

COPING WITH CHILDHOOD CANCER:

A SOCIAL WORK FAMILY CENTERED INTERVENTION

BY

SUSAN ELIZABETH POWELL

A Practicum Submitted to the Faculty of Graduate Studies  
of the University of Manitoba in Partial Fulfilment  
of the Requirements of the Degree of

MASTER OF SOCIAL WORK

WINNIPEG, MANITOBA



SEPTEMBER 1987

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## ABSTRACT

It has long been recognized that a diagnosis of childhood cancer has an impact upon the family as a system as well as upon each member of the family.

This practicum provided the opportunity for social work involvement with nine families newly diagnosed with childhood cancer. A contract was developed with each family, to provide services from the time of diagnosis for approximately three months. The practicum also allowed investigation of the role of social work in the adaptation process, and the development of further skills in family counselling and intervention. Assessment was based on the Double ABCX Model, and interventions incorporated aspects of crisis theory, grief theory and the McMaster Model of family functioning. Evaluation by means of a consumer satisfaction questionnaire demonstrated that the family approach was helpful in the adaptation process.

The approach and the assessment model facilitated appropriate interventions and the many factors identified by family and friends as they adapted to the illness provided an excellent opportunity for skill development.



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Susan Elizabeth Powell

Winnipeg, Manitoba

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## Introduction

One of the most devastating experiences in life for parents is to be told "your child has cancer". Cancer evokes painful images and emotions surrounded by myth and mystery (Ross, 1978). A cancer diagnosis imposes change, disrupts the family's homeostatic balance and unsettles the operational guidelines for interpersonal behaviour (Chesler, Barbarin, Chesler, Hughes & Lebo 1981). The whole family -- parents, siblings, and the sick child, must develop methods of coping with their feelings and fears about the cancer. They must both accept the diagnosis and the subsequent treatment as well as adjust to the practical limitations that cancer may impose. From the moment of diagnosis, their lives are changed. Nevertheless, the family must go on. It must seek to fulfill its function of supporting and nurturing each member.

As the social worker in the pediatric oncology clinic at Health Sciences Centre, I am in the unique position of



being involved at diagnosis or soon after with each family who has a child suffering from cancer. Due to time limitations my previous involvement concentrated on intervening in the initial crisis with whichever family member was available, unless the family was presenting with gross difficulties. Over the four years that I have worked at the clinic, I have felt that social work could be more involved and certainly more instrumental in assisting new families with the many changes and adjustments that are necessary to cope with childhood cancer. With these observations in mind, I have attempted to use this practicum to formulate a comprehensive assessment and consistent social work intervention plan for families newly diagnosed with childhood cancer in order to facilitate family coping skills.

A number of related elements formed the rationale for the intervention. First it is acknowledged by researchers and reported by parents alike that the period around diagnosis constitutes one of the most stressful times in the course of the illness (Blumberg, Flaherty & Lewis, 1980; Chesler et al., 1981; Adams & Deveau, 1984). Support at this time is emphasized as critical to the long term adjustment of the family (Morrow, Carpenter & Hoagland, 1984; O'Malley, Koocher, Foster & Slavin, 1979).

Second, it is of critical importance that the social worker develop a sound knowledge of the family's predominant functioning patterns and of its support network. Such knowledge may enable the social worker to strengthen the family system so that the family will be able to cope with the stresses of the cancer, and may assist the professional in predicting those areas in which the family may need help and attention.

Third, cancer is a family illness. "Each family member will be affected by the disease and in turn will affect the adjustment of others. From the moment of diagnosis their lives are changed" (Blumberg et al., 1980, p. 49). Hence intervention should be aimed at a systematic and consistent involvement of all family members, not just of the sick child. "Inclusion of as many family members as possible in sessions not only allows family members to act as supports to each other but may bring out family strengths that were not otherwise obvious" (Drotar, Crawford & Bush, 1984, p. 115).

My own personal learning objectives associated with this practicum were:

1. To review and become more fully conversant with the literature on the psychosocial issues related to childhood cancer.

2. To explore and expand the role of social work with families with a child diagnosed with cancer.

3. To enhance my assessment and intervention skills in working with families.

This report begins with a summary of the medical aspects of childhood cancer. It is followed by Section I which outlines the current literature on the stresses arising from the disease and on interventions with the family. Section II describes the practicum itself, and includes four case illustrations, evaluation by the families receiving service and recommendations for social work practice.

## Childhood Cancer: Medical Aspects

To most parents the word "cancer", at least at the time of diagnosis, is synonymous with death. In fact, except for accidents, cancer accounts for the greatest number of deaths in children between the ages of three and fourteen (Bracken, 1986). In reality, however, the incidence of childhood cancer is rare, and as treatment continues to improve, it can be hoped that death as an outcome will also be rare. In Manitoba in 1985, 47 children from zero to 19 years of age were diagnosed with the malignancy. In the same year, ten children died of the same disease (Manitoba Cancer Treatment and Research Foundation, 1985 Annual Report).

We usually speak of cancer as one disease, but in reality there are many forms. The common feature displayed by each type of cancer is the uncontrolled growth of abnormal body cells. These cancer cells interfere with the body's functions, either by blocking other organ systems or by displacing normal cells (Bracken, 1986). As of yet, the causes of cancer are not precisely known. They may be genetically transmitted as in retinoblastoma (tumour of the eye), or activated by environmental or viral factors (Chesler & Barbarin, 1987).

A number of different treatments for cancer are available. Surgery, the oldest, is still the first and most widely used treatment for patients with solid tumors. The whole tumor, or as much of it as possible without damaging body functions, is removed. Radiation, invented at the end of the last century, is often used in combination with surgery in the early stages of the treatment of solid tumors. It is also used to treat leukemia to reduce the risk of a relapse due to cancerous cells in the central nervous system. Radiation and surgery are limited to specific body sites, so chemotherapy, i.e. drug treatment, is used as a precaution to destroy any stray cancerous cells not directly removed or radiated. Chemotherapy is also the major therapy in the treatment of leukemia (Bracken, 1986).

Treatment for cancer is long and arduous, lasting approximately two to three years and requiring many tests, some of which are extremely painful, clinic visits and hospitalizations. Side effects of both chemotherapy and radiotherapy can be as devastating as the disease. Common reactions while on treatment include nausea and vomiting, tiredness, hair loss, weight fluctuations, mouth ulcers and skin rashes. A small percentage of children will experience permanent side effects such as damage to body organs, (liver, heart, kidneys), sterility and small stature. Surgery of course can also leave the child physically impaired.

the various side effects can cause much discomfort and anxiety for both parents and child, the use of the three treatment modalities, and especially the introduction of chemotherapy, has led to a dramatic improvement in the cure rate of children with leukemia and solid tumors in the last twenty years. As can be seen in Figure 1, the proportion of children surviving two years from diagnosis has steadily increased.

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INSERT FIGURE 1 ABOUT HERE

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The percentage of children with a diagnosis of cancer who survive for five years after diagnosis is displayed in Table 1.

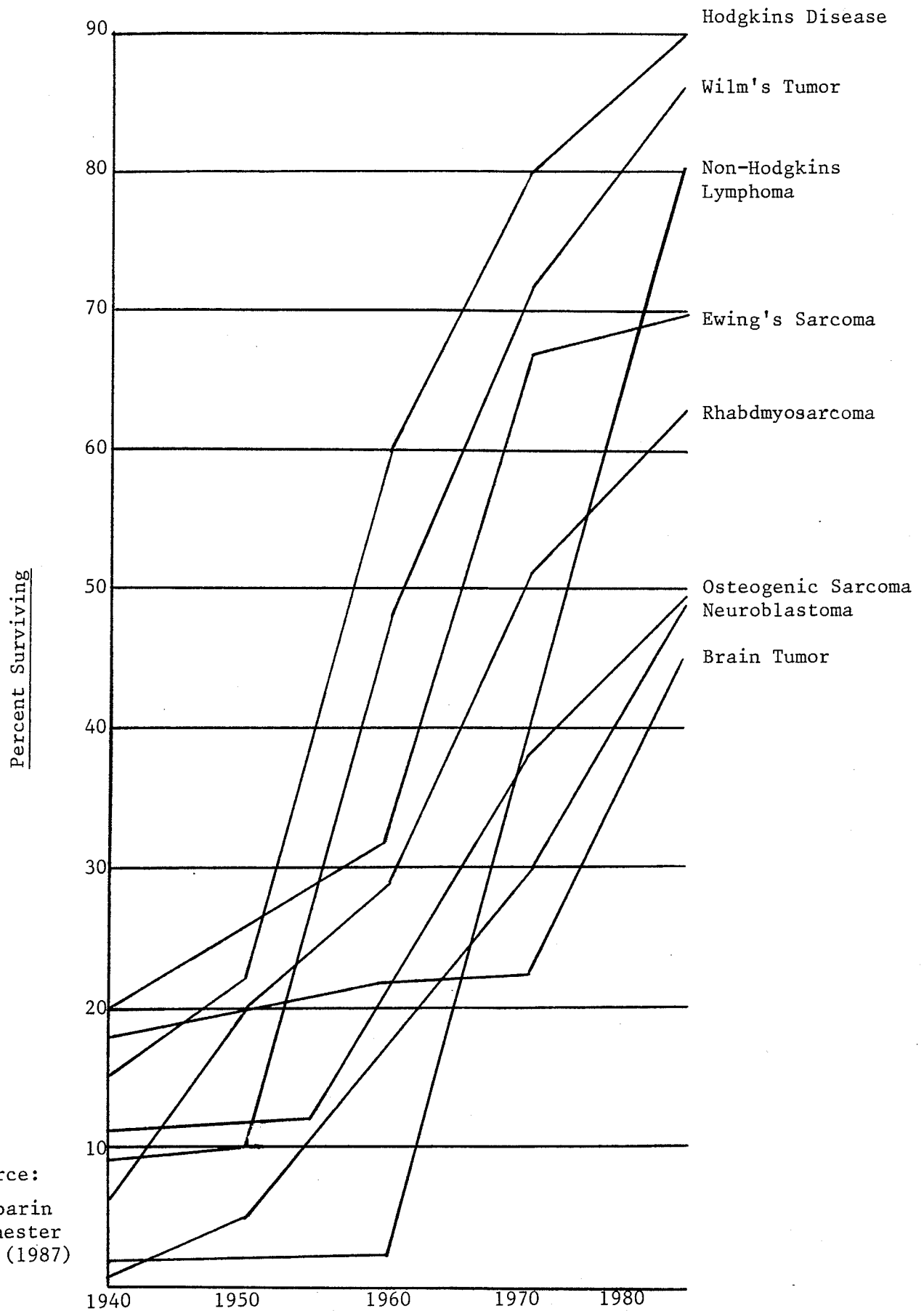
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INSERT TABLE 1 ABOUT HERE

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Figure 1

Proportion of children with solid tumors surviving two years from diagnosis



Source:  
Barbarin  
& Chester  
(1987)

Table 1

Percentage of Children with Cancer who Survive Five Years  
After Diagnosis

Cancer Group	% Survival at Five Years
Bone Cancer	30
Acute Lymphocytic Leukemia	34
Neuroblastoma	40
Glioma Cancer (brain)	59
Wilms' Tumor (kidney)	70
Retinoblastoma (eye)	85
Hodgkin's Disease (lymph glands)	90

Source: Chesler & Barbarin, 1987.



These medical advances have in turn provoked a shift in psychosocial emphasis away from assisting the family to cope with death, towards helping the child and family prepare to live. Living with cancer creates new issues in the care and management of the child and in the maintenance of family and other social relationships.

Without successful emotional rehabilitation, neither the successful treatment of the tumor, nor the successful correction of physical problems will have great meaning (Chesler & Barbarin, 1987, p. 11).

SECTION ONE

LITERATURE REVIEW

## CHAPTER 1

## Psychosocial Impact of Childhood Cancer on the Patient

In order to have a clear and comprehensive understanding of the effects of a diagnosis of childhood cancer on the family, a review of the impact of the disease on each family member will be presented, followed by an outline of its influence on the system as a whole. This of course is very artificial, as what affects the child and her or his subsequent reactions or indeed what affects the parents and their reactions will in turn affect all components of the family.

Impact on the Young Child

Many authors describe the physical and psychological effects of the illness and treatment on the young child (Katz, 1980; Spinetta, 1981a; Deasy-Spinetta, 1981). Hair loss, although readily accepted by the pre-schooler, can cause the nine to ten year old to feel very self-conscious. Weight fluctuations, so that at one time the child is bloated and at other times painfully thin, can represent frightening changes in body image. Amputations can be particularly difficult, and require the child to make emotional as well as physical adjustments (Kagen-Goodheart,

1977). "Furthermore our body conscious society exacerbates the difficulties by idolizing "the perfect body" in theatre, athletics, advertising and so on" (Gogan, O'Malley & Foster, 1977, p. 43). All in all, the long period of treatment with its various side effects may make the child feel bombarded with drugs and radiation, as if he or she is an experimental object (Gogan et al., 1977). Physical changes together with emotional fears can make the child feel very different from his or her peers. This may be especially difficult for the latency aged child who identifies strongly with the peer group, and may reduce positive feelings of self-esteem and emotional well being.

Loss becomes a key issue for the child diagnosed with cancer, whether the loss is of health, present abilities, future capabilities or body parts. The child, in order to come to terms with the losses, must grieve and withdraw a certain amount of psychic investment or attachment to that which is or will be lost. Geist (1979), in a dialogue with an eight year old youngster with osteosarcoma who has just been told he must have his leg amputated, poignantly illustrates the difficulty in disinvesting. "But I've had my leg for eight years," implores the child, and proceeds to inveigle the psychologist into promising some hope for its future return. The child also faces another loss which is often overlooked, that of his or her role or position within the family that contributes to family integration.

Indeed children contribute enormously to family growth and their resistance to mourning seems to reflect painfully their indomitable need to defend their place in the family by urgently denying their weakness or loss (Geist, 1979, p. 8).

Issues of self control and competence are especially critical for the child with cancer. From infancy on the child's major developmental task is mastery of self, of relationships and of the surrounding environment (Brunnquell & Hall, 1982). A child's sense of control can be disrupted when restrictions are placed on physical activities such as being confined to a hospital room, hooked up to an intravenous pole, tube fed or kept away from interaction with others because of a low immune count. For children up to seven or eight, feeding oneself is of considerable importance. "When they are suddenly told not to eat, and are fed through a tube, a great blow to their self-esteem has been struck" (Brunnquell & Hall, 1982, p. 36).

Closely connected to the issues of self-control and competence are those of dependence and independence. The child's forced dependency on parents and staff at certain times during treatment can lead to a severe sense of worthlessness (Katz, 1980). Thus the young child attached to an intravenous pole or weak from medication, who must rely on others to dress him or her and to take care of essential toileting needs, may develop a sense of inadequacy

in relation to his or her peer group. The situation can be compounded if parents and staff, out of a sense of pity, continue to relieve the child of his or her active role in caring for him or herself. Dependence rather than independence is thus encouraged unwittingly. Findlay, Smith, Graves and Linton (1969) considered that all ten chronically ill children in their study displayed a greater than normal dependency on parents, usually the mother.

One would expect that, given all these issues and the fact that cancer is a life threatening illness, there would be an abundance of research on its psychological impact on the child. In fact, much of the literature on the emotional effects of childhood cancer focuses on the family, and in particular, the family of the dying child. Actually very little research has been conducted on the emotional response or reactions of the child. "This emphasis on families and caregivers is probably due to the fact that, for years, children with cancer seldom remained healthy or alive long enough for their feelings about the illness to be analyzed" (Blumberg et al., 1980, p. 491).

Now as more children live longer and are cured, we need to be aware of their understanding of the illness and to take note of their reactions, so that they can be helped to cope in the most healthy and adaptive way.

This practicum focuses on living with cancer, but we must not deny the reality that cancer is a very serious illness, and that certainly some children will die from the disease. Therefore a salient question is: "What do children understand about their illness?"

At one time young children were protected from the fact that their illness was possibly fatal, because it was felt they could not fully understand the concept of death. This view was based on work done by Nagy in the 1940s (Gogan et al., 1977). Nagy interviewed healthy children on their perceptions of death and found that until about age nine, children were unable to grasp the irreversibility and universality of death.

Now researchers are in agreement that children as young as four or five, even if not told directly, realize the seriousness of their disease, and even anticipate their premature death (Binger et al., 1969; Spinetta, 1981a, Márky, 1982). Binger et al. (1969) found that "younger children, though not expressing fear of death per se manifested concern about separation, disfigurement or hurt" (p. 415). In another study of children over time on treatment for leukemia (Powazek, 1980), 46 percent of the sample had at some time discussed the fear or the possibility of death with another person, and even more had

hinted at the topic. This would suggest that they were very much aware of the issue.

Obetz, Swenson. McCarthy, Gilchrist & Burgert (1980) found a general association between the period when the child was becoming aware of the seriousness and implications of the disease, and his or her emotional reactions such as anxiety, depression and sleep disturbances. These disturbances lasted from a few weeks to one and a half years and generally occurred in the first two years of treatment.

Other authors have also documented behavioural and emotional disturbances in the patients and expanded on the connection between anxiety and self-concept (Márky, 1982; Katz, 1980; Spinetta, 1981a). Spinetta (1981a) in his studies of leukemic children found that these children expressed a greater degree of anxiety, both hospital-related and non-hospital related, than chronically ill children in the control group. He found that they were not only more anxious, but that over time the anxiety increased during clinic visits, whereas the controls adapted to such visits.

In a later study of 127 children aged from five to seventeen years in the classroom, teachers indicated that in comparison with a matched control group, children with cancer did not initiate activities, did not talk about the activities, and had less of a tendency to try new things



(Deasy-Spinetta, 1981). Thus, the child with cancer tends to take a self-protective stance. Anxiety is not specifically mentioned in this study, but we may deduce that the lack of risk-taking may indicate heightened anxiety and a perceived lack of competence and confidence in self. Children in long-term remission fared better than either those in remission but still on treatment, or those in relapse.

Schuler et al. (1981) examined 48 children treated for leukemia but in continuous remission for three and a half or more years and off all therapy. They found a significant difference between the levels of anxiety and frequency of a disturbed self-image in the test group, as opposed to children in a control group: (anxiety -- children treated for cancer 63.1%; controls 9.8%; disturbed self image -- children treated for cancer 70.4%; controls, 6.1%). Anxiety and self-image were measured in the study by using the "world test." This is a procedure where children construct their world from 250 familiar objects, and are then assessed on the basis of the number of objects used and the way in which they are used.

The children who from the time of diagnosis received psychological care consisting of psychotherapy, social care, creative activities, music therapy and education, exhibited fewer emotional problems than those children who had been

attached to clinics with no such services. However, although emotional problems were relieved for the children receiving psychological care, they still exhibited more problems on the anxiety and self-image scales than the controls. Unfortunately Schuler gives no information about the make-up of the control group.

While still noting behavioural changes and emotional reactions to the disease, other authors present a much less dismal picture. Márky (1982), for example, proclaims that after the initial treatment period, the children in his study "represented an emotionally healthy group who along with their parents returned to normalcy with the passage of time" (pp. 57-8). Powazek et al., who interviewed children on treatment and in long term remission also concluded that, although the children had some reservations about whether they were in fact cured, they showed healthy life adjustments.

Often cited as a further possible consequence of a long term illness is the relationship of the child with other people. Deasy-Spinetta (1981) found that children with cancer attended school as willingly as their peers, did not express apprehension regarding school, and did not differ significantly from their colleagues on many issues. While at school they played with friends and were not teased or injured any more than their peers. They did not spend

their days either brooding or arguing. However, the children participated less in both formal and unstructured playground activities, had a greater tendency not to reach out, and had fewer friends than children in the control group. These findings may reflect the necessity of children with cancer to be absent from school for treatment and/or hospitalization over a period of years. As well, physical limitations imposed by the illness or treatment may make it more difficult for the child to join in activities and to develop friendships. Re-entry after the diagnosis, when body changes are becoming apparent, is especially stressful for the child. Out of embarrassment, he or she may withdraw from contact with peers and become isolated (KagenGoodheart, 1977). On the other hand, because cancer is a mysterious, often fatal disease, friends may shun the sick child, because the uncertainty of the child's prognosis creates a threat to their own mortality (Gogan et al., 1982).

Spinetta (1981a) investigated how high levels of anxiety and fear might affect the interpersonal relationships of children with a life threatening disease. Each child was given dolls representing four figures in their hospital life (mother, father, nurse, doctor), and asked to place the dolls wherever she or he liked in a three-dimensional replica of a hospital room. Children with leukemia placed the dolls at a greater distance from the

doll representing themselves than did the matched group of children with other chronic diseases.

The Schuler et al. study (1985) described earlier clearly found that children with cancer exhibited more feelings of isolation than either their siblings or the control group. Of particular interest is the finding that the children who received psychological care during treatment actually showed slightly fewer feelings of isolation than did those in the control group. This fact supports the value of early psychosocial intervention.

Whether children tend to distance themselves from people, or others indeed withdraw from them, the end result is that the child is placed in an extremely vulnerable and isolated position which may severely hamper interpersonal relationships as the child moves to the next stage of life, that of being an adolescent.

#### The Impact of Cancer on the Adolescent

Adolescents, of course, share many of the same issues as younger children with cancer, but the illness takes on new dimensions when added to the changes characteristic of the teenage years. Development for the adolescent may be seen as proceeding along a given course and "although a

crisis such as a severe illness alters the course, the tasks and concerns of that developmental period still appear unchanged for the ill child" (Blumberg et al., 1980, p. 73). The teenager must develop a comfortable body image and self-esteem, create an identity through socialization, establish independence from parents, adjust to sexual maturation and begin to prepare for the future.

Contrary to expectations, adolescents with a life threatening illness do not inevitably exhibit psychopathology. Most, including those with cancer, do not demonstrate either increased chronic anxiety or lowered self-esteem, when compared to healthy peers (Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980). In fact, in one study of teens with cancer, mothers and fathers each reported more impact from the illness on the patients than did the patients themselves. All agreed that the teenagers were hopeful and coped with the illness well (Zeltzer & LeBaron, 1981). Some adolescents even cite positive aspects of having cancer, such as a sense of mastery and greater empathy towards others (Orr, Hoffman & Bennets, 1984). Zeltzer (1980) considers that "the limited expectations of others may be more disabling to the adolescent than the disease itself" (p. 70).

A study which compared healthy adolescents' perceptions of the impact of illness with the perceptions by

teens with a chronic illness, found that healthy teens reported more disruption when sick in two areas, namely: popularity and peer activities (Zeltzer, Kellerman, Ellenberg & Rigler, 1980). This led the researchers to hypothesize that "healthy adolescents have not needed to develop stable coping mechanisms for illness and may be poorly equipped to deal with occasional interruptions of peer activities" (Zeltzer et al., 1980, p. 136). They also postulate that because ill adolescents have learned to live with varying degrees of constant or frequent life disruption, they develop a heightened stress tolerance and do not become overly anxious or react with inordinate distress to the problems of daily living (Kellerman et al., 1980).

However, even if the teenager copes well, there are still many changes and adaptations he or she will have to make in order to live with the uncertainty and ambiguity of the disease. In other areas examined by Zeltzer et al. (1980), adolescents with cancer reported more disruptions due to illness than healthy teens and listed more problems associated with the illness than any of the other groups of adolescents with a chronic illness. Major issues reported were the effect of the illness on body image, school related disruptions and illness induced family problems (Zeltzer et al., 1980).

During the latency years peer identification is a crucial issue, but as the child progresses through the adolescent years peer approval becomes the issue of critical importance. Young people are extremely sensitive about their appearance and will spend long hours preening themselves in front of the mirror or assiduously studying fashion magazines, fearful that they may not look just right and that they may be rejected by peers.

The strong emotional reaction of the adolescent patient to any form of disfigurement such as hair loss is in part the result of what he perceives as an injury to self-esteem. The consequent feeling of inferiority and often withdrawal from friends who might even react correctly to the patient, create a considerable problem, because the adolescent relies strongly on the peer group as a transitional step between his relationship to the family and to "a new love object" whether a girl friend or a fiancée (Marten, 1980, p. 157).

Farrell and Hutter (1980), in their in-depth study of three adolescents, found that changed perception of self due to altered appearance was the most significant concern expressed by all subjects. Teens described loss of hair as the most psychologically difficult condition to accept and one patient rated it more devastating than even the loss of her leg (Farrell & Hutter, 1984), and as more stressful than even the diagnosis (Chesler & Barbarin, 1987). For females, physical changes may signify a loss of feminine attractiveness, which is why hair loss can be such an important issue. Males, on the other hand, may feel that

they have lost their virility or sex appeal. Therefore, for many teens, the treatments themselves and their effects are seen as worse than the disease itself (Zeltzer & LeBaron, 1981; Zeltzer, 1980).

Re-entry into school may be especially traumatic for the teenager. Physical appearances may make the adolescent feel very different and self-conscious. Often teens fail to recognize that aggressive remarks made by peers arise not out of hostility but from fear (Marten, 1980). All three subjects in Farrell and Hutter's study (1980) either curtailed school attendance or withdrew, but admitted to feelings of loneliness because of lack of contact with school friends.

The family of course is the major support system for the adolescent. However, cancer is such an emotionally laden illness that often the whole family begins to interact with the patient in a changed way. Parents may become overprotective and over-indulgent, thereby encouraging regression, so that the adolescent may find it very difficult to progress in the developmental task of emotional autonomy (Zeltzer, 1980; Marten, 1980; Farrell & Hutter, 1980).

