls (his sisters) have no idea what to do around him when he behaves that way. Like I really feel when he gets angry it's almost like one person taking one drink too many. You can't turn it off after that.

After beginning participation in the Feeling Great program, Nicholas' ability to control his anger and frustration, and deal with it in an effective manner, led to improvements in family interactions and in overall family functioning. Nicholas' parents describe their interactions with Nicholas as less volatile and have learned techniques that help them to regain control of his explosive behavior. Moreover, Nicholas' behavior with his siblings has improved and their relationship has become much less strained.

I cannot believe how much this program has done for our family. Without these techniques I cannot honestly tell you where we would be at this point. We as parents were beginning to argue more about Nicholas and the girls were beginning to resent him. They were forgetting how much fun he could be because he was always angry. He is still like that a lot, but I feel if there was something ongoing and we could enter into it, [it] would help our whole family heal.

These behavioral improvements were so dramatic his mother describes the program as ‘a cure’; “[The Feeling Great program] cured it. Honestly ... I don’t know where we might have ended up, in a family break-up or something. Because it was really getting bad. We had nowhere to turn”.

Helping Parents Learn Mental Skills

Although the child with cancer, in this case Nicholas, is the main concern for both parents and health care providers, the effect of a cancer diagnosis, and the reality of living daily with this disease, has a profound effect on the family. This effect impacts most significantly on the parent who assumes the role of primary care giver. In this family the mother assumed this role and experienced a great deal of physical, mental and emotional stress.

You’re left with one parent almost always being there. And there’s no way you’re going to leave that child for any period of time, other than to run out quickly and get something to eat and a shower and come right back. So you’re in this room, all alone, with someone who’s sick. And you have no idea how it’s going to turn out. So you’re just left there. You’re thoughts are building and building and building. And if there was some way to channel them in a different way. Because I find, I know there are not as many stressful and scary things now, but I can channel those thoughts, and just put them away. But in the beginning of treatment you can’t take anything out of your head. Everything’s in your head.

The mother’s involvement in the program included reading the Feeling Great book and listening to audiotapes with Nicholas. This

helped her develop her own effective coping skills which she applied regularly during stressful situations. She describes her use of these skills during a situation where Nicholas was having a seizure.

If I hadn’t gone through the relaxation therapy with him, I wouldn’t have been in control of the situation as much as I was ... I found myself saying things like, ‘I’ve done everything I can do. There’s nothing else I can do. I need to wait for the ambulance’ ... When we got to the hospital he was still unconscious and I was actually getting up tight ... I left the room and I found myself leaning up against a wall, holding onto the wall, deep breathing enough that a nurse came to see if I was okay ... I basically said, ‘Yes, leave me alone. I’m breathing. I’m relaxing. I’m just fine. I’m okay now’. And I went back into the room .. and then I was better able to cope with what I wasn’t able to control ... I find I do a lot of taking these thoughts and placing them in a drawer for another time. Because I can get very paranoid myself with ‘what ifs’, and ‘what the future holds’, and thinking negatively when it’s not doing you any good to think negatively, because nothing has happened. So think positively and everything’s fine. But it’s hard to control.

This program provided Nicholas’ mother with an effective means of helping to support her child during painful and/or distressing situations in the hospital environment, thereby reducing her feelings of helplessness. It also helped provide simple and effective tools she could use in the home environment to parent her child more effectively. As she describes, “the book ...

also has a different approach to dealing with the children. The better we handle our frustrations, and stress, and anger, the better they respond”. Moreover, the Feeling Great Program helped her develop a more positive outlook for the future, “Although I still have fears I am really beginning to believe that we are near the end of this nightmare and heading towards a cure! How’s that for positive thinking?”

The Learning Process

Although improvements in coping were obvious very early in the program, Nicholas’ mother indicates that the level of coping he has currently achieved did not happen “over night”. “This really, really worked. But it took a long time. It didn’t work over night. But I started to see signs”. While learning new mental skills, there were a number of times when Nicholas was either unable or unwilling to apply these skills effectively. During these situations he would sometimes revert back to his former reactive coping behaviors, as he describes.

When chemo time came I ran away two times. I went in the [treatment] room all by myself. I didn’t let mom pull my pants down to take my emla off (topical anaesthetic). I kicked mommy. I pushed the ladies chair. Jody’s daddy had to hold me down. I screamed one big one. I didn’t want to listen to my music. I kept my knees up and my needle hurt a little bit. Then it was all done and I told my mommy I love her. I was scared.

