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Adjustment Issues Related to Long-Term Cancer Survival: A Review of Literature

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LOYOLA UNIVERSITY CHICAGO

ADJUSTMENT ISSUES RELATED TO LONG-TERM CANCER SURVIVAL
A REVIEW OF LITERATURE

A THESIS SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
MASTER OF ARTS

DEPARTMENT OF COUNSELING AND EDUCATIONAL PSYCHOLOGY

BY

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ABSTRACT

Literature addressing psychological issues faced by long-term cancer survivors is reviewed. A historical survey of cancer survivorship literature is presented, outlining how cancer survivorship literature has changed as survival rates rose. Survivorship literature is also reviewed, with respect to coping strategies employed by these cancer survivors. Despite minor difficulties documented in the literature, childhood cancer survivors, adult cancer survivors, and adult survivors of childhood cancer were found to have no evidence of major psychopathology as a result of their cancer experience.

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CHAPTER 1

INTRODUCTION

Survival rates for cancer patients have continually risen over the past 30 years (American Cancer Society, 1994). This rise in survival is due to several factors. Early diagnosis and treatment have been made possible by better diagnostic and imaging equipment. Public education in the form of workshops, media services, and brochures has focused on early detection and self-exams, such as breast exams. However, the greatest advances in cancer management have been made with anti-cancer agents such as chemotherapy and radiation. Medical research investigated the ways in which these agents could be used most efficiently, that is, to halt the cancer without compromising the life of the individual.

When cancer survival rates began to rise in the 1960s and 1970s, researchers began to ponder the question of quality of life for this population. Psychologists began conducting research designed to uncover how cancer and its treatment had affected the life of the individual. Psychological testing instruments were developed in the 1970s to assess adjustment to illness, and are still commonly used today in research with cancer survivors.

The purpose of this thesis is to review literature regarding the psychological consequences of cancer survival. The question posed is, What psychological side effects are involved in being a cancer survivor? A secondary purpose of this thesis is to review the changes in cancer survivorship literature over time. This thesis will review literature found in psychological and medical journals, as well as relevant book chapters and unpublished research and dissertations. The time period covered in this review is roughly from the late 1960s to 1994.

The relevance of this thesis is evident from the number of cancer survivors that are alive today. Cancer patients in the 1900s had little hope for survival. In the 1960s, 1 in 3 cancer patients was alive 5 years after diagnosis. Currently, 40% of individuals diagnosed with cancer this year will survive 5 years or more (American Cancer Society, 1994). This figure represents 452,000 Americans. Thus, the number of long-term survivors is increasing, making more long-term survivors available to study.

Cancer is defined as a group of diseases characterized by uncontrolled growth and spread of abnormal cells (American Cancer Society, 1992). If left unchecked, these cells have the capacity to invade body tissue, organs, and bones, where they could cause death. The goal of modern cancer therapy is to arrest the spread of these abnormal

cells before they cause death, while preserving the life of the individual with cancer.

The Random House Dictionary (1980) defines a survivor as "one who remain or continue alive or in existence or use" (p. 877). For purposes of this thesis, the term "cancer survivor" will refer to those individuals who were thought to be free of disease for at least 2 years. Some authors use the term "recovered from cancer", others use the term "ex-cancer patient", still others refer to this population as being "cured of cancer". According to the American Cancer Society (1994), while an ever-increasing number of patients are maintaining long-term remission (indicating freedom from disease) or are encountering longer survival rates (despite presence of cancer), the term "cured of cancer" can only be applied in individual instances by the attending physician. Despite the variety of terms used in the literature, the term "cancer survivor" will be used throughout this thesis to refer to the population of individuals who are thought to be free of disease for at least 2 years. This population is referred to in this thesis as long-term cancer survivors. This thesis reviews only literature involving long-term survivors. This 2-year span seems enough time for the trauma of diagnosis and treatment to fade, leaving "true" psychological side effects available to assess. In Chapter 3, an adult cancer survivor is defined as one who was diagnosed with cancer at the

age of 18 or over. Similarly, in Chapter 4, a childhood cancer survivor is defined as one who was diagnosed with cancer before the age of 18.

Webster's Third New World International Dictionary Unabridged (1981) defines the word psychological as "relating to...arising in, or acting through the mind, esp. in its affective or cognitive functions" (p. 1833). The same dictionary defines a consequence as "something that...follows from a form of necessary connection or from a set of conditions" (p.482).

Despite the thorough way literature was reviewed for this thesis, a limitation could be that some literature involving psychological consequences of long-term cancer survival was inadvertently overlooked. The Psychinfo and medical databases were searched, bibliographies of existing studies were searched, but it is possible that not all the research was gathered and reviewed. Also, since this thesis focuses on survivors who were thought to be free of disease for a minimum of 2 years, literature studying any survivors who were thought to be free of disease for less than 2 years was not chosen for review, even if the research was combined with long-term survivors.

In Chapter 3, much of the research reviewed was conducted with survivors of Hodgkin's disease and testicular cancer. Although these 2 cancers have very high rates of survival and hence are frequently chosen for study,

the fact that survivors of these 2 types of cancers are highly represented in Chapter 3 is another limitation of this study.

This thesis is organized into 5 chapters. Chapter 2 addresses survivorship in general, and reviews literature involving survival from life-threatening events, including cancer survivorship. Chapter 3 reviews literature on adult long-term cancer survivorship. Chapter 4 reviews literature on long-term survivors of childhood cancer, including adult survivors of childhood cancer. A summary, conclusions, and recommendations are given in Chapter 5.

CHAPTER 2

SURVIVORSHIP

As this thesis concerns itself with cancer survivors, it is relevant to explore the nature of survivorship itself. In recent years, thanks to rising survival rates, cancer has been classified as a life-threatening disease rather than as a death sentence.

How do those faced with life-threatening events cope with their plight? Silver and Wortman (1980) compared several theories of how individuals cope with aversive uncontrollable life events. They identified commonalities shared by these theories: (1) there is a general pattern of response to the event, (2) individuals facing aversive life events respond in predictable ways (e.g., shock, grief), (3) individuals commence through a series of stages or steps during the crisis, and (4) the crisis is ultimately resolved. Silver and Wortman assert that although many models of coping with undesirable events have these assumptions in common, there is little empirical evidence to support them. Silver and Wortman challenged the notion that all life crises are ultimately resolved, and refer to studies (Lindemann, 1944; Parkes, 1970; Reichsman &

Levy, 1972) that concluded that a life crisis is to some extent re-experienced for the remainder of the individual's life.

There is literature to indicate that survival from cancer requires a process of recovery. Some authors have described the process of long-term cancer survival as a series of phases or steps. Mages and Mendelsohn (1979) offered a series of issues faced by the cancer patient. When considering long-term survivors, Mages and Mendelsohn identified the issues of facing damage done to the body as a result of the cancer itself and its treatment, maintaining continuity, and possibility of recurrence as realities faced by this population. To adapt to bodily damage from the disease or its treatment, including loss of body parts, cognitive function, or stamina, individuals must mourn the loss and capitalize on other strengths to enhance self-esteem. In regard to maintaining continuity, the survivor must form a new balance between him/herself and the environment. Mages and Mendelsohn report that cancer survivors' perceptions, values, and priorities are often substantially altered by the cancer experience. Therefore, the need exists to integrate the experience and make necessary changes in the survivor's life.