Adolescents consider dependency a weakness and though they may need to be dependent on parents and staff when on



active chemotherapy, as soon as the treatment effects wear off they often rebuff parental affection. This dependence-independence cycle can be very frustrating for parents. As one parent commented: "when she zigs, I zag, and we just can't seem to get our zigs and zags synchronized" (Farrell & Hutter, 1984).

Over-protective parents may also hinder sexual development, by not leaving the adolescent sufficient privacy or by not encouraging normal other sex peer relationships. There is also evidence that parents and staff consider the adolescent with cancer asexual (Zeltzer, 1980).

The adolescent with cancer is well aware of course of the seriousness and implications of the disease. Kellerman et al. (1980) found a significant difference between the ill and healthy groups' measures of control over the future in regards to health. The nature of the disease means that some adolescents will have their future prematurely curtailed. According to Zeltzer (1980), "Most adolescents who are in fact dying know that they are dying whether or not they verbalize their feelings" (Zeltzer, 1980, p. 91). He considers that chronically ill children tend to be preoccupied with issues surrounding death, whether their own or others'. Farrell and Hutter (1980), on the other hand, found that their subjects focused on life and living rather

than on death. In fact, one young woman several days prior to her death hosted a small party for her friends, despite her numerous physical problems.

How adolescents adapt to the diagnosis and the treatment depends on many variables, including other stresses in the adolescents' life, parental and oncology staff support, as well as the course of the illness and response to the drugs. Coping strategies used by children and adolescents will be discussed in a later section.

#### Long Term Effects of Childhood Cancer

As more children survive childhood cancer, there has been growing emphasis upon the study of the psycho-social adaptation of these survivors. However, the results of these studies are far from consistent. O'Malley et al. (1979), using qualitative and quantitative material to test the levels of self esteem, social adjustment, anxiety and depression in 115 patients who had been off treatment for at least three years, reported that 59 per cent of the survivors had a high rate of psychological adjustment problems with twelve per cent of the sample rated as markedly or severely impaired. Unmarried patients, both men and women over 21 (36), showed more evidence of symptom formation than those who were married. Women with physical impairments tended not to be married whereas the same

physical limitations did not appear to affect men's chances of marrying. A small study by Obetz, Swenson and McCarthy (1980) of 18 children and their parents, who had been in remission from leukemia for four years, but were still under 21, found the children healthy, robust and happy. They were described by parents as enjoying school, being candid and trusting with parents, having many friends and being highly self-sufficient. However, the sample displayed many continuing death anxieties and vaguely defined apprehensions related to physical concerns. Medical check-ups were particularly anxiety provoking. These fears were denied in the interview and were often a taboo family subject.

The results of other studies illustrate different conclusions. Holmes and Holmes (1975) investigated the effects of childhood cancer on 124 adults who had been off treatment for at least ten years. These survivors, far from exhibiting high rates of psychological mal-adjustment, were not educationally impaired in any way and in fact enjoyed normal or near normal lives. As a group they had made excellent adjustments and suffered very few residual problems related to their disease and treatment. It should be noted however that this study relied solely on self-report questionnaires whose accuracy may well be questioned. As well, a seemingly high number of unmarried survivors over twenty (36 out of 41) reported that their disability or their previous illness was a factor preventing

consideration of marriage. Only 18 out of the total sample of 124 suffered marked physical disability from the effects of the illness or the treatment.

A more extensive recent study by Teta et al. (1986) of 450 adult survivors, using an abbreviated psychological evaluation - consumer satisfaction interview to detect the occurrence of a definite major depressive syndrome, found that the frequency of depressive symptoms did not differ significantly from the incidence among siblings who were also interviewed. The only group that appeared to be at risk were female survivors of genital cancer who were eight times as likely to suffer from depressive symptoms than survivors of skin cancer. Concerns over health were cited by survivors as the reason for depression far more frequently than reasons offered by siblings. Although a control group from the general population was not used, scores of the 450 subjects were within the normal range for the general population. Many of the survivors in this study had suffered from cancers which required a relatively easy protocol of treatment, such as skin cancer and lymphoma. Only twelve of the total sample of 450 had been diagnosed with leukemia, which demands long and arduous treatment.

Survivors do, it seems, experience discrimination in terms of employment, college and life insurance because of their history of cancer (Teta et al. 1986; Koocher, 1981).

Many of the people who had experienced problems described feelings of emotional distress and worthlessness at being rejected (Koocher, 1981).

Summary: The Impact of Cancer on Young Children  
and Adolescents

Are we looking at a population in distress, who are exhibiting psychopathology, or are we seeing a group of emotionally healthy children who are reacting normally to an abnormal situation? "In an editorial comment in 1973 in a volume dedicated to the care of the seriously ill child Anthony conceded that the field of study of the child with a life threatening illness remained, at best, confused" (Spinetta, 1981a, p. 6). Today, although many more articles have been published, there is still a dearth of well controlled, scientific studies on the impact of cancer on the developing child. Even when control groups are used, details of their composition are often not fully described in the article. Furthermore there is no consistency in the type of controls used. Sometimes control groups consist of children with other chronic illnesses, sometimes children hospitalized on surgical wards and sometimes children from the same school classes as the experimental group. Thus it is often exceedingly difficult to make comparisons. The field of study can still best be described as "confused",

and to the preceding questions the answer is still somewhat unclear.

A notable area in which differences are reported is in the levels of anxiety of younger children and adolescents with cancer. Schuler et al. (1981, 1985) and Spinetta (1981a) found heightened anxiety levels in latency aged children, whereas Kellerman et al. (1980) reported that the adolescents in their study did not exhibit any more anxiety than their healthy peers or other patients with a chronic illness. They suggest that unlike the Spinetta study, which rated children who were in hospital and therefore might be expected to be experiencing disease-related stress, all their subjects were out-patients, who thus were less likely to be experiencing illness related trauma. Another explanation is that the older children, unlike their younger counterparts, evaluated themselves in terms of anxiety. Younger children were assessed by using projective tests and by questioning parents and staff. Typically adolescents use denial as a coping mechanism and may need to downplay feelings such as anxiety, in order to exert some control over their situation. It may also be that latency aged children react differently to their illness than adolescents.

Some evidence is now emerging that children, particularly adolescents, develop adaptive coping mechanisms

in order to meet the challenges, stresses and strains of cancer and its treatment. Although the reports are far from consistent, it appears that many long-term survivors are productive members of their communities with jobs and families and are not exhibiting gross psychological difficulties (Holmes & Holmes, 1975; Teta et al., 1986).

Nevertheless, we must not deny the fact that cancer is both stressful and disruptive. Powerful emotions are provoked as treatment with all its side effects progresses. Anger, sadness, frustration and depression in these circumstances may be necessary and in fact adaptive for the child. Such feelings are also observed in family members whose reaction will be more fully reviewed in the following chapter.

## CHAPTER 2

### The Impact of Childhood Cancer on Family Members

#### Impact of Cancer on Siblings

The problems associated with being a healthy sibling of a child with cancer have long been documented in the literature (Binger et al., 1969; Findlay et al., 1969; Peck, 1979). Early studies relying on the parents' perceptions of the situation found the long-term impact on siblings to be profound and far reaching (Peck, 1979). Peck noted that twelve out of the twenty families she studied with more than one child, cited some difficulties with siblings. In eight of the families parents reported that problems were still occurring even though the ill child had been off treatment for at least two years. Likewise Binger et al. (1969) found that in half of the twenty families he studied, well siblings exhibited difficulties in coping such as poor school performance, severe separation anxieties and abdominal pains. Further studies using siblings' own perceptions have raised two major concerns: changes in family life, and worries over their own and their sibling's health.



Changes in family life constitute the most often cited consequences of the diagnosis of cancer (Kramer, 1984; Spinetta, 1981b; Koch-Hattem, 1986). Kramer noted in her in-depth study of eleven healthy siblings that the greatest source of stress was the parental preoccupation with the sick child. "A triad forms between the mother, father and ill child, while the healthy siblings are left on the periphery of family life" (Kramer, p. 46).

Koch-Hattem's (1986) findings closely parallel those of Kramer. Sixteen of the 33 siblings interviewed reported that the patient received more attention, caring and material possessions since the diagnosis. Siblings coped with their anger and envy in a variety of ways, but several indicated that they coped by getting sick themselves. This study notes that since the diagnosis nearly half of the siblings had spent more time at home participating in the patient's care, and helping their mothers. This resulted in the siblings' being less involved in extra-familial activities. Koch-Hattem summarizes that "spending more time at home may also result in increases in chores, conflict and anger and in a feeling of having fewer activities that are fun" (p. 115). It might be assumed that the siblings' isolation and relative neglect might give rise to feelings of anger and hostility towards parents. However, Cairns, Clark, Smith and Lansky (1979) found they were the least

likely (less than the patients) to blame parents and hypothesized that "this reluctance to express anger probably reflects insecurity about their precarious position in the family -- a fear that anything they say or do may make things worse" (p. 487).

Two areas often mentioned by siblings in connection with changes in the family are the "empty house" and being "boarded out" (Kramer, 1984; Iles, 1979). As one sibling poignantly explained, "The hardest thing [is]... staying here by myself,... especially on the days he [ill sibling] goes to the clinic." Thus the well siblings are often left with little family support to help them through hard times. In fact, Spinetta (1981b) considers that the siblings "lose out on both ends" (p. 140). Not only were siblings left unsupported during crisis times, but when the patients were doing well, the parents' focus turned to other non-disease related issues and the sibling continued to be left out.

During the crisis times, siblings are often "boarded out", which can be both enjoyable and supportive for the child. "We went to my cousin's house, that was fun" (Iles, 1979, p. 374). At these times grandparents often step in and take over responsibilities (Kramer, 1984). Sometimes there are less satisfactory arrangements, as one child explained: "Once when M.... was going to the doctor, this lady I didn't know took me in" (Iles, p. 375).

An extensive three year study undertaken by Spinetta (1981b) found that though the family on the whole met the medical needs of the patient and the day-to-day demands of the family relatively well, there were difficulties in meeting the family's emotional needs. The siblings' needs were met at a lower level than either those of the patient or the parents. This lack seems to have affected the overall adaptation of siblings to the situation. "We find the siblings scoring at less adapted levels on some of the objective measures than their brother or sister with cancer" (Spinetta, 1981b, p. 15). It should be noted that the patients in turn fared worse than the controls. Thus siblings were less adapted than either group.

A second issue for the healthy sibling is worry and concern over the ill child. Menke, in her study of 33 children with different chronic illnesses found that the siblings of children with cancer and cystic fibrosis worried the most about how the patient was doing (Menke, 1986). Both diseases of course are potentially fatal. The siblings found it especially difficult to watch the ill child have to deal with anxiety or pain, and to witness physical and personality changes (Kramer, 1984). The most disturbing physical changes are hair loss and weight fluctuations (Kramer, 1984). Siblings indicated that the ill child was often teased at school (Iles, 1979). The siblings found it

hard to cope with the personality changes due to the illness and the medications, as the patient became "moody and hard to get along with" (Kramer, 1984).

Perhaps the siblings' biggest fear is that the sick child will relapse and die. "I listen to her sleep and I worry about her. I'm afraid her tumor will come back. I spend more time with him because I'm afraid he might die" (Koch-Hattem, 1985, p. 114). Siblings see many similarities between themselves and the patient, based on the many experiences they have shared as part of the same family. Well siblings thus develop fears of their own health and possible death (Sourkes, 1980).

The similarities between patients and their healthy siblings were striking. Both siblings and patients had a negative body image and high anxiety scores. It is easy to understand why patients would be concerned about their own bodies. They experience changes in sizes, bruises, loss of hair [and] painful procedures.... Although the healthy siblings do not experience these assaults directly, the sick child's illness has such a profound effect on them that they suffer severe anxiety about their health. The anxiety is expressed in physical symptoms (Cairns et al., 1979, p. 486).

Not all the effects of cancer on well siblings are negative. The experience can also bring about positive and adaptive responses, such as increased sensitivity, empathy and increased medical knowledge, pride in taking care of one's own needs and the needs of younger brothers and

sisters (Kramer, 1984; Iles, 1979). Menke (1986) found that parents described few behavioural problems. Lavigne (1980) conducted one of the few controlled studies of children with various chronic illnesses, one being cancer. With regards to total problems, he summarized that siblings of cancer patients did not seem more disturbed than siblings of healthy children. These findings closely parallel those of Cairns et al. (1979), who, though not using a formal control group, obtained results on self-esteem and "Family Relations" tests similar to results found among children who came to the institute for normal pediatric care.

#### Summary: The Impact of Cancer on Siblings

As with the studies on the impact of cancer on the patient, there are few well-controlled studies addressing its effects on healthy siblings. Research efforts appear scattered and diverse. Sample populations are small, few studies attempt to use control groups, and comparisons made use material which is primarily anecdotal and descriptive.

We could not say that all or even most siblings develop problems. Many children will indeed grow and mature from the experience. However, the growing literature shows that siblings bear multiple stresses, so that they can be accurately termed a "population at risk." During periods of heavy treatment, such as during the time immediately

following diagnosis, parents focus their attention upon the well-being of the patient, often leaving siblings with little support and nurture. Therefore it is crucial that intervention begin at an early stage, in order to educate parents on the needs of siblings and to include siblings in the treatment plans.

### Impact of Cancer on Parents

In childhood cancer it is the parents rather than the child who first hear the diagnosis and are aware of its serious implications. In one study (Binger, 1969), the diagnosis was seen by the parents of children who had died of leukemia as the hardest blow they had to bear. In the weeks that followed diagnosis most parents experienced physical distress, depression and inability to function, anger, hostility and self-blame. A high percentage of family members continued to exhibit emotional disturbances after the death of their child. Some of the disturbances were so great that they interfered with functioning to the extent that the person needed psychiatric attention.

Unlike the retrospective study cited above, Kaplan, Smith, Grobstein and Fishman (1973) attempted to study 50 families as they progressed through the course of the illness from the time of diagnosis to the death of the child two or three years later. They considered that 87 per cent

of the parents failed to resolve successfully even the initial tasks of coping: namely, experiencing the pain and comprehending the seriousness of the diagnosis. Many parents denied the reality of the diagnosis to such an extent that they used euphemisms in talking of the illness and refused to allow their children to be told about their illness.

It is obvious that parents are faced with numerous difficulties upon receiving a diagnosis of childhood cancer. These include acceptance of long and arduous treatment without assurances that the disease will be cured; observation of their child in physical and emotional pain; anxieties surrounding their child's present and future vulnerabilities; possible financial problems; restrictions of career mobility; and disruptions to family life (Blumberg et al., 1980; Tritt & Esses, 1986). It is not surprising therefore that parents, given the stresses involved, exhibit many emotional problems.

Schuler et al. (1985) investigated 81 families whose children had various types of cancer over a five year period from the time of diagnosis, in order to evaluate changes in family relationships and individual functioning. Pre-diagnostic values were determined retrospectively on the basis of the evaluation of parents and other relatives' accounts of the family's former relationship, and the

stability of its members. In this way, before and after comparisons could be made. When compared to the pre-diagnostic situation, it was found that parents had a high frequency of emotional disturbances and that family relationships showed dramatic changes. Eighteen percent of fathers and thirteen percent of mothers in this study developed somatic complaints. These were more prevalent among parents who were very cooperative, i.e. those who were strongly motivated and well controlled. Other studies have indicated even higher incidences of such symptoms. Half of the mothers and a third of the fathers reported not feeling healthy in one study (Márky, 1984). In yet another it was noted that 88 percent, 21 out of 24, reported an increase in somatic complaints such as headaches and backaches (Powazek et al., 1980). Somatic complaints have long been recognized by professionals as a way of showing anxieties that may be difficult or impossible to verbalize, or even to experience (Márky, 1984).

Emotional distress, especially anxiety and depression, seem to be common features of parental reactions to childhood cancer (Hurley, 1983; Magni, De Leo, Carli, Tshilolo & Zanesco, 1986; Powazek et al., 1980). Powazek et al. (1980) concluded that "the overall maternal profiles based on psycho-pathological measures at the time of diagnosis were more disturbed than patient profiles" (p. 147). Forty-five percent of mothers exhibited high levels



of anxiety whereas only two percent of the patient sample received similar high scores. High levels of depression were also recorded for mothers. However, at the six month period following diagnosis the scores on these measures showed a significant decrease. This would correspond with the time when the child has usually gained remission and family interaction can be expected to return to some level of normalcy.

Other studies have not identified a similar decrease over time in psychological distress. In Magni et al.'s controlled study (1986) of forty-one parents and twenty-one patients which evaluated psychological distress throughout the various stages of the disease, the experimental group consistently scored higher than the control group. Scores between the first assessment which took place soon after diagnosis, and the second interview at eight months were slightly reduced on some of the distress scales. Values for anxiety and depression, on the other hand, remained abnormally high. "It appears that emotional arousal does not diminish but persists over time" (Magni et al., 1986, p. 287). At the twenty month period after diagnosis there was even an increase in moderate psychological distress, with depression given as the most prevalent symptom after sleep disturbances. It should be noted that this study took place in Italy, and that treatment offered by medical staff was

exclusively medical, with no special attention paid to psychological aspects.

A small study by Hurley (1984) conducted nine months after the diagnosis of childhood cancer, lends support to some of the findings cited above: that psychological distress, especially anxiety, persists over the treatment period. By the use of a self-report questionnaire and the Psychological Stress Evaluator, which used the human voice as a medium to manifest a psychological response to stress, it was revealed that the majority of parents are as anxious as hospitalized medical-surgical patients who have been diagnosed with cancer themselves. Magni et al. hypothesise that "it is possible that the arousal of emotional distress is actually an inherent part of normal processes of adjustment to the disease" (p. 287).

The recognition that there are many stresses for parents has led many authors to question the impact of childhood cancer on the marital dyad. However, the findings are far from uniform. A small study by Peck (1979) of 24 families with a child with either leukemia or Wilm's Tumour, found that a quarter (6) of the families had suffered a marriage breakup. The stresses associated with a diagnosis of cancer had in some of these families exacerbated existing marital relationship problems. Lansky, Cairns, Hassesein, Wehr and Lowman (1978) also noted increased marital strain

in parents of children with cancer, in comparison with parents of children with other chronic illnesses and parents of healthy children, although divorce rates were no higher than the national average.

Other authors have suggested that a diagnosis of childhood cancer has the apparent effect of improving family functioning and enhancing marital relationships. Barbarin, Hughes and Chesler (1985) studied the marital functioning of fifty-five families. Most respondents indicated that the quality of their marriage had in fact improved since the diagnosis of cancer. This surprising phenomenon has also been reported by other researchers. For example, in Kupst et al's (1984) study, thirty-three percent of the parents stated that they had a closer relationship since the diagnosis. Six families of the twenty-four interviewed by Peck (1979) also indicated that their marriage had grown stronger. Schuler et al. (1985) noted that, although at stressful times during treatment the marital relationship had a tendency to deteriorate, there were very few people in the sample who became divorced, as parents considered it a shared responsibility to help and be with the sick child.

Barbarin et al. (1985) suggest that the effects of childhood cancer upon the marriage may not necessarily be as debilitating as were once supposed. However, they warn against too hasty a generalization, as other factors such as

social support, past experiences, and use of professional help may affect marital functioning. Barbarin et al. found that parents whose children were diagnosed more than three years previously rated their marriage as less favourable than those whose children were within three years of diagnosis. It may be that early in the illness process the focus is on working together for the survival of the child. Marital discord or dissatisfaction may be glossed over.

#### Summary: Impact of Cancer on the Parents

Marital discord may not be as prevalent as once was supposed, but childhood cancer poses many stresses and strains upon parents. Early studies often reported psychological and adjustment problems of parents in families where the child was either in a terminal stage or had died. As medical advances have significantly increased the length of time the child may live, and the chances of complete cure, we may suppose that there are fewer strains and stresses on parents. This in reality may not be so. In fact the chances of an extended life span may add to the parents' emotional stresses. At one time a diagnosis of cancer meant certain death and parents could prepare accordingly. Now parents must not only come to terms with the fact that their child has a life threatening illness but must also accept lengthy treatment with an uncertain outcome.

This uncertainty can be as or even more stressful for parents than death, and it may continue for many years. Therefore it is no wonder that parents report many somatic symptoms, increased anxiety and depression and other emotional disturbances. Given the many stresses for parents and especially the uncertain prognosis of the disease, psychosocial intervention appears critical as a support to foster healthy adaptation.

#### Impact of Cancer on the Family System

Until recently research into aspects of childhood cancer has examined its impact on the individual family member and/or the dyadic sub-system (Spinetta, 1984). Therefore studies have concentrated on the sick child, the siblings and/or the parents. Although over the years there have been articles dealing in some manner with families, rather than focussing on the individual, they have not attempted to assess the relationship between family functioning and childhood cancer in a scientific multi-variate manner. As Tritt and Esses (1986) explain, this is surprising, considering "it has long been speculated that chronic illness in a child creates inevitable strains which are likely to impact deleteriously on other family members" (p. 118). The paucity of studies reflects the complexity of such research in collecting and analysing multiple sources

of data, as well as the lack of available objective measures for assessing families (Tritt & Esses, 1986). A few multivariate studies are now emerging which concentrate on various aspects of family functioning in the family with childhood cancer.

Blotcky, Raczynski, Gurwitch and Smith (1985), in their study of thirty-two patients and their parents, examined the influence of family functioning on early feelings of hopelessness among pediatric cancer patients. They used a variety of measures to assess family functioning in five areas; namely, member satisfaction with family life, the mother-child relationship, parents' coping efforts in regard to their child's illness, parents' level of subjective distress about the illness and the extent of the child's interaction with the family and with other relatives. Results showed that early feelings of hopelessness in children with cancer were related to how well mothers and fathers coped in the context of a serious illness. Of note in this study is that fathers were assessed as important as mothers to their child's adjustment.

Two specific patterns of parental coping were inversely related to feelings of hopelessness in the child. These were fostering family integration and maintaining self stability. However, as Blotcky et al. (1985) explain, some

parental behaviours, designed to increase a sense of optimism in their children may not be the behaviours that lessen the parents' own level of subjective distress. Therefore trying to obtain medical information which lowers parental distress and at the same time maintaining family integration which impacts positively on the child, but does not necessarily reduce the parents' feelings of distress, may be an impossible task, and may require parents to oscillate from one set of coping behaviours to another, in response to the particular needs of family members. Blotcky et al. (1985) suggest that more longitudinal research needs to be conducted on family functioning, and in particular, on various coping behaviours of parents and children.

Chesler and Barbarin (1987), using a sociological model, intensively studied stress and coping responses of ninety-five families. Patients, siblings, parents, schoolteachers, family friends and medical staff were all interviewed. The authors used a time line chart in which patients and other family members described critical events and stages in the disease process, and the amount of stress associated with each. Structured, semi-structured and open-ended questions were used in face to face and telephone interviews. The data collected were subject to both qualitative and quantitative analysis, to compare stress, coping mechanisms and social support patterns across various family structure characteristics.

Chesler and Barbarin (1987) expand, as have other writers, on the difficulty of agreeing on a standard criterion of coping, except for gross inappropriate behaviour such as alcoholism, child abuse and dramatic denial. They point out that what may be effective coping behaviours for one family or for individuals within that family may be ineffective for others with different values and experiences. Results indicated that parents who reported coping well as a family also reported less personal stress associated with the medical situation, a willingness of family members to subordinate personal preferences to family needs, and positive and supportive relationships with extended family. The issue of causation remains undecided: does the existence of the illness encourage the development of these mechanisms, or are these ways of coping pre-existent? Further research is obviously needed in this area.

Kupst et al.'s longitudinal study of 64 families with a child with leukemia is to date probably the most extensive and comprehensive work to measure coping strategies and family functioning (Kupst, Schulman et al., 1982; Kupst et al., 1983; 1984). They measured the families using objective raters and self report scales at four different time intervals over a two year period. Parents were asked to complete the Current Adjustment Rating Scale (CARS) at the scheduled time intervals as well as at times when there



was a change in the child's medical condition. The CARS scale is a 12 item Likert type scale designed to assess current functioning, satisfaction, and aspects of social popularity.

As well, medical staff completed the Family Coping Scale which focusses on reponses of family members to a crisis in three areas: emotional reactions to the illness; cognitive understanding of the realities and implications of the illness; and behavioural reactions to the illness. Mean scores were recorded for mothers, fathers and children. Psychosocial staff also rated families based on taped interviews with a clinical intervenor on such variables as openness of communication, ability to live day-by-day, quality of relationship and adequacy of support.

Results indicated that people used different and sometimes contradictory forms of coping such as minimizing the diagnosis, and talking about fears. Nevertheless, most of the families were judged by medical, nursing, and psychosocial staff to be coping well two years after diagnosis. Similar results were obtained from the families' self-scores at each time interval, though subjectively the families experienced themselves as coping poorly at the time of diagnosis. Coping was found to be an interrelated variable among family members. Therefore if parents were functioning adequately, the children also were not likely to

be exhibiting major problems. Positive coping was related to the age of the ill child. Families with older children coped better than those with younger ones. Negative coping was associated with the presence of pre-existing problems or concurrent stresses, such as pregnancy or marital stress.

### Summary

The relationship between childhood cancer and various aspects of family functioning is extremely complex and research on this area is in its infancy. Many variables can impact upon the family's response to the disease, such as the age of the child, the developmental stage of the family and of its individual members; resources of the family, both internal and external; quality of interaction within the family; progress and course of the illness; and perception of the illness. As of yet it is not completely clear what factors distinguish families who have difficulty in coping from those who cope well (Tritt & Esses, 1986). Therefore it would be foolish to try to understand the results of the above studies as a straight cause-effect model. It is with great caution that we may say that many families can and do adapt and adjust, coping well with the demands of the illness. Furthermore, there are indications of a strong connection between the coping abilities of parents and the subjective feelings of the child (Blotcky et al., 1985; Kupst, Schulman et al., 1982; Kupst et al., 1983, 1984).

