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UNIVERSITY OF ALBERTA

ADOLESCENTS WITH OSTEOGENIC SARCOMA:
HOW CAN WE HELP THEM COPE?

BY

ROCHELLE A. YANOFSKY



A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND
RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF
MASTER OF EDUCATION
IN
COUNSELLING PSYCHOLOGY
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL, 1993



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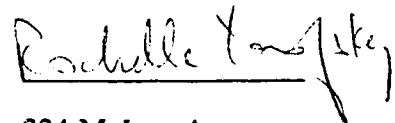
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **ADOLESCENTS WITH OSTEOGENIC SARCOMA: HOW CAN WE HELP THEM COPE?** submitted by **ROCHELLE A. YANOFSKY** in partial fulfillment of the requirements for the degree of **MASTER OF EDUCATION in COUNSELLING PSYCHOLOGY.**



Dr. Ronna Jevne



Dr. Lorraine Wilgosh



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JULY 26, 1993

Abstract

The role of the health care professional involved in the treatment of adolescents with osteogenic sarcoma includes helping them cope with the cancer experience. One way to gain an understanding of their needs, concerns, and preferences is to view the cancer experience from their perspective. Thirteen individuals who were diagnosed to have osteogenic sarcoma in adolescence were asked to describe the experience of living with osteogenic sarcoma. Semistructured interviews and the constant comparative method of data analysis were used in this retrospective exploratory descriptive study. The participants described their experiences with chemotherapy and surgery, the rehabilitation process, and the impact that the diagnosis and treatment had on their lives. The themes of control and choice, hope, trust, being normal, and getting on with life were particularly prominent. Another prominent theme was the desire for empowerment. That is, the participants wanted to be informed, to play a role in the decision-making process, and to be treated as strong, intelligent young adults who were capable of making sound decisions and achieving any goals that they set for themselves. The experience of living with osteogenic sarcoma is described in the first paper of this thesis (chapter II), while the process of empowering adolescents with osteogenic sarcoma is discussed in the second paper (chapter III). Recommendations are made regarding the ways in which others can help adolescents with osteogenic sarcoma cope with their disease and treatment.

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CHAPTER I

INTRODUCTION

I am a pediatric oncologist. I went into medicine because I wanted to help people. After a long period of training, and six and one-half years of clinical practice, I decided that something was missing. I felt like a technician, ill-equipped to help my patients and their families cope with the cancer experience. I didn't know what their needs were, and I wasn't satisfied with the way that I related to them. After much emotional turmoil, I decided to temporarily leave medicine to pursue some formal training in counselling psychology. My objective was to improve my communication skills and learn how to help people cope with crisis.

This thesis has provided me with an opportunity to formally study the needs of adolescents with osteogenic sarcoma (a type of bone cancer). This group of cancer patients is unique in that their therapy involves aggressive chemotherapy as well as mutilating surgery that renders them permanently different from other people. Before embarking on this study, I had only a rudimentary understanding of the psychological issues related to amputation. I was therefore particularly interested in learning more about these issues. Although the literature contains some information about the concerns of adolescents, including adolescents with cancer, there is little information available describing the cancer experience from the perspective of the adolescent with cancer. Similarly, there is little information available to guide the efforts of the health care provider in helping the adolescent cope with chemotherapy and mutilating surgery.

A descriptive exploratory study seemed an appropriate place to start. I took the opportunity to talk with 13 individuals who were diagnosed to have

osteogenic sarcoma in adolescence. When I began, I focused on their informational needs (both the process and the content). I quickly realized that what was more important was gaining an understanding of the cancer experience from their perspective. Equipped with this knowledge, I could identify many of their needs and find ways to help them cope with the cancer experience.

This thesis will be presented as two separate papers. The first paper (chapter II) describes the experience of living with cancer from the perspective of adolescents with osteogenic sarcoma. The information presented in this paper has been derived from the data obtained in the interviews. Recommendations are made regarding how others can help adolescents with osteogenic sarcoma cope with the cancer experience.

The second paper (chapter III) focuses on adolescents with osteogenic sarcoma and their desire for empowerment. Recommendations are made regarding some of the ways that the health care professional can help them become empowered. The information presented in this paper is based on information obtained from the interviews as well as my perception of the needs of adolescents with osteogenic sarcoma, having gained some understanding of the cancer experience from their perspective.

The final chapter contains a concise summary of the ways that others can help adolescents with osteogenic sarcoma cope with the cancer experience. The practical aspects of applying this knowledge, as well as the consequences of applying such an approach are also discussed, along with recommendations for the training of health care professionals.

Chapter II

ADOLESCENTS WITH CANCER: THE EXPERIENCE OF LIVING WITH OSTEOGENIC SARCOMA

Introduction

Progress in the field of pediatric oncology has resulted in a dramatic rise in the survival rate of children with cancer (Pizzo & Poplack, 1989). Along with this change, the attention of caregivers has shifted to preparing these children and their families for living with cancer. The needs of cancer patients can be most effectively determined and met if their experience of living with cancer is understood. Yet the literature contains few studies describing the experience of living with cancer from the perspective of the adolescent with cancer (Rechner, 1990). Similarly, little information is available about how adolescents experience mutilating surgery, such as limb amputation (Ritchie, 1980).

Osteogenic sarcoma is a type of cancer which originates in bone. It is the most common malignant tumor occurring in adolescence. Treatment consists of multidrug chemotherapy and surgical removal of the bone tumor. The surgical treatment of osteogenic sarcoma of the extremity consists of either limb amputation or complex limb-sparing surgery. Rotationplasty is a surgical procedure in which the ankle joint is used as a knee joint, converting the individual from an above-knee amputee to a below-knee amputee. Five year disease-free

survival rates of 60 percent or more are currently being achieved in patients who present with osteogenic sarcoma which is localized to one bone (Pizzo & Poplack, 1989).

Adolescence may be defined as the period of life which begins at about age 11 years and ends at about age 21 years (Steinberg, 1989). It is a critical period in psychosocial development, and can be disrupted by cancer and its treatment. The experience of cancer may affect the normal development of body image and self-concept, relationships with others, autonomy, sense of identity, and life direction (Adams, 1984; Blotcky, 1986; Zeltzer, Ellenberg, & Rigler, 1980). The impact of being different may be devastating when the norm is conformity to the peer group (Adams, 1984; Blotcky, 1986; Kagen-Goodheart, 1977).

Adolescents with cancer are concerned about losing control, increased dependency, loss of privacy, changes in their physical appearance, how they are perceived by others, painful procedures and treatments, being a burden to their families, and about what the future holds (Adams, 1984; Adams & Deveau, 1988; Blotcky, 1986; Kagen-Goodheart, 1977; Kellerman & Katz, 1977; Sitarz, 1988; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986; Van Dongen-Melman & Sanders-Woudstra, 1986). Their goals are to get on with life, be normal, and keep their world affected by cancer separate from their normal adolescent world (Rechner, 1990). Having a positive attitude and maintaining relationships with friends are also important to them (Orr, Hoffmans, & Bennetts, 1984; Rechner, 1990).

Adolescents with osteogenic sarcoma must undergo mutilating surgery which results in a permanent visible disability. In general, adolescents with cancer who undergo limb amputation adjust well and lead full, productive lives (Boyle,

Tebbi, Mindell, & Mettlin, 1982; Tebbi, Petrilli, & Richards, 1989; Weddington, Segraves, & Simon, 1985). However, few articles have been published describing the experiences of children and adolescents undergoing and living with limb amputation or limb-salvage surgery (Gottsauer-Wolf, Kotz, Knahr, Kristen, Ritschl, & Salzer, 1991; Kaiser, 1988; Ritchie, 1989). According to the literature pertaining to amputation in childhood and adolescence (Kaiser, 1988; Kindon & Pearce, 1982; Ritchie, 1989; Walters, 1981), despair, discouragement, angry denial or passive acceptance characterize the initial reaction to amputation, with a period of grief, mourning, and loss of self-esteem occurring following limb amputation. The changed physical appearance is gradually incorporated into the body image, with attention shifting to rehabilitation. Vivid and persistent phantom sensations are common, as are concerns about the appearance of the stump; the appearance, function, and fit of the prosthesis; what the adolescents' limitations will be; and how people will react to them. Other amputees are an important source of information, support, and hope (May, McPhee, & Pritchard, 1979). Moderators of self-esteem include the support of family and friends, as well as perceived physical appearance (Varni, Rubenfeld, Talbot, & Setoguchi, 1989).

The current study describes the experience of living with osteogenic sarcoma from the perspective of 13 individuals who were diagnosed to have osteogenic sarcoma in adolescence.

Methodology

Subjects

Individuals who were diagnosed to have osteogenic sarcoma between the ages of 10 and 21 years and were being followed at one major urban cancer center were eligible to participate in this exploratory descriptive retrospective study. A convenience sample of at least 7 individuals was sought. All potential participants received a letter of introduction which described the study (appendices A and B). They were then contacted by phone and asked whether they would participate in the study. Written informed consent was obtained from the participants (and one of their parents, in the case of minors) at the beginning of the formal interview (appendices C, D, and E). Thirteen of the 18 individuals contacted agreed to participate in the study. Three of the individuals who refused to participate currently live in another city; they cited the distance factor as their reason for not participating. Another individual was temporarily out of the country at the time that the interviews were being conducted. The fifth individual who refused to participate is living with recurrent osteogenic sarcoma and had some concerns about how he would react to being interviewed. The characteristics of the individuals who agreed to participate in this study are described in Tables II-1 and II-2.

Data

During semistructured interviews, participants were asked to describe their experience of living with osteogenic sarcoma, starting from the time that they first suspected something was wrong until the time they were interviewed. An

Table II-1**Characteristics of the Participants**

<u>Sex</u>	(n)
Male	6
Female	7
<u>Age at Diagnosis</u>	(n)
10 to 12 years	4
14 to 16 years	5
19 to 21 years	4
<u>Time Since Diagnosis</u>	(n)
2 to 3 years	6
5 years	1
8 to 14 years	6
<u>Age at Interview</u>	(n)
13 to 15 years	3
21 to 30 years	10

Table II-2**Characteristics of the Participants**

<u>Site of Cancer</u>	(n)
Lower limb	8
Upper limb	4
Other	1
<u>Status of Cancer and Treatment</u>	(n)
Currently on chemotherapy	0
Recurrence experienced	2
Evidence of cancer present	1
<u>Marital Status</u>	(n)
Single	10
Married or engaged	4
Married with children	2
<u>Occupational Status</u>	(n)
Going to school (full-time)	6
Working (full-time)	6
Neither	1

interview guide (appendix F) was used as a conceptual framework, with the number of questions varying from one interview to the next, and each interview building upon information obtained in previous interviews. A pilot study was conducted to test and refine the research design and the interview questions. The information sought from the data included: 1) the characteristics of the experience of living with osteogenic sarcoma; 2) the informational needs of this population; and 3) the factors influencing the communication process. The interviews were audiotaped and transcribed verbatim. Additional sources of data included medical records, as well as the investigator's field notes and memos which were collected on an ongoing basis, both prior to and following each interview.

Each participant was interviewed on one occasion in a private setting which was free of distractions. Nine of the participants were interviewed in their homes, two were interviewed in a university clinic, and two were interviewed in a hospital-based clinic. The length of the interviews ranged from one to four hours. The participants were not interviewed a second time because of the investigator's time constraints.