Mullan (1985) offered a phased approach to cancer survivorship, which he termed "seasons of survival". For long-term cancer survivors, Mullan identified the phase

of extended survival, in which treatment is completed and fear of recurrence is at its peak. In this phase, the survivor is faced with the task of re-entry, or the process of coming to terms with altered body image and other effects of the cancer experience. Once a survivor weathers the season of extended survival, he or she enters the season of permanent survival, when the individual can be optimistically termed "cured". Mullan pointed out that the season of permanent survival brings with it a kinship with the previous seasons which affects the individual for better and for worse. It is the duality of this situation that needs resolution by the permanent survivor.

Survival from cancer can bring both physical and emotional changes. These changes affect the way that survivors see themselves, their experiences, and the world around them. Surviving a life-threatening illness and trying to pick up one's life where one left off are difficult under the best of circumstances. Survival literature also indicated that cancer survivors undergo cognitive changes as a result of their cancer experience. These changes act as coping mechanisms for the survivor, as he or she tries to integrate the cancer experience and re-enter the life which cancer threatened.

In order to integrate his or her cancer experience, the survivor must search for meaning in the experience. The search for meaning following a trauma is well-documented

in the literature (Frankl, 1963; Silver & Wortman, 1980; Taylor, 1983). Extracting meaning from a traumatic event increases the sense of control one has over the event itself and over possible recurrences of the event. Rothbaum, Weisz, and Snyder (1982) referred to this phenomenon as interpretive control, which they defined as the belief that one can extract the meaning of an event and thereby solve it. Cancer survivors exercise interpretive control when they attempt to discover why they became afflicted with cancer in the first place. Taylor, Lichtman, and Wood (1984) studied 78 breast cancer survivors and reported that 95% of this population offered an explanation as to why they had developed cancer. These explanations seemed important to some survivors during recovery and long-term survival. This phenomenon may be related to the cognition that if survivors can find the origin of their cancer, they can take steps to extricate it permanently from their lives. Rothbaum et al. referred to this idea as predictive control, defined as an individual's belief that he or she can forecast events and thereby plan for a favorable outcome. Cancer survivors are sometimes left without the strategy of predictive control because, although it is certain that they would like to plan for a healthy future, fear of recurrence or actual recurrence of cancer itself may make it difficult to plan events with maximum confidence.

Taylor (1983) asserted that adjustment for threatening events centers around 3 cognitive themes: (1) a search for meaning of the event, (2) an attempt to remaster the threatening event in particular and one's life in general, and (3) an attempt to raise self-esteem and feel better about one's self after the threat. She also maintained that the ability to resolve these themes rests upon the formation and maintenance of illusions. Taylor defined illusions as ideas that are maintained by viewing known facts in a particular light because a different view would result in a less positive picture. Therefore, cancer survivors view their cancer experience in a way that most helps them feel they have derived meaning from the experience, remastered their lives, and enhanced their self-esteem. For example, Taylor stated that cancer survivors make downward comparisons when evaluating their condition against others. That is, they compare their situation with those who have the same or worse situation than they themselves face, and hence view themselves as coping favorably. If a real person does not exist with which to make downward comparisons, an imaginary person is manufactured. Taylor's point is that everyone is better off than someone else, as long as one picks the right dimension for comparison.

Taylor, Wood, and Lichtman (1983) studied survivors of victimizing events and concluded that in addition to

making downward comparisons to enhance one's self-esteem, the survivor engages in other cognitive processes to reduce the perceptions by self and others that he or she is a victim. Taylor et al. maintained that status as a victim is aversive, because it carries with it loss of control, low self-esteem, and because "normals" perceive victims as frightening and their reactions translate into negative consequences for the perceived victim.

Taylor et al., (1983) suggested options that the victim may choose to reduce their negative status as victim. One is termed "passing", in which victims fail to mention their victimizing event in social or other situations because it puts them at risk for being viewed as a victim, with all the negative consequences that go with it. Depending on how they view their own cancer experience, cancer survivors are put into the situation of opting to "pass" in social situations, in job interviews, and in intimate relationships. Of course, if one suffers from obvious ramifications of the cancer experience (e.g. amputation, scarring), the option of "passing" may become limited.

Taylor et al., (1983) reported that another mechanism for reducing social perception of victimization is to focus on events that make the survivor appear advantaged. For example, cancer survivors may view themselves as having an especially effective support system which gives them

the perceived or real advantage over those who do not have such social support. Taylor et al. stated that survivors of trauma create hypothetical worse situations and create normative standards for coping behavior in a trauma situation that makes their coping seem remarkable.

Do cancer survivors perceive themselves as victims? Cella (1987) stated that cancer survivors may see their triumph over cancer as positive, have pride in themselves for having done successful battle with a deadly foe, and feel no reason to keep their accomplishment a secret. However, to be honest with everyone about a cancer history can put the cancer survivor at risk for job discrimination (Hoffman, 1991), denial of some or all health insurance coverage (Fobair et al., 1986), or social shunning (Mullan, 1985). This predicament, to be proud of defeating cancer yet being afraid to mention it for fear of "punishment" by employers or peers seems especially difficult.

Survivorship literature reflects the fact that the cancer experience can affect a survivor's working world. Fobair et al. (1986) summarized the following difficulties their 403 subjects had attributed directly to the cancer experience: denial of life insurance (11%), denial of other benefits (6%), not being offered a job (12%), termination of employment following therapy (6%), conflicts with supervisors or coworkers (12%), rejection by military (8%). In this study 42% of this sample had reported at

least 1 of these problems. A finding of interest, however, was that this same sample reported their work ambition to be the same, if not greater, than before their diagnosis. Kornblith et al. (1986) noted that 42% of their cancer survivor sample reported 1 or more insurance problems, the majority of which were denial of life (31%) and health (22%) insurance. Only 11% reported actual vocational problems: being encouraged to leave a job (6%), being fired or laid off (5%), being demoted (1%). However, when asked to consider the overall socioeconomic impact of their illness, 36% stated that their illness had a negative impact. Cella (1983) found that 27% of his survivor sample perceived their careers to be compromised by the cancer experience. In a 1988 study comparing the work experiences of Hodgkin's disease survivors with those of testicular cancer survivors, Bloom et al. suggested that Hodgkin's disease survivors experienced more difficulty in completing work tasks than did the testicular cancer survivors.

Several studies (Bloom et al., 1988; Cella, 1983; Siegel & Christ, 1990) reported that cancer survivors worked less hours per week than they did before diagnosis. Although this finding may be expected during the treatment and recovery phases of the cancer experience, it is also reported by long-term survivors, which may indicate that it is not merely a function of treatment effects. One possible explanation, as postulated by Siegel and Christ

(1990) and Bloom et al. (1988), is that work activities are less valued after illness than before illness. Some cancer survivors reprioritize life factors after successful treatment, and work values are sacrificed in favor of values such as family and greater availability of leisure time.