Parental stability appears to influence the child's coping abilities. However, in terms of actual coping behaviours which enhance positive functioning, both Chesler and Barbarin (1987) and Kupst et al. (Kupst, Schulman et al., 1982; Kupst et al., 1983, 1984) suggest that they may in fact be different for each family and family member. Blotcky et al. (1985) further add to the complexity of the issues by presenting the hypothesis that behaviours which may assist parental functioning may also hinder child adaptation and vice versa.

How do these findings fit in with previous research cited in this review? Many studies have indicated that parents, siblings and patients displayed heightened emotions. These led to the child with cancer taking on a self-protective stance, and perhaps having a lower self-concept and self-image than peers. Siblings tended to worry excessively about their sick brother or sister as well as about their own health and welfare, while parents reported a greater than normal incidence of somatic complaints.

We should realize that many of the earlier works were based on a psychopathological model, so that researchers expected to find dysfunction. Later efforts such as those cited in this last section of the review, use a stress model to assess families. In this model, the illness is seen as

the stressor which can introduce positive tasks, challenges and opportunities for growth and learning, as well as contribute to problems in adaptation and coping. Therefore a response to the stressor may be heightened anxiety or somatic complaints, but the family as a whole may also be coping in a functional manner with the situation.

It should not be supposed that, because these recent studies based on the stress model are uncovering fewer pathological problems in families with childhood cancer that no support or intervention is now needed. Stresses and challenges still remain, and many problems still have to be addressed by families faced with a diagnosis of childhood cancer (Chesler et al., 1981; Van Donegan-Melman, Pruyn, Van Zanen & Sanders-Woudstra, 1986).

It is clear that the impact of childhood cancer on a family continues over time. Although the shock and sudden changes accompanying diagnosis may make that the most stressful time for most parents, continuing treatments and checkups (even when the outcomes are positive) are also stressful. While these stresses may be moderated by successful treatment of the disease or exacerbated by relapse and/or death they continue to have long term impact on parents' feelings, orientations to their children, and ways of managing their personal and social tasks (Chesler et al., 1981, p. 41).

It is therefore to the specific topics of stress and coping strategies that this report now turns.

## CHAPTER 3

### Stress and Coping

Family response to the stresses of cancer is variable and unpredictable. Some families in fact grow stronger and thrive as they confront the diagnosis and its attendant demands. Other families are weakened by successive crises and in some cases the cancer may contribute to separation or divorce (Patterson & McCubbin, 1983).

Some thirty years ago, Hill developed the ABCX Family Crisis Model, in an attempt to explain and understand the variability of family response to any crisis (McCubbin and Patterson, 1983). According to the theory, how vulnerable a family is to crisis depends on the interaction of the stressor (a factor) with existing resources (b factor) and with family perception (c factor). The x factor represents family adaptation. Therefore one family faced with a diagnosis of cancer in a child (the stressor) may perceive it as a challenge and as an opportunity to grow (c factor). Inner strengths may be mobilized to deal with the crisis and friends and relatives may be called upon to give support (b factor), so that the family unit is strengthened by the event (x factor). Another family faced with a similiar

diagnosis may define it as a catastrophe (c factor), and feel overwhelmed by the stresses. It may lack personal or family resources (b factor) so that members cannot support each other. This can lead to family crises where members become disorganized, routines disintegrate and stability is threatened. Coping is the central process used by families as they seek to adapt and adjust to new demands. It involves an interaction of resources, perception and behavioural responses.

McCubbin and Patterson (1983) have extended the Hill ABCX model, calling it the Double ABCX Model. Post-crisis variables are added to the existing pre-crisis variables of the original model, in an effort to describe additional life stressors faced by the family and new resources which the family must call upon, in order to achieve a satisfactory resolution of the crisis. The extended Double ABCX Model, as it relates to childhood cancer, is shown in Figure 2.

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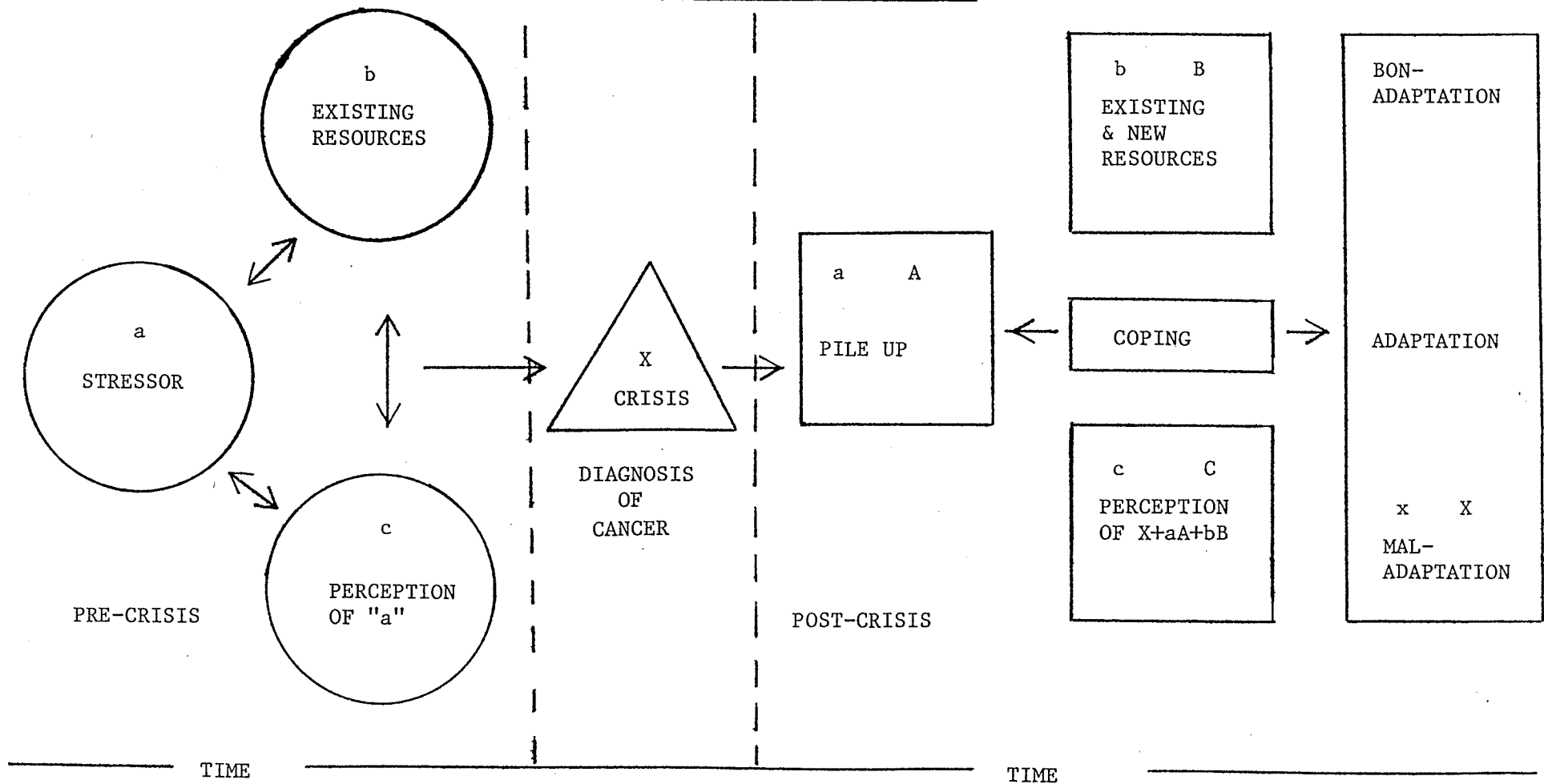
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As this model was selected as the organizing framework for the practicum, it will be described in some detail below with specific reference to childhood cancer.

Figure 2

The Double ABCX Model of Family Adaptation in Childhood Cancer.



Adapted from:

McCUBBIN AND PATTERSON (1983)

## I. The aA Factor: "Pile-up" of Family Demands

McCubbin and Patterson (1983) suggest that because family crises evolve and resolve over time, families seldom deal with a single stressor but rather experience a pile-up of demands (Aa factor). They outline five broad types of stressors contributing to this pile-up in the family system faced with a crisis: the initial stressor and its hardships; normative transitions; prior strains; the consequences of family efforts to cope; and ambiguity both intrafamilial and social. Each type of stressor will be more closely examined in the following section.

### The Initial Stressor and its Hardships

Inherent in a stressful event such as the diagnosis of cancer are the specific hardships which increase and possibly intensify the difficulties faced by families. Chesler et al. (1981) categorize the stresses or hardships for individuals and families as follows:

1. Instrumental or practical problems, such as coping with treatment and side effects, and returning the child and family to normalcy.

2. Intellectual problems, such as understanding the nature of the diagnosis, treatment and prognosis.

3. Social and emotional problems, such as mobilizing personal and social resources to deal with the disease and



its effects, coping with sadness, finding sympathy and help from family.

4. Existential problems or dilemmas, such as integrating the events of childhood cancer into a coherent view of the world, and understanding the meaning of their religious convictions.

Van Donegan-Melman et al. (1986) present a somewhat different conceptual model of the initial stressor, based on theories of attribution and social comparison. They use the model to explain both the problems experienced and the coping mechanisms used by families. Four stresses are identified and elaborated in this model: uncertainty, loss of control, threats to self esteem and negative feelings.

The first, uncertainty, is defined as a lack of information about a value system which is important to a person, and is the most striking feature of childhood cancer. Thus, families do not know whether to prepare their child and themselves for life or death. Parents may become uncertain of how to discipline the patient and even whether they should allow treatment to continue. Children, especially teenagers, may feel uncertain about how their peer group will react to their body changes and whether they will be accepted as a friend.

The second stress, loss of control, is defined as the inability to manage or influence events, and can negatively influence a person's mental health status. Therefore, patients are confronted with increased dependence on others, loss of privacy, restrictions on their way of life, and sometimes over-protective parents as well. Parents, on the other hand, may feel they have transferred control as the primary care-givers of their child to physicians and hospital staff.

The third stress, threats to self-esteem, is related to the image an individual has about his or her body, psychological state and social functioning. Thus, children with cancer may face loss of self-esteem because they are placed in a new role of being ill or different. Adolescents may be affected by changing physical appearances and capabilities so that they withdraw from peer relationships.

The last stress outlined by Donegan-Melman et al. is the presence of common negative feelings such as anger, guilt, shame, loneliness, apathy, bitterness and confusion. Depression, anxiety and fear are felt by both patient and family.

### Normative Transitions

Along with the stresses of the illness itself, families may also experience additional demands or opportunities arising from developmental issues or life cycle changes which call for family or individual adjustments (McCubbin & Patterson, 1983). For example, having a baby diagnosed with cancer may be a difficult and added burden upon the young married couple who are attempting to stabilize a family identity. A child with cancer can threaten grandparents who are approaching their own mortality. Likewise developmental tasks can be affected by the illness so that the teenager is not allowed or encouraged to become emotionally independent from parents. Very few authors who have studied life threatening illnesses in children have taken into account the additional stresses involved for the child and family during periods of normative transitions. One exception is Drotar et al. (1984), who postulate that psychological problems in children with a life threatening illness often occur at crucial times in the developmental cycle.

### Prior Strains

Many families have unresolved problems from previous stresses, transitions or ongoing difficulties in connection with work, school or parenting, and must contend with these

as well as the stresses inherent in a diagnosis of childhood cancer. Kalmins, Churchill and Terry (1980) found that in half of the families with family discord, problems existed before the diagnosis, and the illness did not change the situation. In fact, parents tried to control the difficulties in order to create a good environment for the sick child. Thus an alcoholic father attempted to limit his intake; a step-father tried to improve his relationship with the ill child, and an unhappily married couple endeavoured to control their quarrelling. These attempts were generally unsuccessful in addressing the discord. Other authors have found that a diagnosis of cancer may exacerbate pre-existing problems, so that coping abilities are affected (McCubbin & Petterson, 1983; Kupst, Schulman et al., 1982; Kupst et al., 1984). Thus McCubbin and Petterson (1983) hypothesise that prior strains "contribute to the pile-up of demands families must contend with in a crisis situation" (p. 15).

#### Intra-Family and Social Ambiguity

McCubbin and Patterson (1983) suggest that a crisis can create boundary ambiguity within the family system, with some uncertainty as to who is inside and who is outside the boundaries. An obvious example is the situation where parents of the sick child are separated or divorced. Medical staff may interact with them as if they all belonged to one family. The child may also demand attention from

both parents. This may result in blurred boundaries and increased stress for the parents. The family's ability to manage stress may also depend in part on the "efficacy and/or adequacy of the solutions the culture or community provide" (McCubbin & Patterson, 1983, p. 16). These social or community prescriptions for coping with cancer, however, may be unclear or lag behind the times, and may offer little to families struggling to manage a difficult situation. Friends and neighbours may avoid contact with the family, being unsure of what to say or how to help them, or they may indicate that they would not put their child through the ordeal of chemotherapy. Both stances may alienate the parents, and increase their guilt, thereby adding to their stress (Chesler & Barbarin, 1987).

#### Consequences of Family Efforts to Cope

Stresses and strains can emerge from the specific behaviours used by the family to cope with the crisis. For example, a family may decide that the mother should give up work, to give more attention to the child. This may relieve the strain for the parents in trying to juggle work responsibilities with the child's medical regime, but it may also add alternative stresses. The loss of one income may cause financial problems, and the mother may feel lonely and frustrated at home all day with the child. A decision to move nearer to the hospital may relieve the stresses of

travelling, but create other stresses, such as meeting new friends, fitting into the neighbourhood, and arranging new schools.

Kalmins et al. (1980) studied forty-five families over a period of twenty months from the time of diagnosis. Only five did not experience other stresses besides that of caring for the child with leukemia, whereas fourteen families had to cope with four or more stressful events over the period of time. One of the striking findings of this study was the high percentage of families (44 percent) who had to deal with one or more major health problems in another family member.

Thus, in addition to adapting to the illness itself, the family often has to deal with many other stressors and strains which can occur simultaneously, vary in intensity and result in "pile-up". According to Patterson and McCubbin (1983), the health and well-being of the ill child can be affected by this pile-up. The results of studies of children with cystic fibrosis found that:

a pile-up of life events and strains particularly in the areas of intra-family development and relationships, family management and decisions, and family finances had an adverse effect on the child's health, as measured by a decline in the functioning of his/her respiratory system (Patterson & McCubbin, 1983, p. 29).

Families who have a "pile-up" of family life changes and strains are also characterized by more conflict and therefore are more vulnerable than those experiencing fewer life stresses and strains.

## II. The bB Factor: Resources

"Resources are the psychological, social, interpersonal, and material characteristics of individual family members, of the family unit and of the community which are used to meet demands and needs" (Patterson & McCubbin, 1983, p. 29). Two types of resources are generally used by a family in response to a situation such as the diagnosis of a child with a chronic illness: existing resources already in the family's repertoire, which help the family deal with the crisis; and new resources which are strengthened and developed in response to new demands.

Many investigators have attempted to assess the variables and therefore the resources that may influence coping in families with childhood cancer (Chesler & Barbarin, 1987; Kupst et al., 1983; Tritt & Esses, 1983). These variables include socio-economic status, age of child, support systems, communication within the family, religious beliefs and psychological resources.

### Socio-economic status

Stress emanating from the illness cuts across all classes. However, evidence has been gathered that in some areas of functioning more affluent families experience somewhat less stress than families of a lower socio-economic level (Chesler et al., 1981). Level of education and father's occupational status are also associated positively with coping abilities (Chesler et al., 1981; Kupst, Schulman et al., 1982; Kupst et al., 1984). Families in a higher socio-economic bracket can more easily absorb the extra costs incurred as a result of the treatment, such as parking and transportation, eating meals in the hospital or a restaurant, and taking time off work, than less well-off families. As well, they have more opportunity to use such stress relieving techniques as going out to a show, eating out in a restaurant, spending money on relaxing vacations and hiring babysitters.

### Age of Child

Information on the impact of the age of the child on the family is far from consistent. Kupst et al.'s (1982, 1984) findings indicate that families with an older child cope somewhat better than families with a younger child. This may be because parents need to spend more time in helping with the physical care of the infant or toddler than



with the adolescent. Parents may feel that they must stay in hospital overnight with a five year old, but a thirteen year old may not want or require such constant attention. However, in another study, parents indicated greater family stress when the ill child was seven or older (Chesler & Barbarin, 1987). Older children may need less physical care than younger ones, so that parents may feel that they are coping better. Nevertheless it may be more difficult to talk with older children about their illness because they are more likely to comprehend the seriousness of it and be distressed by it. This distress no doubt reverberates onto the parents, and may increase the level of stress in the family unit.

### Support Systems

A growing body of literature cites the role of support both actual and perceived as a contributory factor to adaptive coping. Morrow et al. (1984) examined the correlation between the supportiveness and helpfulness of eleven possible sources of social support and parental psychosocial adjustment to cancer as measured by the multi-dimensional Psychosocial Adjustment to Illness Scale (PAIS). The scale assessed the quality of an individual's adjustment to an illness in seven areas, namely: vocational environment, domestic environment, sexual relationships, extended family relationships, social environment,

psychological distress and health care orientation. Support from spouse, friends and relatives was strongly correlated with positive total psycho-social adjustment in parents whose child was on treatment.

Chesler et al. (1981), who examined the role of support as a predictor of good coping and adjustment in fifty-five families with childhood cancer also found that spouses and close friends were listed as the most helpful people. Although both parents reported receiving strong support from their spouses, mothers reported less support from their spouses than did fathers. For wives, spousal support was associated with the husband's participation in the care of the sick child. Wives who took sole responsibility for the sick child reported lower levels of spousal support than wives whose husbands participated in the child's care (Barbarin 1985).

Many studies have found that fathers tend to absent themselves from involvement with their ill child, leaving most of the care to the mother (Binger et al., 1969; Findlay et al., 1969; Cook, 1984). On the other hand, men in one study expressed feelings of being left out of their sick child's care and life and of being isolated from support (Cook, 1984).

In North American society, men still have the responsibility of being the primary economic provider for the family. Upon diagnosis, men are faced with two competing sets of obligations; those relating to their jobs and those connected with family and being with the sick child. Another conflict between work and family may involve employers who are reluctant to give men time off during their child's illness, and see the care of the sick child as the job of the mother (Cook, 1984). There is now some indication that fathers do indeed play an important role in the stability of the family under stress, and also in the well-being of the sick child (McCubbin, Cauble & Patterson, 1982).

Close friends and extended family members are also rated by parents as high on the list for helpfulness (Chesler et al., 1981; Morrow et al., 1984). Invoking emotional support from friends and relatives can reduce feelings of loneliness and provide a stabilizing influence for the family going through the treatment of a child with cancer (Adams, 1979). However, people who are sources of help may at times also be sources of added stress. They may question the child's treatment, and offer conflicting advice. Such questionable supports may serve to highlight the parents' sense of pain, isolation or inadequacy (Chesler & Barbarin, 1984). Friends of families with childhood cancer may express some difficulties themselves.

Their desire to help the family can be complicated by their own emotional distress and by their concerns about being intrusive and invasive of privacy. Some friends may find it hard to avoid the dilemma of not raising some issues or pushing too hard on other issues (Chesler & Barbarin, 1984).

Data indicate that parents of children with cancer receive more help than other family members and that mothers receive more help than do fathers. It appears that mothers in general are able to express a broader range of feelings to friends, which then makes it easier for helpers to respond appropriately. Fathers, on the other hand, tend to have a harder time talking about their feelings and in allowing themselves to be vulnerable enough to ask for help from friends (Chesler et al., 1981). McKeever (1981) in one of the few studies looking at the role of fathers in families with a child with chronic illness found that none of the ten fathers she interviewed used friends to help them deal with stresses or solve problems. All the men indicated that their wives were their major support, and it was only with them that they discussed concerns about the sick child. Obviously this reliance on the wife for comfort and support can place quite a strain on the marriage, especially if the wife feels she must care for her husband as well as the sick child.

Morrow et al. (1984), who also studied the psychosocial adjustment and social support of parents whose child was off treatment or whose child had died, found that level of support was not an indicator of adjustment. They suggest that the impact of death for parents is so substantial that social support may not have a large enough effect to influence such an impact. Parents whose child is off treatment may not need to continue to use a support network in order to cope with the stresses of active treatment.

#### Communication in families with childhood cancer

Openness of family and parental communication about the illness in the family is consistently correlated with good coping and adaptation in both parents (Kupst, Schulman et al., 1982; Kupst et al., 1984), and children (Spinetta, 1981; Drotar, Crawford & Bush, 1984). Vollman, Ganzert, Picker and Williams (1971), working with bereaved families, found that families with open internal communication were more able to express feelings of sadness and loss as well as the less acceptable reactions of anger, guilt and relief. Dealing with the stress by attempting to assess and absorb the reality of the situation, rather than by trying to deny it, helped families to cope more effectively with the crisis.

Children whose parents are open with them have been found to cope better with both the positive and the negative aspects of their illness. In fact, children's anxiety levels and interaction with meaningful figures in the illness environment are directly related to the family's pattern of communication about the illness. Children from families with open communication placed models of family members and hospital staff closer to a doll representing themselves in a replica of a hospital room. They also had a better self-concept and were less defensive than children from homes where the illness was not discussed (Spinetta, 1981a). Kellerman, Rigler, Siegel and Katz (1977) rated seven children over a period of time on mood levels and amount of talking about their illness. They found that those who talked the most about the cancer were also rated the least depressed. However, some families may avoid discussing strong feelings, especially sadness, and may need continuing help to begin to verbalize their emotions (Adams & Deveau, 1984).

Kaplan et al. (1973) graphically outline the plight of a thirteen year old youngster whose parents had steadfastly refused to talk to him about the seriousness of his illness. Eventually the mother was helped to talk with the boy, but the father and adolescent sister were not included in the discussion. After the boy's death, the sister exhibited emotional problems by refusing to go near

the boy's bedroom. The family was forced to move. Powazek et al. (1980) found that attempts at hiding the seriousness of the diagnosis only provided a temporary reduction of anxiety for the patient. In the long run, communication in the family was so affected, that members could not use each other for support in dealing with emotional stress.

Farrell and Hutter (1984) reviewed the literature in regard to adolescents coping with their illness. They concludes that it is important for open communication to take place between the teenager and significant others, and that this should be instituted and encouraged at the onset of diagnosis. As one teenager advocates, "you really have to pull together as a family from the very beginning. You must get your lines of communication straight so that you understand and they understand. Frequently you have to volunteer the information to your brothers and sisters because they are afraid to ask you directly what is going on" (Deasy-Spinetta, 1981a, p. 192).

Powazek et al. (1980) found that mothers were much more likely to discuss their children's illness than either fathers or siblings, even though all had comparable levels of preoccupation about the disease. Not surprisingly, fathers and siblings in this study demonstrated much difficulty in adapting to the emotional stress invoked by the illness. Parents who cannot talk either to each other

or to their children about the illness and other related issues, may find that such patterns of communication isolate them from each other as well as from their children and from other supportive networks (Drotar et al., 1984).

Adams (1979) postulates that the pattern of response between family members at the time of diagnosis is a guideline to the nature of family communication as a whole. He outlines four general patterns as described below:

1) open communication - open emotional response

In this response family communication is straightforward and open. Emotional responses are focussed on mutual supports and caring for each other. The family is well integrated with clear definitions of roles, relationships, leadership and power distribution, and will regain a healthy homeostasis with little professional input.

2) open communication - disrupted emotional response

Communication patterns in this response are superficial and focus on instrumental or task oriented discussions. Any discussion at the feeling level is avoided, and parents attempt to deal with the illness by denying it or by withdrawing. Parents cannot express care of or show concern for each other.



### 3) disrupted communication - open emotional response

In this response the parents are able to support each other emotionally, care for the child, and share their sadness but they are not able to discuss the illness and its implications. The partners appear to protect each other from the realities of the disease. This may be a temporary response to the diagnosis, or may show a spousal relationship built upon a base laden with anxiety where both parents worry to the point of losing all objectivity.

### 4) disrupted communication - disrupted emotional response

This response pattern may result from the present crisis, but it is often the effect of long standing family difficulties such as the emotional instability of one or both parents, marital conflict, and financial, employment, alcohol, medical or other social problems.

## Religious Beliefs

The connection between religious beliefs and the coping abilities of individuals and families has been alluded to in the literature. Yates, Chalmer, St. James, Follansbee and McKegney (1981), in one of the few studies to address this connection, found that in adult cancer patients, an association existed between religious beliefs and higher levels of well-being, satisfaction and happiness.

No evidence was discovered of dramatic religious shifts, nor major changes in religious activity or beliefs.

In connection with childhood cancer, Schuler et al. (1985) noted that "families who have deep religious feelings seem to have coped better with the physical and emotional strains imposed by the malignancy" (p. 178). Chesler and Barbarin's (1987) findings parallel those of Schuler et al. Parents in their study reported that religious beliefs were helpful in dealing with the emotional problems of the situation. Unlike Yates et al.'s study previously mentioned, a substantial proportion (36 percent) reported an increased level of faith in God during the course of the illness, and only eleven percent reported a decrease in religious belief or practice. Thus it appears that religious belief may indeed help some families make sense of what is happening to their child, providing them with additional emotional support through the experience.