During these times of overwhelming fear Nicholas was unable to apply the mental skills he was learning. After these frightening experiences Nicholas would often express regret for his actions and would talk about “what went wrong” and what he could do differently next time. Over time, the

frequency of these traumatic situations decreased and Nicholas became more consistent in his use of proactive coping strategies. However, learning to consistently use these skills took considerable time and involved a number of different learning processes. These processes included repeated practice of mental skills, parental reinforcement, overcoming bad memories of treatment, altering expectations for pain, developing trust in the mental skills and his ability to apply them, gradually enhancing self-control and the ability to adapt skills and incorporate additional approaches.

Repeated Practice of Mental Skills

Involvement in the Feeling Great Program enabled Nicholas to practice using mental skills in a relatively stress-free environment, without the immediate presence of painful medical procedures. Although these sessions occurred in the hospital, they took place in an environment free of medical equipment and hospital staff. These two factors appeared to be integral to his successful skill development. His mother confirmed the importance of this factor, “The fact that the person teaching him never hurt him in any way, and was also a person who was very relaxed around children made a big difference to him”.

Nicholas’ practice also occurred in the home environment with his mother, who regularly practiced skills such as relaxation and imagery before bed.

We have been practicing relaxing every night before he goes to bed. All I do is start relaxing him from his toes and do every part of his body until we reach his hair once, and then say goodnight, and then I tell him to do it once himself. Before it took him approximately 30 minutes to fall asleep by the time he stopped talking to himself. Well every night

since he [started the relaxation activities] he has been asleep in five minutes.

Stress-free practice environments enabled Nicholas to learn and apply the skills in a relatively relaxed situation, which made him better able to use the skills during situations that involved increasing levels of stress.

Parental Reinforcement

Both of Nicholas' parents were deeply committed to the Feeling Great Program and placed a high level of priority on participation, even traveling an extra two-hour distance to a much further treatment location to ensure his involvement. Nicholas' parents supported his learning by maintaining regular contact with the program facilitator, sharing past and present experiences, and discussing weekly events including effective and ineffective coping attempts. This ensured that weekly sessions were relevant to Nicholas' current needs. Nicholas' parents also fostered skill development by practicing skills with him at home and reminding him to use the skills he was learning during stressful situations. Often Nicholas' mother would use her own creativity to guide Nicholas through procedures and complement skills Nicholas was learning in the program.

I used the relaxation on Nicholas yesterday as he had to have a MRI and they wanted him to try it awake. Before it would have never worked, but he stayed so calm and didn't move for over 30 minutes. I told him to pretend he was in a spaceship and he was going to the moon and that he was an astronaut. The technicians were amazed that he did it because he was so young. Also, we chased rainbows while the nurse unhooked his IV ... he kept his eyes closed and

I kept 'Changing Channels' for him. It didn't work perfectly but the nurse noticed a huge difference in his reactions from before the relaxation.

The consistent support and reinforcement offered by his parents was an integral part of the learning process and provided an important compliment to the formal Feeling Great sessions Nicholas was involved in.

Overcoming Bad Memories of Treatment and Altering Expectations for Pain

One of the most important, and difficult, steps in helping Nicholas acquire and implement effective mental skills was overcoming traumatic memories created by painful treatment experiences. Nicholas had encountered countless physically and emotionally distressing medical situations. These memories created an association between specific events, such as blood work and intramuscular injections, and specific emotions, such as fear and anxiety. In short, he expected pain, fear and distress during these situations. Reducing this fear was an important part of the process of developing improved coping skills. As pointed out by Nicholas' mother:

What his fear was, was a fear of procedures, not a fear of the treatment. Because the treatment never really made him that sick. It was what was being done to him that caused him pain. So he would be screaming when he saw the needle, it was nowhere near him, and he'd start, the anxiety leading up to the needle. And if he didn't see [the needle], or know what was going on, he never felt the chemo. He never felt the stinging or anything in his leg. He didn't even know he had treatment ... If we could get over this initial fear [procedures would run much more smoothly].