Data Analysis

The data were analyzed and coded manually for descriptions, patterns, common themes, and relationships, using the constant comparative method of analysis. Data collection and analysis proceeded concurrently. Two levels of coding were created and the data were analyzed for meaning units. The descriptive categories which evolved from the research questions were: 1) living with osteogenic sarcoma; 2) informational needs; 3) factors affecting communication; and 4) preferred and actual information sources. All of the themes

in each category were compiled on an ongoing basis and were reanalyzed once all of the interviews had been completed. The themes of trust, hope, control, and choice were prominent in the pilot interview. These themes were therefore sought in the subsequent interviews, and were expanded into separate subcategories. Upon reviewing all of the themes in the subcategory of "hope," it became apparent that one of the overriding hopes was to be normal. This theme was therefore expanded into a separate subcategory, and the data were reanalyzed for sub-themes.

The themes in the category of living with osteogenic sarcoma were grouped into the following sub-categories: 1) the initial diagnosis; 2) the chemotherapy experience; 3) the amputation experience; 4) the rehabilitation process; 5) living with amputation; 6) ongoing fears of recurrence; 6) cancer as a positive experience; and 7) interpersonal relationships.

The following steps were taken to ensure the credibility (or truth value) of the data: 1) The interview guide was reviewed by two psychologists who have experience in the area of chronic illness and disability; 2) a pilot sample was obtained to assess and ensure content validity; 3) The investigator's interviewing style was reviewed by her supervisors; 4) the interviews were transcribed verbatim; 5) the investigator compared the audiotapes with the typed transcripts; and 6) the participants were asked to review and comment upon the truth value of the "findings" section of this paper.

The following steps were taken to ensure the auditability (or reliability) of the findings: 1) an audit trail was maintained through the collection of comprehensive field notes describing the evolution of the research question, and

the collection and analysis of the data; and 2) a secondary coder reviewed the researcher's coding of two interviews for consistency and accuracy.

Fittingness (or external validity) was achieved by the use of theoretical triangulation, integrating information available in the literature with the final results.

Findings

The participants described their reactions to the diagnosis of osteogenic sarcoma, their experiences with chemotherapy and surgery, the rehabilitation process, and the impact that the disease and treatment has had on their lives. They also described ongoing intermittent fears of recurrence of their cancer as well as intermittent feelings of loss. The cancer experience was described as a positive one overall. The themes of control and choice, hope, trust, being normal, and getting on with life, were particularly prominent.

The Diagnosis of Osteogenic Sarcoma

The symptoms for which the participants first sought medical attention included pain, a lump at the site of the cancer, and sometimes a fracture through the tumor. Delays in diagnosis were common. Physicians and/or family members were simply not thinking cancer. Symptoms were commonly attributed to a sports injury, overexertion, or growing pains:

I was involved in a lot of sports, so I was always getting hurt. I noticed that my leg was really giving me a problem, but I didn't think too much about it because in the past my pains always went away....It really

surprised me when I heard that I had cancer, because I had expected that it was a bit more drastic than a sprained ligament, but I didn't exactly think they'd have to take my leg off for it.

The words "bone cancer" conveyed the seriousness of the situation to them, but the terms osteogenic sarcoma, osteosarcoma, and tumor were poorly understood. One participant remembered saying "oh phew, it's not cancer" when she was told that she had osteogenic sarcoma. Other participants described their understanding of these terms in the following ways:

I can remember him saying that I had osteosarcoma, and going on and on with all of these big words, and I didn't understand it. And then he said bone cancer, and of course the key word was cancer.

The doctor came in and told me it was a tumor, and I started laughing. I thought no problem, just take it out....But when I heard cancer, right away I wanted to know what it was and what was going to happen to me.

Even after a full description of the disease and the treatment plans had been given to them, they did not really know what to expect. According to one of the participants:

It was hard to understand because some people get sick when they have chemotherapy and others don't. So you hope that you're a person that doesn't. And you find out that you might lose your hair and you might not.

So you're not really too sure what's going to happen to you until it happens...I didn't really know what to expect until I had quite a few bouts of chemotherapy. And then I knew what to expect.

The participants described feeling very confused, frightened, and angry:

I was frustrated because I didn't understand what was happening. I felt very stupid about everything that was going on. The unknown is so frightening... I was too tough to be afraid, so I got angry instead.

Most of the participants believed that they would be cured and spent little time thinking about the possibility of death. They described their thoughts about death in the following ways:

Death didn't really bother me...Maybe I didn't realize the significance of my illness. I guess maybe in the back of my mind, but never at the forefront.

I wasn't thinking about dying. Death hadn't really entered my mind...I didn't know cancer could kill you until this and then I still blanked it out of my mind.

The Chemotherapy Experience

The participants described the chemotherapy experience as "the worst experience of the whole thing." Negative experiences included ongoing nausea, vomiting, and a lack of energy, as well as looking and feeling awful. One of the

participants described her reactions to the chemotherapy experience in the following way:

Just to be that sick and feel the medicine go in you and drain every ounce of life out of you, and then to have to work for three weeks to pull that energy back up and to have it wiped out again. It made no sense to me.

Hair loss was a devastating side effect of the chemotherapy for many of the participants, and was described by some as worse than the amputation:

I didn't want chemotherapy because I was going to lose my hair. Now you take a 15 year old girl and you cut off her leg. She can deal with that. Take all her hair away, oh. She would probably rather lose the other leg. Vanity is a big thing for a 15 year old. It was for me anyway.

It was harder for me to lose my hair than it was to lose my leg...At age 12 I was getting to the point where my appearance was extremely important to me, and I didn't really think I had much of an appearance any more.

Other negative experiences were related to the side effects of the anti-nausea drugs. One participant described being on nabilone as feeling "like an airhead with a big smile on your face even though you felt awful inside." Other participants described the lack of control which they felt after receiving antiemetics like maxeran, largactil, and gravol:

I didn't like having the maxeran and gravol, because I was groggy. I could be laying in bed and someone could take me. I have no control.

One participant described having severe reactions to the antinausea drugs maxeran and benadryl:

My entire body was nauseous... I kind of felt dizzy and feverish and would shake. Then I started getting almost wild. I would grab my sleeve and twist it around and I'd claw at the bed and the pillow...I just felt so sick and at that time I really, really wondered if I should just quit because this was only a month after I started chemo.

Other negative experiences were related the pain associated with repeated attempts by the health care professionals to insert an intravenous catheter for chemotherapy:

The big concern at that point was to try and either make sure that the IV didn't go interstitial, or if it did, to not let the nurses know that, so they wouldn't have to restart it again...I didn't want to get poked with another IV.

The participants described a feeling of loss of control over their lives during chemotherapy, and viewed the treatments as interfering with getting on with life. "It's like a year sort of taken up for doctors," said one participant. "It's just hard to

be sick", said another participant. "You look out at the trees and see kids playing ball, and here you are. It's not the kind of feeling you like."

The participants were concerned about whether the chemotherapy would work or "whether it was a useless procedure". The lack of visible proof or a guarantee that the chemotherapy was working and the view that the chemotherapy was a precautionary measure to prevent the spread or recurrence of the cancer made it more difficult for them to tolerate the negative experiences associated with chemotherapy. One participant described his feelings on this matter as follows:

The chemo I had was all precautionary, so a lot of the time I didn't want to go because I couldn't see going through the chemotherapy if I didn't have cancer.

The participants also described a loss of privacy during the time on chemotherapy. One individual stated that he felt like he was being treated "like cattle" when he received chemotherapy in the halls of the outpatient clinic, and described the loss of privacy that he experienced as follows:

I am a very private person. I really don't want people to see me feeling sick with my hair falling out... I don't want others watching me and making it worse.

Many found the hospital experience impersonal and dehumanizing. They described their relationships with most of the housestaff as extremely unsatisfactory:

The only thing I hated is when all those interns would come to my room and I would have to undress....One guy was checking my heart and everything and he said to me "You're a little bit fat, aren't you." When the interns were there for a month I would get to know them and we would have fun and everything. Those were the ones I liked.

Other negative experiences were related to the development of complications, such as mouth sores and infections. Waiting was also cited as a negative experience related to the chemotherapy:

The processing between being admitted, to getting started, to getting the drugs took too long. You start to think too fast and your anxiety builds up.

Thoughts of prematurely stopping the chemotherapy were common:

You just want to give up and forget it. Just unhook yourself and walk out of there and crawl into a hole and die...You've had it up to here and you're just sick of it. You don't want to feel any pain anymore...You've been fighting so hard and if your outcome isn't good, it just doesn't seem like there's any point.

Only one participant actually discontinued his therapy prematurely. The others continued on, citing the encouragement and the support that they received from friends and family as giving them the strength to continue:

The one thing for me was my family. Whenever I wanted to say shove it, they were there to say, "hey you have to go through this." It was kind of nice because it was a "we" thing. It wasn't just me going through it. I know they went through it too.

Amputation

The participants described their initial reaction to being informed of the possible or definite need for amputation as one of shock and disbelief, followed by intense sadness and anger, and a feeling that life was over:

The first time that they mentioned amputation, it was a real blow. I cried and I thought to myself, "That's it, my life is over."

I thought, "Oh my God, what would I do. I would have to kill myself. It would be so traumatic and terrible."

When the time interval between learning of the need for or possibility of amputation and the actual amputation being performed was prolonged (from several weeks to two years), the surgery was ultimately viewed as a chance for relief from pain and immobility, and an opportunity to get on with life:

It wasn't like I was losing a leg. It was like I was losing a ball and chain that had been around me for two years.

It was very painful to even have my leg. I thought, "If I can have this operation and get rid of the pain, then I can try to get on with my life."

Two participants had less than one week between the time that they first learned of the need for amputation and had the surgery performed. These individuals accepted the amputation least well initially. They were extremely angry with their parents for allowing the surgery:

I think I should have had more time with it. I don't care afterwards, because it's gone. But before it's like, "Okay, take my last looks, feel my last pains, wiggle my last toes."

I thought it was unfair that I wasn't able to get the cast off and maybe run once more, and have that freedom of mobility before they did the amputation.

None of the participants were forewarned about the fact that they would experience phantom sensations, causing some to initially think that their limb had not been amputated or that they had woken up during the surgery:

The phenomenal thing that you experience is that you think your arm is still there...You can always feel it...My first reaction when I woke up from the surgery was that they didn't do it.

I started moving my leg a little bit. It hurt but I thought it wasn't gone because it felt like it was still there. So I thought, "Oh, oh, I'm awake in the surgery."

All of the participants believed that the surgery played an important role in their survival and cure. One participant described her thoughts on this matter in the following way:

I definitely believed in the surgery. When you can see something growing so fast that it is out of control, you know that it must be taken off or taken out or it will overrun your body.

It was difficult for them to accept the fact that so much of the limb had to be amputated. This point is exemplified in the following quotes:

That was the hardest thing for me. "What? You said it was a small bump. You have to take my leg?"

It always seemed a shame to me that I had to lose the rest of it, when the only part that was bad was this area just above the knee.

The participants often wondered about other alternatives. The option of limb-salvage surgery was viewed as preferable to amputation:

I didn't know if I'd come out any better, but I decided to go for it because I could still have an amputation if there were any problems... So I was gaining whichever way I went.

Four participants had the rotationplasty procedure performed. Although they initially found the appearance of the reconstructed limb unattractive, they chose this option rather than amputation because it allowed them to have better limb function, and a more normal gait. All were glad they chose to have this procedure. The following quotations describe some of their initial reactions to hearing about rotationplasty:

They told me about the procedure, rotating my foot around and all the rest. And I thought they were nuts, because it's hard to visualize. I couldn't believe that they'd want to do something like that.

I said I didn't want my foot on backwards because I didn't want everyone to see it. He (the doctor) said that it would be hidden in the prosthesis.

I said, "Well fine. If I'm walking as normally as possible then let's just do it. I don't care about appearance."

Two participants had limb salvage surgery performed to reconstruct the upper arm. Both were glad they chose this option, even though one had serious complications and subsequently had an amputation performed. She found meaning

in knowing that she had contributed to the initial knowledge about limb-salvage surgery.