#### Psychological Resources (Personality Characteristics)

Psychological resources, it has been suggested, correlate with coping abilities, but little research seems to have been attempted in the area. A study comparing two groups of adult cancer patients, one which scored poorly on a psychological test measuring discomfort given at diagnosis and the other which scored well on the same test, found no

overall significant difference between the groups in adaptation to the illness, as measured by an Inventory of Current Concerns (ICC) after a four week period. On individual scales there was a significant difference. Patients who scored poorly on the psychological test also reported more health concerns, family concerns and concerns regarding friends on the ICC (Block, 1984). McCubbin and Patterson (1983) cite two personality characteristics which appear to influence how effectively people cope with stressful situations: a good self-esteem and feelings that one has mastery over one's life.

Thus a wide variety of resources are used by families in order to cope with the stressful situation. When families have insufficient resources so that they cannot adequately meet demands, the result is likely to be conflict in the family. Patterson and McCubbin (1983) generalized from their studies of children with cerebral palsy that families cope better when they have the resources of a) member self-esteem; b) open communication, c) mutual assistance and support, d) problemsolving abilities, e) physical and emotional health and f) a sense of mastery over the events they are experiencing.

### III. The cC Factor: Perception

In the face of a diagnosis of childhood cancer, the family must struggle to give it meaning and to redefine the situation. At first parents may see the illness as hopeless, shameful, overwhelming and beyond their ability to manage. "Family efforts to redefine a situation as a challenge, as an opportunity for growth, or to endow the situation with meaning appear to play a useful role in facilitating family coping and eventually adaptation" (Patterson & McCubbin, 1983, p. 30). The ability to perceive a situation in a positive way is of course affected by the nature of the stressor and the characteristics of the family.

The severity of the child's diagnosis and prognosis can obviously generate feelings of anxiety and hopelessness (Adams, 1979). Parents of deceased children report higher levels of stress than do parents of living children, and parents of children who have relapsed report more stress related to the disease and treatment than parents of children who have remained in remission (Chesler et al., 1981). Similarly children in long term remission fared better in the classroom than those in remission but still on treatment and also better than those who had relapsed.

The cultural and ethnic background of the person and family, as well as prior personal experiences may give each individual an unique perspective of a similar event (Chesler et al., 1981). Thus for example, one person may have been socialized, according to his or her ethnic background, to regard any crisis as a challenge, while another person may have learned to view the same situation in terms of its negative consequences. People from different ethnic groups may not only perceive the situation in a different light but have different expectations of the medical staff. Spinetta (1984) found that attempts to encourage Vietnamese families to participate in decision making about their child's treatment resulted in the parents' having doubts about the physician's ability and expertise. Prior experience of cancer or death can help the person through the presenting crisis, or conversely make the situation unbearable if grief is still unresolved. Thus the use of genograms may be particularly helpful in understanding how past family events may affect the family's present functioning and perception of the situation.

#### IV. Coping Strategies

"Pile-up", resources and perception are all critical components of coping strategies. "Coping includes the behavioral responses of family members as well as the

responses of the family unit, in an attempt to manage the situation. Coping is their ability to acquire the resources needed for family adaptation" (Patterson and McCubbin, 1983, p. 30). Professionals and families report a variety of coping strategies used in dealing with the emotional impact of childhood cancer (Barbarin et al., 1985; Kupst et al., 1984; Van Donegan-Melman et al., 1986; Patterson & McCubbin, 1983; Kaplan, 1981).

Before expanding on these coping strategies it may be beneficial to look at the tasks the family as a whole must accomplish. Kaplan (1981, p. 46) outlines these:

1. Recognizing and accepting the child's loss of good health to a chronic disease.
2. Accepting painful and prolonged treatment for the child in the hope of gaining remissions.
3. Being aware of the possibility of the child's eventual disability and death from the disease.
4. Realizing that the child's age and experience affect his or her understanding of the disease and its consequences.

#### Coping Strategies -- Children and Adolescents

Spinetta (1981a) is one of the few researchers to attempt to categorize the coping strategies of young children. He concludes that the young patient is certainly able, with help from family and staff, to make use of

strategies to relieve some of the attendant distress of the disease and its treatment. Coping strategies used by young children include searching for information needed to meet the stress, preparing for anticipated problems such as treatment effects or school related issues, maintaining a positive and hopeful outlook and keeping an active commitment to daily tasks. The ability of the child to use these manoeuvres may rest to a large extent on the interaction with the parents, and how well the parents are coping themselves with the situation. If parents are coping well, then children usually do well (Kupst, Schulman et al., 1982; Kupst et al., 1984; Blotcky et al., 1985).

In contrast with the paucity of information on the coping strategies of young children, strategies used by adolescents are well illustrated in the literature (Marten, 1980; Chesler & Barbarin, 1987; Zeltzer et al., 1980). Common mechanisms cited are listed below:

Denial is much used by adolescents to protect them from being overwhelmed by the diagnosis and its implied threats to the body. Denial may prevent the teen from becoming unnecessarily anxious about the illness, and permit him or her to live as normally as possible. Denial may lead to negative consequences if over-used as a coping mechanism.

Information seeking, along with the closely related mechanism of intellectualization, is used to lower the anxiety caused by the illness, by learning enough about the disease to establish cognitive mastery and a sense of intellectual control. Van Donegan-Melman et al. (1986) suggest that if children are not given factual information through formal channels, they will try to reduce uncertainty and anxiety about their condition by turning to informal sources, such as by comparing their treatment with other adolescents and by questioning staff.

Over-compensation, in the form of vigorous sports or intellectual pursuits is sometimes used by patients to prove that they are no different, or are even better than adolescents without cancer.

Expression of Anger is a normal reaction of the adolescent to his or her abnormal situation, and as such should be accepted with understanding by medical staff. Geist (1977) noted that staff often grossly underestimate the intensity of the youngster's rage at the diagnosis of a life threatening illness. They attempt to "cheer up" the patient, or see angry emotions as a sign of maladjustment. Thus they undermine the patient's spontaneous endeavours to verbally express feelings, which may lead to displaced anger erupting in misbehaviour or directed towards self, family or staff (Marten, 1980).



Two other strategies utilized by adolescents are maintaining a positive outlook (Orr et al., 1984; Zeltzer et al., 1980), and keeping communications open with family and friends (Chesler & Barbarin, 1987).

#### Coping Strategies -- Siblings

Research on healthy siblings of children with cancer highlights the stresses for this population, but fails to expand on mechanisms they may use to cope with the situation. We can only suppose that strategies would be similar to those used by the sick child and adolescent. The nature of sibling adaptation, like that of patient adaptation, probably depends less on the child's coping mechanisms than on how the family manages communication, problem solving, and relationships among physically healthy and ill siblings (Drotar & Crawford, 1985).

#### Coping Strategies -- Parents

Chesler and Barbarin (1987), in delineating the coping strategies used by parents, identify two coping styles: internal-passive strategies, and external-active strategies. Internal-passive strategies include denial, optimism, acceptance of the situation, maintenance of

emotional balance and reliance on religion. These strategies are aimed at controlling and managing emotional reactions. External-active approaches include search for information, problem-solving and seeking help from others, and are aimed at managing and manipulating events and resources in the social environment. The passive or emotionally focussed strategies appear to be the most useful in helping parents respond to the emotional stresses of the disease. Chesler and Barbarin found that parents' level of education correlated with the kinds of strategies used. Those with higher education made more use of the external-active strategies, such as information-seeking and problem-solving and less use of denial. Gender also influenced the kind of approaches used. Mothers report reliance on religion and search for information more than fathers, whereas fathers report using denial more than mothers. The use of denial as a major coping mechanism by fathers has been reported in other studies (McKeever, 1981).

Patterson and McCubbin (1983), in a similar vein to Chesler and Barbarin (1987), identify and elaborate on three different styles of coping used by parents to manage family life successfully when a child has a chronic illness. While both parents use the same coping patterns, the effects on family life are different. Mother's coping patterns are directed at enhancing the emotional well-being of the family. Father's coping patterns, on the other hand,

support the systems maintenance dimensions of family life. Although not specifically stated by the authors, it is assumed that parents tend to use a predominant style of coping with the illness. Each coping style is made up of several coping behaviours. The three styles these authors identify are briefly outlined below:

Maintaining family integration, cooperation and an optimistic definition of the situation. Parents using this style emphasize doing things together as a family, strengthening relationships and developing and maintaining a positive and optimistic outlook on life. Denial and avoidance are used in a positive way to allow the sick child and the family to function as normally as possible. Acceptance of the situation can enable the family to adapt to the need to live one day at a time (Van Donegan-Melman et al., 1986; Barbarin et al., 1985).

Maintaining social support, self-esteem and psychological stability. Seeking support and comfort from friends and family, and talking about the illness to others can help the family to maintain a feeling of well-being and reduce negative feelings. Although the active coping strategy of eliminating the harmful condition has limited appropriateness in the case of a life threatening illness, attempts to remove the negative consequences of the illness can enhance a sense of mastery and restore self-esteem (Van

Donegan-Melman et al., 1986). Many parents manage psychological tensions and strains by the maintenance of emotional balance and the avoidance of mood swings (Barbarin et al., 1985).

Understanding the medical situation through communication with other parents and consultation with the medical staff. Obtaining information from medical staff and books in order to reduce feelings of uncertainty, fear and anxiety, as well as to gain a better understanding of the diagnosis, can be a help to parents. Parents also seek to develop relationships and to connect with other parents who have a child with cancer. These connections help to reduce feelings of anxiety and isolation as parents share information on the illness (Van Donegan-Melman et al., 1986).

#### Coping Strategies -- The Family

"The family as a unit with specific social functions and experiences deals with stress differently than do its constituent members" (Chesler & Barbarin, 1987, p. 120). Chesler and Barbarin elaborate on the strategies needed to achieve adequate family coping:

Managing internal emotional relations. The family must attempt to meet members' needs for intimacy, empathy, personal affirmation and support. In order to achieve

nurturance of emotional relationships, strategies include: a) working together as a team, to reinforce in each other a sense of hope and confidence about the future; b) sharing information and feelings; c) maintaining open communication to promote joint problem-solving and coordination of tasks; d) paying special attention to the needs of major subsystems, i.e. marital and sibling systems.

Adapting flexibly to new tasks. The family must aim to maintain a balance between change and stability, or seek a new functional level of equilibrium. Strategies include: a) maintaining the household, redistributing chores and responsibilities, caring for young children; b) sacrificing individual needs and comfort so that the family can function better; c) creating opportunities for emotional growth and social maturation for all family members.

Managing external relationships. The family must decide how open or private it wants or needs to be in contacts with others. The demands of childhood cancer can very easily exceed family resources. Thus strategies include: a) finding and using help from family and friends, i.e. babysitting, transportation; b) finding and using help from agencies, e.g. homemaker service; c) managing financial considerations; d) regulating other demands for attention.

### V. The xX Factor: Adaptation

The outcome of these efforts by the family to achieve a new balance results in what McCubbin and Patterson (1983) term adaptation, or Factor xX. Adaptation is on a continuum from "bonadaptation" to "maladaptation", and reflects the outcome of family efforts in two major areas: the balance in capabilities and demands between individuals and the family unit, and the balance between the family and the larger community. This may be clarified by referring to Table 2.

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INSERT TABLE 2 ABOUT HERE

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A model of adaptive coping is presented by Kupst and Schulman (1980). They feel the following three outcomes are desirable:

1. The family works towards a cognitive understanding of the realities of the disease and its implications.
2. The family is able to deal with the emotional aspects of the problems, and completes the grief process through anticipatory mourning.
3. The family works towards a reorganization of its outlook and behaviour, and organizes an action plan that enables it to care for the child, deal with other responsibilities, and make use of other available resources.

Table 2

Range of Outcomes of Family Efforts to Balance Functioning Following  
a Diagnosis of Childhood Cancer

STRESSES ARISING FROM DIAGNOSIS OF CANCER

MALADAPTATION-----BONADAPTATION

deterioration in family integrity	family integrity strong
individual development curtailed	member development enhanced
family unit development curtailed	family unit development enhanced
loss of family independence and autonomy	family independence and control of environmental influence.

(Adapted from McCubbin and Patterson, 1983)

It can be seen, therefore, that a family with childhood cancer can grow and support its members and retain control of environmental factors (i.e. bonadaptation). On the other hand, the diagnosis may impose such a strain that the family disintegrates and cannot support personal growth in its members, so that eventually a loss of control and autonomy takes place (i.e. maladaptation).

### Summary

The foregoing review provides much evidence that a diagnosis of cancer imposes many stresses and strains on individuals and the family as a unit. As discussed, the family may also be facing concurrent stresses unrelated to cancer such as marital dysfunction, normative individual or family transitions, or other health problems. The negative consequences of a cancer diagnosis are obvious; however, there may also be positive consequences which promote family growth and well-being. Families employ many active strategies to cope with the stresses, gain understanding of the situation, and relieve tensions.

Empathic social work intervention beginning at diagnosis can help to foster family growth by encouraging open lines of communication, so that members can understand



each other's feelings and share these feelings. In addition, professional guidance can focus on helping families to expand their coping repertoire, to improve problem solving abilities and to enhance overall interpersonal relationships, so that they can grow with the demands of the illness.

Such counselling may not only improve the current quality of family life; it may help develop patterns of family sharing and problem solving that prevent problems from occurring later (Chesler & Barbarin, 1987).

Cancer then can become an opportunity for "bonadaptation" rather than "maladaptation".

## CHAPTER 4

### Intervention

Although much is written about the difficulties and stresses facing families in which a child is diagnosed with cancer, there appears to be a severe dearth of factual information presented on interventions. Kupst, Tylke et al. (1982) point out that "the information given about the interventive strategy is often incomplete, vague and presented in theoretical terms so that it is difficult for the clinician to replicate" (p. 32).

Some of this vagueness in describing interventions may result from the usual model of service used by social workers intervening with oncology families in a secondary setting (Tylke, 1981). The general approach to the family is through "outreach" rather than on a referral basis. A referral can help a client to define a difficulty and may mobilize him/her towards a resolution. The outreach approach attempts to educate the individual or the family to an acceptance of their need for help. Tylke postulates that this approach can make it more difficult for the social worker to formalize a clear contract of service, so that few

expectations are placed on the family by way of appointments, development of a professional-client relationship and content of interviews. She suggests that the thinking behind this somewhat atypical relationship is "not to make families more anxious by expecting them to discuss their difficulties but to give them the message that when they were ready someone would be available to them" (Tylke, pp. 20-21).

Tylke outlines a number of recommendations for social workers in the oncology setting. First, intervention should be based on sound theoretical knowledge. Second, a contract should be developed with the family, clearly defining goals and expectations of both the family and the worker. Lastly, intervention should be family focussed and begin at the time of diagnosis. Other authors also suggest that work with the family should commence at the time of diagnosis or soon after (Morrow et al., 1984; O'Malley et al., 1979; Adams, 1981; Drotar et al., 1984; Kaplan, 1981). Early intervention has also been suggested by families themselves as a means of support and help in coping with the stresses (Peck, 1979; O'Malley et al., 1979; Adams-Greenly, 1985).

Kaplan (1981), using Lindemann's theories of stress suggests a brief and early interventive approach to prevent disorders from arising as the person and family struggle to regain a new balance. He outlines a strategy of multiple

interventions directed at encouraging the expression of grief, promoting problem solving abilities, providing or gaining resources and helping parents to maintain a balance between the needs of the sick child and other family members. Interventions should not be narrowly conceived but should include systems modification as a way of supporting individual and family coping efforts.

Ross (1978) and Adams-Greenly (1985) also advocate the importance of early intervention, but both see contact with the family as extending over a longer time period. Ross (1978) connects interventions to the crucial stages of the illness, which she outlines as: before the diagnosis, the diagnostic period, remission, relapse, and death. Although the social worker cannot contact the family prior to the diagnosis, Ross suggests as part of the assessment process that the worker attempt to understand the pre-morbid functioning of the family, so that plans can be based on realistic needs and goals. Of particular importance are the quality and nature of parenting and marital and sibling relationships. During the diagnostic period the worker should assist the family to mourn and acknowledge the realities of the situation, but also help members to move on toward beginning hopefulness. At this time healthy relationship patterns which allow opportunities for growth, open communications and mutual support should be promoted.

The goal of the social worker is to help the family to maintain its continuity.

During remission, which is usually characterized by healthy denial, contact with the family may be minimal. Ross recommends that the worker be aware and prepared to intervene if there is evidence of external factors causing stress or maladaptive behaviours, detrimental to the family. Relapse from a medical standpoint brings the child closer to death, and may be more difficult for the family than the acceptance of the original diagnosis. The family will often need help to gain the energy to resume treatment and to rekindle hope. During the final period, that of death, the worker should be available to discuss practical questions concerning the death as well as assist the family in its grief work. Ross advocates that the worker should continue involvement with the family after the death of the child.

Adams-Greenly (1985) also pays attention to the stages of the disease, but outlines interventions based on the distinct coping tasks of each period. For example, in the diagnosis stage, she suggests that the patient and family have five tasks: processing medical information, providing an age-appropriate explanation of the illness to the patient and siblings; expressing appropriate emotional reactions; reorganizing family life to meet the demands of treatments and preparing the patient for re-entry into

school. Interventions based on these coping tasks may include patient and family education about the medical condition and treatment and about the developmental needs of children; crisis theory strategies to help the family to initiate and to reorganize itself to accommodate the demands of treatment; resource provision, ego-supportive counseling, and support groups.

She also emphasises the need to assess carefully the different factors in the family's functioning, such as its level of cohesion and communication, coping capacity, predominant defence mechanisms and family history. Each of these broad areas is further refined and appropriate interventions suggested. Thus an assessment of family cohesion and communication should include an understanding of the adequacy of knowledge of the illness by all family members, the degree of emotional openness, the existence of alliances in the family and the harmony or disharmony of coping styles. Interventions would include support groups, self-help groups and individual or family therapy.

Other authors encourage both early intervention and an approach which includes the whole family (Adams 1981; Drotar et al., 1984). Despite its apparent simplicity, authors also acknowledge that difficulties may occur in implementing it (Adams, 1981; Drotar et al., 1984). In a recent survey of family therapy programs in pediatric care

clinics, seventeen of the twenty-one hospitals which responded provided some form of therapy, but none routinely saw the whole family (Tylke, 1980).

Both Farrell and Hutter (1984) and Drotar et al. (1984) describe a model of intervention which includes all family members. Farrell and Hutter use crisis theory in their "Family Network" intervention with adolescent patients and their families. The model calls upon the assembled strengths of the family and its own network to mobilize and generate internal resources (i.e. to problem-solve).

At the time of diagnosis the physician and the social worker meet with the immediate family to discuss the diagnosis and treatment. An initial assessment is made focussing on the individuals' fears and needs, past experiences, and social support and resources. The following day the social worker again meets with the family to answer and review any practical concerns such as transportation or babysitting. Parents and children are invited to make a list of extended family members, friends, neighbours, schoolteachers and other significant people in the adolescent's life. If the family consents, a family networking meeting is organized to take place within a few weeks. The adolescent and parents decide who among friends and extended family they wish to invite to this meeting. The social worker and the physician jointly facilitate the

session, which has as its agenda the ventilation and acknowledgment of the emotional responses of individuals.

Each person present is encouraged to relate openly his or her concerns about the diagnosis and treatment. Concrete needs of the parents and the adolescent, which were identified earlier, are presented to the group, and suggestions are invited from the group regarding problem resolution. Further meetings are held throughout the treatment process. Farrell and Hutter maintain that this approach is especially effective in working with "hard to reach" families.

Drotar et al.'s "family-centred" approach (1984) also rests on the principle of giving consistent attention to all family members, and not just to the affected child. Consistent with other authors, they also suggest that this approach is best implemented at the onset of the disease rather than in response to problems. Drotar et al., who are among the few authors to relate theory to intervention, advocate the use of the structural family systems model with its salient concepts of sub-systems, boundaries and alignment. Through direct observation of family transactions the worker can assess how members carry out functions such as stress management and integration of the illness in family life; how subsystems operate in respect to one another and specifically who is included or excluded in



family tasks; and who joins with whom for what purpose and in which situations. Interventions evolving from the structural perspective include supporting the parents' relationship, involving fathers and mothers in the care of the child, reinforcing the family's ability to communicate together for the purpose of decision making and strengthening individual autonomy.

Little research has, however, been conducted into outcomes of psychosocial intervention. One notable exception is the controlled intervention presented by Kupst, Tylke et al. (1982). Sixty-four families of children with leukemia were provided with a program of intervention over a two year period. Coping skills were measured at designated intervals by means of a self-rating scale and also by staff of the clinic. Both qualitative and quantitative measures were used. Goals outlined for the program were to help family members: 1) to achieve an understanding of the reality of the illness, 2) to manage their emotional distress, 3) to utilize resources, both their own and those of others to care for the child, 4) to attend to other responsibilities, and 5) to support and communicate with each other.

Newly diagnosed families were assigned to one of the three intervention groups: total, moderate or no intervention. An intervener (psycho-social clinician) met

with each family within forty-eight hours of diagnosis. The intervener for the 'total' intervention group met with the assigned family each day that the child was hospitalized and each time that the child was brought to clinic for treatment. In this treatment category, active attempts were made to engage the family in illness-related issues. The intervener for the 'moderate' group met families on a weekly basis, but was not aggressive in attempts to discuss illness or family related issues. People assigned to the 'no-intervention' group were seen only for assessment of family functioning at the regularly scheduled interviews that were set for all participants in the study. These regular interviews took place at diagnosis, and at six months, one year and two years after diagnosis. All families continued to have access to normal clinic supports, such as child life therapists and social workers.

In the initial stage, interveners helped families to manage emotions and maintain confidence and mastery, to normalize reactions, and to anticipate future situations. The interveners supported the need for information and strengthening of resources. Surprisingly, overall results did not show a significant difference in family functioning between each of the groups at the end of the two year project. A note of caution should be added here, as the Family Coping Scale used by staff to rate families has a very restricted range of scores. Seventy-two percent of

families scored over 30, two years after diagnosis, which denotes appropriate coping. Psychosocial intervention appeared to be effective only in the early phase of the illness. Mothers in the 'total' and 'moderate' groups rated themselves as coping better at this time than those who were assigned to the 'no intervention' group. As Kupst, Tylke et al. (1982) point out, psychosocial intervention is still evolving as we learn more about the ways in which families cope and function with childhood cancer and as the medical picture changes. There is still a great need for the practical application of research.

The literature reviewed in this section demonstrates the variation in and the complexity of the responses of the family to a diagnosis of childhood cancer. The process of adaptation to the disease creates difficulties and opportunities, problems and challenges, joys and sorrows for the family as it seeks to make emotional and practical adjustments. Strategies and techniques are suggested for the social worker who is assisting the family in this process. The practicum design outlined in the following section is based on the theoretical considerations discussed in this review.

SECTION TWO

THE PRACTICUM

## CHAPTER FIVE

### Design of the Practicum

#### The Setting

The setting for this practicum was the pediatric oncology clinic at the Manitoba Cancer Treatment and Research Foundation and the Children's Hospital. Both facilities are within the Health Sciences Centre complex in Winnipeg, Manitoba. The pediatric oncology clinic is a primary referral centre for children with oncological diseases for the Province of Manitoba as well as northwestern Ontario and eastern Saskatchewan. Care of the patient and family is provided by a treatment team, consisting of a pediatric oncologist, a social worker, a clinical nurse, a home care coordinator, a child life therapist, a teacher and a chaplain. Approximately one hundred children are followed as outpatients by the clinic, and twenty children are newly diagnosed each year with cancer.

#### The Clients

The clients consisted of families with a diagnosis of childhood cancer newly referred to the pediatric oncology

clinic at the Manitoba Cancer Treatment and Research Foundation. A total of nine families were seen over a period of five months. The families were Caucasian, with the exception of one Asian family. Four families resided in Winnipeg and the rest in various small towns in Manitoba and north-west Ontario. Two families were headed by single parent mothers; three families were reconstituted, with the father in each case being the stepparent; and four were original two-parent families. At the time of diagnosis five of the mothers were working outside of the home, four full time and one part time. Three were full time homemakers and one was in receipt of sick benefits. All the fathers were employed. Six of the families could be described as of the middle socio-economic class. Of the remainder, one was upper class, one working class and one family was on social assistance.

Of the nine patients, five children had a diagnosis of leukemia, four with childhood leukemia (ALL) and one with adult leukemia (AML). Two had lymphomas, one had a Wilm's tumor, and one had a brain tumor. The ages of the patients ranged from eleven months to twenty-one years. Six of them were male and three were female. All patients lived with at least one biological parent, except for one child who was adopted.

Within the nine families there were eleven siblings, four of whom were half brothers and half sisters. Their ages ranged from six months to thirty-one years. In two families

the patient was the only child. Four families had two children; two had three children and one family had four children. These demographic characteristics are summarized in Table 3.

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Meetings with the family took place weekly or more frequently immediately following the diagnosis, and then every two or three weeks for the duration of the three month period. No family was seen less than six times; five families were seen for six to nine sessions, three families for eleven to fifteen sessions and one family was seen more than sixteen times. In four of the families most of the members were seen at each session. In three, the whole family was seen on only two occasions. I was unable to meet the half sibling and common-law husband in one family, while in another family, I had no contact with the half-sibling. In most cases the people not seen or seen less frequently lived out of the city or were adult siblings of patients. In six of the families some contact was made with members of the extended family: grandparents, aunts and uncles. Sessions were organized to include more than the nuclear family in three instances. The length of the sessions varied from half an hour to two hours.