Another possible explanation for cancer survivors' decreased work hours involves failure of survivors to return to premorbid levels of energy. This finding has been reported in several studies and literature reviews (Bloom et al., 1988; Fobair et al., 1986; Gritz, Wellisch, & Landsverk, 1988). Authors disagreed regarding whether this failure to recover precancer energy levels is related to length of time since completion of treatment. Type of treatment may also be a factor in energy return; those survivors who have had more rigorous treatment may have a slower recovery than those that were given a less toxic treatment regimen. Bloom et al. (1988) queried whether the work-related difficulties reported by the cancer survivors were the result of slow energy return due to treatment effects or of subtle job discrimination.

Hoffman (1991) estimated that 25% of cancer survivors experienced some form of job discrimination solely because of their cancer history. Many types of job actions may be affected by a cancer diagnosis: dismissal, failure to hire, demotion, denial of promotion, undesirable transfer, denial of benefits, or hostility in the workplace.

Kornblith et al. (1986) reported that 11% of their cancer survivors reported experiences of gross job discrimination. In a review of literature pertaining to job discrimination experienced by cancer survivors, Hoffman (1991) suggested that research in this area can only measure the perceptions of the survivors. Therefore, what is viewed as discrimination in the eyes of those receiving the perceived discrimination may be judged as sound business practice by others. Dobkin and Morrow (1985) suggested that job discrimination may occur in a subtle fashion. Siegel and Christ (1990) stated that the complaint of being passed over for jobs or promotions may be more imagined than real. The complaint may represent the survivor's tendency not to compete for certain positions or assignments because of an anticipated discrimination or feared loss of security and benefits. Conversely, some survivors who may feel the need to prove to themselves or others that they have fully recovered from the cancer experience may put themselves at risk for perceived job discrimination by trying to overcompensate. These survivors may strive for jobs for which they are not entirely qualified, or they may burn themselves out in the workplace.

Hoffman (1991) reported that the experiences of those who have jobs at the time of their diagnosis are different than those who are seeking employment post-treatment. Mellette and Franco (1988) concluded that survivors who

return to a previously held job posttreatment seem to have few problems provided that they can meet job requirements. Schmale et al. (1983) reported that one factor related to the well-being of their cancer survivors was no change in employment status. Perhaps the security of benefits or the affirmation received from being able to continue to perform a task mastered prior to illness play a role in the positive adjustment of the previously employed survivor who returns to the same worksite after treatment.

Unfortunately, a consequence of long-term cancer survivors remaining at the same job at which they were employed upon their diagnosis is a feeling of being locked into that job for fear of losing benefits or fear of not being hired at another company due to their cancer history (Greenleigh Associates, 1979; Mullan, 1984). Spouses of cancer survivors may encounter a similar predicament, fearing loss of benefits for their husband or wife. Despite the great advances being made in increasing survival rates for those who have had cancer, many insurance companies refuse to insure a cancer survivor even after he or she has retained a long-term remission or is pronounced "cured" by the attending physician.

Hoffman (1991) stated that a common myth regarding the employment of cancer survivors is that they are unproductive and a financial drain. Several studies (Greenleigh Associates, 1979; Mullan, 1984) reported that

survivors are able to perform job duties and achieve satisfactory job performance ratings. In a widely cited study of cancer survivors employed at the Metropolitan Life Insurance Company, Wheatley, Cunnick, Wright, and van Kueren (1974) discovered that turnover rates for cancer survivors were no different from the noncancer survivor population. The cancer survivors were also found to have high job performance ratings and modest rates of absenteeism.

Legally, cancer survivors do now enjoy some recourse from job discrimination. The Americans with Disabilities Act (ADA) of 1992, by classifying cancer survivors as disabled, makes it illegal to dismiss or fail to hire an employee on the basis of his or her cancer history. This newer, more specific legislature replaced the Rehabilitation Act of 1973. However, the ADA has yet to be rigorously tested in the court system because it is so new.

Even though cancer survivors are challenged by their history in the workplace, the social stigma of cancer seems to be abating. Soiffer (1991) wrote of the various stigmatizing effects of Hodgkin's disease survivors, and stated that cancer's negative connotation as a death sentence has been somewhat forgotten in the face of the AIDS epidemic. AIDS has seemingly replaced cancer as the worst thing that could happen to a person.

Despite the physical, emotional, and cognitive changes

which a cancer survivor may endure and despite any discrimination a cancer survivor may face, does the survivor wind up worse off overall for having had the experience? Survivorship literature indicates that, in general, cancer survivors are none the worse for wear. Studies of long-term survivors (Cella, 1983; Fobair et al., 1986; Taylor, 1983) indicated that many of those affected by cancer are able to find some positive aspects, such as shifting of values and priorities (Mages & Mendelsohn, 1979), enjoyment of life's "little things" (Taylor, Lichtman, & Wood, 1984), and a greater appreciation of life (Cella, 1983) as long-term emotional side effects of having survived cancer. Studies of married survivors (Gritz, Wellisch, Siau, & Wang, 1990; Siegel & Christ, 1990) report that the cancer experience is often seen as a strengthening force in the relationship. The finding that cancer survivors work less hours after the cancer experience than before may reflect the reprioritizing that Mages and Mendelsohn (1979) reported. Survivors may put more value on family and leisure activities than work after facing and overcoming the deadly disease.

In conclusion, the professional literature reports that serious hurdles exist for cancer survivors. These hurdles include physical ramifications of the illness and social stigma of having had cancer. Cancer survivors have a variety of coping mechanisms available to them to assist

them in overcoming perceived and real social stigma. Social, advocate, and legislative support exist for cancer survivors who encounter difficulties socially or in the work place. However, some professional literature regarding cancer survivorship concludes that there are positive aspects of the cancer experience as well, and that, for some cancer survivors, the experience provides a greater appreciation of the lives they struggled to preserve.

CHAPTER 3

ADULT CANCER SURVIVORS

Of the 8 million Americans alive today with a history of cancer, many were adults at the time of diagnosis. The psychological consequences of adult long-term cancer survival have been frequently studied in recent years. The survival rates of cancers typically affecting young adults, such as testicular cancer and Hodgkin's disease, have risen dramatically in the past 35 years (American Cancer Society, 1992). Thus, survivors of testicular cancer and Hodgkin's disease provide an opportunity to study long-term psychological consequences of cancer survival. For this reason, much of the research investigating psychological consequences of adult cancer survival has been conducted with survivors of these two diseases. Research regarding psychological difficulties these survivors face may not only enhance future patient education for survivors of these particular types of cancer, but may generalize to cancers for which survival rates are also increasing, such as breast cancer and leukemia.

Early literature dealing with psychological consequences of adult cancers focused mainly on positive

effects gained from the experience of having had cancer. In 1975, O'Neill suggested that the cancer survivor embarks upon a series of steps to emotional recovery after successful treatment. According to O'Neill, a cancer survivor must first conquer fear of recurrence which he or she may accomplish by outlasting published survival rates for his or her particular type of cancer. These survivors gain perspective and, after coming to the realization that all humans share vulnerability, they relay their cancer experience, as well as fear of recurrence, from the present into the past.