The Prosthesis and the Rehabilitation Process

The participants had misconceptions about what the prosthesis would look like, when they would receive it, and how it would be attached. They were concerned about what their limitations would be as amputees, how others would react to them, and what life as an amputee would be like. As illustrated in the quotes that follow, those who sought information about the prosthesis and life as an amputee found that other amputees were the best source, with much of the information being communicated nonverbally.

She would show it to me and that helped answer my questions.

Once I saw her walk I felt a bit better and I knew that I had made the right choice... She walked really well...And her leg looked real.

One lady lost her left arm too and she had a family and she carried her baby around. It made you look forward to what was out there.

The prosthesis was viewed as a constant reminder of what had happened:

Every time I get up now in the morning, I put on the prosthesis and it's a reminder that this happened six years ago...No matter how good I feel, if I'm dancing or whatever, it's there.

The initial reaction to the prosthesis was sometimes negative:

I hated this thing. I was hopping at the speed of light, I could move on one leg. I hated it and I wouldn't wear it. I can't walk, it's uncomfortable, and I feel like I'm dragging around a piece of dead wood.

Ultimately, most of the participants saw the prosthesis as a part of their body and refused to go out in public without it. They felt helpless, less normal, and more noticeably different from others when they weren't wearing their prosthesis:

It's not me. I am in heels, nylons, a dress, and with an arm in my pocket. That's me. I mean me is also sitting here without my prosthesis, but not at work.

When I had the artificial leg on, I felt relatively normal, but when I didn't have it on I didn't feel very normal... I felt much more helpless and like more of a cripple when I didn't have it on.

You feel really self-conscious and helpless without your prosthesis, in that you're not as mobile.

They couldn't get around as quickly on crutches, and crutches tied up their hands. Many of the participants would take the prosthesis off at home, particularly on a hot day, when wearing the prosthesis was uncomfortable.

Most of the participants, particularly those with osteogenic sarcoma in the lower limb, described the rehabilitation process as hard work, requiring determination, motivation, and perseverance. Progress often seemed slow

At first there were no results in physio and I was getting pissed off. I was doing these stupid bean bag throws, and I'm like, "What am I doing this for?"

Walking. Taking a step onto something that you can't feel underneath you and trusting that it's going to be there for you ...You have to have a lot of courage to make those steps, especially with no crutches and no canes. And as you go from crutches, to a crutch or to a cane, you can see your progress. It feels like it's taken forever. But when you look back it's only been a few months.

The stump would swell on hot days or during chemotherapy treatments, making the prosthesis very uncomfortable to wear at those times:

I would get on my legs for five hours a day and then I would go for chemotherapy and I'd have to start all over again. It ticked me off.

There were a tremendous number of small adjustments that had to be made. The participants described the process of making those adjustments as follows:

You challenge yourself on the simplest things, which brings everything to its smallest scale. And you rebuild it so that it works for you. You make an adjustment going down the stairs. You make adjustments sitting on the toilet, in the shower, and in the bathtub.

I remember the first day I did up a pair of jeans with one hand. It took me probably about four hours to figure it out...It's stuff like that. Just stupid little things that take the time to figure out. Things you take for granted all the time.

"It's all up to you," was the phrase they used to describe how well they would walk, and what their limitations would be. There were no obstacles that were insurmountable if the desire to accomplish the task was great enough.

Living with Amputation

The worst part of being an amputee was having to deal with the reactions of other people, and particularly with people staring at them. An initial phase of extreme self-consciousness and oscillating self-esteem was common following amputation. The participants often went to great lengths to hide the fact that they were amputees. They dressed in clothing that would hide their prosthesis, and often made up stories about what had happened to them if someone noticed something unusual about their appearance or gait. They expended a tremendous amount of energy trying to "look normal". The following quote illustrates the initial phase of living with amputation:

I made a bit of a pact with myself that I was going to do everything I could to hide it. I was going to learn to walk as well as I possibly could to get to the point where people hopefully wouldn't notice anything different about me....I took stairs two at a time, so that I could climb them at roughly the same speed as other people....I was conscious of how I would fit and what side my leg was on compared to other people. Because if they bumped it, they might figure out that it wasn't a real leg.

This phase of extreme self-consciousness gradually lessened over a variable period of time; as the participants came to accept themselves as normal, desirable, and worthy of acceptance by others, they began to expend less energy trying to hide the fact that they were amputees, and described starting to live life the way they wanted to:

I'm getting to the point where I don't like it preventing me from doing something I want to do... It came to a point where if anybody asked, I would say, "It's an artificial leg"... I was getting a little less paranoid about people knowing, and more interested in getting it out of the way.

They began to wear the clothes they wanted to wear, and to see others who reject them because of external appearances as not the type of person they would like to befriend anyway. They cited the support and encouragement of family members and friends as important in helping them accept and believe in themselves:

When I met my fiance I started to wear dresses and I started to wear no socks... It was like this thing came over me. If one person who is a total stranger can love me and he knew everything that was happening to me, like I'm sure there's a lot more people too. They don't necessarily have to love me. They just have to realize that it's a part of life.

The participants described ongoing episodes of "feeling robbed," which commonly occurred when they felt "different", or when they could not do the things that they wanted to do easily or well:

There are situations where you want two legs because you just wish you could be like everybody else that you see around you. So you don't have to be different.

Every actual or potential rejection was viewed as related to being an amputee.

Many of the participants had dreams in which they were whole, with all limbs intact. A few chose to hang onto daydreams and fantasies of having a normal limb again (or a bionic replacement) someday. Some of the participants named their stump, their prosthesis, or their crutches, and one individual painted her prostheses. These individuals felt that doing so helped them accept the prosthesis and the stump.

Interpersonal Relationships

Family and friends were very important in helping the participants cope with their illness. Initially, most of the participants wanted to "go it alone"; they later realized that they wanted and needed the support of others. They often realized how important the support of their family was after they met others who had to go through the experience without that support:

When I was in hospital, and I was just laying there, I'd see this lady beside me. She was by herself all the time...I'd see her face when my mom or dad or friends walked in and they'd say "hi" to her and ask her how she's feeling. I saw the light in her eyes and smile on her face, and thought, "Ya, she does need people around her." And she was a strong lady.... That was when I realized that you do need family and friends.

The participants described supportive individuals as strong, hopeful people who "were there" for them, accepted them as they were, treated them normally, believed in them, and encouraged them in their efforts to achieve goals. The following are examples of the supportive roles played by their families:

They're good. They're supportive. They won't stop me from trying anything. Some of them will even encourage me to try something.

My mom was always there. She was always really positive. She would say, "It's only a short time in your life"...She was always trying to make me feel better about the way I looked too....She would come up with new styles

for hats and new makeup styles, like putting on eyebrows. Nobody ever knew I lost my eyebrows...And she would listen.

The participants found that if they accepted themselves, others would too:

If you have the ability and the confidence to be who you are, then that's all it takes. Because then people around you don't treat you like you're some china, that they have to be very careful about what they say.

After the diagnosis of cancer was made, the participants found that some friends deserted them. They ultimately saw cancer as a blessing in disguise, in that it helped them quickly find out who their real friends were.

In general, the participants did not talk about the cancer experience and their feelings with their friends who did not have cancer. Their relationship with their friends was one of doing normal things together. Their friends lived the experience with them:

We were growing together. They knew what my limitations were... and how I dealt with situations...The only time they stepped in for my defense was when I wasn't there...That, "No, she's not a gimp, she's not a cripple. She can do anything she wants to."

The participants were more willing to discuss their cancer-related experiences with other cancer patients and amputees, although not all chose to do

so. Some stated that they "did not feel the need" to talk with other people in their situation:

I felt that I could take it on and be on my own. I wasn't sure that there was anything that anybody else could tell me that would help.

Those that chose to interact with others in a similar situation found the experience a positive one. They felt understood by others with cancer. The feeling of being understood was often described as coming from nonverbal communication. "We could relate to each other and not have to talk about it all the time. It's just sort of there between you." They found others with cancer to be a source of hope for getting through the treatments, a source of hope for a normal life, good health, and cure, and a sign that they weren't alone. "We weren't sick together but separately we were." For the participants who were young adolescents at the time that the cancer was diagnosed, relationships with other cancer patients or chronically ill children often focused on normal adolescent activities and interests:

We'd cruise the halls or play pool. Normal things. It made you feel like a human being again.

The older adolescents spent more time discussing their cancer and their lives. They often came away from such discussions feeling that their problem "seemed trivial compared to anybody else's."

Positive interactions with the health care team were characterized by demonstrations of caring, hope, and respect for the individual. "It's so nice to have

somebody come who is not directed toward illness that's treating you as a person, not like a sick person." The participants appreciated health care professionals who were honest, open, patient, and willing to spend time and listen, as well as to set limits when necessary:

She (the nurse) always knew when to touch my hand. She always knew when to smile. She knew when it was time for tea and toast after I had puked my guts out...And she never freaked out when I lost my cool. She would just look at me and say, "Get on with it, get it over with, and then we'll continue."

He (my doctor) was giving me everything that I asked for, and that's not good for me.

The participants expressed anger toward and subsequently avoided health care professionals that they perceived as incompetent or cold and uncaring, who treated them as nonpersons, were judgmental of them, minimized their concerns, rushed, withheld information from them, violated confidentiality, denied them any control or choice, or conveyed messages of hopelessness:

I trusted them, they lied to me, and now I don't trust them...All I can do now is wonder ..."Are they telling me the truth?"

She (the doctor) came in in a whirl and started talking about 100 miles per minute.... And she talked to my parents. She never really talked to me and

I immediately resented her for that. Like, "This is me, talk to me. I'm a person."

Ongoing Fear of Recurrence

Fears of recurrence often surfaced around the time of clinic visits. However, the clinic visit was also seen as a chance to discover a recurrence early enough that there was still hope for cure. Getting normal results at the time of the clinic visit reassured them that all was well:

As an appointment for a checkup approached, I'd start imagining all sorts of things...And then I'd go in and they'd check me out and everything would be fine. And I'd breathe a big sigh of relief and off I'd go again, for another few months. And I'd come back and go through the whole thing again.

I get really down about a week before. It's just knowing that I went through all that once before. Even if you try to keep it out of your head, you still think, "Well, I might have to do it again."

Some were frightened when they heard that another individual had experienced a recurrence, while others were not:

I had seen other kids go through it. I think they had leukemia...When their cancer came back I would ask, "What are my chances of that happening?"

When you see people that are in the same position as you are and it's not working out, you really wonder.

It really frightened my parents, but it didn't frighten me. It didn't mean it would happen to me.

Cancer as a Positive Experience

The cancer experience was viewed as a positive one overall. The participants felt that the experience had made them stronger, and more confident in their ability to overcome obstacles. The experience heightened their sensitivity to the needs and feelings of others. They wanted to help others in a similar situation, and usually took great pleasure in playing the role of amputee-visitor for others with osteogenic sarcoma. The cancer experience altered their perspective of life, helping them appreciate it more fully:

You don't know the freedom you have unless it's taken away. So you become that much more appreciative of it.

I think that it's like being given the ability to see colors that people can't place, and to smell things that people can't smell. It just gives you that edge that makes everything a little bit more special.

Choice/Control

The participants found that having a positive attitude helped them cope with their cancer and the treatment for their cancer. They believed that being hopeful was a matter of choice, and took responsibility for finding ways around obstacles:

You have to have the right attitude. If you say, "Well I'm helpless", then you are helpless. But if you say, "Look, I'm going to get up and face this head on", you will, and you'll win too.