Table 3

Family Demographic Information

Ethnic Origin		Family Structure		Area of Residence	
Caucasian	8	Female Single Parent	2	Winnipeg	4
Asian	1	Reconstituted	3	Rural Manitoba	4
		Two Parent	4	N.W. Ontario	1
Socio-Economic Status		Number of Children Per Family		Sex of Patients	
Upper	1	One child	2	Male	6
Middle	6	Two children	4	Female	3
Working	1	Three children	2		
Social Assistance	1	Four Children	1	Age Range:	11 months - 21 years
Sex of Siblings		Diagnosis		Number of Contacts	
Male	5	Leukemia ALL	4	5 or less	0
Female	6	Leukemia AML	1	6 - 10	5
		Lymphoma	2	11 - 15	3
Age Range: 6 months - 31 years		Brain Tumor	1	16 or more	1
		Wilms' Tumor	1		



### The Intervention

The intervention was designed to assist the family with the process of adaptation to childhood cancer during the first three months following diagnosis. It was expected that issues would continue to be identified and interventions planned throughout the process, as the medical condition of the child improved, deteriorated or stabilized. The contract with each family was to meet with them for an unspecified number of sessions over the three month period. It was not a contract which necessarily focussed on prior identified problems. Only one family had specifically requested social work services. My sanction for involvement with the remainder of the families was as a consequence of my membership on the hematology team. Thus the cancer clinic service was presented to families as involving a multi-disciplinary team which included social work.

The intervention process had four components:

1. Assessment.
2. Interventions directed toward relieving the crisis and initiating mourning.
3. Interventions directed towards specific issues, reorganization, roles and adaptation.
4. Termination and evaluation.

Although the above are presented as discrete entities, the first three components often took place concurrently and

sometimes not in the order outlined. Most often the diagnosis constituted a crisis for the family and intervention was aimed at cushioning and relieving this initial stress before a full assessment could be undertaken.

### Assessment

Assessment was an ongoing process in this practicum and therefore proceeded hand in hand with intervention. The Double ABCX model, fully explained in Chapter 3, was used as the overall assessment tool. At each session, I constantly sought to understand the family in terms of the three major elements of the model: pile-up, resources and perception, and the effects of the interaction among them. This model, based on an ecological perspective, quite naturally led to the planning of appropriate interventions as I attempted to work with the family to relieve stresses and increase their resources.

For more in-depth assessment, aspects of the McMaster Family model were used (Epstein, Bishop & Levin, 1978; Epstein, Bishop & Baldwin, 1982). The model describes six areas of family functioning: problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control. It allows both affective and instrumental issues to be addressed.

As a further assessment tool, I administered the Family Crisis Oriented Personal Evaluation Scale (F-COPES) during the first month following the diagnosis to parents and children, both patients and siblings twelve years old and over (Olson, McCubbin, Barnes, Larsen & Wilson, 1985; see Appendix 1). F-COPES draws on the three integrated coping dimensions of the Double ABCX Model: pile-up, family resources and perception measuring the coping skills of the family as a whole. It consists of five subscales with various items. The respondent is asked whether or not the family takes a certain approach to a problem. The subscales are as follows:

The 'reframing' subscale. (Items 3, 9, 12, 14, 17, 20, 24, 26). This reflects the family's tendency to redefine a stressful situation in order to make it more manageable.

The 'passive appraisal' subscale. (Items 13, 19, 29, 31). This assesses the capacity of the family to accept problematic events without severe emotional disruption.

The 'seeking spiritual support' subscale. (Items 15, 25, 30, 33). This focusses on the family's use of spiritual resources to understand and withstand events.

The 'mobilizing the family to acquire and accept help' subscale. (Items 8, 10, 11, 21, 23). This assesses the family's tendency to accept help from others.

The 'acquiring social support' subscale. (Items 1, 2, 4, 6, 7, 18, 21, 27, 32). This taps the family's ability to gain support from neighbours, friends and relatives.

There is moderate to high internal consistency for each subscale (.63 - .83) and test-retest reliability correlations over four weeks of .61 - .95 (Olson et al., 1985).

The norms for the F-COPES inventory are based on a national sample of 1,140 couples (2,280 adults) and 412 adolescents. The survey sample was selected from the membership of policy holders of Aid Association for Lutherans (AAL), which is a fraternal life insurance company based in Wisconsin. The sample included only married couples who were primarily Caucasian and Lutheran. Thus the norming sample has some limitations. Separate norms are available for adults and adolescents (males and females) on each subscale and for the overall scale.

As the target population of this practicum has special and specific characteristics, I added four questions to the scale, which were based on coping strategies as outlined in the literature review. The added questions were:

Talking within the family about the illness.

Concentrating on the sick child.

Keeping busy.

Avoiding talking or thinking about cancer.

The Scale was used in working with families to identify areas of strength and weakness. For example, a low score in the "reframing" subscale indicated that the person or indeed the whole family may have been viewing the situation as stressful or hopeless, and may have been feeling somewhat demoralized. Counselling in this case involved exploration of the meaning of the diagnosis for each person in the family, and assistance in viewing certain aspects of the situation in different ways. On the other hand, a high score in the "acquiring social support" subscale indicated a strength, in that the family was able to mobilize help in time of need. The four questions which I added did not form a subscale, but gave a measure of further dimensions of family functioning. For example, a person or family who used "keeping busy" as a way of coping may have needed much help in ventilating about the illness and in coming to terms with their emotions. For each family the raw scores and the mean score of each subscale were represented in graph form.

Children under twelve, both patients and siblings, were asked to draw pictures of themselves and their family. The drawings showed with great immediacy how the child viewed self and his or her relationship to other family members.

A further assessment tool was the use of genograms which provided a quick format for recording information about

the family members, their relationships and their positions within the family. As McGoldrick (1985) notes, scanning the genogram allows present day issues to be seen in the context of the family's evolutionary patterns. For example, perceptions about cancer may be to a great extent influenced by the incidence of cancer and the outcome of the illness in prior generations.

#### Interventions Directed Toward Relieving the Crisis and Initiating Mourning

These interventions were usually initiated at the first meetings, though aspects of crisis intervention theory and grief therapy were used throughout the three month period. Consistent with both these theories, the emphasis at this stage was on encouraging the members of the family to ventilate painful feelings about the diagnosis in order that they might come to terms with it. Feelings were universalized and normalized and personal reactions were interpreted to make them comprehensible for members. Families were helped to identify their own familiar and individual coping mechanisms that they could use to gain control of the situation.

Practical plans were also discussed, such as transportation, financial matters and babysitting arrangements, in order to relieve initial stresses. This phase of the intervention was in some cases as short as one session, and in

other cases consisted of several sessions extending over a period of a few weeks. Usually the family began to accept and adapt to the situation when medical tests were completed and treatment had begun. Families could then begin to feel that "something was being done", and were ready to move on.

#### Interventions Directed Towards Specific Issues, Reorganization, Roles and Adaptation

Interventions in this stage varied considerably but emphasis was placed on healthy adaptation. The initial crisis was over and families needed to organize to accommodate the demands of the illness. Often during this process, new issues arose, either related to the child's medical condition or to the extended family, causing added stresses. Techniques included clarifying medical information, linking the family with social resources, implementing role rehearsal techniques, reframing the situation, reality feedback, helping the family to expand and strengthen their social network, anticipating possible future outcomes, and play therapy.

#### Termination and Evaluation

Usually the last session was used as a review of the family's functioning from the time of the diagnosis. Most family members expressed some pride in the fact that they had "made it" thus far, and were surprised that they had been able

to use strengths of which they had been previously unaware. In some families termination did not take place. At the three month period two children were in the terminal stage of their illness, and so supportive intervention still continued with the families. Another two families asked for further services, as there were still outstanding issues to be addressed. Each family was asked to complete an evaluation form to be discussed fully in Chapter 7.



## CHAPTER 6

## Case Illustrations

This practicum provided the opportunity to observe the responses of nine very different families to a diagnosis of childhood cancer. Much is written in the literature on both the stresses involved as well as the family and individual factors and coping styles which influence adaptation. One stress appeared to stand out above all others, and certainly affected the adjustment process. This was the stress arising from the disease itself. Unlike some crises, where one event constitutes the trauma, the diagnosis is only the beginning of a series of events, each one of which may take on the nature of a crisis.

In the first few months the family must deal with at least one and often all three of the treatment modalities of surgery, radiotherapy and chemotherapy. Secondly, the side effects of these treatments, such as nausea, vomiting, weight loss, weight gain, toxicity, behavioural change and high fevers were distressing as well as scary for parents and patient. The family's uncertainty about what it faced and about what new stresses might occur was forever present. All parents saw cancer at least at first as being synonymous with

death, and any medical difficulty or change in their child reinforced this perception. Nevertheless, certain factors appeared to promote healthy adaptation, irrespective of the medical prognosis. The most important of these are outlined below:

- an ability to redefine the situation in a positive way.
- an openness to social supports and an ability to use them effectively.
- an ability to adapt flexibly to a new situation.
- an ability to shut out or limit the impact of additional stressors, so as not to become overwhelmed.
- an ability to keep lines of communication open both within the family and with external institutions.

The four cases outlined here will highlight these factors. The analysis is drawn from both process notes and taped interviews. Following these case presentations, common themes which emerged with all nine families will be described.

Family A: Adaptation in a Family with a Limited Support SystemIdentifying information

Patient: Lisa  
Diagnosis: Wilms' tumour  
Treatment: Surgery, chemotherapy for one year

Family: See genogram (Figure 3)  
Marie - mother, 29 years  
Phil - father, 30 years  
Jane, 3 years  
Lisa, 10 months

Summary of F-COPES (Figure 4)

Intervention

When I first met the family in Lisa's hospital room, they were waiting for the tumor to be staged, after its surgical removal. Stage 1 or 2 would mean a good prognosis, while Stage 4 would indicate a much more serious cancer. The waiting was causing great stress. Phil was managing to hang on to hope as the doctors had indicated they thought the cancer was at Stage 1 or 2. Marie was in great distress with tears flooding down her cheeks. "How could this be happening to us"

Figure 3

Family A

Heart  
Problems

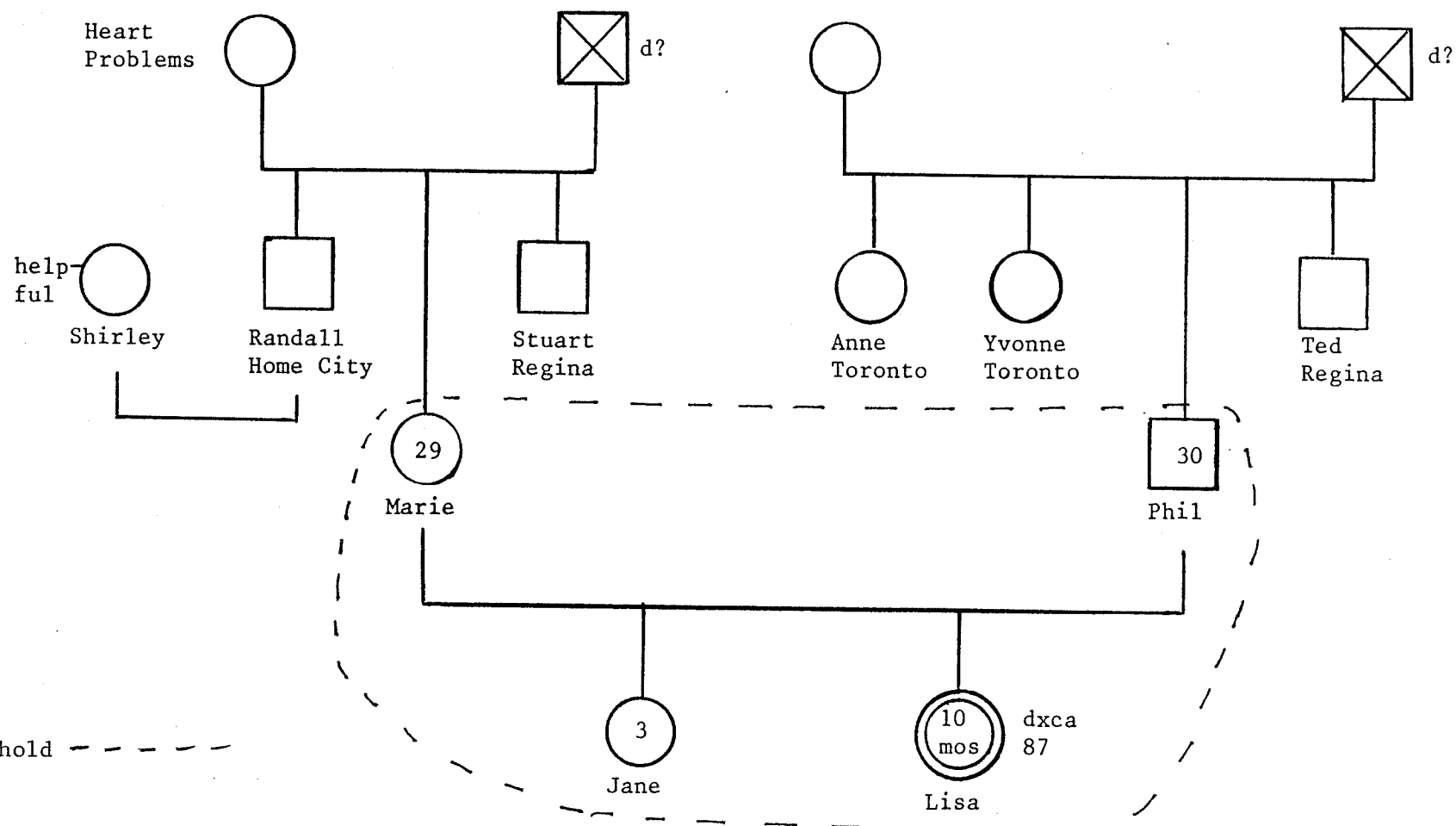
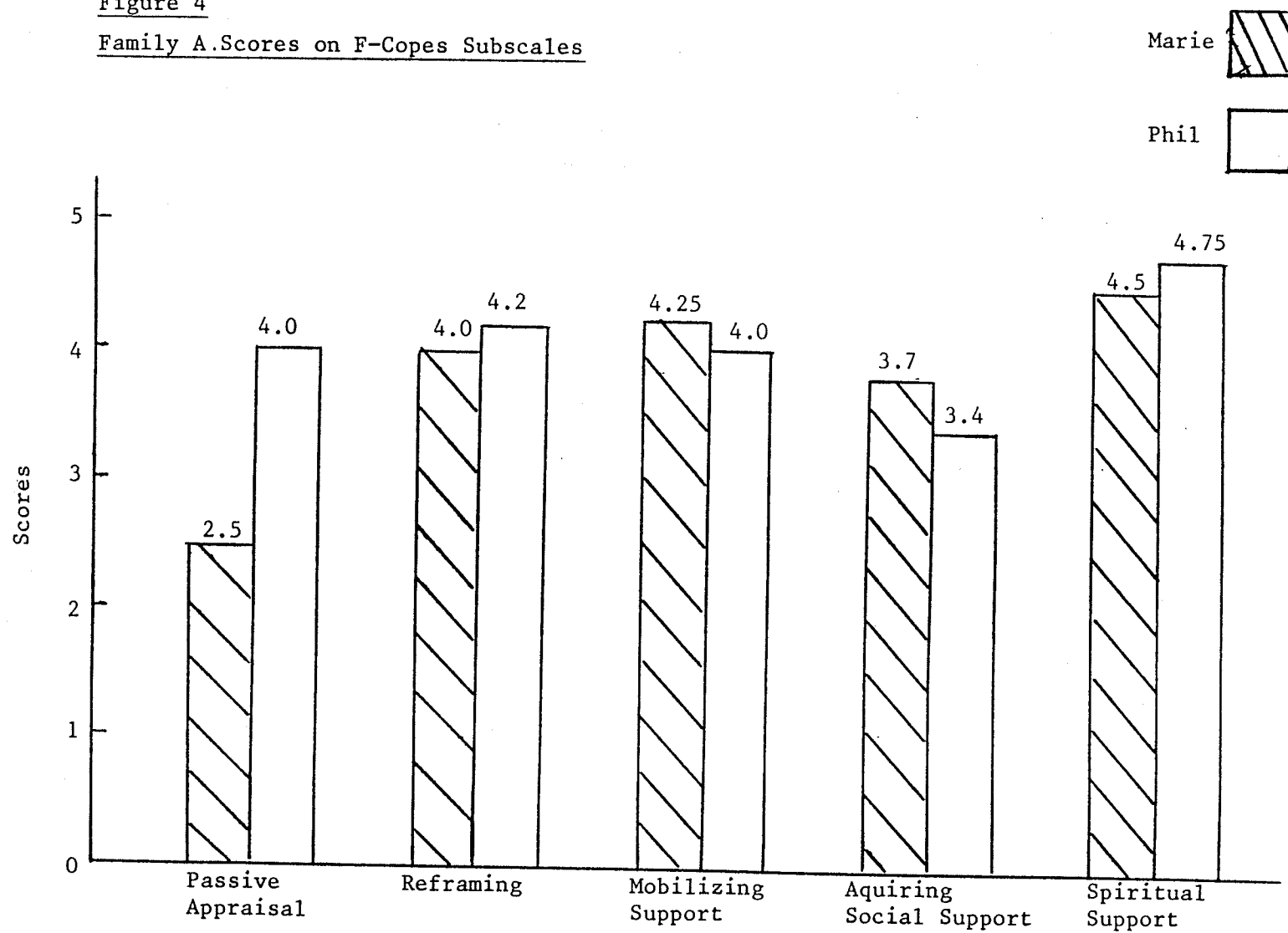


Figure 4

Family A Scores on F-Copes Subscales



Averages of each Subscale.

she remarked over and over again. I offered support in assuring her that it was very normal to cry in the circumstances and was a good way of relieving some of the tensions of the situation.

The couple seemed somewhat emotionally disconnected. Marie was clearly asking for support from Phil, but he found it easier to busy himself soothing Lisa. It appeared as if Phil felt trapped between ministering to his daughter and to his wife. The family was still in shock, and therefore it was not appropriate to press the issue. Consistent with crisis theory, I gave them both as much support and empathy as possible, in order to help them express their fears and anxieties about the crisis.

Since their mutual support system seemed weak, I asked if family and friends could provide support. Their answer was a clear negative. They did not want anyone to know about Lisa's condition in their home town. The illness had raised the fear that they would receive pity from others, and this would be damaging to their self-esteem. During the first session three year old Jane ran in and out of the room with toys to show her parents. They were too overwhelmed to give her the time or attention she was seeking. I concluded the session by outlining ways in which the parents could relax while waiting for the staging.

Two days later, when I visited again, the scene looked much the same. The tumour had been staged at a "two", which had relieved some of Phil's anxiety. He was feeling hopeful. The result had done nothing to relieve Marie's anxieties. She could not bring herself to say the word "cancer", and visibly shuddered when I used it. Tears flowed again. I gently encouraged her to ventilate her feelings about the cancer and to talk about its meaning for her, so that she might gain some control over the situation. Phil as before avoided any expression of feelings. Marie's bleak perception was not helped by Phil's lack of support. Both were coping in isolated ways with the stresses of the diagnosis. This was leading to "pile-up".

Since both were feeling helpless, Marie because she could not change the situation, and Phil, because he could not help Marie, an intervention was necessary to assist the family in gaining some mastery. Emotional issues seemed overwhelming, so I changed the focus to practical ways the family could use to lessen stresses. They were able to effectively problem solve, and together proposed some solutions. Marie would have a break in the afternoon and leave the hospital. Jane could stay in the playroom at this time. Later the three of them would have supper together, leaving Lisa for a short time with the nurses.

By now the realization was growing that they would need to tell some people about Lisa's diagnosis, but they found this prospect very scary. Their anxieties about telling people, and their expectation of no support were creating obstacles. As a means of addressing this, role playing was used to rehearse what to say and how to explain the situation to various people.

The family were soon to be discharged to their home town two hundred miles away. I was concerned that the family, and in particular Marie, would become completely overwhelmed by "pile-up". They seemed to operate in isolation from each other and their external support system was limited. Marie's mother had her own health problems, and the only brother that Marie felt she might like to tell was on vacation. She had no particular friends at the dietary department of the local hospital, where she had worked for the past seven years.

Phil, on the other hand, thought people at his place of employment would be quite supportive, but these people were not Marie's friends as well. He did not feel close to any of his brothers or sisters, who all lived in other cities, and did not expect any support or help from his mother. After much discussion, Marie was able to identify the local public health nurse as a support. She had had a good relationship with her during her pregnancies, and after the girls were born. I arranged to contact the nurse.



Concerns that Jane's emotional needs were not being met were still present, but could not be adequately assessed since she had been in the playroom during this session. My enquiries about her brought the reply that she was fine.

Over the next three months the family was seen in person every three or four weeks. This included a home visit to their rural community. As well telephone contact was maintained with them in between the visits. The sessions focussed on encouraging the family to strengthen their network, increasing their communication and affective involvement with each other and helping the family, especially Marie, to reframe their perceptions of the illness. The scores on the F-COPES scales did not reflect difficulties in these areas. The couple used spiritual support as a means of coping with the situation, and this was indicated by their high scores on this subscale.

Marie's great anxieties and fears tended to act as a barrier to the family's acceptance of the diagnosis and healthy adaptation. Much intervention was directed at encouraging both parents to talk about these fears, both in the sessions and later at home. Finally both were able to acknowledge their perception of cancer as synonymous with death. Phil had managed to hang onto hope but for Marie the word "cancer" still meant "deadly". This acknowledgment allowed me to help them to begin grief work and give each other support.

Although Marie expressed fears most in the family, I felt that Phil was also experiencing some difficulties. He confided that he was having trouble concentrating at work, and in an effort to block the pain, he worked even harder. I encouraged the couple to acknowledge and talk about the uncertainties involved in Lisa's diagnosis. Although given a good prognosis, ten percent of children with her disease would relapse. This especially scared Marie. Her perception of the illness was unrealistically pessimistic.

This necessitated that I inject some realism into the scene. Each of them was asked to describe how Lisa looked. Both admitted in this session that she looked pink and healthy and was rarely irritable even on treatment. I suggested that each time they had "bad thoughts" about the cancer, they should think of Lisa as she looked now, very much enjoying life. Reality was further reinforced by sharing with the family all the factual information I had about the cancer, especially in relation to the excellent prognosis. Over the months, "reality testing" was often used as a technique to encourage the family to reframe its perception of the illness. Encouraging the parents to watch their children joyfully playing together served better than any words to reinforce the situation in an inescapable way.

Often in the sessions I made a point of spending time playing with Jane. She loved the attention and this quite

naturally at times led to talking about the needs of siblings. At other times it provided a role model for the parents who often seemed to focus entirely upon Lisa. I considered Jane's unmet needs as potentially damaging to the family. This preventative approach would, I hoped, encourage the parents to offer her appropriate and positive attention.

An obstacle to the couple's mutual support was that their perceptions of the situation were diametrically opposed. I presented a positive way for the couple to view their differences. Phil could be very hopeful because he knew Marie would do the worrying. On the other hand, Marie could do the worrying for the family because she knew that Phil would keep up family hope. Obviously they needed each other to accomplish these important tasks. This reframing seemed to hit home, since Phil laughed in a good natured way and even Marie looked less tense at the end of this particular session.

The importance of having a support system to rely on for emotional and practical help in coping with such a diagnosis as childhood cancer was explained to the parents a number of times. Phil indicated that he did not need anybody. He received support from fellow workers. Consequently he was oblivious of the need to encourage Marie to expand her very limited network.

Marie's family had proved somewhat more understanding than she had anticipated. A sister-in-law, whose own parents had been treated for cancer, was particularly helpful. Throughout the sessions I strongly encouraged this connection. Although her mother showed concern about her granddaughter, the support she could give to the family was limited, as she herself was sick, and was hospitalized for a time. This added to the "pile-up" of stress for Marie, the only daughter. Not only was she worried about her mother, but she also visited her each day for a three week period.

Marie seemed to want to reach out to people, yet was ambivalent. For example, she got very excited when the mother of a child who had died from leukemia a few years ago had offered to babysit. I strongly encouraged her to accept the offer, but in the end she did not. Her anxieties and distrust of others prevented her. She expected little from other people and unhappily this is often what she received. Although she was very upset that colleagues at work did not contact her to ask about Lisa's condition, if anyone did enquire about the illness, she experienced this as overinquisitiveness. This pattern exemplified a self fulfilling prophecy that nobody would care enough to offer her support.

She certainly perceived her work environment as unsupportive and as well felt stressed at trying to juggle work and Lisa's appointments at the local clinic. These stresses

were addressed, and she was able to decide on a leave of absence. This provided some relief, but ended up creating other stresses, including a loss of independence, income and self-esteem, and more importantly a loss of adult company. As a homemaker alone all day with the children, Marie started going out in the evenings to the shopping centre. Usually she was alone. This new behaviour could have reflected her need for a change of setting and time out from child care responsibilities. As well, Marie appeared to need adult contact yet sought it at a distant level rather than with friends. Phil found this activity difficult to accept. It seemed that he did not want his wife to become too independent from him.

In summary, the diagnosis and treatment constituted a major stress for this family. Although both could intellectually sanction further treatment, they continued to find it difficult to watch their child receiving hurtful therapy. Other stresses such as travelling into the city for treatment, Marie's mother's hospitalization and the unsupportive work environment contributed to the heavy stress for this family. These stressors combined with the family's limited support system, and Marie's negative perception of the situation increased their vulnerability.