In 1976, Kennedy, Tellegen, Kennedy, and Havernick conducted psychological tests with 22 cancer survivors who had survived various types of cancer for 5-20 years. They observed that cancer survivors experienced elation, increased zest for life, and a greater appreciation of the commonplace. They reported that cancer survivors had positive attitudes, were more relaxed, and were less concerned about the nonessentials of life. They concluded that recovery from cancer was a good experience for character development. These early positive observations made about cancer survival could be related to the fact that early survivors were few in number. O'Neill (1975) coined the term "cancer gestalt" referring to the time period in the 1970s when cancer was equated with death. Thus, in the 1970s, to merely have survived the cancer

experience, and to be saved from the "clutches of death" was a tremendous accomplishment and may have been seen as not only a positive physical outcome but a positive emotional outcome as well.

In the early 1980s, literature dealing with psychological aspects of cancer survival began to reveal negative effects as well as positive ones. Maher (1982), referring to Durkheim's (1933) concept of anomie as a condition evoked by either positive or negative change, proposed that the concept of anomie may be applied to cancer survivors. She suggested positive as well as negative consequences occur as a result of the cancer experience. In a 1982 study of cancer survivors a median of 4½ years off treatment, Maher identified negative consequences such as withdrawal of intensive social support and survivors' ambivalence regarding the discontinuation of cancer treatment as negative consequences the cancer survivors reported.

Cella (1983) conducted an investigation comparing psychological characteristics of 60 male Hodgkin's disease survivors with a control group of 20 healthy men. Among his findings was the observation of lower intimacy motivation of the cancer survivors. The survivors were less inspired to indulge in behaviors promoting intimacy in interpersonal relationships. However, Cella concluded that although the cancer experience does carry with it

psychological risks such as increased exhibition of psychiatric symptomatology, these risks do not extend beyond the realm of normal adaptation. After a comparison within the patient sample of survivors recently off treatment versus those distantly off treatment, Cella suggested that extended remission may result in greater life appreciation and perhaps character growth. Schmale et al. (1983) found that 3 year cancer survivors, while not significantly different from healthy controls on measures of anxiety, depression, positive well-being and vitality, did report a lower sense of self-control and more worries about aches and pains than did the control group of healthy individuals.

In a review of psychosocial effects of cancer survivorship, Dobkin and Morrow (1985) remarked that empirical studies measuring effects of adult cancer survivors were sparse. In the latter half of the 1980s however, literature examining psychological side effects of cancer survivors became more plentiful. There was an increase in the appearance of research articles and book chapters about psychological issues faced by survivors of particular types of cancer, such as testicular cancer (Gritz, Wellisch, & Landsverk, 1988; Reiker, Fitzgerald, & Kalish, 1990; Reiker et al., 1989) and Hodgkin's disease (Carpenter, Morrow, & Schmale, 1989; Fobair et al., 1986; Kornblith et al., 1986; Kornblith et al., 1988; Siegel & Christ, 1990; Soiffer, 1991). Another trend in literature

regarding psychological adjustment of long-term cancer survivors in the latter half of the 1980s involved the study of individual issues rather than overall psychological adjustment. Issues such as psychosexual adjustment (Anderson, Anderson, & deProsse, 1989; Kornblith et al., 1988; Mumma, Mashberg, & Lesko, 1992) and employment adjustment (Bloom et al., 1988; Hoffman, 1991; Mellette & Franco, 1988) were explored. The remainder of this chapter will be devoted to a review of literature exploring individual psychological consequences faced by adult cancer survivors.

Fear of recurrence and death. Recovery from a life-threatening illness such as cancer brings with it long-lasting fears regarding a recurrence of the disease and eventual death from the disease. Perhaps these fears are grounded in the uncertain nature of survivorship itself. As previously discussed, the American Cancer Society (1992) stated that the proclamation, "cured of cancer", can only be applied in individual instances. In most instances, there are no guarantees that the cancer will not return. Siegel and Christ (1990) referred to the fear of cancer recurrence as a virtually ubiquitous phenomenon among cancer survivors and one that, while it may decrease the longer a survivor remains disease free, never completely vanishes. Events such as follow-up visits (often conducted in the same location the survivor received treatment) or

anniversaries of diagnosis may exacerbate fears. In a study designed to survey needs of short-term (less than 24 months) versus long-term (more than 24 months) cancer survivors, the most prevalent concern among both short-and long-term survivors was general physical health and recurrence of the disease (Stalker, Johnson, & Cimma, 1989). Cella and Tross (1987), in a comparison of short-term survivors (less than 2 years) with long-term survivors (more than 2 years), found a trend toward lessening of death anxiety over time. Fear of recurrence and death is a real and lasting phenomenon of long-term cancer survivorship. This fear may vary in degree and across time from survivor to survivor, and may manifest itself in the domain of survivors' interpersonal relationships.

Interpersonal relationships. The psychosocial sequelae of illness can interfere with recovered cancer patients' capacity to form intimate relationships. This and other changes brought about in the realm of interpersonal relationships are among the most significant and far-reaching consequences of the illness (Siegel & Christ, 1990). One change in interpersonal relationships of cancer survivors may occur when treatment ends. During the treatment phase, the cancer patient often receives much emotional support from family, friends, and the treatment team. This support may be withdrawn as soon as treatment terminates. For instance, visits to the doctor

become less frequent. Carpenter, Morrow, and Schmale (1989) suggested that patients may rely on their physicians for psychological comfort and may feel abandoned as visits to the doctor become more dispersed. Family members of the survivors may have the desire to put the unpleasantness of the illness behind them or, as Siegel and Christ (1990) suggested, have the preconception that remaining optimistic and distracting the survivor from thoughts of illness is best. Therefore, family members may be reluctant to let the survivor talk about his or her feelings and, thereby, work through the range of emotions associated with the termination of treatment. With the loss of these social supports, the survivor may feel unable to express current concerns to those he or she may have relied upon for past encouragement. This consequence may have long-term manifestations, even for the long-term cancer survivor. Perhaps the survivor who is discouraged by family and friends from talking about his or her illness loses a valuable avenue to integration of the impact of that illness. The survivor who receives reinforcement for avoiding the subject of his or her illness may receive the incorrect message that talking about a cancer history is taboo, not only with family and friends, but with other acquaintances as well. Both Fobair et al., (1986) and Stalker, Johnson, and Cimma (1989) reported that disclosure of their cancer history is an important concern for

long-term cancer survivors. Cancer survivors who are discouraged from disclosing their illness to others may find it difficult to relate to others openly. Cella (1983) stated that a history of cancer may alienate cancer survivors from peers by increasing their sense of isolation. The cause of this isolation is not clear. Perhaps cancer survivors who elect not to disclose their history of illness find that the harboring of this secret constricts their ability to relate to peers in ways that have nothing to do with cancer. Or perhaps the life-threatening cancer experience itself sets cancer survivors apart from peers by leaving the survivors with a different life view.