If you want to do something badly enough, there's a way....So use your own ingenuity and creativity to think up new and different ways to do things that you used to enjoy, or would like to do. The key really is that it's not the end of the world. It's simply a little blip in your lifetime. Adjust to it and keep going.

It's all up to you. If you want to go on with your life and make it the best that you can, have kids, whatever, you can if you want to. If you don't want to, you won't....You can't dwell on something that you can't change.

Some of the participants believed that their mental attitude played a major role in their cure:

I think it's your own mind, your gusto, your will. I don't think it has a lot to do with the drugs. I mean I suppose statistics show that. But if just as

much energy was given to a person's head and well-being, I wonder whether the statistics would be the same.

I was very in tune with my body and my mind. I really believed that I had the ability to control my disease and my destiny in a lot of ways.

Control was viewed as an important factor in coping with their illness and treatment:

I don't care how young the kids are. This is their body and if they're going to have anything to do with their disease and helping to cure themselves, they have to be given that control. They have to be given the opportunity to make some decisions for themselves.

The participants relinquished a fair amount of control at the time of diagnosis. Feelings of anger, fear, and helplessness were experienced when they were treated as passive participants in their care:

I didn't have control of my situation. I was kind of flailing and I was being pushed around...I was scared and I was mad....I felt like I was being manipulated.

They ultimately took back some control once they knew more about the system and about their disease and treatments:

You're so unfamiliar with the procedure, and you're just a naive kid and these people are trained and they know what they're doing, so you don't really question what they're doing....When you get into the groove and see the patterns happening, you can say, "Hold on a second here."

This was particularly evident when trust in the competence of a member of the medical team wavered, treatment was ineffective, the participants' threshold for tolerating ongoing discomfort and disruption of their lives was exceeded, or they were regarded as passive participants in their care:

I got sick and tired of them saying it (the chemotherapy) didn't do anything. So I said, "No. It's time I had control here"...When I realized that I could have control, ya, I stopped it.

I didn't really want to talk to him (the psychologist), but my mom made me go...I was a bit rude but I wanted to be rude because I didn't want to talk to him.

The participants expressed a desire to have some control over the amount, type, and timing of the analgesics and antiemetics that they received. Some chose to vomit or be in pain rather than experience the loss of control associated with the side effects of the antiemetics or analgesics:

The pain I could deal with. I wasn't happy about not being in control, not being alert enough to deal with whatever somebody might be wanting to do to me.

Efforts to maintain control often focused on choice, which depended on information about the disease, the treatment, and the impact that the diagnosis and treatment would have on their lives. The younger adolescents demanded information from their parents, and used the phrase, "it's my body and my disease", to justify their right to receive information.

The amount and type of information that the participants wanted varied. A few of the participants preferred to obtain less detail. One individual in particular became angry when health care professionals tried to give her information about the details of the rotationplasty procedure, and introduce her to others that had undergone similar surgery. "I need to discover it for myself. I can't keep comparing myself to somebody." She preferred to rely on her trust in the medical staff, rather than learn about the intimate details of the surgery.

Some of the participants wanted detailed information about the tests being performed and the medications being administered. They would not consent to proceed until all of their concerns had been adequately addressed:

I basically came to the point where I wouldn't let anybody do anything to me unless I knew why it was happening, who ordered it, and what it was supposed to accomplish.

Most of the participants wanted to be given the choice of talking with others, and to have some control over the location, timing, and content of those discussions. They wanted to play a role in the decision-making process, especially with regard to the type of limb surgery to be performed, and the type of prosthesis chosen.

Hope

The interviews contained numerous messages of hope, many of which were stated implicitly. These included messages of hope for survival, wellness, and cure:

They would say the tumor was shrinking and I got my hopes up. I thought that if I kept taking more it would go away. It never did. And then they said, "Well, it's time to stop. We have to do more." That made me die a bit.

One of the overriding hopes of the participants was to be normal:

When my hair started growing back they would all come around and feel it. That made me feel good. That gave me hope. "Look you're growing hair. It's going to come back. I'm going to be normal."

The participants hoped that they would have the strength to get through the treatments, adapt to the changes, and overcome obstacles. They hoped that they could "go through it and live through it and...lead a normal life afterward." In

addition, some expressed the hope of accomplishing something meaningful during their lifetime. A few expressed hope of finding meaning in their suffering, seeing themselves as chosen to accomplish a mission which they did not yet understand. Some of the participants also expressed the hope that one day they would have a normal (or bionic) limb to replace the one that they had lost.

The negative experiences associated with chemotherapy inhibited hope:

(During chemotherapy) I drew pictures of a person standing over a grave. All of them had teardrops, and they were all women. As soon as my chemo stopped I started drawing happy things. Couples, men and women together. And they always had smiles on their faces.

I need something more in my life than being in this hospital room and waiting to be cured...I did it for six years and I can't do that anymore because it took a lot away from my life...I can never make up the six years of worrying, but I certainly try and make it better.

Pity also inhibited hope:

To take away hope they could have just sat around and felt sorry for me. I've had people who have done that and it doesn't make you feel much better...It can definitely bring you down.

I started to lose myself...They were always carrying me everywhere and doing things for me.

It was not the event that gave or took away hope, but rather the perception and meaning that the event had for the individual. For example, seeing other amputees walk poorly motivated some of the participants to work harder in physiotherapy. The experience served as an incentive rather than as an inhibitor of hope.

The participants described themselves as the primary source of hope. The support of others, particularly family members, was important in maintaining hope, especially at times that the participants lost hope. Proof (that the participant could achieve the goal, or that others had been able to do it) fostered hopefulness, with "living proof" conveying a more convincing message of hope than verbal statements. Knowing that they had surpassed some milestone also fostered hope.

Hope resources (or inhibitors) included the health care professionals, friends, family, other cancer patients and amputees, as well as unconventional therapies, such as faith healers and vitamin E:

He (my doctor) was a person who gave me lots of hope...Just his whole attitude and presence were more important than what he was saying...He was very confident in how successful this chemo is...That made you say, "Yah, right on."

It's such an easy feeling to say, "I give up, I hurt too much"...But if you have something to look forward to, like if you see someone else being further ahead than you and doing really well, it makes you feel, "Well geez, I have to hold on. If you can do that, I can do it too."

One lady lost her left arm too and she had a family and she carried her baby around and it made you look forward to what was out there.

The kids were a big part of the reason I had so much hope. It's just seeing them and knowing that there was hope and that there was a good outlook.

If he (a faith healer) was alive when I was diagnosed, I would have gone to him first, before the doctors, because I believed in him.

Vitamin E was part of my treatment...We believed in it. And I believe that anything you believe in strongly enough is going to help you.

The participants conveyed many implicit hopes for their relationships. These included hopes that they were not alone and that others would "be there" for them. They hoped that others would accept them as they were, treat them normally, and encourage them in their efforts to overcome obstacles and achieve their goals.

Desire to be Normal

Being normal was one of the major hopes and goals of the participants. Being normal was defined as looking normal, interacting with "normal people" (who were not amputees or cancer patients), and being involved in "normal" activities. "Being different" was sometimes equated with "being abnormal", particularly in the early stages of the adjustment process.

In general, the participants attempted to get on with life as it was before the diagnosis of cancer was made. They wanted to "assimilate into a normal lifestyle, be a normal person", and "fit in with normal healthy people." Most of the participants avoided conferences and camps for cancer patients or amputees. "It brought back memories that I'm not the same as other kids." They would only associate with other amputees and cancer patients in the hospital or clinic setting:

It was fun because I was in the hospital and we were all there at the same time. For me to specifically meet them, that I had no interest in, because that's like saying, "I am this poor disabled person, and therefore these are the people I should hang around with."

A lot of the time you just deal with cancer and it's finished. You're healthy. And the last thing that you want to do is go to a camp and see a whole bunch of bald kids and all of these reminders of what it was like for you when you were sick.

I always viewed that as a fallback. If I couldn't make it in the real world then maybe I'd have to settle for hanging out with other amputees.

Those that did attend camps and conferences for amputees or cancer patients found the experience a positive one:

When you do go to these camps there's always so many similar experiences. They're the only people that you can actually talk to...They

know what you've experienced, your pain....I met a lot of wonderful people there.

Once the participants had accepted themselves as normal despite their amputation, they found the conferences for amputees to be an excellent source of information about types of prostheses which would facilitate resuming normal activities.

The participants ultimately accepted themselves as normal despite "being different":

It's important to be yourself and to be sure of who you are and not feel that you have to be like everybody else....You have to convince yourself that different is good because you are different....All you have to do is really believe that what you are isn't bad, isn't disgusting, that you're unique...And you make it work to your advantage.

Discussion

In order for health care professionals to help the adolescent with osteogenic sarcoma cope with the cancer experience, they must have some insight into the experience of living with osteogenic sarcoma from the perspective of the adolescent with cancer. Armed with this understanding, they will be able to identify needs, concerns, and preferences, and devise effective helping strategies.

The experiences of adolescents living with osteogenic sarcoma have been described in this chapter. One point that stands out from understanding their experience is how distressing the cancer experience is for them. It is not surprising that many of them think about discontinuing their chemotherapy prematurely. The distressing aspects include ongoing nausea and vomiting from chemotherapy, being different ("abnormal"), the painful procedures, the violation of privacy, waiting, the loss of control, and the disruption of their normal lifestyle. The health care professional can help adolescents cope with the cancer experience by instituting measures to reduce their discomfort, minimize waiting, and lessen the disruption of their lives. The health care professional can also help by respecting their need for privacy, by giving them more control and choice, and by treating them as "whole" people.

Adolescents with osteogenic sarcoma need to know that there is hope, and that there are others who care about them, accept them as they are, and will not desert them. They need to know that others see them as normal, attractive and desirable, and have normal expectations of them. They often lose sight of the progress that they have made, and need encouragement from others as they attempt to overcome obstacles, be normal, and get on with life.

Adolescents with osteogenic sarcoma want to be empowered. That is, they want to be treated as strong, intelligent young adults and to be involved in the decision-making process. As health care professionals, we can help them become empowered by providing them with optimal emotional support, by meeting their informational needs, and by encouraging them to participate in the decision-making process. The topic of empowering adolescents with osteogenic sarcoma is discussed in chapter III.

Health care professionals must pay attention to their own verbal and nonverbal communication, and realize that information is most powerfully conveyed through nonverbal communication, such as body language, actions, and "proof".

In general, the information obtained in this study regarding the concerns of adolescents with cancer concurs with the information which is available in the literature. However, the fact that the negative aspects of the chemotherapy experience represent a major threat to compliance has rarely been emphasized (Cohen, 1986; Dolgin, 1988). Although the importance of giving the adolescent as much control and choice as possible has been stressed in the literature, little has been written about the types of issues over which adolescents want to have some control. This study has identified some of these issues.

The maintenance of hope is crucial in helping the adolescent cope with the cancer experience. Methods of fostering hopefulness have not been stressed in the cancer literature, nor has the importance of nonverbal communication. Although social support plays an important role in maintaining hope and coping with cancer, little has previously been written about how to be supportive to the adolescent with cancer. This study identifies some of the messages of support that adolescents with cancer need to receive, highlights the importance of nonverbal communication, and provides some insights into how to foster hopefulness.

This study also expands on the available knowledge about the experiences of adolescents living with amputation. The evolving nature of the adolescents' views of amputation and their ongoing intermittent feelings of loss have not been previously described, nor have the processes of rehabilitation, adjusting to the prosthesis, and life as an amputee. Although the importance of the amputee-

visitor as a source of information and hope has been cited in previous studies, what has not been stressed is the fact that not all individuals undergoing amputation want to have another amputee visit. The fact that most adolescents with osteogenic sarcoma prefer not to be closely associated with other amputees or cancer patients has only been alluded to once previously in the literature (Tebbi, Stern, Boyle, Mettlin, & Mindell, 1985).