In reviewing the progress of the family at the three month period, both parents felt that they were coping

adequately, but admitted that "it was certainly not easy". Marie's perception had improved somewhat over the period, and she had begun to allow herself a few grains of hope. Encouraging both parents to ventilate, providing some reality testing in the situation and offering them role rehearsal techniques all helped them to cope in the process of adaptation.

The Double ABCX Model provided a useful framework for understanding this family, and pointed to appropriate interventive approaches. This case suggests that adaptation is very problematic in a family which lacks intimacy and mutual support, and which is prevented by anxiety and personal fears from reaching out to others. Without supports, attitudes do not change and reframing is difficult to achieve.

Family B: Adaptation to Childhood Cancer  
in a Reconstituted Family

Identifying Information

Patient: Rachel  
Diagnosis: Leukemia  
Treatment: Radiotherapy and chemotherapy for two years

Family: See genogram (Figure 5)  
Jean - mother, 31 years  
Bill - stepfather, 39 years  
Rachel, 7 years  
Paula, 2 years  
Derek, 6 months

(Philip - estranged father, 36 years)

Summary of F-COPES (Figure 6)

Intervention

Bill looked aghast as he was informed that Rachel had leukemia. A tall rugged man, he had brought his step-daughter alone to the Clinic on the advice of the local family physician

Figure 5  
Family B

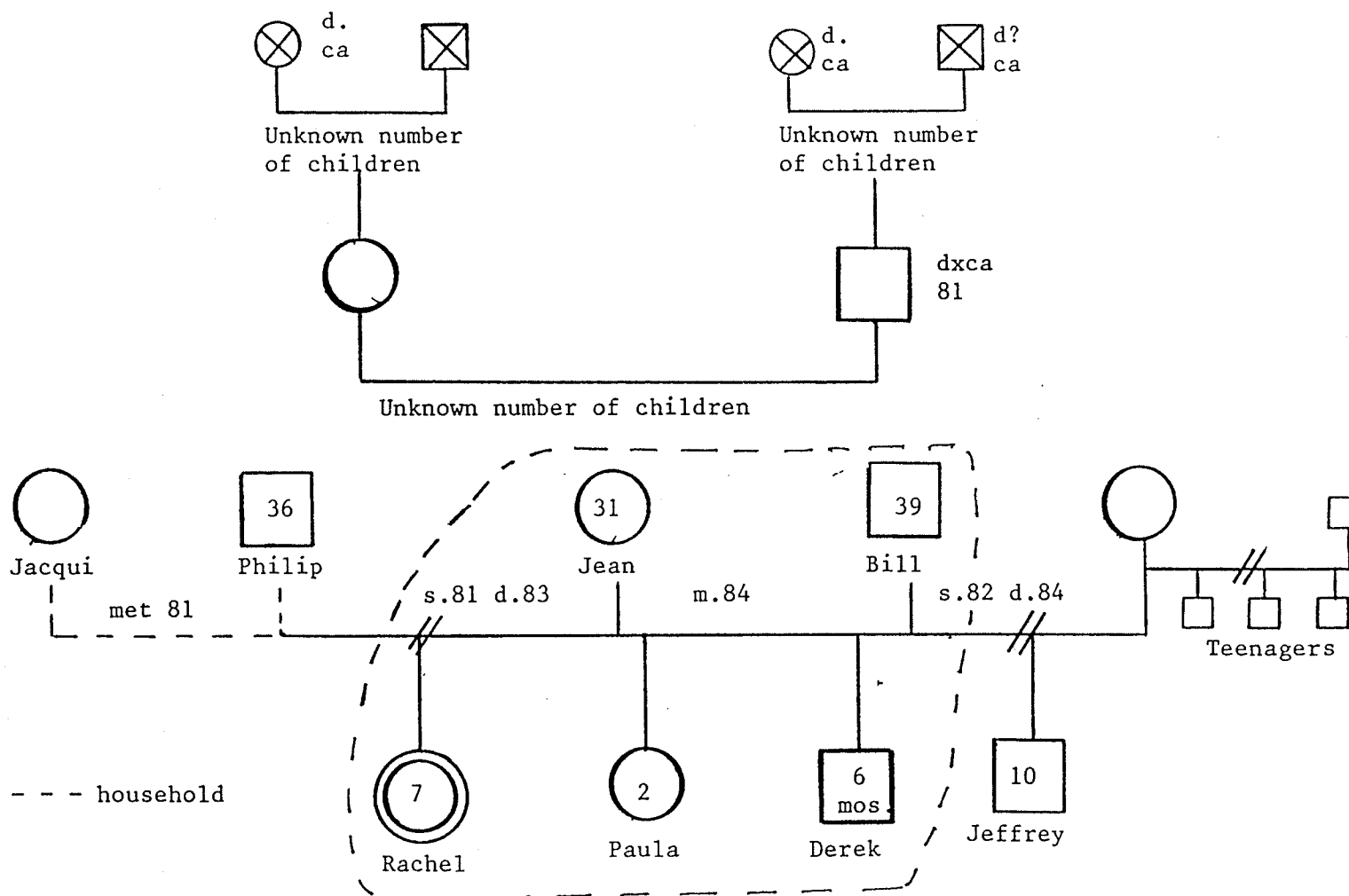


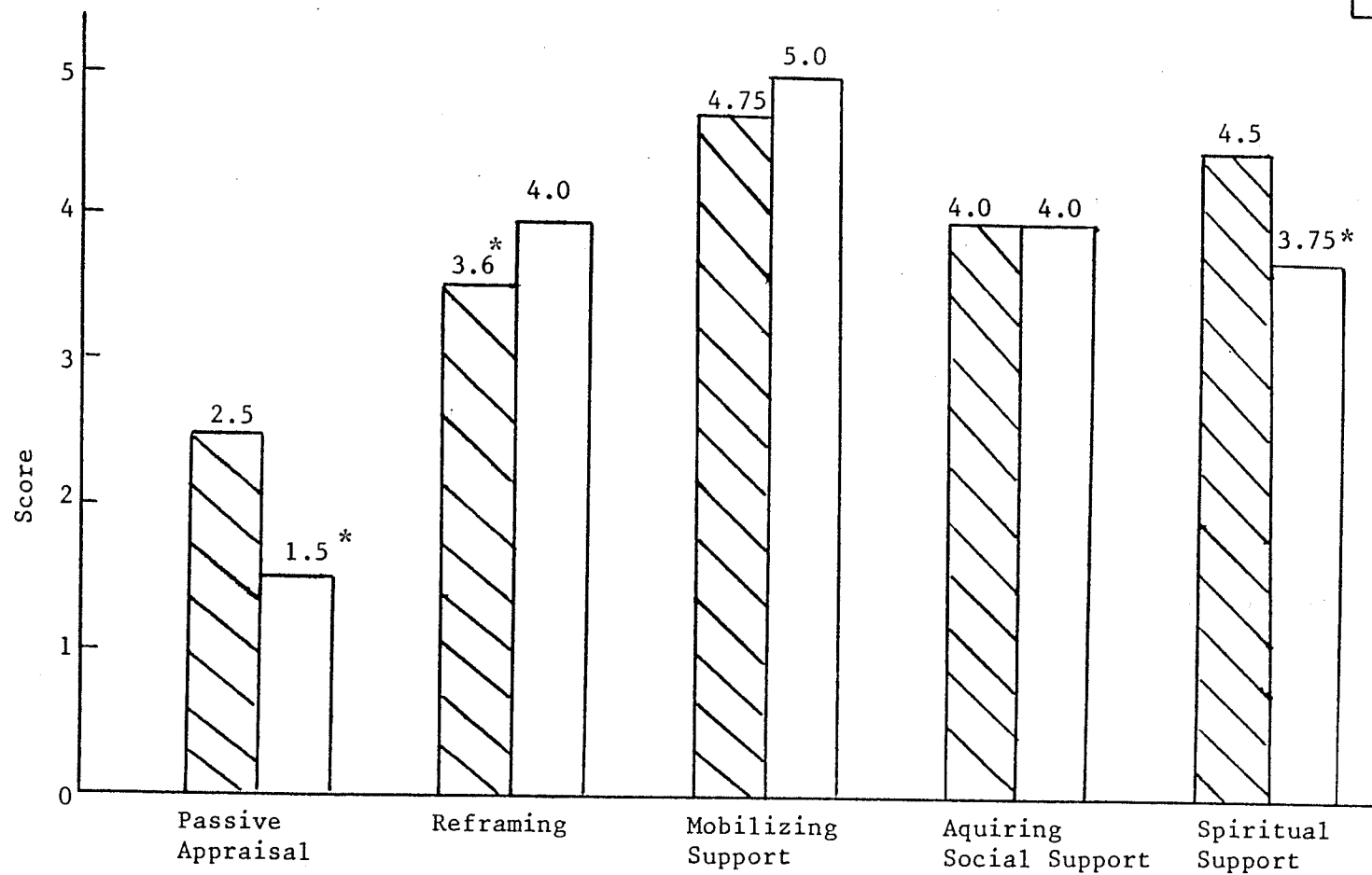




Figure 6

Family B Scores on F-Copes Subscales

Jean   
Bill 



\* Denotes below norm.

Averages of each subscale.

who had suspected anemia. Bill carefully pulled Rachel onto his knee and cradled her. "This has been a shock for you. Would you like to phone your wife?', I remarked. Bill grabbed the suggestion. The couple decided to delay treatments until the next week, when the whole family including Rachel's natural father and his wife could come in. I supported the decision.

All four parents met with the doctor to discuss Rachel's medical condition. The next day I met with Bill and Jean and the three children at the clinic. Rachel was still tearful from an injection she had just received. Jean appeared stressed. Seeking to give this mother as much support as possible I complimented her on the way she handled Rachel's resistance to receiving the "poke". She would need plenty of self-confidence to take charge many more times during the two years of treatment.

The parents readily admitted that it had been a difficult weekend, but as the interview progressed, the strength of this family soon became evident. Bill made an analogy between the pain felt at getting a sore tooth fixed and the pain at having to get the cancer treated. Jean put an arm around Rachel, and remarked "Rachel and I have never had toothache. We're lucky". Jean was already attempting to reframe the situation for Rachel. I encouraged this process of reframing and encouraged them all to talk about their feelings at watching Rachel receive her treatment. In turn, I asked

Rachel what it was like to be the recipient. Finally she admitted it was scary and tears came to her eyes. Jean also admitted being fearful. Bill was quiet, but reached out to his wife. The family had started the grieving process towards redefining the medical procedures as 'hurtful but necessary'.

During this first session, the couple confided that there had been rough times at the beginning of their marriage three years ago. They were still working on their own relationship, as well as the relationships with step-children and with their ex-spouses. Jean became the spokesperson. She explained that she was the talker and Bill the listener. He tended to bottle things up and she had to get him to talk. At the beginning there had been quite a few arguments, but now both felt they were more easy-going with each other, and more able to laugh about mix-ups.

I finished the interview confident in the ability of this family to cope. However the family had indicated that their previous relationships and the newness of their own marriage contributed to strain. As well, scores on the F-COPES scale suggested that although the family had a strong support system, it was experiencing some difficulty in managing the situation. Bill's low score on the "passive appraisal" subscale may have indicated that he was feeling overwhelmed, whereas Jean's low score on the "reframing" subscale reflected her struggles in attempting to look at the situation in a more

positive way. Therefore I arranged to follow the family in the role of supporter, clarifier and educator.

A week later I met with the family in the hostel. They thought that they had managed well over the last week. The clinic regime, treatment and drug names were becoming somewhat more familiar. A stress had emerged over the weekend in connection with Philip. Usually Rachel visited him every other weekend, and the family had cordial but limited contact. Now the physician had suggested one parent be in charge of giving Rachel her medication until after the two week course of radiotherapy. Therefore at the weekend, Philip had visited Rachel in her home. Bill and Jean were trying to treat Rachel as normally as possible, a position strongly encouraged by myself. Philip, they felt, was treating her as a sick child, and being too solicitous about her well-being. He tended, they thought, to concentrate on the negative aspects of the disease.

Bill and Jean were unsure how to handle the situation, as they realized the relationship between Rachel and her father was important. They were trying not to talk about it in front of Rachel, as they felt it would upset her. However, the thought of weekly contact with Philip was causing Bill and Jean to feel stressed. It may also have provoked past hurtful memories for Jean. Continuing difficulties between the two sets of parents could be most harmful for Rachel. She would be caught in the middle.

I responded to the situation and intervened to relieve some of the stresses. With Rachel included, parents were asked to identify with Philip's difficult position of being the "outsider". This they could easily do. At the same time I strongly supported their parenting styles, and reinforced the style with Rachel by explaining how the "guys" at the clinic "tell" parents they have to treat kids the same as before the diagnosis. I sought to relieve the parents of being labelled as the "bad guys". Communication was now opened up between Bill and Jean and Rachel. Parents could feel confident in their parenting style. I arranged to make contact with Philip.

Ten days later at the clinic I met with Philip and Rachel. "Rachel is Number One... and she knows it", Philip told me, while lovingly looking down at his daughter. Rachel beamed up at her father. Two of his grandparents had died from cancer, and he was finding it difficult to maintain a positive outlook. He kept thinking of those children who do not respond to treatment. Obviously his over-solicitous approach to Rachel reflected his fears about the outcome of her illness. He had had to fight in court for visiting rights, and cancer posed the threat of another loss. He was in distress, but more importantly, his perception could make it difficult for Rachel to keep hopeful throughout treatment. I knew unless Rachel's medical condition changed, I would not see him again in the city as he liked space and solitude and distrusted

people. I gave him as much space as possible during the interview and avoided any attempt to delve into his background, while at the same time I worked at helping him to see the situation in a more positive way.

An opening came when he recounted with pride the adventurous weekends of fishing, boating and swimming with his daughter. I encouraged him to resume the weekends as soon as Rachel had finished radiotherapy, explaining that she would need the normalcy of doing what she had done before diagnosis, to give her security through the treatment. In the session I encouraged them to plan their weekends together. Philip needed to know that there was a future for his daughter. He asked many practical questions about Rachel's treatment. I gave all the medical information I had, and suggested that he talk with the doctor, which he did. Finally I placed on him the responsibility to maintain hope, so that Rachel would be able to gain strength from him. He held Rachel's hand and exclaimed "We'll make it." I did not meet him again.

As time went on Bill and Jean adjusted to Philip's involvement and though the task of joint parenting created additional stress, his presence at weekends did not overwhelm the family. This would suggest that the boundaries between the two families were well maintained. The nature of Philip's interaction with Rachel returned more or less to the pre-diagnosis level.

Further family meetings were directed toward helping the family identify their own strengths and coping mechanisms, and to use them in the present situation. The parents had experienced many stresses and changes over the last few years. Just after the break-up of Jean's marriage, her father had been diagnosed with cancer. His health appeared good at present, but there were many unanswered questions about his illness which resulted in uncertainties for the future. One and a half years ago, Jeff, Bill's son by his previous marriage, had left the family to live with his mother. This had left Bill and Jean with many feelings of regret. Although the family had coped well with these difficult situations, Jean especially was feeling somewhat powerless, that they could neither anticipate nor prepare for ensuing problems, a position that could easily result in "pile-up". Thus, in order to help them gain some mastery, much linking was done between coping skills used in these past events and ones that could be used in the present and future situations. The family was encouraged to rehearse how in the future they would handle anticipated stresses associated with Rachel's medical condition.

In summary, this family presented as basically healthy with a good strong support system of family and friends. They demonstrated their strengths by working hard to redefine the situation in a positive and challenging way. This greatly helped Rachel to accept her illness. The family members were

flexible in their allotment and division of roles, and were very supportive of each other. All of this helped the process of reorganization. On a general level communication was good, and there was no attempt to hide facts about the cancer from Rachel. Bill, however, found it hard to talk about himself. Though this frustrated Jean at times, they both indicated that Bill opened up when he needed to. Nevertheless in the sessions they avoided dealing with the issue of Bill's reticence. This may not have indicated dysfunction, since often it is too difficult for a family to deal with the adjustments demanded by the illness and also to address other relationship issues. In the future it may constitute some difficulty, as Jean may feel emotionally unsupported by Bill. Stresses, besides those resulting from the illness and treatment themselves, arose from the increased contact with Philip, and from his differing perception and parenting style. Once family coping skills were identified and clear boundaries set up between themselves and Philip, stress was reduced, and this family proceeded towards a basically healthy adaptation.

This case illustrates well the stresses for reconstituted families of the sharing of the parenting role, and how a negative perception in one set of parents can contribute to much stress in another. It also highlights the importance of interactions aimed at the visiting parent as well as the custodial parent.



Family C: Adaptation in an Immigrant FamilyIdentifying Information

Patient: Benjamin

Diagnosis: Leukemia

Treatment: Chemotherapy and Radiotherapy

Family: See genogram (Figure 7)

Lottie - mother, 32 years

Benjamin, 10 years

(Matthew - estranged father)

Summary of F-COPES (Figure 8)

Intervention

Benjamin was brought to the clinic by his mother, Lottie and aunt, Lily, three days after the family's arrival in Canada from their own country in Asia. He had been diagnosed with leukemia six months previously, but was not in remission because he had not been given sufficient medication.

Over the next week I learned how distressing the situation had been for Lottie, a single parent, and for

Figure 7  
Family C

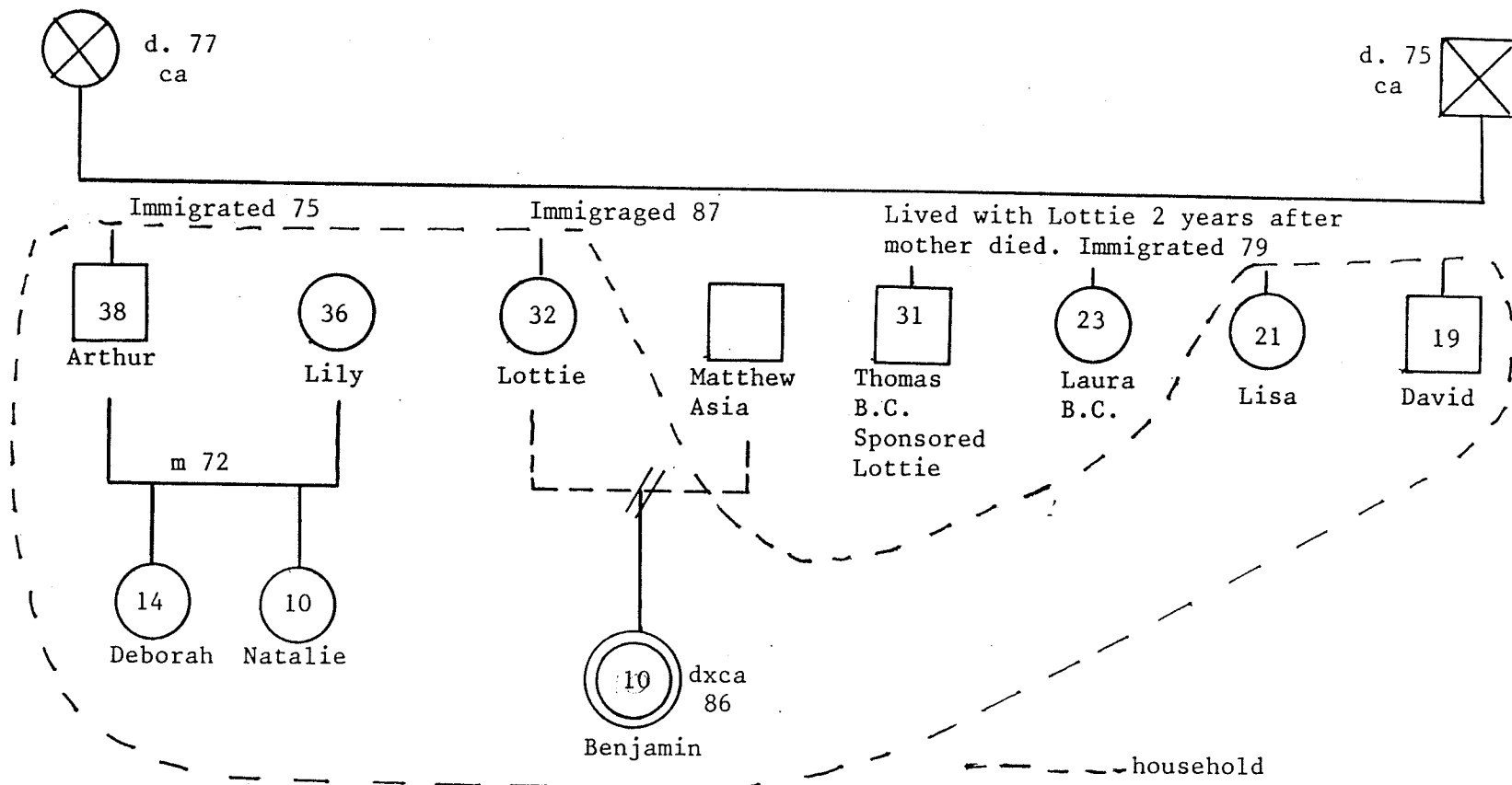

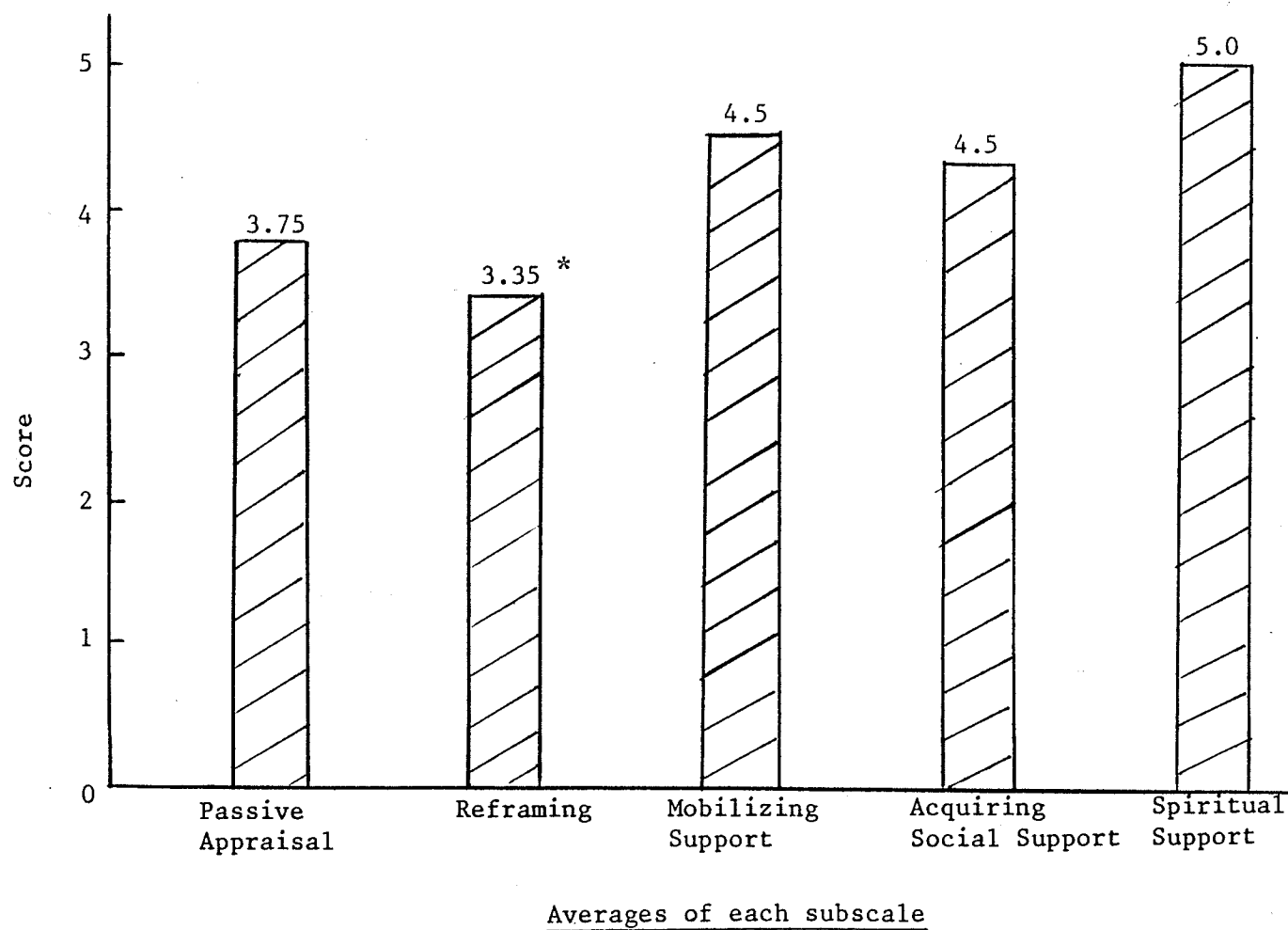


Figure 8

Family C Scores on F-Copes Subscales

Lottie 



Benjamin, her only son. In their own country medical coverage was not free and payment had to be made in advance of all treatments. Lottie had sold everything she owned and the extended family in Canada had also helped financially, but still there was not enough money to buy appropriate medical care. The extended family in Winnipeg was struggling financially and was now left with a number of unpaid bills as a consequence of helping Lottie. These debts clearly worried Lily.

Now that Benjamin was receiving treatment in Canada, the family had become very hopeful that his disease could be successfully treated. This was a second chance and the family grasped it gratefully. The only person who did not seem to share this hope was Benjamin himself. He appeared sad and depressed, and had hardly uttered a word during the interviews, although he understood English. His aunt expressed concern about him, as she had not seen him laugh or smile since his arrival. A drawing he made of himself, in response to my request, showed only the upper part of his body, which he then immediately erased (see Appendix 2). This seemed to confirm the hopelessness he was showing in his physical appearance. Lottie however felt that hope was returning in Benjamin and denied that he might be feeling sad, explaining that he had always been quiet.