The literature describes both positive and negative consequences of cancer survivorship for marital relationships. Based on their detailed clinical interviews, Siegel and Christ (1990) found that, of those that were married at the time of diagnosis, 50% felt strongly that their marriages had been strengthened as a result of having weathered a crisis. Other survivors reported no change in their marriages. Similarly, Gritz, Wellisch, Siau, and Wang (1990), who studied long-term testicular cancer survivors and their wives, concluded that the great majority of marriages they studied were strengthened and that couples were more closely bonded after the illness than before. Craig, Comstock, and Geiser (1974) conducted a study of 5 year or longer breast cancer survivors. After a

comparison of the survivors with both population controls and neighborhood controls, they concluded that breast cancer survivors were no more likely to be psychosocially impaired (including having a higher incidence of divorce) than the control groups.

In regard to marital disruption, Fobair et al., (1986) reported that 49% of their sample who were married at the time of their diagnosis and later separated or divorced attributed their marital disruption to their illness. Based on this finding, Fobair et al. postulated that marital stress which may have accumulated during illness may be temporarily put aside during treatment only to resurface and cause marital breakups later. This study's findings intimate that marital disruption may be a consequence of long-term cancer survival, or of cancer itself. However, Carpenter et al., (1989) reported that long-term survivors (2 years or more) had no higher rate of divorce or separation than did short-term survivors. There seems to be more research evidence supporting the strengthening of intimate relationships as a result of the cancer experience than the dissolution of intimate relationships as a result of cancer. The conflicting research conclusions regarding intimate relationships of cancer survivors may reflect difficulty in other areas in which cancer can take its toll, namely, infertility, sexuality, and body image.

Infertility, sexuality, and body image. Infertility,

sexuality, and body image are frequently affected as a consequence of long-term cancer survivorship. These areas are extremely important due to high survival rates for cancers affecting young adults. Higher survival rates make possible childbearing and childrearing for this population, relatively new phenomena.

Infertility, defined here as the inability of either a male or a female to produce offspring, can occur in cancer survivors in 1 of 2 ways. Removal of all or part of the reproductive system can obviously pervasively affect fertility. Iatrogenic infertility, or infertility caused by treatment, is the second way in which fertility may be altered. During the treatment phase, when the objective is disease management, preservation of fertility is of secondary consideration. Sperm banking for males and freezing of ovum for females are options which are available for the young adult cancer patient. However, Cella and Najavits (1986) suggested that cancer patients often deny the possibility of infertility until it is too late to consider useful options such as sperm banking, and that this denial may have roots in patients' inability to think realistically about a theoretical future. They concluded that infertility, either threatened or actual, has a long-term impact on the lives of cancer survivors.

Accurate data are difficult to gather regarding infertility, since some cancer survivors have been tested

as infertile while others only perceive infertility. Whether perceived infertility is based on actual experience (such as attempting to become pregnant and being unable to) or is a manifestation of depression or lower self-esteem due to the cancer experience is unclear. Some researchers (Kornblith et al., 1986; Kornblith et al., 1988) report incidence of real and perceived infertility together. Reiker, Fitzgerald, and Kalish (1990) conducted a study of 153 testicular cancer survivors designed to measure the impact of potential infertility on cancer survivors. Based on measures of psychological variables such as mood disturbances and mental outlook, they suggested that men may face their potential infertility without disturbing their overall psychological well-being. The effects of potential infertility upon overall psychosexual functioning, defined here as sexual ability, interest, and satisfaction (Cella, 1983) have been studied. Mumma, Mashberg, and Lesko (1992) compared psychosexual functioning of adult leukemia survivors who have received a bone marrow transplant with that of adult leukemia survivors who had received chemotherapy only. Since bone marrow transplants present a greater risk for infertility, these researchers postulated psychosexual functioning would be decreased for bone marrow transplant recipients. However, they found no significant differences in psychosexual functioning between the 2 groups of cancer survivors. Similarly,

Kornblith et al. (1988) compared psychosexual functioning of Hodgkin's disease survivors who had been treated with 2 different chemotherapy regimens, 1 known to be more gonadotoxic than the other. They found no significant differences in psychosexual functioning between the 2 groups.

Taken together, these two studies suggest that greater potential infertility does not necessarily lead to decreased psychosexual functioning. However, there are data to suggest that the sexual experiences of cancer survivors are altered after treatment. Reiker et al. (1989) stated that 30% of their sample of testicular cancer survivors reported distress regarding their sexual performance. Gritz, Wellisch, and Landsverk (1988) studied testicular cancer survivors as well, and reported that nearly all of their sample reported a higher frequency of sexual dysfunction after the cancer experience than before. One-third of this sample also stated that sex was less satisfying now than prior to diagnosis. The standard treatment procedure for management of testicular cancer includes orchiectomy (removal of one or both testicles). Perhaps sexual dysfunction or decreased sexual satisfaction in these survivors may be a function of emotional distress relating to the loss of these organs. However, decreased sexual interest and satisfaction of survivors of other types of cancers have been demonstrated as well.

Fobair et al. (1986) reported that 18% of their large sample (n=403) of Hodgkin's disease survivors experienced a loss of interest in sexual activities and 20% reported a decrease in sexual frequency. Kornblith et al. (1988) noted that when their survivors rated overall current sexual satisfaction, their average ratings did not differ significantly from those of healthy controls. However, when these survivors were encouraged to consider the impact of cancer upon their sex lives, 37% reported at least 1 sexual problem. Most commonly reported were problems of decreased sexual satisfaction, decreased sexual interest, and decreased sexual activity. In a study of female Hodgkin's disease survivors, Chapman, Sutcliff, and Malpas (1979) reported that 73% of their sample indicated they had mild or no sexual interest post-treatment as compared to 8% before treatment. In a similar survey of male Hodgkin's disease survivors, Chapman, Sutcliff, and Malpas (1981) reported that 50% of their sample indicated their sexual interest had never returned to its preillness level.

To the contrary, there is evidence that the cancer experience, while it often has a negative impact on psychosexual functioning, can improve the sex lives of long-term cancer survivors. Cella (1983) found no significant differences between survivors and controls on their ratings of sexual satisfaction and, whereas 18% of the survivor sample reported poorer sexual performance,

44% indicated that their sexual functioning had improved. Similarly, Siegel and Christ (1990) reported that, while 22% of their survivors indicated a decrease in sexual interest since illness, 12% reported an increased interest since diagnosis. Over one-half of their sample (57%) reported increased satisfaction with their sex lives since diagnosis.

Perhaps the differences in psychosexual adaptation of cancer survivors have their roots in body image. Evidence suggests some cancer survivors have poorer body image when compared with peers who had never been ill. Cancer survivors who have undergone body-altering treatment (such as amputation) or those who carry scars may be particularly at risk for impaired body image. Siegel and Christ (1990) commented that cancer survivors often experience anger at their bodies for having failed them. Siegel and Christ's study revealed 24% of their survivors admitted that they felt less physically attractive than before illness. Fobair et al. (1986) reported 26% of their sample felt that their physical attractiveness had decreased as a result of diagnosis and treatment. Mumma et al., (1992) found that, regardless of treatment received, their cancer survivors had poorer body image than a control group of healthy individuals. They also reported that survivors' poorer body image increases as time since last treatment increases, and they postulate that the decrease of denial

of the impact of the illness may contribute to this finding.