The major limitations of this study are its retrospective design and reliance on accurate recall of experiences that occurred many years prior to the study. Ideally, the validity of the results of this study should be confirmed in a study which utilizes a prospective longitudinal design. The generalizability of the findings should also be assessed by studying adolescents with osteogenic sarcoma and other forms of cancer who have been treated at other treatment centers, as well as adolescents undergoing various forms of mutilating surgery.

Recommendations

The health care professional must attempt to make the cancer experience more tolerable for adolescents with osteogenic sarcoma, and must encourage them to become active participants in their care. All individuals playing a supportive role must convey caring, hope, acceptance, and encouragement to the adolescent, as he or she attempts to overcome obstacles, be normal, and get on with life. The specific and unique issues that are of significance to the individual adolescent with cancer can only be understood by attending to his or her verbal and nonverbal communication.

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CHAPTER III

EMPOWERING ADOLESCENTS WITH OSTEOGENIC SARCOMA

Introduction

Adolescence may be defined as the period of life which begins at about age 11 years and ends at about age 21 years (Steinberg, 1989). It is a time of tremendous change, and is characterized by increasing autonomy, a preoccupation with body image, a desire for acceptance by and conformity to their peer group, the search for identity, and the emergence of sophisticated thinking abilities (Kaiser, 1988a; Kellerman & Katz, 1977). Adolescence is a period of transition, marked by intense physical, emotional, and social changes, as well as developmental challenges that are part of the passage to adulthood.

Having a life-threatening chronic illness such as cancer makes the transition through adolescence much more difficult (Adams & Deveau, 1988; Adams & Guido, 1984; Blotcky, 1986; Kagen-Goodheart, 1977; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986). The cancer experience is characterized by a loss of control and privacy, increased dependence on others, and ongoing feelings of uncertainty about the future and about relationships. Furthermore, the aggressive anticancer treatment programs that are responsible for the improved prognosis of many pediatric malignancies constitute major sources of distress for the adolescent with cancer. Most adolescents find their anticancer treatment program difficult to endure (Dolgin, 1989; Sitarz, 1988; Van

Dongen-Melman, & Sanders-Woudstra, 1986). For many, the pain and discomfort associated with the treatment and procedures are more distressing than the disease itself. The chemotherapy experience is particularly arduous, and is often characterized by thoughts of prematurely discontinuing therapy. Ongoing feelings of nausea and vomiting, and the disruption of their normal lifestyle are often more than they can bear.

Adolescents with cancer want to be normal and to get on with life (Rechner, 1990). They want to look "normal" (rather than different), do normal things, and interact with "normal" people. The treatment they receive often causes a temporary or permanent change in their physical appearance, rendering them different from their peers. Having to undergo mutilating surgery such as amputation leads not only to a distortion of their body image, but also to a loss of their sense of wholeness (Kaiser, 1988a; Kindon & Pearce, 1982; Sitarz, 1988). The perception of being different may lead to feelings of inferiority and a loss of self-esteem.

The health care professional involved in the treatment of adolescents with cancer must try to make the cancer experience more tolerable for them, and help their adolescent patients cope with the treatment. However, the available literature offers little guidance regarding how to help adolescents cope with the cancer experience.

A logical prerequisite to the development of effective helping strategies for adolescents with cancer is the acquisition of some understanding of their needs, concerns, and preferences. The best way to gain that understanding is to view the cancer experience from their perspective.

The author has had the opportunity to study and gain an understanding of the experience of living with cancer from the perspective of thirteen individuals who were diagnosed to have osteogenic sarcoma in adolescence. Osteogenic sarcoma is a type of cancer which arises in bone. It is usually diagnosed in adolescence, and is treated with the combination of aggressive multiagent chemotherapy and mutilating surgery (either amputation or complex limb-sparing surgery).

The experience of living with osteogenic sarcoma has been described in chapter II. The information presented in the current chapter originates from the data obtained in the interviews, as well as from the learning acquired by gaining an understanding of the experience from the perspective of adolescents with osteogenic sarcoma.

A prominent theme that emerged from the analysis of the experience of living with osteogenic sarcoma was the desire for empowerment. That is, adolescents with osteogenic sarcoma want to be informed, to play a role in the decision-making process, and to be treated as strong, intelligent young adults who are capable of making sound decisions and achieving any goals that they set for themselves. The health care professional can help adolescents with osteogenic sarcoma cope with the cancer experience by helping them become empowered. This involves the provision of emotional support, meeting their informational needs, and developing a relationship with them which is characterized by mutual trust, respect, collaboration, and shared decision-making.

A review of the general concept and process of empowerment will be followed by a discussion of the process of empowering adolescents with osteogenic sarcoma.

Empowerment: A Review of the Literature

Empowerment may be defined as a social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order for them to feel in control of their lives (Gibson, 1991). The concept of empowerment is a dynamic and transactional one, involving relationships with others. Power is both given and taken. The outcome is not necessarily having more power, but feeling more powerful. Although empowerment most often implies a process whereby power is gained, it also includes minimizing the loss of power (Gray & Doan, 1990). The focus is on solutions rather than on problems, and addresses people's strengths, rights, and abilities, rather than their deficits. Conflict, tension, and growth are inextricably intertwined in the process. There will inevitably be tension between the goals of empowerment and the desire to preserve the institution (Gibson, 1991).

The concept of empowerment is based on a world view which is characterized by the following set of beliefs about the individual: a) that the individual is of great worth and dignity; b) that the individual has the right and ability to make decisions and act on his or her own behalf; c) that the individual often knows what changes have to be made and will strive to grow in a positive direction; d) that every person should have an equal opportunity to maximize his or her potential, and is deserving of societal help in attempting to do so; e) that many competencies are already present or at least possible, given niches and opportunities (Dunst, Trivette, Davis, & Cornwell, 1988; Emener, 1991; Gibson,

1991; Lord & McKillop Farlow, 1990; Rappaport, 1981); f) that individuals have the best understanding of their own needs (Gray & Doan, 1990); and g) that it is desirable for individuals to have the greatest degree of control possible in determining various aspects of their lives (Gray & Doan, 1990).

Empowerment is a labour-intensive process which makes demands of the individual, who must empower himself or herself (Gibson, 1991; Rappaport, 1985). It is nurtured by the effects of collaborative efforts which help to develop, secure, and use resources that will foster the individual's sense of control and self-efficacy (Gibson, 1991; Lord & McKillop Farlow, 1990). Empowerment is situationally determined. An individual may want and need to have control over certain aspects of his or her life and not others. Empowerment will therefore "look different" depending on the situation and the individuals involved (Rappaport, 1981, 1985). The process is highly individualized and is related to timing and to the interaction of external resources and internal motivations. The transition to empowerment may be very uneven, and may be characterized by a constant struggle to maintain a sense of empowerment (Lord & McKillop Farlow, 1990).

Antecedents to empowerment involve factors pertaining to the individual, the external environment, and the relationship between them. For the individual involved, the first event in the process of empowerment is the actual or potential loss of power or control (Gibson, 1991). It is the violation of the individual's sense of integrity, not intellectual analysis of the situation, that activates the process (Gibson, 1991; Lord & McKillop Farlow, 1990). Threats to self-interest elicit feelings of frustration, outrage, or a sense of confrontation, and motivate the individual to try and regain some control of the situation. The mobilizing episode has some particular symbolic or emotional significance for the person involved. In

most cases, the motivational trigger leads to change because the individual learns that he or she has a voice, and that there are others who will listen and understand (Lord & McKillop Farlow, 1990). The willingness to question is also an important factor. As the process evolves, individuals sense their growing consciousness of their own capabilities and rights, and experiences a shift in their perspective (Lord & McKillop Farlow, 1990).

Kieffer (1984) has described four stages through which the individual passes in the process of empowerment. During the first stage (the era of entry), the participation of the individual is exploratory, unknown, and unsure, while authority and power structures are demystified. The second stage (era of advancement) is characterized by a mentoring relationship, as well as supportive peer relationships. Opportunities exist for collaboration and mutually-supportive problem solving. A critical understanding of the situation is gained with the assistance of an external enabler. The individual develops a plan of action and accepts responsibility for choices.

In the third stage (the era of incorporation), activities focus on confronting the barriers to self-determination, while the fourth stage (the era of commitment) is characterized by the integration of the new personal knowledge and skills into the individual's world.

The antecedents to empowerment in the external environment include the availability of information and the provision of support by others (Lord & McKillop Farlow, 1990; Price, 1988). In order to enable the individual to become empowered, others must have attributes such as courage, commitment, flexible understanding, flexibility, an appreciation of diversity, tolerance, cooperation, empathy, and a willingness to listen and compromise (Gibson, 1991).

who has already lived through a particular situation can serve as a mentor or guide to an individual who is struggling with that same situation (Lord & McKillop Farlow, 1990). A supportive environment is also characterized by the presence of assertive, confident people who accept and value the individual unquestioningly, and believe in his or her capabilities (Lord & McKillop Farlow, 1990).

An empowering relationship is an equal partnership, in which the people of concern are treated as collaborators. It is characterized by participatory decision-making, mutual goal-setting, negotiation, and a certain amount of risk-taking on the part of both the individual and the external environment (Dunst et al., 1988; Gibson, 1991; Price, 1988). Mutual trust and respect are vital antecedents to the empowerment process.

The outcome of empowerment for the individual is a sense of mastery, control, self-efficacy, satisfaction, connectedness, and growth, as well as a feeling of hope (Dunst et al., 1988; Gibson, 1991).

The traditional medical model of health care is disempowering. The health care professional is viewed as the powerful expert provider, and the patient as a disease and a passive recipient. Assertive health care recipients are labelled as difficult, manipulative, or obstructive. Dissatisfaction with the medical model of health care has led to a rise in other models of health care, particularly the empowerment model (Funnell et al., 1991). In the latter model, health care recipients are encouraged to be assertive. They are regarded as the experts on their own lives, and are viewed as equal and active partners in the treatment program.

Reciprocal trust is a necessary component of satisfying and effective health care relationships involving chronic illness (Thorne & Robinson, 1988). That is,

health care recipients must trust their health care professionals, and health care professionals must have trust in the health care recipients' ability to make sound decisions with regard to illness management. From the perspective of the health care recipient, reciprocal trust fosters the development of competency with illness management, and promotes increased trust in the health care professional.

The evolution of trust in health care relationships involving chronic illness parallels the evolution of the empowerment process in that setting. Health care relationships evolve through three distinct stages over time (Robinson & Thorne, 1989; Thorne & Robinson, 1988, 1989). These stages represent changes in perspective which occur as an inevitable result of discrepant expectations between health care receivers and health care providers. The first stage, called naive trust, is characterized by patients and their families believing that the health care professional has an intrinsic understanding of what matters to them. Their expectations are inevitably unmet, and dissatisfaction ensues. The second stage is called disenchantment, and is characterized by shattered trust in the health care system. The triggering factor may be a relatively small incident that is simply the "last straw" in a progression of mounting frustrations, or a specific episode, such as evidence of incompetence in medical management. During this stage, patients and their families are frustrated, angry and confused, and may exhibit disruptive behavior. In the third stage, called guarded alliance, selective trust in specific professionals replaces generalized trust in the system, and informed decision-making takes the place of blind compliance. During this stage, health care recipients usually take more responsibility for their illness and their treatment, and become empowered in the process.

Methodology

Subjects

Thirteen individuals who were diagnosed to have osteogenic sarcoma between the ages of 10 and 21 years and were being followed at one major cancer centre participated in this study. The characteristics of the participants are described in chapter II.