Lottie was now very bright and cheerful, in contrast to my first contact with her, when she was valiantly holding back the tears in her eyes. As indicated by the scores on the F-COPES scale, Lottie had a strong support system and also gained comfort from her religious activities, but was experiencing difficulty in redefining the situation in a more manageable way. There seemed to be a strong need for her to deny, as Benjamin certainly appeared more than just quiet. Thus a plan of intervention was devised to address this and the other identified family needs.

As a first step, their financial difficulties were somewhat relieved by arranging with creditors that outstanding bills be paid on a monthly basis. The extended family decided against Lottie applying for social assistance, preferring instead to manage the situation themselves. Second, sessions were planned for mother and son to help them adjust to a new culture as well as adapt to a very aggressive treatment regime. It was hoped that by encouraging the family to share feelings about their losses in moving and about the cancer and its treatment, Benjamin could regain some hope and Lottie would have less need to use denial.

It was demonstrated quite quickly in the first session with the family that mother and son would need to be seen separately. Lottie tended to take over when Benjamin tried to talk and as Benjamin was willing to let his mother do this, it

became difficult to prevent. Lottie was only willing to talk about happy feelings when Benjamin was present, and brushed aside any attempt to explore their sadness. Such feelings were far too threatening. Therefore Benjamin was seen alone for play therapy sessions.

Benjamin understood English, but had problems in speaking the language. Therefore "talking" was mostly achieved through drawings of feeling faces. In this way Benjamin was encouraged to speak about his life, both now and in his own country. He was especially sad at losing contact with his father. Lottie had earlier indicated that there was no longer any involvement between Benjamin and his father, but in the play therapy sessions he talked often about regular visits with his father. We spoke about the sadness of saying goodbye, and I suggested that Benjamin keep in touch with his father through letters.

Over the weeks Benjamin changed from a sad little boy to one who, although still reserved, looked happier and more hopeful. His drawings reflected both this change and his adjustment to Canadian life (see Appendix 2).

Lottie in her individual sessions talked about life in her own country, but denied any strong feelings of grief or sadness at leaving. All her five brothers and sisters were in Canada and she had been the only one remaining in Asia. She

had worked out her priorities: her son's health came first and everything else, including anything she might like to do for herself was second. She repeatedly told me how good it was in this country and always seemed to be smiling.

In joint sessions she appeared even more happy and chirpy. She avoided expression of other feelings in front of Benjamin. She rationalized this by stating that if he knew she was worried in any way, he would think his treatment was not working. She could acknowledge that Benjamin probably knew when she was worried or unhappy, even when she said nothing. This acknowledgment however did not change their interaction. I had hoped that the sessions might provide a forum for them to talk about the situation, but their communication was always limited and concentrated on "nice" things.

Underneath Lottie's apparent cheerfulness was the major fear of what the future might bring. Cancer for her meant certain death, and for this family, this perception was very realistic. There had been many deaths due to cancer in the family, and when Benjamin was first seen in the clinic, he was not in remission. Lottie's predominant coping style was to avoid as much as she could the realities of the situation. "I don't think of it", she would reply and become extra bright and smiling.

Culture also played a part, as it dictated that Lottie be polite to those who were helping. She would have found it very difficult to complain about the hospital, the clinic or even the situation in which she found herself.

The use of avoidance was further reinforced by the fact that Benjamin was doing well on treatment. He looked happy and was attending school regularly. Denial and avoidance therefore permitted them both to live day by day and not to dwell on what the future might hold. Recognizing their need to maintain denial at this time, I continued to give the family support and practical help.

Toward the end of my three month contract with the family, Benjamin was hospitalized with a serious infection. Ward staff were concerned because he seemed depressed and was refusing to eat. Tube feeding was being considered. Lottie looked worried but denied it as usual.

I concentrated on working with Benjamin and again used the technique of drawing feeling faces to interact with him. He felt confused because everyone talked at him in fast English. He did not always understand them, so often did not answer. This was communicated to staff. Benjamin did not like being in hospital and gave this as the reason for not eating, even though Lottie was bringing in food from home. However, he also knew that he needed to eat in order to be



discharged. After much discussion through drawings, Benjamin was able to decide on a food he might be willing to try -- chocolate popsicles. The next day he was discharged. He had begun eating a little.

Tension could be seen in Lottie's face during Benjamin's hospital stay. Denial was becoming increasingly difficult for her to maintain, and was causing her to experience "pile-up". After I had relayed to her a number of times how worried she had looked during Benjamin's illness, she finally admitted to being very scared. At this moment she was able to release some of her pent-up feelings. She wept openly for the first time since arriving in Canada. This release of feelings helped her to talk about her fears and to initiate anticipatory mourning. We spent time discussing how she would cope if and when Benjamin relapsed. I encouraged her to look at the coping skills she had used when she had faced the many other losses in her life. Unfortunately, when Benjamin came home from school, she immediately put on her smiling facade. She still could not allow herself to share her feelings with her son.

Unknown to any of us at that time, this afternoon meeting was a rehearsal of what was to come. Benjamin relapsed the next week. There could be no more treatments. I spent time with both of them, helping them to prepare for the death. Benjamin was angry: he wanted to be up and around

doing things instead of dying. Lottie, like any caring mother, prayed for a miracle to save her son.

One evening the three of us reviewed the photographs of Benjamin which had been taken since his arrival in Canada. When he slept, Lottie recounted the hopes and dreams she had had for her only child. As could be expected she found it difficult to talk to him of his approaching death, but did not try to deny to him or to herself the reality that he was dying. Two weeks after relapsing Benjamin died. I remained involved to offer supportive counselling.

In summary, although this family was new to the country, they could rely on a strong support system, comprising the extended family, friends and the church community. Free and sophisticated medical care provided relief as well as the hope of a cure. Stresses arose for Lottie from her need to keep feelings bottled up inside, and to present a bright and cheerful facade. This facade hid much unresolved grief, resulting from her mother's death and from her break-up with Benjamin's father. This unresolved grief hampered her ability to acknowledge feelings associated with the present illness. Denial was also reinforced by the dictates of her culture.

Supportive involvement helped Lottie finally to express her fears. Through the use of non-threatening play therapy

techniques, Benjamin was also assisted in talking about his cancer and about the losses he had experienced in coming to a new country. Unfortunately communication between mother and son remained always limited.

Unlike the other families followed in this practicum, who needed to adapt to living with cancer, this family was required to adapt in the end to an approaching death, a much more difficult and emotional proposition both for the family and for me.

Family D: Adaptation in a Family with Multiple StressesIdentifying Information

Patient: Leonnie  
Diagnosis: Lymphoma  
Treatment: Surgery and chemotherapy for two years

Family: See genogram (Figure 9)  
Hazel - mother, 32 years  
Martin - mother's friend  
Leonnice, 12 years  
Joy, 2 years  
(Ian - estranged father)

Summary of F-COPES (Figure 10)

Intervention

Despite the fact that this was the only family who in fact requested social work service, in the final count they proved to be one of the most difficult to engage. The ward staff expressed great concern that this mother, a single parent, might not be able to cope with Leonnie when she was discharged. Leonnie was developmentally slow as a result of a genetic problem. Although her chronological age was 12 years, she functioned at a seven year old level. Before coming to the

Figure 9  
Family D

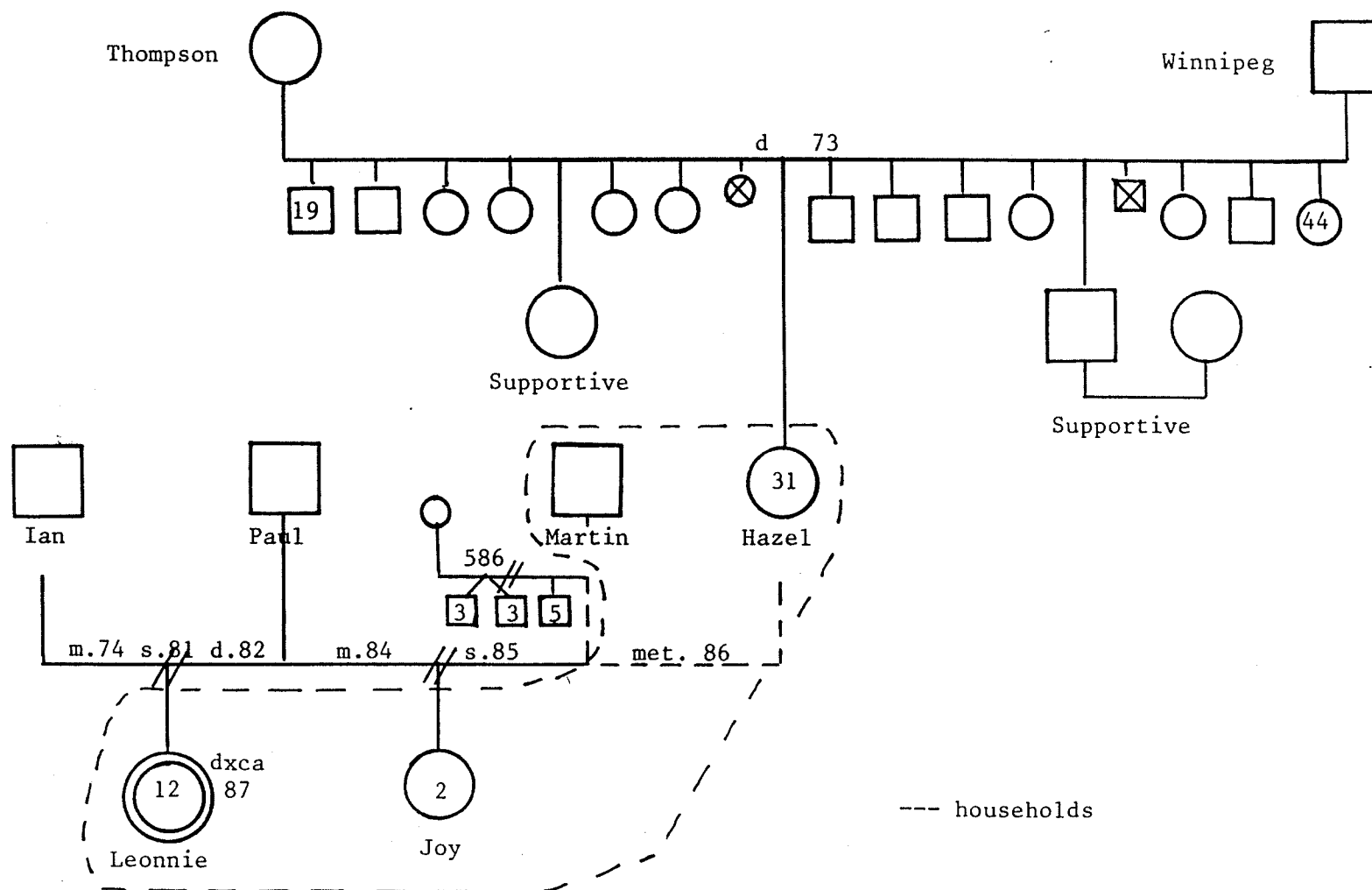


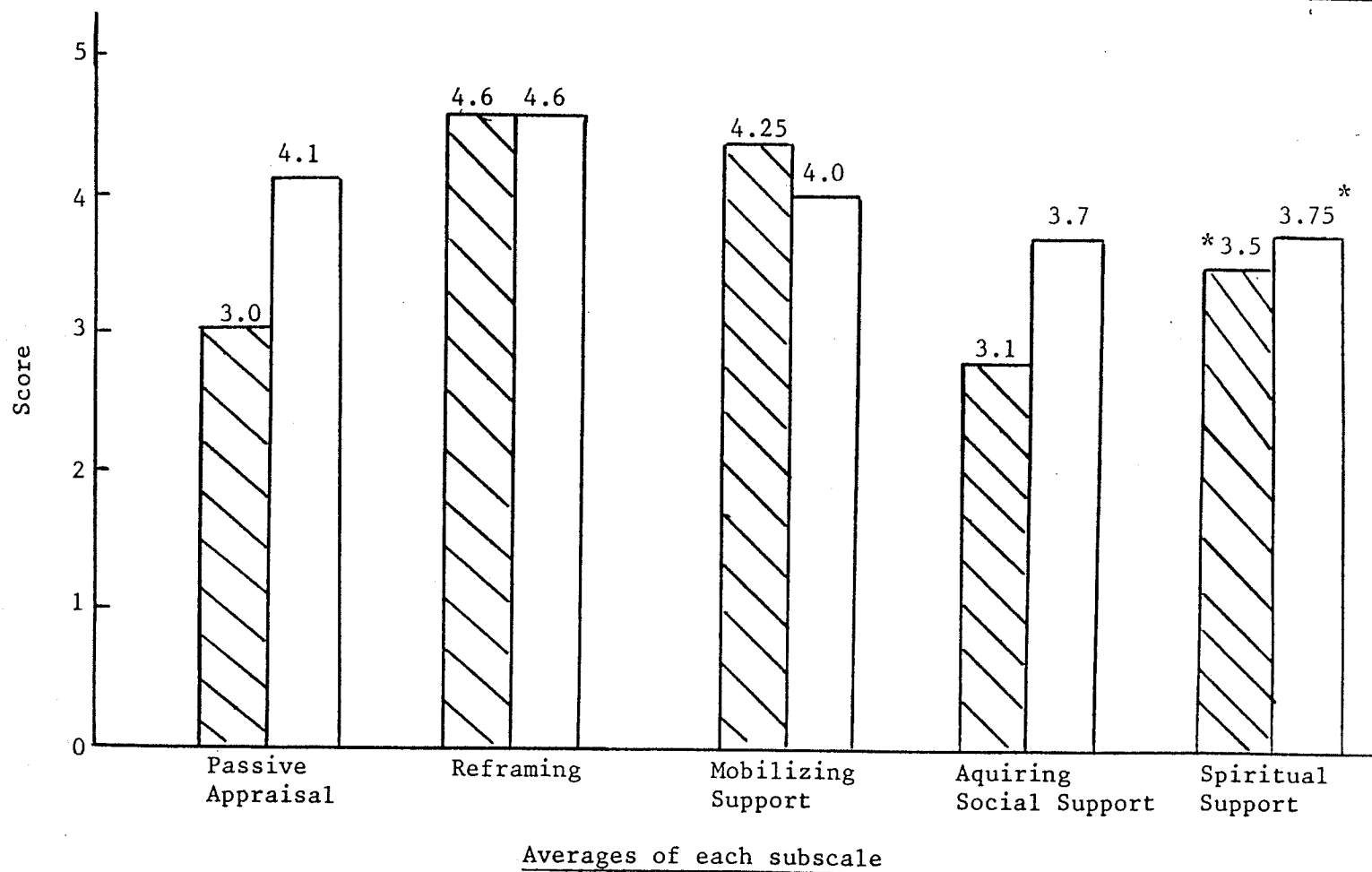
Figure 10

Family D Scores on F-Copes Subscales

Hazel



Ian



\* denotes below norm.

Children's Hospital, where the diagnosis of cancer was made, she had spent five weeks in another hospital. The long hospitalization and many medical procedures had left her very afraid. She now screeched if anyone went near her. No amount of preparation could have made me ready for Leonnie's high pitched: "Get out, get out", when I entered her room. Her mother, Hazel, looking very tired, apologized, calmed her down and explained that usually her daughter was friendly and lively rather than depressed and afraid of strangers.

Over the next few days I saw the family three times. Leonnie controlled her mother and the sessions by her behaviour. Attention directed towards her produced high pitched screams. No attention produced the same result. Hazel would start speaking with her daughter in a firm voice, but quickly gave way to pleading. She acknowledged that she was exhausted, but refused to leave the room, feeling embarrassed that Leonnie might create a scene. Furthermore she did not trust the nurses. Mother and daughter appeared locked in a symbiotic relationship where each experienced the needs of the other. Naturally any attempt on my part to set limits with Leonnie resulted in even more piercing screams, which in turn caused Hazel to feel more embarrassed.

Inquiries about the cancer brought the unemotional response that the diagnosis was a relief rather than a shock. Likewise questions about the genetic problems elicited no

feelings, but only the information that Leonnie attended a special grade 3 class because "they say she is slow".

Leonnies screams, Hazel's obvious embarrassment and her unemotional response all served to keep people at a distance. All emotions were very tightly controlled. She dared not let go, but backed away from empathy and support.

Her noticeable isolation prompted me to explore the extent of her support system. Although she was one of a large family, with 16 siblings, she considered them "no help", because "they expect me to be crying all the time." When further pressed, she acknowledged that a brother and sister living in the city had been helpful in babysitting Joy. She had separated from Leonnie's father, Ian, five years ago. Leonnie visited him during school holidays and he had visited his daughter in hospital at the weekends from his home two hundred miles away.

Three years ago Hazel had married for the second time, but the marriage had been short lived. Joy was the result of this union. She now had a relationship with a new friend with whom she had lived for the past several months.

Hazel had requested social work service because she needed someone to look after Leonnie when she was discharged, so that she could return to work. She had taken time off from



her job in a hotel to be with her daughter, but now the bills were piling up. Martin, her friend, gave her some money for his keep but she did not want to rely on him as he had to contribute to his former family. Homemaker services were arranged and a team meeting organized to coordinate the discharge. Hazel refused to meet with me before Leonnie's appointment in the clinic in two weeks' time. "I don't want to see anyone from the hospital", she bluntly told me.

Over the next weeks, mother and daughter sank further into their own symbiotic world. The next session saw them sitting huddled together in a corner of the waiting room. Leonnie never went to the playroom, and continued to scream if anyone tried to engage her in conversation. Hazel made no attempt to talk with other parents. As if to complete the withdrawal, Hazel planned to keep Leonnie out of school. Family meetings were hasty affairs, with Leonnie making noisy demands and Hazel feeling embarrassed about her daughter's behaviour and her looks. (She was beginning to lose her hair.)

All efforts to give support and empathy or to normalize and universalize the situation and the behaviour of the child failed dismally. I was unable to engage the family. Furthermore several outside institutions were expressing concerns about Hazel. As the parenting situation grew worse, my sanction to be involved with the family became weaker. Hazel had decided to go back to live with Leonnie's biological

father, from whom she was legally divorced. Therefore she no longer felt she needed services and told me that "everything is fine." By their refusal to acknowledge or express feelings and by their denial of any difficulties, the family indicated that they had not even begun to accept Leonnie's medical problems. Twice Hazel "forgot" to fill out the F-COPES scale. When I pushed the family to continue seeing me, on the grounds that "most families meet with me", Hazel consented to a meeting outside of clinic time, which would include Ian.

The meeting never took place. Hazel asked to see me alone. She no longer wanted to live with Ian. She had proposed the living arrangements initially because she had felt very anxious about looking after Leonnie. Now Hazel was afraid of what Ian might do when she informed him of her decision not to live with him. He had been abusive in the past. I took care to work within Hazel's framework and not to broach the emotionally painful subject of the cancer. Hazel rehearsed how and when she would tell Ian the news, and planned an "escape route" should one become necessary. She was also assisted in formulating an explanation for Leonnie. At the next meeting Hazel recounted that things had gone well. She looked happier and was now back with Martin.

Working on this matter together had resulted in a growing level of trust between Hazel and me. I continued to tread warily, avoiding anything which might have been construed

as a criticism of her parenting style. Hazel still maintained very firm control over her emotions. After much discussion she was able to recognize that she dealt with stress through withdrawal and avoidance. Now the tight relationship with Leonnie was becoming in itself more and more stressful. I suggested that Leonnie might also be finding the relationship "too close", and that this might be at the root of her behavioural problems. A plan was devised to help mother and daughter to gain some emotional distance from each other. With more psychological and physical space, it was hoped that the family might begin to mourn Leonnie's loss of good health and to accept the diagnosis realistically. An eventual goal was for Leonnie on clinic days to be involved in appropriate children's activities in the playroom and for Hazel to make contact and become acquainted with some of the other parents. In this way mother and daughter might expand their support network. Although it seemed that mother and daughter were having much difficulty in accepting the diagnosis, their scores on the F-COPES scale indicated no problem areas. Once again I encouraged Martin's involvement, as he was still living with the family. Hazel rejected the suggestion again, saying "he has his own problems". The prospect of his involvement was still too threatening.

In order to operationalize this plan, the first priority was to extinguish Leonnie's screaming. Now with Hazel's sanction, I spent time alone with Leonnie, getting to

know her and letting her talk. This attention she loved. Gradually the screaming stopped and her attitude changed to eagerness when she saw me. It was also arranged that the Child Life Therapist spend time with her, to further her adjustment to the treatment process, through the use of medical play. Hazel was instructed how to be firm with Leonnie when her behaviour was inappropriate. She was encouraged to list the positive qualities of Leonnie's personality, rather than concentrating on her negative behaviour and changed appearance. Hazel herself was introduced to some other parents.

Leonnice was still not attending school, and continued to follow Hazel's example by saying that she did not like school or her teacher. Over a number of sessions, it was explained to Hazel that absence from school constituted a further loss for Leonnie, as not only would she suffer a loss of health with the diagnosis of cancer but also a loss of peer interactions. Gradually Hazel accepted that Leonnie needed the stimulation and activity of school life.

At the same time Hazel's avoidant behaviour was preventing her from explaining Leonnie's medical conditions to the coordinators of Day Care and Homemaker services. They in turn were feeling uncertain about what Leonnie's needs were and how they might meet them. A network meeting was arranged with Hazel, hospital staff, school staff and coordinators of the

services, to discuss Leonnie's medical condition and care. Leonnie returned to school on a half time basis the next day.

A series of meetings was held with Hazel individually, to encourage her to face realistically and appropriately her daughter's medical problems. First, an appointment was made for her to talk with a clinical geneticist, as she had never fully understood the nature of Leonnie's genetic problem. Second, Hazel was assisted in expressing her feelings about the impact of Leonnie's problems on her life. This process was greatly helped one week when Leonnie's blood counts were too low for her to receive chemotherapy. Hazel was very angry. By using this as a concrete example, I was able to lead Hazel to an awareness that she often underestimated the effects of the illness. She bottled up her feelings until something happened, and then they exploded inappropriately.

In summary, adaptation in this family has been impeded by many risk factors. Pile-up resulted from the stresses of the long prior hospitalization, earlier and continuing medical problems apart from cancer, unstable conjugal relationships, financial difficulties, Leonnie's behaviour and an inadequate support system. These stresses, coupled with Hazel's primary coping mechanisms of withdrawal all served to make it extremely difficult for the family to progress in the process of adaptation.

Painfully slow yet significant progress was made in improving communication patterns between mother and daughter, and in normalizing the situation. Through information sharing, connecting the mother with resources, through support and encouragement, some reframing of the situation began to take place. Perceptions both of the underlying genetic problem and of the diagnosis of cancer were gradually improved. The family support system, which was initially limited to an unhealthy mutual dependence between mother and daughter, slowly expanded to include other helping professionals and parents. This multi-faceted intervention over the three month period ultimately made it possible for the family to initiate grief work.

At the conclusion of the three month period, the treatment plan remained to work with this family through the process of adaptation. A goal would be for Martin to be involved in some of the sessions, in order to enhance the adaptation of the family.

### Overall Adaptation

A focus of this practicum was on how each individual family in the study coped with a diagnosis of childhood cancer. However, it may be useful to any future work in this area for some general comments to be made on the process of adaptation of the whole study group of nine families.

Although the stresses arising from the illness itself stood out above all other stresses, the sheer number of adjustments faced by each family and their ever-changing nature were also noteworthy. Families learned to live cheek by jowl in one room of the hostel, or conversely to live apart for lengthy periods of time. Wives learned to drive in city traffic in order to bring the child for treatment. Husbands learned to take more responsibilities in the home. Siblings adjusted to staying with various babysitters; and patients adapted to hospitalizations, clinic appointments and body changes.

A number of other external factors created stresses for families, with medical problems of other family members causing the most trouble. In one family the mother was recovering from a serious operation when her son was diagnosed with cancer. In another family the grandmother suffered from extensive heart problems and was hospitalized. The most traumatic situations were found in two families who each had a grandfather in the terminal stage of cancer. One grandfather

had been diagnosed before his grandson's cancer, but he had relapsed. The other grandfather was found to have an incurable cancer two months after the child's diagnosis. These events were especially difficult for the patients' parents, who, watching their own parent die on the one hand were at the same time attempting to maintain hope for their child's cure. Both sets of parents coped appropriately by making their child's treatment their priority, but this did not lessen the emotional strain.

Other stresses arose from the solutions adopted by families to relieve the original stressor. Although both parents usually took time off work for a week or two following the diagnosis, only one man extended this time. In every other case it was the woman who organized her work environment. Of the five women who were working at the time of the diagnosis, two gave up work, one took a six month unpaid leave of absence and one took two months off. The son of the only woman who continued working was older and did not need a parent to accompany him to the clinic. The mother on unemployment sick benefits at the time of her son's diagnosis extended the period on the grounds of her stress.

These arrangements certainly relieved the women of having to juggle employment and clinic appointments, but had other repercussions besides the obvious financial consequences of absences from work. Most women felt a loss of independence



and self-esteem. As well they missed the opportunity to socialize with other adults. In fact this proved so difficult for one woman that my inquiry as to how things were going since she was now at home elicited a flood of tears.

In the seven families headed by two parents, five of the couples seemed supportive of each other. Both husband and wife were seen in clinic, both took turns to stay with the child in hospital and both were willing to take on new roles and responsibilities. In two families support for the mother appeared limited. One father was having difficulty in accepting the diagnosis, and the other couple were in a relatively new common-law relationship. The male partner did not take on any responsibilities for the child and the mother did not want him to.