In general, psychosexual adaptation may be affected by the cancer experience. Research indicates that the effect can be positive as well as negative. Real or perceived infertility may play a role in psychosexual adaptation. Body image, which may be poorer for those survivors who have had body-altering surgery, may also affect psychosexual adaptation.

In conclusion, this chapter has reviewed literature concerned with psychological consequences of long-term cancer survival. Fear of recurrence and death, difficulties with interpersonal relationships, potential infertility, and poor body image have all been examined in the professional literature regarding cancer survivors. Despite the documentation of these problems, there is also research evidence to demonstrate that the cancer survivor is able to emerge from the cancer experience without major psychopathology or pervasive life disruption. In a 1989 review of literature of survivors of various types of cancer, Welch-McCaffrey, Hoffman, Leigh, Loescher, and Meyskens summarized that, although uncertainties persist for about 3 years after treatment, there is no overall evidence that psychopathology is a correlate of long-term cancer survivorship.

CHAPTER 4
SURVIVORS OF CHILDHOOD CANCER

Childhood cancer will strike 7,800 children this year (American Cancer Society, 1994). It is estimated that, as of 1990, 1 in 1000 Americans who are 20 years old has a history of cancer in childhood (Meadows, Krejmas, & Belasco, 1980). Also, by the year 2000, an estimated 1 in 1000 20-29 year-olds will have a childhood cancer history (Meadows & Hobbie, 1986). This chapter focuses on survivors of childhood cancer, and will consist of a review of the professional literature regarding psychological consequences of long-term survival of childhood cancer.

This chapter will be organized into several sections. First, the earliest literature regarding childhood cancer will be reviewed. Next, the different types of childhood cancer and their most common consequences are discussed. Finally, this chapter will focus on individual issues faced by 3 groups of survivors: childhood cancer survivors who are still children; adolescent cancer survivors; adult survivors of childhood cancer.

Three decades ago, childhood cancer was equated with

certain demise. The cancer diagnosis was seen as a death sentence and the patient was seen as a dying patient from diagnosis onward (Van Dongen-Melman & Sanders-Woudstra, 1986). Thus, early literature centered on the problems of the terminally ill. As Koocher, O'Malley, Gogan, and Foster (1980) reported, children with cancer received only palliative care, and their families received support and preparation for the loss of their child. Literature focused on whether or not to communicate the diagnosis, and the imminent death that went along with it, to the child. This subject was difficult to discuss before the work of Kubler-Ross (1969), which facilitated acceptance and understanding of death (Koocher & O'Malley, 1981).

Advocates of the "protective approach" (Plank, 1964; Howell, 1966) argued that children should be shielded from the cancer diagnosis. They argued that, before age 10, a child has no concrete conceptualization of death and, therefore, a child under the age of 10 has no fear of death. Parents were dissuaded from telling their terminally ill children their fate and causing them confusion about a situation they did not originally fear.

Conversely, some early literature also reflects an open approach to communicating the cancer diagnosis to children. Several researchers (Vernick & Karon, 1965; Bozeman, Orbach, & Sutherland, 1955; Friedman, Chodoff, Mason, & Hamburg, 1963) maintained that protecting the

child from his or her diagnosis, and the grave nature of the illness may be more destructive than telling the child the truth. Avoiding the issue may only serve to encourage unrealistic fantasies of the child, which in turn may cause anxiety and depression. Share (1972) advocated an open approach where children could feel free to express concerns about their illness, and this approach was prevalent in literature in the 1960s and 1970s (Karon & Vernick, 1968; Kellerman, Rigler, Siegel, & Katz, 1977).

In the late 1960s and early 1970s, survival rates for childhood cancer began to rise, thanks to the combined effects of surgery, radiation, and chemotherapy. For the first time, literature measuring quality of life among these young survivors began to appear. With the advent of aggressive treatment for childhood cancer, researchers began to ponder the question, "Is the life saved worth living?" (Holmes & Holmes, 1975). In other words, does treatment render such deleterious effects that quality of life post-cancer is severely impaired? Unlike treatment for adult cancers, childhood cancer treatment affects organs and bones that are still growing, and the effects of aggressive treatment regimens were not well known in the 1970s.

Holmes and Holmes (1975) conducted a study of 124 childhood cancer patients who had survived 10 years or more. Their objective was to determine whether the

"drastic, dangerous, and often mutilating approaches utilized in modern cancer treatment are justifiable." With the exception of 9 patients who had been treated for brain tumors and suffered severe mental and physical limitations, Holmes and Holmes found that their sample of long-term survivors had adjusted to life post-cancer. Nearly half their sample reported no recognizable sequelae as a result of their cancer experience, and only 14.5% had marked disabilities related to the cancer or its treatment. Almost half the sample had married, and 34 had children, all of but 1 who had been born healthy. Of the 124 survivors, 90 reported that their cancer experience had no effect on their current life. Holmes and Holmes concluded that overall adjustment of their sample was high, and that the aggressive treatment characterized by modern cancer therapy was justified.

Li and Stone (1976) conducted a similar survey in which they studied 142 survivors of childhood cancer. All but 5 of the subjects had completed treatment 2 years or more before their participation in the study. Despite the presence of what was termed "major defects in treated organs" in 52% of the population and a second primary cancer rate of 12%, Li and Stone concluded that the majority of survivors were currently living active, productive lives. Also, 61% of these patients had attended college, indicating that the absence from school that often accompanies

treatment had no long-lasting effect on completion of education.

These early studies, like the early literature addressing adult cancer survivorship, focused on positive aspects gleaned from the cancer experience. However, these studies were conducted using mail questionnaires and phone calls with the patient him- or herself or a family member. It is possible that subtle problems or late effects could have been missed without in-depth interviews. Also, these studies were conducted before the advent of standard psychological inventories and scales, such as the Psychosocial Adjustment to Illness Scale Self-Report (Derogotis, 1977) and the Profile of Mood States (McNair, Lorr, & Droppleman, 1971). Therefore, conclusions should be drawn from these studies cautiously given these methodological shortcomings.

Although this thesis focuses on psychological consequences of long-term cancer survival, a brief summary of the physical side effects of common types of childhood cancer and its treatment is warranted. Physical side effects such as learning disabilities and loss of limbs can, of course, affect the child's psychological adjustment. These effects could be primary, causing a direct impact on psychological functioning, or secondary, in which they produce psychological responses to other disease functions. Therefore, the physical side effects and their psychological

counterparts are entwined (Gotay, 1987).