Data

During semistructured interviews, participants were asked to describe their experience of living with osteogenic sarcoma, starting from the time that they first suspected that something was wrong until the time that they were interviewed. They were also asked to describe their informational needs. The information sought from the data included: 1) the characteristics of the experience of living with osteogenic sarcoma; 2) the informational needs of this population; and 3) the factors influencing the communication process. A more complete description of the methodology is contained in chapter II.

Data Analysis

The data were analyzed and coded manually for descriptions, patterns, common themes and relationships, using the constant comparative method of data analysis. Two levels of coding were created and the data were analyzed for meaning units. The descriptive categories which evolved from the research questions were: 1) living with osteogenic sarcoma; 2) content-related

informational needs; 3) factors affecting communication; and 4) preferred and actual information sources. The themes in the category of content-related informational needs were grouped into the following subcategories: 1) general informational needs; and 2) specific informational needs regarding osteogenic sarcoma, limb surgery, the prosthesis, chemotherapy, and life as an amputee and a cancer patient. Both implicit and explicit informational needs were recorded. The themes in the category of factors affecting the communication process were grouped into the following subcategories: 1) factors related to the adolescent with cancer; 2) factors related to the environment (including family, friends, health care professionals, and society-at-large); and 3) the impact that those factors had on the relationship with the adolescent with cancer. The subcategories and themes in the category of living with osteogenic sarcoma have been presented in chapter II, along with a more complete description of the method of data analysis.

Findings

A prominent theme that emerged from the analysis of the experience of living with osteogenic sarcoma was the desire for empowerment. That is, adolescents with osteogenic sarcoma want to be informed, to play a role in the decision-making process, and to be treated as intelligent, strong young adults who are capable of making sound decisions and achieving any goals that they set for themselves.

The process of empowering adolescents with osteogenic sarcoma will be presented using Gibson's (1991) concept analysis of empowerment as a

framework. The antecedents to empowerment will be discussed in relation to the adolescent with cancer and the environment. The antecedents to empowerment in the environment will be discussed under the headings of 1) provision of emotional support and 2) meeting informational needs.

Antecedents to Empowerment: The Adolescent with Cancer

Most adolescents with cancer are not ready to be empowered at the time of diagnosis. They are overwhelmed, confused, frightened, and angry about having cancer, and are unfamiliar with the health care system, the disease, and the treatment for it. Unless they have had previous experience with the health care system, particularly in relation to management of a chronic illness, they will relinquish control to the members of the health care team, trust them implicitly, and assume that the health care system will recognize and meet all or most of their needs. They do not know how to ensure that their needs are recognized and met by the system into which they have been thrust.

Once they are more familiar with the health care system, the disease, and the treatments, and know what to expect, they are more ready and interested in taking back some control. Some of the experiences that may motivate them to take back some control are as follows: 1) their tolerance for discomfort or disruption of their normal lifestyle has been exceeded; 2) their needs have not been taken into consideration by the health care team; 3) they have experienced a loss of trust in the health care team. This may be the result of mixed messages, withholding of information, or breach of confidentiality. Similarly, trust may have

been lost as a result of perceived incompetence of a member of the health care team, or ineffective treatment. 4) They may have become angry with members of the health care team for conveying messages of hopelessness, treating them as nonpersons, or regarding them as passive participants in their care.

The amount of control desired and the areas over which the adolescent wishes to have control will vary from one individual to the next, as well as within each individual over time and in different situations. The following are examples of issues over which adolescents with osteogenic sarcoma may wish to have control: 1) the amount and type of information they want; 2) from whom they want to get that information; 3) whom they would like to be present during those discussions; 4) the amount, type, and timing of analgesics and antiemetics; 5) the type of limb surgery performed; 6) the type of prosthesis (or artificial limb) selected; 7) whether they wish to talk with other adolescents with cancer, and if so, to whom and when; and 8) whether they wish to talk about how they are coping or see a mental health care professional, and if so, to whom, when and where.

Antecedents to Empowerment: The Environment

Provision of Emotional Support

In order to enable adolescents with cancer to be empowered, others must provide them with ongoing emotional support. The category of supportive others includes all health care professionals, as well as friends, family, and society at large. According to adolescents with osteogenic sarcoma, supportive individuals display the following characteristics: 1) they are strong, hopeful individuals, who

are able to confront or set limits when necessary; 2) they are interested in trying to understand the experience from the perspective of the adolescent with cancer, value what the adolescent has to say, and take the adolescent's thoughts and feelings into consideration when making decisions; 3) they promote continuing support from the adolescent's preexisting support network, and do not supplant that network with professional networks; 4) they are nonjudgemental, accept the adolescent as he or she is, and are present (or at least available to the adolescent) at times of need; 5) they regard the adolescent as a strong, intelligent young adult who is capable of making sound decisions, and encourage the adolescent to participate in the decision-making process; 6) they treat the adolescent normally, and have normal expectations of him or her; and 7) they believe in the adolescent's ability to overcome obstacles, help the adolescent see the progress that he or she has made, and provide encouragement to the adolescent as he or she attempts to achieve goals and get on with life.

Meeting Informational Needs

One of the prerequisites for empowerment is the availability of relevant information. In order to meet the informational needs of adolescents with osteogenic sarcoma, the health care professional must understand their content- and process- related informational preferences. This involves gaining an understanding of what they want to know, when they want to receive that information, whom they want to convey that information, and whom they want to be present during those discussions. In addition, the health care provider must

understand what enhances and inhibits the communication process, as well as how the adolescents' informational needs change over time.

The issue of content-related informational needs will be discussed first, and will be followed by a review of the process-related informational needs of adolescents with osteogenic sarcoma.

Content-related Informational Needs

It is important to remember that the information conveyed must be tailored to the individual, since the amount and type of information desired will vary from one individual to the next. Although in the minority, a few adolescents do not want to get too much detailed information, and become angry when health care professionals try to inform them. Of course, in order to determine the unique informational preferences of the individual, the health care professional must ask the adolescent about his or her informational preferences and pay attention to verbal and nonverbal communication during the period of interaction.

Nevertheless, there are certain types of information that are likely to be sought by the adolescent with osteogenic sarcoma. These content-related informational needs will be discussed under the following headings: a) general informational needs; and b) other content-related informational needs, including informational preferences regarding limb surgery, the prosthesis, chemotherapy, and about life as an amputee and a cancer patient.

General informational needs.

It is vital that health care providers prepare the adolescent with osteogenic sarcoma for what is to come. All of the information should be presented at the

outset, rather than in a piecemeal fashion. Caregivers should provide information about what is being done, why it is being done, and whether it is really necessary. They should also provide information about how they can help the adolescent cope with the disease and the treatment. For example, if the adolescent were nauseated or in pain, what would they do to help?

Adolescents with osteogenic sarcoma need to hear that they have cancer, and that they need chemotherapy and surgery to save their lives. They want and need to know how they are doing throughout the duration of their treatment and follow-up. In addition, they want and need to know that there is hope for survival and cure, feeling healthy again, getting through the treatment, getting back to normal, and for having a normal and a meaningful life. This information is usually conveyed most effectively by nonverbal or indirect communication. Proof is the most powerful way of conveying this information, with "living proof" being more powerful than verbal assurances provided by the health care professional. "Living proof" may be defined as an experience which proves to the individual that he or she has achieved a goal, or that others in a similar position have been able to achieve that goal. The latter situation usually occurs when the adolescent with osteogenic sarcoma has an opportunity to interact with others who have cancer or who have undergone limb amputation.

The other general informational needs of most adolescents with osteogenic sarcoma centre around their hopes regarding relationships with others. Again, this information is conveyed most effectively through nonverbal or indirect communication. Adolescents with osteogenic sarcoma need to know that they are accepted, valued, and loved as they are. In addition, they need to know that others see them as strong, intelligent, attractive and desirable, believe in them, and see

their potential. Adolescents with osteogenic sarcoma also need to know that they are normal, that others have normal expectations of them, and that others will be there to support them and offer encouragement. They need to know that they are not alone. They also need to know that others are strong and hopeful, and will have the courage to say or do whatever needs to be said or done. This includes setting limits or confronting them when necessary.

Other content-related informational needs.

The specific questions which adolescents with osteogenic sarcoma may have about the disease, surgery, the prosthesis, chemotherapy, and about life as an amputee and a cancer patient are listed in Tables II-1 through II-5, respectively.

The terms osteosarcoma, tumor, and osteogenic sarcoma are poorly understood by adolescents with osteogenic sarcoma. The term "bone cancer" better conveys the seriousness of the situation to them. The health care provider must explain carefully why limb amputation is necessary, and review all of the possible alternatives with them, since it is difficult for most of them to understand why so much of the limb must be lost when only a small part is diseased. Adolescents with osteogenic sarcoma need to know what the stump or reconstructed limb will look like, and that it will feel like their (amputated) limb is still there. They also need to know that most obstacles in the rehabilitation process can be overcome if their desire to accomplish the task is great enough.

Adolescents with osteogenic sarcoma want to be informed about the details of the chemotherapy program. In addition to wanting information about all of the possible side effects of the chemotherapy, they also want information about the type and severity of side effects that they are likely to experience. In addition,

they want to receive information about how effective the treatment is likely to be. This information is conveyed most effectively by meeting others with osteogenic sarcoma who have undergone similar therapy and are surviving without any evidence of cancer.

Health care providers may also convey information about the anticipated effectiveness of treatment by describing their local experience with osteogenic sarcoma, or by quoting available statistical information about disease-free survival with a given treatment program. It is important to realize that some adolescents with osteogenic sarcoma do not want to hear about statistics. Therefore, before launching into a discussion of the available statistics, health care professionals would be wise to ask their adolescent patients whether they wish to receive this information.

Adolescents with osteogenic sarcoma are concerned about how others might react to seeing someone who has been labelled as having cancer, and who "looks different" because of hair loss and/or limb amputation. They are also concerned about whether they will still be able to have a normal life. Besides living the experience, the best sources for this type of information are others who have had a similar experience. This includes other individuals with osteogenic sarcoma or other forms of cancer, and occasionally others who have undergone limb amputation for reasons other than cancer.

Process-related Informational Needs

Information sources.

Younger adolescents (age 10 to 12 years) often prefer to receive information about their disease and the treatment from their parents, while older adolescents will usually prefer to receive information directly from the health care professional, with their parents attending all major discussions. However, there are exceptions to these generalizations, which can only be discerned by asking the adolescent about his or her preferences.

Most adolescents prefer to obtain information about the prosthesis, the rehabilitation process, and about life as an amputee from other adolescents with osteogenic sarcoma, as well as from their prosthetist. The preferred sources of information about living with cancer are other adolescents with cancer.

Most adolescents with cancer prefer to obtain information through direct communication, rather than through the use of audiovisual aids. Some adolescents with osteogenic sarcoma are interested in reading (or having their parents read) brief pamphlets about osteogenic sarcoma which describe not only the facts, but also the human story of living with osteogenic sarcoma.

It is important to remember that adolescents with cancer are exposed to multiple sources of information outside of the health care relationship and their preexisting support network. They may obtain information from such sources as television, newspapers, magazines (such as Reader's Digest), books, writing, drawing, dreams, bodily sensations, movies, music, faith healers, religion, celebrities (such as Terry Fox), and even strangers. Information gained outside of

the health care relationship may be very influential, and will affect the interaction between the adolescent with cancer and the health care team.

Timing.

The timing of information delivery is also important. Adolescents with cancer want to receive all of the information about the disease and the treatment at the outset, so that they know what to expect. Delivery of information in a piecemeal fashion destroys trust, diminishes hopefulness, and inhibits effective coping.

Adolescents with cancer also need ongoing ready access to relevant information. Their desire for information is usually greatest during the period of active treatment.

The communication process.