Nicholas' mother felt that there was only one way to overcome these expectations of pain and fear and that was, "[Undergoing treatment] a few times without it hurting ... And then he'd go, 'That didn't hurt'. Realizing that didn't hurt". The realization that procedures didn't hurt that much, and that he had some control over how he reacted, helped Nicholas recognize that the pain associated with medical procedures could be effectively managed by using proper coping skills. This understanding helped decrease his reactive coping behavior and treatments became substantially less traumatic and painful.

Developing Trust

Overcoming negative memories was closely linked to another important component of the coping process; developing trust. Before Nicholas could apply these skills consistently he had to develop trust in the skills themselves, in his ability to apply the skills and in his parents and staff to help get him through the procedure as painlessly as possible. This level of trust was not easily achieved, as his mother describes. "Trying to show him that if we do this, [saying] 'Trust me'. It's getting his trust [that] it won't hurt. So it was really difficult to get his trust".

Although Nicholas did learn to trust the mental skills, and his ability to implement them, he had a more difficult time developing trust in staff members. Often, what appeared to be a simple procedure created a great deal of pain and anxiety for Nicholas, and he had difficulty trusting staff members after these negative experiences.

It got to the point, what we had to do was have the same nurse do his bloodwork, the same nurse do his needle. Because he had built up a trust in them. Because all you would need to happen would have one per-

son not get the vein, and have to re-try, then the next time we came for bloodwork we'd be starting all over again ... Because they broke his trust.

Developing this trust required a great deal of time and effort on the part of both Nicholas' parents and the hospital staff. With continued effort and persistence from these individuals Nicholas did learn to develop a more deeply rooted sense of trust. His mother describes his progress, months after his involvement in the Feeling Great Program, "Treatment is going well, really well. He actually went for bloodwork on his own on Thursday. He is very trusting".

Enhancing Self-Control

Gaining self-control was also a large part of the coping process. Before Nicholas could apply these skills consistently and effectively, he had to begin to take control of his own thoughts and feelings, especially related to fear and aggression. Overcoming these feelings was extremely difficult for a four-year old and his mother describes the struggle he undergoes prior to some procedures. "Nicholas told me (mom) the other day when I asked him why he didn't just go in for his treatment without causing a fit, and he said, 'Because his head wants to (go in for treatment), and his tummy tells him to run away'". Although Nicholas understands the need to undergo these painful procedures, and although he wants to cooperate, his fear is sometimes so overwhelming that he cannot control his behavior. At these times he often tries to escape the treatment area or physically strikes out at those around him.

When he has to deal with new faces he reverts to baby talk and very often refuses to do what they want for fear of being hurt ... At these points he becomes very hyper and doesn't

practice much of what he has learned. Then there are times when it starts out that way then all of a sudden he controls himself and is fine.

In these stressful situations, if he is able to regain control, he will remember the mental skills he has learned and shift focus to using these skills. Despite his sometimes overpowering fear, Nicholas eventually overcame many of his fears, “The most important lesson that Nicholas learned was to be able to control his fears, that he had control of what his mind was thinking”. In addition to controlling himself during invasive procedures Nicholas also learned to control his feelings of anger and aggression in the home environment. His anger outbursts decreased considerably, “He can control himself so he doesn’t flip out and do these, like you know the normal kid things [when he’s angry]. He’ll control that”.

Alternating and Adapting Mental Skills During the Course of Treatment

Nicholas used several different techniques to deal effectively with his distress. These techniques included listening to relaxing or happy music on a walkman, closing his eyes and imagining various positive events or ‘Special Places’, listening to his mother talk to him or ‘Change Channels’ for him, having his mother draw numbers on his face with tissue or her finger, and performing ‘Spaghetti Toes’ muscle relaxation and ‘Jelly Belly’ diaphragm breathing. His mother felt that it was important to alternate the types of skills he used during procedures and the approach to treatment, stating, “I had to keep changing what was effective”. She often had to be very “hands-on” and creative in her efforts to help Nicholas. Sometimes she would need to grab his attention either verbally or physically by talking to him or holding his hands in order

to help him refocus and remember to use his mental skills.

Sometimes I can get him back on track by telling him to relax, look at me, and think of something else. Or it may be as much as telling him he won’t be allowed to go on the computer or Nintendo when he gets home. A lot of times we would go shopping on our way home for a small reward for bravery. I frequently would need to pull his face to me and talk over his talking and get him to concentrate on only me and to block the sight of the needle so he didn’t see it.