In one of the two single parent families, the extended family with whom it lived was very supportive (Family C). In the other family, the extended family gave its attention to the child, a teenager. Overall, for all nine families, much help, both emotional and practical, came from members of the extended family. They cooked, cleaned and babysat. As well they offered empathy and often a shoulder on which the parent could cry. In six families, parents deemed one or more members unhelpful. The relationship with such persons was generally not cordial before the diagnosis and usually the illness did nothing to improve the situation. Problems arose in one family

because the nature of the illness was not understood and the parent was criticized for sending the child to school and for not keeping her in bed. In yet another family the grandparents were so emotionally overwhelmed themselves that they avoided visiting the sick child. Two families did not expect much support from their respective extended families and were somewhat surprised when care and concern were obviously shown.

Friends seemed to have been rated low as identifiable figures of support. Perhaps the limited time parents could spare for socialization in the months following diagnosis made it more difficult to maintain these more fragile relationships. Only two families mentioned friends as a source of support, and in each case the friends were very close and long-standing.

Parents, especially fathers, found it difficult to talk of the seriousness of the disease, but only one couple gave up trying to communicate with each other about the illness. Hope was generally maintained by "putting on a good front". The older the child, the harder it was for parents to speak of their fears in front of him or her. The two adolescents in the study were also reluctant to talk in their parents' presence and took on a stance that they themselves should cope with the illness alone. Thus parent and child sought to protect each other from the stresses of the illness.

Adequate financial resources, although unable to cure the child, certainly made life easier for the parents. Unlike their poorer counterparts, rich parents had the option of taking time off work and did not face unpaid bills.

Perceptions about the situation often reflected past experiences with cancer, and how the family of origin had coped with the illness. Besides the two families with a grandparent dying of cancer, there was a history of the disease in four additional families. Except in one case where the patient's mother had been successfully treated, the result had always been death. Although the fear of death was ever present, most parents managed to reframe the situation well enough, so that they could carry on with life and not become overwhelmed. The few parents who had difficulty in changing their perceptions of the situation seemed unable to block negative thoughts about the future, and expected that things would go wrong. No strong connection was discovered between the medical prognosis and the parents' perception of the situation.

Parents and children used a variety of techniques in order to cope with the illness, such as living day by day, seeking medical information, getting away, not looking back, crying and denial. Most were used by men and women alike, but denial tended to be used in different ways by the two sexes. Men in this study used it to avoid dealing with their feelings. It was as if a release of emotions would have made them too

vulnerable. Women expressed their feelings but used denial to block out some of the possible realities of the situation. For adolescents, denial represented their major way of coping. Only rarely, and only when they felt very safe did they let down their guard.

At the three month period only one family was having difficulty in adapting to the illness. Relationship problems were present prior to the diagnosis and the illness exacerbated the difficulties. Two other families, whose social and relationship problems were identified at the time of diagnosis came through the initial period quite successfully, though both sets of parents had had to confront many issues. Four patients exhibited some emotional and/or behavioural difficulties during the three month period. Most difficulties were associated with the receiving of the painful treatment. In two cases problems were resolved, in one situation the child's behaviour showed some improvement, and in only one instance did emotional difficulties continue. The two latter children had exhibited emotional and/or behavioural problems before the diagnosis had been made. No siblings experienced difficulties which were strictly related to the disease. Unless the medical condition had changed unexpectedly, most children were in remission by the end of the three months, and families were in healthy denial.

## CHAPTER 7

### Evaluation

This practicum was formulated with the major objective of designing and implementing a comprehensive social work plan for families newly diagnosed with childhood cancer.

The extent to which this objective was fulfilled will be explored in the next section. Recommendations for the practice of social work with these families will then be offered. The final section will review my personal objectives in undertaking this practicum.

#### Evaluation of Services to the Clients

Designing a process to evaluate the service component of this practicum was somewhat difficult. I did not feel justified in presenting families with a problem list to check soon after they had received a life threatening diagnosis of childhood cancer. My past experience suggested that families would invariably see the problem as "the child has cancer". Of course, the illness is the major problem. Furthermore, it is impossible for families to know at the point of diagnosis the number and scope of adaptations they will need to make over

time in order to accommodate the illness. Throughout the three month period issues were being identified as the adaptation process evolved.

Family functioning scales were also considered and were tested on willing families before the start of this practicum. The scales were found not to be sensitive enough to detect changes over a short period of time. Originally it was planned that the F-COPES Scale, which was used as an assessment tool, might form a pre- and post-intervention measure. However, the scale did not prove as useful as I had anticipated. The scores on the subscales were often not consistent with my clinical judgment, based on a number of sessions. For example, in Family A, Marie was very clearly having great difficulty in reframing the situation into anything positive, but her score on the "reframing" subscale was above the norm. The norms were established with a population of married Lutherans, which did not include any single parents. This is a serious drawback when dealing with a heterogeneous population. These characteristics of the norming sample may be reflected in the findings that only seven of the twenty people who completed the F-COPES scale were above the norm on the "seeking spiritual support" subscale. Scores on all the subscales of the five families excluded from the case illustrations may be viewed in Appendix 3.

A consumer satisfaction questionnaire was drafted as a means of evaluating the service (Appendix 4). Questions reflect the five major sub-categories suggested in the literature: accessibility, apparent professional skillfulness, physical surroundings, staff-patient interaction and outcome (Woodward, Santa-Barbara, Levin & Epstein, 1978).

The questionnaire included both open ended and closed questions, and required ten to fifteen minutes to complete. Seven families filled out the questionnaire. Of the remaining two families, one did not return the form. In the other, the child was in the terminal stage of the illness and it was deemed inappropriate to ask the family at that time to evaluate services.

Responses to the questions are summarized as follows:

1. When asked how soon after the initial diagnosis was contact made with the social worker, four families indicated that they met her at the time of the diagnosis, two families within one week and one family over four weeks after the point of diagnosis. The last respondent was the recently arrived immigrant family, whose child had been diagnosed six months earlier.

2. Related to the timing of the first contact, five families considered it to be just right, one felt contact was made too

early, and one person stated that he was too upset at the time of diagnosis to remember clearly.

3. In response to a question regarding the number and location of the contacts, three families indicated that they met with the social worker in their own home as well as in the hospital. All three felt the number of visits were just right. Of the remaining four, three were only seen at the hospital and one was seen at the hostel as well as the clinic. Two families would have liked to have been visited in their own home; one would not have wanted a home visit, and one person did not answer the question, but remarked that a home visit "may be good for (sibling), though he seems to be doing O.K.".

4. When requested to indicate how helpful the family meetings had been, all respondents indicated that the meetings had been of help. Four families rated them as very helpful and three as helpful. Four families offered comments about the meetings in the space provided. These included:

- "Helped me understand and get through the first few months."
- "Well, she has given me support morally."
- "(It) gave us a chance to talk things over."
- "Social worker tried over informing at too early a date."

This latter family, however, also found the meetings "helpful".

5. All respondents felt that the number of meetings held were just right.



6. The families were asked to examine a list of topics, and to check those which were discussed in the sessions with the social worker. The following topics were identified. They are presented in descending order of frequency.

- the illness itself (7)
- feelings of sadness (7)
- feelings of helplessness (7)
- relationships with other family members, such as grandparents, aunts and uncles (6)
- relationships within the family (6)
- financial issues (6)
- long term prognosis (5)
- concerns about the behaviour or coping of the patient (5)
- feelings of anger (4)
- services from other agencies (4)
- side effects of treatment (4)
- the medical treatment (4)
- concerns about the behaviour or coping of brothers and sisters (3)
- difficulties with sleeping, eating, health (3)
- job related issues (2)
- school related issues (1)

7. Families were asked to list two major issues or concerns which they had discussed with the social worker. The following issues were listed (their frequency is noted in parentheses):

- coping within the family (3)
- coping with the worries and severity of the illness (3)
- fears about what will happen
- coping with side effects
- dealing with the ill child
- how (son) acts
- work
- economic security

In relation to the degree of change experienced by the families in the areas listed above, one issue was assessed as much the same, four issues as somewhat better and eight as much better. One family failed to assess one issue.

8. No topics, other than those listed in questions six and seven, were identified by any families as issues which they had wanted to discuss with the social worker.

9. Five families recommended that the family meetings would be a help to other families in a similar position. The other two thought that perhaps they would be helpful.

10. Asked if they would like to participate in further meetings, one family stated "no", one family replied "perhaps" and five responded with a "yes". Of the six families who responded "yes" or "perhaps" to further meetings, three wanted them "as needed". One respondent had pencilled in "When

(son) comes in". One family wanted further meetings "at any change in the medical condition of the child". Another two families checked both "as needed" and "at any change in the medical condition of the child".

11. Four families added comments in the space provided at the end of the questionnaire. These included:

- "Disappointed with the Cancer Society's assistance program for child-related expenses." (Note that the Social Work Department has no authority over services given by the Cancer Society).
- "Everything was really great. I'm so thankful for it."
- "Services have been very good and helpful."
- "Services much appreciated."

### Summary

Responses to Questions 1 and 2 tend to reaffirm the necessity that contact with the social worker be made at the time of diagnosis. Replies to Question 3 suggest that families appreciate home visits, which can be more relaxed than those in the hospital or clinic, where the family is often waiting to see the doctor. For the social worker, it is certainly valuable to see first hand the interactions of the family in their own setting.

Overall responses indicated that the services were useful in a number of different ways. The counselling sessions were reported to be helpful by all families and included all the topics that they needed to talk about. Twelve of the fourteen issues discussed in the sessions were described as better after the intervention, while only one reflected no perceived change. Five out of the seven families would recommend the service to other families in the same situation. The other two indicated that "perhaps" the service should be offered to families. Finally all but one family indicated that they would like to participate in further family meetings in the future. This would indicate some measure of satisfaction with and benefit from services offered.

#### Critique of the Model of Service

This practicum, based on an "outreach" model of service, yielded various conclusions regarding social work services to families with childhood cancer. Four salient areas of the model will be discussed here:

Family Centered Approach. This approach, which is strongly advocated in most recent literature on childhood cancer, was both valuable and helpful. However, as was also suggested in the literature, it was sometimes hard to implement. The greatest obstacle was not the families themselves, who rarely objected to meeting as a family, but the distance of many homes

from Winnipeg. Thus for most of the rural families, meetings with the whole family were infrequent or did not happen at all. Given the stresses already inherent in the diagnosis, I could only feel justified in suggesting a trip to the city for all family members if there were many unresolved issues.

At times it was obvious that a certain member or members of a family needed extra attention. For example, individual play therapy sessions were conducted with Benjamin in Family C. The individual work was, however, always part of a larger family goal or objective.

Although they made no specific comments on the family aspects of the intervention, families all deemed family meetings helpful.

The approach was certainly valuable from my perspective, since I was able to gain a clearer understanding of the nature of the dynamics and interactions within the family. This comprehensive knowledge made it easier to focus appropriate interventions to individual or family adaptation.

Contract for Service. A major emphasis in this practicum was to formalize a contract with clients for service. Only one family approached over the five month period refused service. As explained in the practicum design, the contract was based on a specific length of time, (i.e. three months), rather than on

problems or issues identified. The contract proved extremely valuable in helping to establish a professional relationship with families. Definite appointments were set and families came to expect family meetings on a fairly regular basis as part of the oncology clinic social work program. The contract allowed me to outline ways in which I could help the family in the process of adaptation. This gave focus to the initial meetings and helped to highlight the importance of the family's attending to psychosocial as well as medical issues.

Some families required more meetings than others. This depended on the number and nature of the issues facing the family, its resources and its perception of the situation. Yet again, distance proved a problem, as some rural families came to the city only once every three to six weeks. The telephone played an important role in keeping abreast of family functioning, but was limited, as conversation could only take place with one person at a time. In one case a referral was made to the local Child and Family Services Agency, which decided that the situation did not warrant their input. I remained involved.

The Double ABCX Model. As an overall model of assessment, the Double ABCX Model allowed information about the family to be organized in a way that was not problem focussed. The three salient areas of "pile-up", resources and perception, and the interaction between them were noted as the family adjusted to

the illness. Strengths and weaknesses in the family system could be identified and interventions planned to relieve stress or increase resources. Stresses that led to pile-up could be particularly well identified through use of the model.

The limitation of the model was its very broadness. It could not be used to assess family interactions and dynamics. As mentioned earlier, the F-COPES scale, based on the Double ABCX Model, proved less useful than anticipated.

Interventions. As suggested in Chapter 4, a variety of techniques was used with families in order to promote their healthy adaptation. At the time of diagnosis, crisis intervention and grief therapy techniques were used. Later, interventions were made to help families to develop mastery of the situation, practical assistance was given and resource and network building undertaken.

One intervention used extensively in this practicum, and not given much attention in the literature, was that of "anticipatory adaptation". This preventive approach involved helping the family to identify individual and family coping mechanisms and encouraging members to rehearse how they would use their skills to handle anticipated medical and other stresses. This helped to make the future less frightening and more manageable for families.

### Recommendations

Recommendations arising from this practicum are as follows:

1. That social work services be implemented at the time of diagnosis and that they focus on the whole family as the client.
2. That interventions be flexible and broad enough to offer age appropriate services to individuals and families, which would include counselling, practical assistance and strengthening of support systems. They should also contain a preventative and educational component, to enable families to anticipate future stresses.
3. That social work services be extended both in time and scope, so that out of town clients may expect the same levels of service as those offered to residents of Winnipeg. The services need to incorporate both community based intervention (i.e., that which may be offered in the client's home), as well as hospital based treatment.
4. That social work develop a formalized plan of service, based on a contract which should include both the services to be offered and their duration.



5. That a formal program of social work services be offered to all families, which would include regular family meetings for all members of the family. These meetings should begin at the point of crisis, and should continue for a specific period of time. The severity of stresses arising from the diagnosis and the number and scope of adaptations necessary to accommodate the illness were identified in this practicum as being of such magnitude that any program of intervention should extend over at least three months.

#### Evaluation of Personal Objectives

This practicum was intended to provide an opportunity to increase my knowledge of the psychosocial issues involved in a diagnosis of childhood cancer, and to enhance my assessment and intervention skills with this population. In fulfilling this purpose, the practicum provided many challenges and opportunities.

The staggering volume of literature pertaining to psychosocial issues presented a challenge in itself, as I sought to organize, categorize and synthesize the material. Through the process I gained a thorough understanding of the many stresses arising from the diagnosis and of their impact upon individual family members as well as on the family as a whole. The Double ABCX Model provided me with an exciting new

framework for viewing the family and a new way of organizing information. I learned to incorporate and integrate this theoretical knowledge into the assessment process.

The family centered approach demanded that I broaden and develop my interventive skills to include both adults and children. Specifically, I learned new ways of helping families to identify and develop their coping abilities. What I have termed "anticipatory adaptation" proved to be a successful approach to helping parents and adolescents in their struggles to gain mastery over the situation. Yet again I experienced the pleasure of working with children on a one-to-one basis and honed my skills in helping them to express themselves through the media of drawing and story-telling. I sought different ways of connecting with adolescents, which did not rely on traditional "talking" methods. Contact was often made with teenagers by invoking their assistance in drawing family genograms, by play and by light banter. Finally I tested and refined skills in assessment and treatment, which were already available to me.

I became more familiar and comfortable in administering assessment and evaluation instruments, and plan to incorporate such tools in my ongoing practice.

Last, but not least, the challenge of working through and sometimes battling with this practicum has resulted in a

clearer and more precise focus to my practice, an improvement in professional self-esteem, and a growing awareness that I can offer a valuable contribution both to my clients and to the multi-disciplinary team to which I belong.

## APPENDIX 1

## Family Coping

Every person uses different ways of coping with a difficult situation, such as the one you are experiencing - that of having a child in your family diagnosed with cancer. There are no absolutely right or wrong ways of managing. For example, some people like to talk about the illness, whilst others are helped by reading about cancer.

As you think of your family as a whole, how are you dealing with the present situation? Please indicate your response by circling the appropriate number beside each item.

1 = STRONGLY DISAGREE; 2 = MODERATELY DISAGREE; 3 = NEITHER AGREE NOR DISAGREE  
4 = MODERATELY AGREE; 5 = STRONGLY AGREE.

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. Sharing our difficulties with relatives. . . . .   | 1 | 2 | 3 | 4 | 5 |
| 2. Seeking encouragement and support from friends. . . . .  | 1 | 2 | 3 | 4 | 5 |
| 3. Knowing we have the power to solve major problems. . . . .   | 1 | 2 | 3 | 4 | 5 |
| 4. Seeking information and advice from persons<br>in other families who have faced the same or<br>similar problems. . . . . | 1 | 2 | 3 | 4 | 5 |
| 5. Talking within the family about the illness. . . . .   | 1 | 2 | 3 | 4 | 5 |
| 6. Seeking advice from relatives (grandparents, etc). . . . .   | 1 | 2 | 3 | 4 | 5 |
| 7. Asking neighbours for favours and assistance. . . . .  | 1 | 2 | 3 | 4 | 5 |
| 8. Seeking assistance from community agencies<br>and programs designed to help families in<br>our situation. . . . .        | 1 | 2 | 3 | 4 | 5 |
| 9. Accepting that we have the strength within our<br>own family to solve our problems. . . . .                              | 1 | 2 | 3 | 4 | 5 |
| 10. Accepting gifts and favours from neighbours<br>(food, taking in mail, etc.). . . . .                                    | 1 | 2 | 3 | 4 | 5 |
| 11. Seeking information and advice from the family<br>doctor. . . . .   | 1 | 2 | 3 | 4 | 5 |
| 12. Facing problems "head-on" and trying to get<br>solutions right away. . . . .  | 1 | 2 | 3 | 4 | 5 |
| 13. Watching television. . . . .  | 1 | 2 | 3 | 4 | 5 |
| 14. Showing that we are strong. . . . .   | 1 | 2 | 3 | 4 | 5 |
| 15. Attending church services. . . . .  | 1 | 2 | 3 | 4 | 5 |

16. Concentrating on the sick child. . . . .	1	2	3	4	5
17. Accepting stressful events as a fact of life. . . . .	1	2	3	4	5
18. Sharing concerns with close friends. . . . .	1	2	3	4	5
19. Knowing luck plays a big part in how well we are able to solve family problems. . . . .	1	2	3	4	5
20. Accepting that difficulties occur unexpectedly. . . . .	1	2	3	4	5
21. Doing things with relatives (get-togethers, dinners, etc.). . . . .	1	2	3	4	5
22. Keeping busy. . . . .	1	2	3	4	5
23. Seeking professional counselling and help for family difficulties. . . . .	1	2	3	4	5
24. Believing we can handle our own problems. . . . .	1	2	3	4	5
25. Participating in church activities. . . . .	1	2	3	4	5
26. Defining the situation in a more positive way so that we do not become too discouraged. . . . .	1	2	3	4	5
27. Asking relatives how they feel about problems we face. . . . .	1	2	3	4	5
28. Avoiding talking or thinking about cancer. . . . .	1	2	3	4	5
29. Feeling that no matter what we do to prepare, we will still have difficulty handling problems. . . . .	1	2	3	4	5
30. Seeking advice from a minister. . . . .	1	2	3	4	5
31. Believing if we wait long enough, the problem will go away. . . . .	1	2	3	4	5
32. Sharing problems with neighbours. . . . .	1	2	3	4	5
33. Having faith in God. . . . .	1	2	3	4	5

Are there other ways of coping used by your family, which have not been mentioned above? Please list them:

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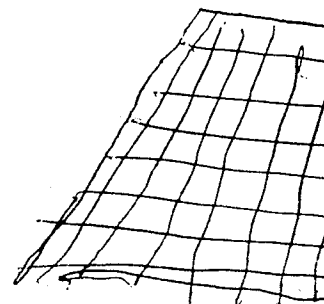
Thank you.

## APPENDIX 2

## Benjamin's Drawings



APPENDIX 2  
Benjamin's Drawings



## Appendix 3

## Scores on F-COPES Subscales

SCALE <sup>1</sup>	MOTHER		FATHER		PATIENT	
	RAW	ADJUSTED	RAW	ADJUSTED	RAW	ADJUSTED <sup>2</sup>
<u>FAMILY E:</u>						
SS	27	3.0*	-	-	32	3.5
MOB	16	3.2	-	-	16	3.2
REF	30	3.7*	-	-	24	2.6*
PA	16	4.0	-	-	9	2.25*
SP	6	1.5*	-	-	8	2.0*
<u>FAMILY F:</u>						
SS	39	4.3	24	2.6*	-	-
MOB	25	5.0	12	2.14*	-	-
REF	36	4.5	34	4.25	-	-
PA	11	2.75	9	2.25	-	-
SP	12	3.0*	4	1.0*	-	-
<u>FAMILY G:</u>						
SS	39	4.3	40	4.4	-	-
MOB	21	4.2	22	4.4	-	-
REF	32	4.0	30	3.7*	-	-
PA	13	3.25	9	2.25	-	-
SP	13	3.25*	-	-	-	-
<u>FAMILY H:</u>						
SS	34	3.7	32	3.5	34	3.7
MOB	20	4.0	21	4.2	18	3.6
REF	26	3.2*	32	4.0	34	4.2
PA	11	2.75	-	-	10	2.5
SP	17	4.25	18	4.5	17	4.25
<u>FAMILY I:</u>						
SS	28	3.0*	24	2.6*	34	3.7
MOB	15	3.0*	13	2.6*	17	3.4
REF	35	4.3	40	5.0	32	4.0
PA	15	3.75	8	2.0*	10	2.5
SP	15	3.0*	12	2.5*	14	2.8*

\* denotes scores below the norm.

<sup>1</sup> SS = acquiring social support; MOB = mobilizing support; REF = reframing; PA = passive appraisal; SP = spiritual support.

<sup>2</sup> The adjusted score is the mean score of each subscale.



## APPENDIX 4

## Evaluation Questionnaire

Your answers to the following questions will improve social work service to families with a child diagnosed with cancer. Please check off the response which you think best answers each question below. A space for comments is provided in selected questions and at the end of the questionnaire. Thank you for your assistance.

1. How soon after the initial diagnosis was your first contact with the social worker?

☐ At the time of diagnosis      ☐ Within forty-eight hours  
☐ Within one week      ☐ One to four weeks  
☐ Over four weeks

2. My first contact with the social worker after the diagnosis of cancer was:

☐ Too soon      ☐ Later than I would have preferred  
☐ At about the right time

3. Did your social worker meet with you in your home as well as in the hospital?

☐ Yes      ☐ No

If Yes, go to 3a; if No, go to 3b.

3a. Were the number of home visits:

☐ Too many      ☐ Not enough      ☐ About right

3b. Would you have liked your social worker to visit your family at home?

☐ Yes      ☐ No

4. How helpful were the family meetings with the social worker?

☐ Very helpful      ☐ Helpful      ☐ A little helpful  
☐ Not sure      ☐ Not at all helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_

5. The number of contacts with my social worker were:

\_\_\_\_\_ Just right      \_\_\_\_\_ Too many      \_\_\_\_\_ Not enough

6. Please examine the list below, and place a check beside the topics that you discussed with your social worker:

\_\_\_\_\_ The illness itself

\_\_\_\_\_ The medical treatment

\_\_\_\_\_ The side effects of the treatment

\_\_\_\_\_ The long term prognosis of the child

\_\_\_\_\_ Relationships with other family members, such as grandparents, aunts, uncles.

\_\_\_\_\_ School related issues

\_\_\_\_\_ Concerns about the behaviour or coping of the patient

\_\_\_\_\_ Concerns about the behaviour or coping of brothers or sisters

\_\_\_\_\_ Feelings of sadness

\_\_\_\_\_ Anger

\_\_\_\_\_ Feeling shocked

\_\_\_\_\_ Feelings of helplessness

\_\_\_\_\_ Job-related issues

\_\_\_\_\_ Financial issues

\_\_\_\_\_ Difficulties with sleeping, eating, health

\_\_\_\_\_ Relationships within the family

\_\_\_\_\_ Services from other agencies

\_\_\_\_\_ Other (please specify) \_\_\_\_\_

7. Please list two main issues or concerns discussed with your social worker:

a) \_\_\_\_\_

b) \_\_\_\_\_

How much change have you experienced in relation to item a)?

\_\_\_\_\_ It is much better          \_\_\_\_\_ It is somewhat better

\_\_\_\_\_ It is much the same          \_\_\_\_\_ It has become worse

How much change have you experienced in relation to item b)?

\_\_\_\_\_ It is much better          \_\_\_\_\_ It is somewhat better

\_\_\_\_\_ It is much the same          \_\_\_\_\_ It has become worse

8. Is there any subject listed above, or not listed above, which you would have liked to discuss with your social worker?

\_\_\_\_\_ Yes          \_\_\_\_\_ No

If Yes, please specify: \_\_\_\_\_

9. Would you recommend family meetings as a help for families with a child with cancer?

\_\_\_\_\_ Yes          \_\_\_\_\_ Perhaps          \_\_\_\_\_ No

10. Would you like to participate in further family meetings with your social worker during the course of treatment?

\_\_\_\_\_ Yes          \_\_\_\_\_ Perhaps          \_\_\_\_\_ No

If you answered Yes or Perhaps, how often would you like the meetings to be held?

\_\_\_\_\_ As needed

\_\_\_\_\_ At any change in the medical condition of your child

\_\_\_\_\_ On a regular basis. How often? \_\_\_\_\_

11. Any other comments you may have regarding the social work service you have received, or on social work services for families with a child with cancer, would be most welcome:

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Thank you!

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