The communication of information must be regarded as a dynamic interactive process between the health care team and the adolescent with cancer and his or her family, rather than a one-way process characterized by a listing of facts by the health care professional.

Health care professionals can do much to enhance the process of communicating with and relating to the adolescent with cancer. The foundation is comprised of an awareness of their own behavior and attitudes, an understanding of what caregiver-attributes are desirable from the perspective of the adolescent with cancer, and some insight into how adolescents with cancer want to be treated.

According to adolescents with osteogenic sarcoma, the health care professional can facilitate communication by being a good listener, conveying a hopeful attitude, communicating in an honest, forthright manner, and by being attentive to nonverbal communication. They prefer to interact with a caregiver who is patient, gentle, caring, friendly, helpful, and concerned. Another desirable characteristic is the ability to relate casually and joke with the adolescent, yet have the courage to say what needs to be said, and to confront or set limits when necessary. Adolescents with osteogenic sarcoma want each of their caregivers to display commitment, dedication, and perseverance, and to be approachable and available. They prefer to interact with a caregiver who is able and willing to explain things well in lay terms, and who takes steps to ensure that they understand the information conveyed. They also prefer to interact with a caregiver who talks slowly, is willing to spend time with them, and does not rush them any more than is necessary during the decision-making process. In addition, they prefer interacting with a caregiver who displays self-confidence and looks as though he or she enjoys their work.

It is important that the health care professional understand the priorities, concerns, and needs of adolescents. In addition, the caregiver must try to understand the cancer experience from the perspective of the adolescent with osteogenic sarcoma. Adolescents with cancer must be regarded as intelligent "whole" people who have thoughts, feelings, and interests, rather than as diseases to be treated. The health care professional needs to be sensitive to and respect the views, needs, and wishes of adolescents and their families, and take any voiced concerns seriously. One of the tasks of the caregiver may be helping adolescents with cancer use their anger, which is a natural byproduct of the cancer

experience, as a resource. The health care team must attempt to honor how the adolescent and his or her family want to be treated and try to act in their best interest.

The characteristics of the ideal support person described earlier in this article apply to the role of the health care professional who accepts the fostering of empowerment as part of their task. This role includes helping adolescents with cancer prepare for what is to come, discussing all options with them, and encouraging them to become active participants in the decision-making process. Other tasks of the health care professional include helping the adolescents see the progress that they have made, offering encouragement to them, and helping them identify and mobilize existing resources.

The optimal relationship between the health care professional and the adolescent with cancer is characterized by its ongoing predictable nature, as well as by the attitudes of mutual trust, respect, caring, and hopefulness. The outcome of optimal communication is the sense of feeling heard and understood for the adolescent, and a sense of purpose for the health care provider.

Discussion

Although much has been written about the concept and process of empowerment, little has been published regarding the process of empowering adolescents with cancer (Price, 1988). Factors which might mobilize the adolescent with cancer toward empowerment have not been cited previously. The insights into the preferences and needs of adolescents with osteogenic sarcoma

which have been described in this chapter are consistent with the empowerment philosophy, and expand on the information available to guide the efforts of health care professionals treating adolescents with cancer.

The information presented in this chapter also expands upon the dearth of information available in the literature regarding the role of social support systems in adolescents with cancer (Orr, Hoffmans, & Bennetts, 1984; Tebbi, Stern, Boyle, Mettlin, & Mindell, 1985; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986), and builds upon the information available regarding the source-related informational preferences of adolescent amputees and adolescents with cancer (Levenson, Pfefferbaum, Copeland, & Silberberg, 1982; May, McPhee, & Pritchard, 1979). In addition, the content-related informational needs of adolescents with osteogenic sarcoma are described more clearly and comprehensively in this chapter than they have been described in the literature (Bradway, Malone, Racy, Leal, & Poole, 1984; Chesler & Barbarin, 1987; Heiney, 1989; Kaiser, 1988; Kindon & Pearce, 1982; Marten, 1980; May et al., 1979; Ohanian, 1990; Ritchie, 1984; Walters, 1981). The information presented in this chapter also expands on the information available in the literature regarding the process of communication in health care relationships (DiMatteo & DiNicola, 1982; Henderson, 1981; Korsch, 1984; Korsch & Negrete, 1972; McIntosh, 1974; Pfister-Minogue, 1983; Thorne, 1988), particularly the process of communicating with adolescents with cancer (Adams & Guido, 1984; Blotcky, 1986; Fochtman, 1989; Karon, 1973; Kellerman & Katz, 1977; Kaiser, 1988; Marten, 1980; Orr, Hoffmans, & Bennetts, 1984; Slavin, O'Malley, Koocher, & Foster, 1982).

The evolution of trust in health care relationships and the evolution toward empowerment have not previously been described in relation to each other. Yet, based on this study, they are clearly related. In fact, not only must trust be reciprocal in empowering health care relationships, but each individual must have trust in his or her own competence.

The information presented in this chapter is preliminary, since it is based on a retrospective study of the experiences, needs, concerns, and preferences of only 13 individuals who were diagnosed to have osteogenic sarcoma in adolescence, and relies upon the accurate recall of facts and experiences. It should be noted that the participants had no difficulty describing their experiences and recalling information about their relationships and the communication process. However, they found it difficult to recall and discuss their content-related informational needs. In addition, it was sometimes difficult for them to look back and talk about what they would have preferred, since they were no longer in the situation and were considerably older than they were at the time of diagnosis.

Ideally, the experiences, needs and preferences of adolescents with osteogenic sarcoma (and other types of cancer) should be studied prospectively in a longitudinal fashion. An attempt should be made to discern any age-related patterns of needs and preferences, to analyze the importance of the various components of emotional support, and to evaluate the relative importance of the factors affecting communication. Also deserving of further study is the role that family dynamics play in the relationship between the health care professional and the adolescent with cancer.

Conclusions

Health care professionals must attempt to help the adolescent with osteogenic sarcoma become empowered. Empowerment fosters hopefulness and personal growth, provides the adolescent with a sense of control and self-efficacy, and enhances coping. In order to assist in the empowerment process, the health care professional must try to establish a relationship with the adolescent which is characterized by mutual trust and caring, honesty, mutual respect, participatory decision-making, and hopefulness. Health care professionals must try to understand the experience of living with osteogenic sarcoma from the perspective of the adolescent undergoing treatment, and should think about the supportive role that they are playing and should play in that relationship. An awareness of the informational needs of adolescents with osteogenic sarcoma, both as a group and as individuals, is also required. Furthermore, health care professionals should pay more attention to nonverbal communication, and work on developing more of the qualities and skills which enhance the communication process.

Although this paper was written about empowering adolescents with osteogenic sarcoma, personal experience has led the author to believe that much of what has been discussed in this chapter seems likely to apply to adolescents with other forms of cancer, adolescents with other chronic illnesses, and to health care relationships in general in the current decade, particularly in relation to management of chronic illness.

The empowerment model of health care is more likely to meet the needs of the health care recipient than is the traditional medical model of treatment. However, in order to promote the transition to the empowerment model, health care

professionals at all levels of training and in all health-care-related fields must be taught about the model and be convinced of its value. The health care professional needs a commitment to serve, rather than to accumulate power for personal use. The transition from the medical model to the empowerment model of health care is long overdue.

Table III-1**Adolescents with Osteogenic Sarcoma: What Do They Want to Know about Osteogenic Sarcoma?**

- 1) What is osteogenic sarcoma?
- 2) What is cancer?
- 3) What causes osteogenic sarcoma? Is it hereditary?
- 4) How does osteogenic sarcoma start and develop?
- 5) How does osteogenic sarcoma cause a hole in the bone?
- 6) How common is osteogenic sarcoma?
- 7) Who gets osteogenic sarcoma?
- 8) Why did I get osteogenic sarcoma?
- 9) How long have I had it?
- 10) How many other people are going through the same thing? Are they going to live?
- 11) What are my chances for survival?
- 12) Can the cancer come back? What are the chances of that happening?
- 13) Is there a test that can tell you what the cancer cells are doing inside of me?
- 14) How is osteogenic sarcoma treated?
- 15) How many types of bone cancer are there and how do they differ?
- 16) How has the treatment evolved since I was diagnosed? What side effects (long and short term) are being seen? Any big breakthroughs? What are the survival rates?
- 17) What are the long term side effects of the xrays and scans?

Table III-2**Adolescents with Osteogenic Sarcoma: What Do They Want to Know about Limb Surgery?**

- 1) Do you have to take the whole limb? Why?
- 2) What are all of the possible alternatives to amputation? What are the pros and cons of the various treatment options?
- 3) Where on my limb will you amputate? Why there?
- 4) What will the stump (or limb-sparing procedure) look like after surgery? What will it feel like?
- 5) How big will the scar be?
- 6) When will the surgery be done?
- 7) How do you do the surgery (cut the leg off, stop the bleeding)?
- 8) How long will the surgery take?
- 9) Where do I go after surgery?
- 10) Can I get up after the surgery?
- 11) What will it be like when I wake up from the surgery?
- 12) How much pain will I have after surgery? What will you do to control it? What are the side effects of the pain medications?
- 13) Will I have phantom pain? If so, when will it stop?
- 14) How long before I can go home?
- 15) What did or will you do with the amputated part of my limb?
- 16) What does the amputated part of my limb look like inside?
- 17) Are there limb transplants or other options for me now as a long term survivor?

Table III-3**Adolescents with Osteogenic Sarcoma: What Do They Want to Know about the Prosthesis (Artificial Limb)?**

- 1) What is a prosthesis?
- 2) What does it look like?
- 3) Where will it fit and how will it attach?
- 4) How does it work?
- 5) How will it feel when I wear and use the prosthesis/limb?
- 6) What am I going to look like with it on?
- 7) Will I be able to walk? How well?
- 8) What will my limitations be? How much mobility will I have?
- 9) When will I get my prosthesis?
- 10) What kind of prosthesis will best suit me?
- 11) How often will I have to change the prosthesis?

Table III-4**Adolescents with Osteogenic Sarcoma: What Do They Want to Know about Chemotherapy?**

- 1) Why do I have to have chemotherapy? Is it really necessary?
- 2) Is the effectiveness of the chemotherapy program proven? Are there any guarantees that it will work?
- 3) How long will I have to stay on chemotherapy and why?
- 4) What are the names of the medications I'm getting, and how do they work?
Why the antidote to methotrexate?
- 5) Why do I have to have the chemotherapy over and over again (versus one good dose)?
- 6) What is the chemotherapy schedule?
- 7) How and where will I get the chemotherapy?
- 8) What are all of the possible side effects of the chemotherapy drugs?
- 9) What can I expect to happen when I get the drugs?
- 10) When will my hair grow back? Will it look any different than my hair originally did?
- 11) How much nausea and vomiting will I have with the chemotherapy?
- 12) Will I lose my hair?
- 13) What are the side effects of the anti-nausea drugs?
- 14) Will I get AIDS from a blood transfusion?

Table III-5**Adolescents with Osteogenic Sarcoma: What Do They Want to Know about Life as an Amputee and a Cancer Patient?**

- 1) What will others think of me?
- 2) How will they react to me?
- 3) What does it feel like to be different?
- 4) Will anyone want to date/marry me?
- 5) How will I hold/carry a baby?
- 6) How will pregnancy affect my body?
- 7) Will I be able to have kids? Will they be healthy?
- 8) What benefits are available to amputees?