Physical effects of childhood cancer. One of the earliest types of childhood cancer to be controlled and cured by modern cancer therapy was acute leukemia (Holmes & Holmes, 1975). Thus, many studies in the 1970s and early 1980s focused on long-term side effects of treatment for acute childhood leukemia. Acute leukemia occurs in approximately 33% of all childhood cancer diagnoses (American Cancer Society, 1994). This type of cancer frequently affects infants and toddlers, who are then subjected to a long course of treatment aimed at bringing about lasting remission and cure. Children with acute leukemia are frequently treated with cranial irradiation, with or without chemotherapy. The literature suggests that this treatment may result in neuropsychological damage, leading to academic difficulties at school and with adjustment to school. Taylor, Albo, Phebus, Sachs, and Bieri (1987) discovered that their sample of 26 school-aged children performed more poorly than their siblings on achievement tests and were more apt than their siblings to exhibit mild to moderate cognitive deficiencies. Children who receive treatment for acute leukemia that includes radiation seem to be at risk for cognitive deficiencies. After comparing several different groups of childhood cancer survivors and patients, Copeland et al. (1988) discovered that those children who had been

treated with both radiation and chemotherapy had the most serious neuropsychological deficiencies.

Another group of childhood cancer survivors that is at risk for cognitive deficiencies related to treatment are those who have been treated for a brain tumor. After leukemia, brain tumors are the most frequently diagnosed children's cancer (Dollinger, Rosenbaum, & Cable, 1991). Treatment for this type of cancer involves radiation to the brain, which, like the cranial radiation used to treat acute leukemia, can cause cognitive deficiencies in children. Packer et al. (1987) administered intelligence tests to children with brain cancers before they began treatment, then repeated the tests 1 and 2 years after completion of treatment. They found that the children who had received radiation therapy tested an average of 24 points lower on IQ tests than they had before the radiation. The data show an inverse correlation in regard to age and amount of IQ loss. Therefore, the younger the child, the greater the intellectual damage.

There are other types of childhood cancer in which the treatment effects are more obvious or physically apparent. For example, a childhood malignancy of the eye known as retinoblastoma often results in the loss of 1 eye. Sarcoma (tumors of soft tissue and/or skeletal system) such as rhabdomyosarcoma and Ewing's sarcoma can result in the loss of a bone or limb. Other childhood cancers

can result in the loss of an internal organ, such as Wilm's tumor, which affects the kidney. Hodgkin's or non-Hodgkin's lymphoma can mean the loss of a spleen, as well as the loss of resistance to diseases. Also, any cancer treatment for a child that involves chemotherapeutic agents or pelvic irradiation can result in that child's infertility.

How do these obvious physical impairments affect the childhood cancer survivor? O'Malley, Foster, Koocher, and Slavin (1980) studied 116 long-term cancer survivors, some of whose cancer treatment had rendered visible physical consequences. They concluded that obvious physical impairments (including facial deformities and loss of limbs) were not correlated with the survivors' current psychosocial adjustment. They declared that cancer survivors who adjust well do so despite the presence of disabling or compromising consequences of cancer treatment. However, in their sample of 138 survivors of childhood cancer, Greenberg, Kazak, and Meadows (1989) found the greatest vulnerability and potential for psychological problems among their survivors who had suffered the most physical effects.

Psychological effects of childhood cancer. Regarding psychological symptomatology as a result of cancer and its treatment, several authors have reached different conclusions. In a landmark study, Koocher and O'Malley (1981) reported that their sample of 117 cancer survivors were at substantially higher risk for psychological

dysfunction than were their sample of survivors of other chronic illnesses. In fact, Koocher and O'Malley's results, which showed that 59% of their sample has some degree of adjustment problems, is frequently quoted in the childhood cancer literature (Fritz, Williams, & Amylon, 1988; Green, Zevon, & Hall, 1991; Gotay, 1987). However, most of the adjustment problems Koocher and O'Malley uncovered were minor in nature (such as anxiety during the time of followup visits). Therefore, this figure of 59% of the sample experiencing adjustment problems should be interpreted cautiously, given the minor nature of some of the adjustment problems.

In a thorough review of the literature regarding psychosocial effects of childhood cancer, Gotay (1987) cites numerous studies that support conclusions drawn by Koocher and O'Malley (1981). She cites several studies (Bamford et al., 1976; Hirsch et al., 1978; Danoff et al., 1982) conducted with brain cancer survivors that concluded that this population has a high incidence of behavioral disturbances, anxiety, and isolation. Chang, Nesbit, Youngren, and Robison (1987) administered the Minnesota Multiphasic Personality Inventory (MMPI) to 42 childhood cancer survivors. Thirty-three percent of their sample was found to exhibit at least a moderate degree of emotional difficulty. While the authors point out that this figure is not substantially different from the normal population,

the MMPI results, combined with the results of structured interviews, indicated that restlessness, withdrawal, and passivity were the most common behavioral problems faced by the sample.

Childhood cancer can result in primary effects, those caused by the cancer itself or secondary effects, those caused by its treatment. Similarly, psychological effects of childhood cancer can be classified into primary effects, those that have a direct impact on psychological functioning or secondary effects, those that produce psychological responses to other consequences of the illness. For example, a child treated for retinoblastoma with removal of the eye will not only have to face the primary effect of the cancer diagnosis, but also the secondary effects of blindness and whatever limitations the blindness may incur (e.g., social stigma, denial of employment).

Children with visible physical impairment, while shown to be vulnerable in 1 study, were shown to be functioning quite well in another. Psychological effects of the cancer experience, such as emotional difficulties, behavioral problems, restlessness, withdrawal and passivity were documented for a portion of each of the samples studied. However, many children were found to be adjusting favorably and even most of those with adjustment difficulties were functioning in their environments. Perhaps the conflict in results can be explained in terms

of the fact that parents of these children are relieved that their children survived the illness and tended to overlook or failed to report behavior problems.

The review of professional literature regarding the psychological consequences of childhood cancer now turns to a focus on literature regarding 3 groups of survivors: childhood cancer survivors who are still children; adolescent cancer survivors; adult survivors of childhood cancer.

Long-term cancer survivors age 12 and under: The youngest cancer survivors, those who are long-term survivors at the age of 12 and under, have been studied along with their families. Assessment of the families' adjustment, as well as ratings by the parents of their perception of the child's adjustment, are common. One reason the family unit is given so much attention in the literature regarding young cancer survivors is that family patterns developed in response to the illness may affect the child's later psychological development. Patterns such as inability to discipline, overprotection of the child even after he or she has been declared well, and failure to promote independence are sometimes exhibited by parents of young cancer survivors (Ross, 1982; Koocher & O'Malley, 1981). As Chang et al. (1987) point out, these patterns, when combined with the uncertain future faced by these families, may not be conducive to normal development in childhood

cancer survivors. The family unit seems especially important to this group of young survivors, and a positive parental attitude to diagnosis, treatment, and remission can enhance the child's own coping (Ross, 1982).

Greenberg et al. (1989) conducted a study with 138 childhood cancer survivors of the median age of 12 years. Over one-third of the sample (35%) had been treated for acute leukemia as preschoolers, and had spent several years in remission. Most of the children in the study scored within normal limits on self-report measures of psychological functioning, such as depression, but, when compared with peers, scored lower than the peers on measures of self-concept and had a more external locus of control than their peers.