Having a variety of different mental skills was essential during his attempts to cope more effectively with stressful experiences. During the process of learning, many different skills would work for a period of time. However, one negative experience while using a mental skill might make this skill temporarily ineffective. Ongoing effectiveness required a great deal of persistence and creativity on the part of his mother as she continuously searched for effective and novel methods of approaching treatment and relaxation.

Positive Outcome

Learning to cope more effectively was a lengthy and challenging process for Nicholas and his family. However, the positive outcomes they experienced justified their investment of time and energy. “What you have taught me, and more importantly Nicholas, has made a major change in his life. His whole life is different. He is not stressed before chemo. He didn’t try to run away. He was ready before they were. Simply amazing”. Overall, the program proved to be valuable in helping this family deal with the fear and distress associated

with childhood cancer. Both Nicholas and his parents gained more effective methods for dealing with feelings of fear, distress, anger and frustration. They also developed a more positive perspective, which helped them live with more joy during this challenging time.

When I thought that we were going to a point of no return, you helped to bring us back. And I am serious. What you have done has made a huge difference in our everyday lives. Dealing with the side effects of Nicholas' treatment was really beginning to wreak havoc in our lives. Just being able to deal with that, makes living with this terrible disease a little easier.

A follow-up interview with Nicholas' mother indicates that, in addition to improving the treatment experience, participation in the Feeling Great Program has also helped Nicholas learn to cope with other sources of stress outside the hospital.

He's done this program, I think it's approximately 2 years ago that he started, and he's still using it everyday. He's starting to use it in school for when he has to do difficult work and instead of getting all frustrated he's taking his frustrated thoughts out of his head and putting them into his desk and then going on to another question. So there are just little places here and there where he's using the program, and he seems overall calmer, not as aggressive.

Discussion

The experiences of this child and his family indicate that Orlick's (1998) mental skills program was helpful in teaching this family to deal with painful and/or distressing medi-

cal procedures, as well as stressful experiences outside the hospital environment. Nicholas used a number of mental skills taught in the Feeling Great Program such as refocusing, positive imagery and muscle relaxation to help him cope with intermittent stressors such as intramuscular injections and bloodwork. Furthermore, Nicholas learned to use mental skills to cope with stressors of a more chronic nature, feelings such as frustration towards treatment and hospital visits. These results support previous studies that found the Feeling Great Program to be successful in teaching a broad, school-based population of children relaxation skills, stress control strategies and more positive perspectives (St.Denis, 1994; Gilbert & Orlick, 1996; Cox & Orlick, 1996). This study also supports the findings of other studies, that found that pediatric patients were able to learn and apply effective coping strategies at a young age, and that the use of these strategies decreased their behavioral distress during medical procedures (Powers et al, 1993; LaMontagne, Wells, Hepworth, Johnson & Manes, 1999; Blount, Powers, Cotter, Swan & Free, 1994; Hockenberry-Eaton, DiLorio & Kemp, 1995).

Another notable outcome of this child's participation in the Feeling Great Program was related to family functioning. Prior to the program Nicholas displayed increasing anger and frustration. These feelings were often expressed through violent anger outbursts and aggressive behavior towards family members. This behavior placed great strain on all the family members and their relationships with one another. The tension on relationships caused by a cancer diagnosis is well documented and both marital relationships and relationships with healthy siblings are significantly affected by this strain (Thoma, Hockenberry-Eaton & Kemp, 1993). After participating in the Feeling

Great Program Nicholas learned to control his anger outbursts more effectively and deal with his aggression in a more positive manner, often through the use of deep breathing, refocusing and a “worry box”. His enhanced self-control improved interactions between himself and other family members and made a significant contribution to the family’s overall harmony.

This program also had a significant impact on the coping abilities of the primary care giver. Parents of children living with cancer identify numerous stressors including role uncertainty, insecurities regarding their ability to properly inform and prepare their child for upcoming treatments, anticipation of their child’s pain and distress, and inability to help the child during this encounter (LaMontagne et al, 1999). Involvement in this program helped the primary care giver deal more effectively with her emotions, such as stress and fear. This enabled her to provide more effective support to her child during stressful situations, decreased her feelings of helplessness, and equipped her with effective parenting techniques to cope with her son’s behavioral issues. The value of improving parental coping behavior is supported by LaMontagne et al (1999), who suggest that the behavior of parents during painful procedures impacts on the child’s experience of distress. Similarly, Blount et al (1994) found that coping skills training for children, combined with parental training in “coping-promoting skills”, such as verbal encouragement and coaching, helped children undergo treatment with less distress. Furthermore, parents who model effective stress management in the home environment help support and reassure the child.