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CHAPTER IV

CONCLUDING REMARKS

In order to help adolescents with osteogenic sarcoma cope with the cancer experience, the individual playing a supportive role must first acquire some knowledge about their needs, concerns, and preferences and gain some understanding of the cancer experience from their perspective. These topics have been discussed in chapters II and III. A number of ways of helping adolescents with osteogenic sarcoma cope with the cancer experience have also been described in these chapters. Briefly stated, others can help adolescents with osteogenic sarcoma cope with the cancer experience:

- 1) by controlling nausea, and lessening pain and discomfort.
- 2) by respecting their need for and right to privacy and confidentiality.
- 3) by giving them some control and choice, and encouraging them to participate in the decision-making process. This requires the provision of accurate and relevant information.
- 4) by minimizing the disruption of their normal lifestyle and helping them "be normal" (that is, look "normal", do "normal" things, and associate with "normal" people). This also involves treating them "normally" and having "normal" expectations of them.
- 5) by keeping waiting to a minimum.
- 6) by providing ongoing support and encouragement to them. This includes "being there" for them, helping them see the progress that they have made, strengthening their pre-existing support systems, and creating opportunities for them to meet other individuals with cancer or other amputees. It also includes

accepting them as they are, and believing in their ability to achieve any goals that they set for themselves.

7) by helping them to become empowered. This involves treating them as strong, intelligent young adults who have important things to say, and who are capable of making sound decisions and achieving any goals that they set for themselves. The antecedents to empowerment include meeting their content- and process-related informational needs, as well as the provision of emotional support.

8) by fostering hopefulness (for survival, wellness, cure, being normal, leading a normal life, being able to overcome obstacles, and for having the strength to get through the treatments). These messages are conveyed most powerfully through "proof", particularly "living proof".

9) by developing a relationship with them which is ongoing and predictable, and is characterized by mutual trust, respect, hope, caring, commitment, collaboration, and shared decision-making.

Since returning to the practice of pediatric oncology, I have attempted to apply what I learned from this study to the clinical setting. I now realize that many of the insights I gained into the needs and experiences of cancer patients pertain not only to adolescents with osteogenic sarcoma, but also to adolescents with other forms of cancer and to their families.

I have found the process of practising medicine according to the empowerment model very satisfying. Difficult decisions have been easier to make when I have involved patients and their families in the decision-making process, and have considered the views they expressed.

I have come to believe that the medical system sometimes operates in ways that satisfy the needs of the system and ignore the needs of the patient. I continue to wrestle with situations in which respecting the wishes of the family means violating the rules by which the medical system operates, and have found no simple solutions to this dilemma.

Learning the art of medicine continues to be a slow, and sometimes painful process. I have found that gaining some insight into the deficiencies of previous interactions is a necessary prerequisite to improving future interactions. However, those insights have not instantly translated into great improvements in the way that I relate to patients and their families. Rather, the improvements have been gradual and incremental. Needless to say, perfecting the art of medicine will be a lifelong process.

There is clearly an obligation for all of us, as health care professionals, to examine the supportive roles that we are playing and should play, as well as an obligation to assess and improve our communication skills. In addition, we should be making teaching the "art" of medicine a priority at all levels of training in the health care professions. Attending to this aspect of the health care relationship will not only improve patient coping and satisfaction, but will also likely enhance our job satisfaction.

APPENDICES

APPENDIX A
Letter of Introduction

Dear _____ (name of patient, or name of patient and name of parents if patient is a minor),

My name is Rochelle Yanofsky. I am a doctor who looks after children and teenagers with cancer, and am currently obtaining my Master's degree in counselling psychology. I am doing a research study investigating what it is like to have osteogenic sarcoma. I am particularly interested in finding out what young people who have osteogenic sarcoma would like to know about their disease. This project is being done in conjunction with Dr. John Akabutu at the Cross Cancer Institute. He has given me permission to write to you to see if you are interested in participating in this study.

I have enclosed an information sheet, which describes the study in detail. Please read this information sheet carefully, and note any questions or concerns that you have. You will be contacted by telephone by Mrs. Eileen Harris, a nursing member of Dr. Akabutu's team, approximately one week after you receive this letter, to see if you are interested in participating in this study. I would like to remind you that participation in this study is voluntary, and that refusing to participate will not jeopardize the medical care that you receive. Once the project has been completed, a summary of the results of this study will be sent to all participants.

My medical colleagues and I are excited about this research project. We hope that the information we obtain will improve our understanding of the needs of adolescents with osteogenic sarcoma, and give us a better idea of how to improve the health care we provide to adolescents with osteogenic sarcoma and their families.

Thank you for your time, and for giving this project your full consideration.

Yours truly,

Rochelle Yanofsky, M.D.

APPENDIX B**Letter of Introduction**

Dear _____ (name of patient),

My name is Rochelle Yanofsky. I am a doctor who look after children and teenagers with cancer, and am currently obtaining my Master's degree in counselling psychology. I am doing a research study investigating what it is like to have osteogenic sarcoma. I am particularly interested in finding out what young people who have osteogenic sarcoma would like to know about their disease. This project is being done in conjunction with Dr. Sharon Allan at the Cross Cancer Institute. She has given me permission to write to you to see if you are interested in participating in this study.

I have enclosed an information sheet, which describes the study in detail. Please read this information sheet carefully, and note any questions or concerns that you have. Dr. Allan will contact you by telephone approximately one week after you receive this letter to see if you are interested in participating in this study. I would like to remind you that participation in this study is voluntary, and that refusing to participate will not jeopardize the medical care that you receive.

Once the project has been completed, a summary of the results of this study will be sent to all participants. My medical colleagues and I are excited about this research project. We hope that the information we obtain will improve

our understanding of the needs of adolescents with osteogenic sarcoma, and give us a better idea of how to improve the health care we provide to adolescents with osteogenic sarcoma and their families.

Thank you for your time, and for giving this project your full consideration.

Yours truly,

Rochelle Yanofsky, M.D.

APPENDIX C

Information Sheet for Potential Participants

Participation in research programs is entirely voluntary. Patients and volunteers are assured that they may decline to participate or may withdraw from the study at any time without prejudice.

THE INFORMATIONAL NEEDS OF ADOLESCENTS WITH OSTEOGENIC SARCOMA

The purpose of this study is to learn more about what it is like to have osteogenic sarcoma as a young person, and especially what young people would like to know about their disease.

Patients who agree to be in this study will be interviewed by Dr. Yanofsky. The details of this study will be explained at the beginning of the interview. Only Dr. Yanofsky (the interviewer) and the participant will remain in the room for the rest of the interview.

During the interview, participants will be asked to answer specific questions. They may choose not to answer any question. They may experience some unpleasant emotions when they recall incidents related to the diagnosis of their cancer. The interviewer will be very supportive and the participants will not be asked to talk about anything they do not wish to discuss. They may tell the interviewer to stop the interview at any time.

If participants wish to obtain additional emotional support, they may contact their physician at the Cross Cancer Institute to arrange for some assistance.

The interview will last about one to two hours. Occasionally, it may be necessary to schedule a second session to complete the interview. Interviews will be held in a quiet place, where privacy is possible and there are few interruptions. Participants will be given a choice of holding the interview in their home (if they live in or near Edmonton) or in the Education clinic at the University of Alberta. They will be reimbursed for parking fees.

All interviews will be audiotaped, so that no information is missed. The audiotaped interviews will then be typed, so that the information can be analyzed. Neither the participant's name, nor any names that were mentioned during the interview will appear in the typed version of the interview.

The only people who will have access to the tapes are the interviewer, and the secretary who types the interviews. The secretary will take an oath of confidentiality, stating that she will not talk about what she hears on the tapes to anyone other than the interviewer. The only other people that will have access to the typed version of a participant's interview are the two psychologists in the Department of Education that are supervising this study (Dr. Jevne and Dr. Wilgosh). Once the entire project has been completed, a summary of the results will be sent to all participants. The tapes and the typed version of the interviews will be destroyed five years after the project has been completed.

Participation in this study may be of no personal benefit to the participants. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved.

Reports or publications which result from this study will not contain any personal information which can be identified with specific participants.

APPENDIX D

Consent form for Patients

**THE INFORMATIONAL NEEDS OF ADOLESCENTS WITH OSTEOGENIC
SARCOMA**

I acknowledge that the research project described in the preceding information sheets has been explained to me and that any pertinent questions I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study, the possible risks and discomforts. I understand that Dr. Yanofsky at phone number 436-5281, Mrs. Eileen Harris at phone number 492-8512, or my physician at the Cross Cancer Institute will answer any additional questions that I have about the research project. The phone number for the Cross Cancer Institute after business hours is 492-8771.

I understand that I will receive a copy of the information sheets and this consent form. I understand that information resulting from this project may be reported, but that I will not be identified.

I have been assured that confidentiality will be respected.

(Name of Subject)

(Signature of Subject)

(Name of Witness)

(Signature of Witness)

(Name of Investigator)

(Signature of Investigator)

Date

APPENDIX E**Consent for Children****THE INFORMATIONAL NEEDS OF ADOLESCENTS WITH OSTEOGENIC
SARCOMA**

I acknowledge that the research project described in the preceding information sheets has been explained to me (my child) and that any pertinent questions I have asked have been answered to my satisfaction. I have been informed of my (my child's) alternatives to participation in this study, the possible risks and discomforts. I understand that Dr. Yanofsky at phone number 436-5281, Mrs. Eileen Harris at phone number 492-8512, or my (my child's) physician at the Cross Cancer Institute will answer any additional questions that I have (my child has) about the research project. The phone number for the Cross Cancer Institute after business hours is 492-8771.

I understand that I (my child) will receive a copy of the information sheets and this consent form. I understand that information resulting from this project may be reported, but that I (my child) will not be identified.

I have been assured that confidentiality will be respected.

(Name of Patient)

(Signature of Patient)

(Name of Parent or Guardian)

(Signature of Parent or
Guardian)

(Name of Witness)

(Signature of Witness)

(Name of Investigator)

(Signature of Investigator)

Date

APPENDIX F
Interview Guide

1) Please tell me about what living with osteogenic sarcoma has been like for you, starting from the time that you first thought that something was wrong, until today.

2 a) Please tell me about times that you had questions or wanted information (for example about the disease, the treatment, and about how all of this would affect your life).

b) What questions did you have? What did you want to know?

i) about your disease

ii) about operations

iii) about tests that you had

iv) about the seriousness of your disease

v) about chemotherapy

vi) about how all of this would affect your life

c) when did your questions come up?

d) How did you deal with your questions? That is, did you try to get the answers?

i) If so, how did you go about getting the information that you wanted?

ii) If not, what stopped you from getting the information?

2 e) How did you decide whom to go to for information?

f) What information did you get in response to your questions?

g) How did that information affect you? In particular, how did you feel, what did you think, and what did you do after getting the information?

h) Knowing what you know now, can you think of any ways to improve the way in which your questions were handled?

3 a) Please tell me about times that you got information from people without asking for it (for example about your disease, the treatment, or how all of this would affect your life).

b) What information did you get?

c) How did that information affect you? In particular, how did you feel, what did you think, and what did you do, after getting the information?

d) What aspects of how the information was given to you were helpful, and what parts were not helpful?

e) Knowing what you know now, can you think of any ways to improve the way the information was given to you?

4 a) Please tell me about the roles that other people with cancer have played in your life.

b) What kinds of things did you learn from them?

c) How did you learn those things?

5 a) Did you read any books or pamphlets, watch any videotapes, or listen to any audiotapes about topics like osteogenic sarcoma, amputation, or chemotherapy? If so, please elaborate.

b) How did you obtain this material?

c) When did you read, watch, or listen to this material?

d) What kind of reading materials (if any) do you think would be helpful to kids with osteogenic sarcoma? When do you think that this information should be given to them?

6 a) Have you attended any conferences, groups, or camps for kids with cancer or amputation?

b) If so, please describe your experience.

c) How did you decide whether to go or not to go?

7) Is there anything else that you would like to add?

8) What was it like to participate in this study?