Implications for Practice

From a practical perspective the results of this study have several important implications that may improve the treatment and

life 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 build trust in children’s ability to apply effective coping methods, the need for repeated practice of coping skills in a relatively stress-free environment and the importance of parental support and involvement.

In this study, overcoming current negative memories was an important step in helping to develop positive coping responses. Similarly, Chen, Zeltzer, Craske & 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 highlight the importance of helping children develop effective strategies at an early stage of treatment in an effort to prevent traumatic memories and increased behavioral distress. This view is supported by Sawyer, Antoniou, Toogood & Rice (1997) who recommend directing efforts at decreasing distress for children and parents early in the treatment process. An additional benefit of early intervention is the opportunity to enhance children’s self-control during stressful situations and create trust in their ability to use mental skills to alleviate pain during treatment.

After participating in the Feeling Great program, Nicholas was able to employ proactive coping responses more consistently and effectively. This improved coping is attributed mainly to repeated practice of mental skills in a stress-free environment. Regular practice of mental skills helped to increase the number of proactive coping responses available to him, improved his ability to apply these techniques and enhanced his confidence in the effectiveness of

the skills. Increased emphasis on consistent practice in a relatively stress-free environment, will help children learn and implement more positive coping methods. Ideally, practice should be encouraged by parents, caregivers, teachers and health-care practitioners.

Parental support was also identified as an asset to high quality mental skill acquisition and implementation. 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 (Powers et al, 1993; Blount et al, 1994; LaMontagne et al, 1999). These findings emphasize the necessity of increasing parental involvement in interventions of this nature, perhaps by including parents and other family members in weekly sessions, by creating a coaching role for parents or by increasing skill use in the home environment.

Finally, this study clearly indicated the importance of maintaining flexibility in mental skill acquisition and implementation. This flexibility should address children's personal preferences, past experiences and contextual factors. Parents and children should be encouraged to adapt skills as necessary and revise these skills to enhance their efficacy and appropriateness. 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.

Future Research Recommendations

The experience of stress and coping is complex and multidetermined. A number of factors influence children's coping and stress responses, such as prior experiences, length of time in treatment, specific medications and support from family and hospital personnel. The goal of this study was not to control these variables, rather to determine how a child could use mental skills in conjunction with these variables. These external factors undoubtedly influence the coping process and therefore must be considered when interpreting the results. Furthermore, a substantial amount of the data is comprised of parental reports and retrospective data, a factor that must also be taken into account.

This study endeavored to identify several key components involved in the process of acquiring and implementing coping skills in a complex situation. Further research that attempts to understand coping as a process, for different populations of children within various contexts, is necessary. Developing a more comprehensive understanding of this phenomenon may enhance the effectiveness of support available to children and their families.

Summary

Nicholas, a four-year old pediatric cancer patient, was 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 was also associated with improved behavioral functioning, leading to fewer anger outbursts and decreased aggression. Creative efforts to introduce these skills to children in the early stages of their treat-

ment, with family involvement, may provide an effective means of enhancing children's coping techniques, improving the experience

of pediatric cancer treatment and enhancing quality of life during this stressful time.

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Finding a Pediatric Cancer Center. Who Treats Children With Cancer? Children and Cancer. Most pediatric cancer treatment centers also include psychologists, recreation therapists or child life workers, teachers, and chaplains. Most teams think of parents as team members and want them to have an active role in caring for their child. The patients, whether they are children or teens, also are part of the team in different ways depending on their age and level of maturity. They play an important part in teaching the patient and family about cancer and its physical and emotional effects. They also help set up care for the patient in his or her home community when referrals are made to home health agencies. Teams of nurses may include Communicating with the pediatric patient and his or her family presents unique challenges and requires special skills. This chapter will address some of the general principles of communicating with pediatric patients and their family members, will explore the unique challenges of working with children and will offer suggestions for meeting these challenges. Table 1 highlights some of the more important differences between pediatric and adult medical care that impact communication. Explaining what is going to happen next helps the patient cope with the illness. Most people have difficulty dealing with uncertainty, and imagined thoughts about what is going to happen are often more frightening than what is really going to happen.