Koocher and O'Malley (1981) discovered that the earlier a child was diagnosed with cancer, the better his or her psychosocial adjustment, as compared to childhood cancer survivors who had been diagnosed later in their childhood. Apparently, a diagnosis in infancy or toddlerhood resulted in lack of memory for both the diagnosis and the treatment. These children were not told that they had had cancer until well after their treatment ended and the experience was over. As part of the same research, Koocher and O'Malley studied communication of the cancer diagnosis to the patient, and its effect on long-term adjustment. They discovered that the earlier

a child was informed about his or her cancer diagnosis, the more likely he or she was to be psychosocially well-adjusted. For those who were diagnosed in infancy, communication of their diagnosis before the age of 6 was correlated with positive adjustment. Those who were informed late (i.e., not told the diagnosis within 1 year or, in the case of infant diagnosis, not before the age of 6) or who were self-informed (i.e., learning the diagnosis from peers or from their hospital charts) felt betrayed and exhibited more fear of the consequences of the cancer.

A final area of concern within this group of youngest cancer survivors is their schooling. School constitutes a large portion of a child's world. The absenteeism associated with hospital stays or feeling ill from treatment can lead to what Lansky (1974) referred to as school phobia. The child who is initially kept out of school for hospital stays or treatment side effects is sometimes afraid to return. Some researchers (Van Dongen-Melman & Sanders-Woudstra, 1986) have indicated that an extreme separation anxiety may prevent a successful return to school. Others (Lansky, List, & Ritter-Sterr, 1986) have cited fear of rejection, difficulty following the curriculum, and parental overprotection as reasons for excessive absenteeism of the successfully treated cancer patient. As discussed earlier in this chapter, certain

treatment modalities may result in lowered cognitive functioning of childhood cancer survivors, and this may contribute to the difficulty in following the curriculum which may, in turn, foster school phobia.

Of critical importance in the psychosocial rehabilitation of young cancer patients is a timely return to school (Lansky, List, & Ritter-Sterr, 1986; Kagen-Goodheart, 1977). Van Eijis (1977) found that teachers' attitudes toward their cancer survivor students influenced the students' reentry into the classroom. For this reason, several researchers (Lansky, 1974; Kagen-Goodheart, 1977) have called for open communication between the student's parents, school and treatment team. Spinetta & Deasy-Spinetta (1981) proposed a program for teachers of cancer survivors that is designed to correct misconceptions about cancer and offer advice about the management of the cancer survivor at school.

Adolescent cancer survivors. Another group of childhood cancer survivors who have special concerns is adolescent cancer survivors, defined here as long-term cancer survivors between the ages of 13-17. Adolescence may be a particularly vulnerable time in which to deal with a cancer history due to the rapid physical and psychological changes (Fritz & Williams, 1988).

Fritz and Williams (1988) assessed psychological functioning in 41 adolescent cancer survivors. They found

that on the whole, the sample was well-adjusted, but the cancer experience had imparted subtle but lasting changes in their attitudes about their bodies. These changes were manifested in the form of low body image, exhibitionistic behavior (e.g., flaunting scars or prostheses), and hypochondriachal behavior. Almost half the adolescents, 46%, exhibited normal dating behavior. However, 27% showed some impairment in dealing with the opposite sex, and another 27%, while socially active, had only formed platonic relationships with the opposite sex. While most of the sample was aware of their possible treatment-induced sterility, over two-thirds had not discussed this possibility with their oncologists. Overall, this sample of adolescent cancer survivors showed a depression rate of 7%, which is not above the average for the general population. Those who were most likely to be maladjusted were those who had suffered a relapse and had undergone additional treatment. Finally, 61% of the adolescents said that they thought the cancer experience had positive aspects in terms of gaining more empathy and self-confidence.

Some long-term adolescent cancer survivors experienced cancer in infancy, toddlerhood, or in their primary school years. While younger survivors tend to have disruptions in their schooling and need rehabilitation around re-entry to school, the task of most adolescent cancer survivors

falls in the area of transitions, such as the transition from grade school to junior high, or from junior high to high school. These transitions may affect social competence (Kazak & Meadows, 1989). When Kazak and Meadows (1989) compared their sample's perception of social support at the beginning and again at 6 months into the school year, they discovered that survivors perceived less support from teachers, family, and friends later on in the school year than they did at the beginning. Kazak and Meadows suggested that survivors may feel more alienated from others as the school year progresses. Smith, Ostroff, Tan, and Lesko (1991) reached a similar conclusion when they studied 58 adolescent cancer survivors. They suggested that these survivors see themselves as more capable than their peers because they had defeated cancer. Smith et al. also stated that these adolescents saw their cancer as a family crisis, and were in need of support and acceptance from their families rather than from their peers. Kazak and Meadows studied 35 adolescents and their families and compared them with 13 families with healthy adolescents. They found that the families with the cancer survivors scored near the norm in measures of psychological and social functioning, and that there were no significant differences between groups. Within the survivor group, Kazak and Meadows found, similar to Smith et al., that family flexibility and adaptability were important predictors

of well-being with the survivors. However, those families whose children were receiving support in the form of educational assistance rated themselves as less adaptable. The parents of these children also rated themselves as more distressed and their children as less socially competent. This finding may have been due to the fact that the children receiving educational assistance are those that were most severely impaired by the cancer or its treatment, and that their families have had to make adjustments to cope with their children's new limitations.

According to the literature, parental overprotection occurs with adolescents and has different effects than it does for younger survivors. Smith et al., (1991) stressed the importance of the balance between parental nurturance and adolescent autonomy for facilitating healthy development of adolescent cancer survivors. Kazak and Meadows (1989) suggested that overprotection by parents can contribute to adolescents' perception of lowered social support.

Adult survivors of childhood cancer. What is in store for survivors of childhood cancer once they reach adulthood? Literature on adult survivors of childhood cancer is somewhat sparse. "Modern" cancer therapy (i.e., consisting of multimodal therapy, and combinations of chemotherapeutic agents) began in 1975, and the children treated with these lifegiving combinations are just now

reaching adulthood. Thus, articles dealing exclusively with the topic of adults who have survived cancer in childhood are not plentiful. Adult survivors of childhood cancer have been studied as part of research assessing many different survivors at varying ages at varying degrees of survivorship. Most often, the variables studied relating to psychological adjustment include employment, marriage, and children.

Green, Zevon, and Hall (1991) studied 227 adult survivors of childhood cancer and found that, overall, survivors felt that their childhood cancer had not affected their achievement of career goals. However, many of these survivors had not disclosed their cancer history to their employers, suggesting possible feared ramifications of their cancer history on their employment or health insurance. In Koocher and O'Malley's (1981) work, 60 of their 117 survivors were age 18 and over at the time of the interview. However, only 8 of these were age 30 or over. Of the 46 survivors that were employed, 24 had experienced some form of job discrimination, most often rejection from the armed services. This figure is similar to that reported by Fobair et al. (1986) for survivors of adult cancer. Similarly, Wasserman, Thompson, Wilimas, and Fairclough (1987) found that a large portion of their adult survivors of pediatric Hodgkin's disease had not shared their cancer history with employers. Outright job

discrimination is difficult to prove (Hoffman, 1991) and studies with adult survivors of childhood cancer have suggested that job discrimination is not prevalent among this population. However, this population, who underwent treatment years ago, has the option of not telling employers about their history.

Health insurance is an important issue for adult survivors of childhood cancer, and studies show that this population is poorly covered. Wasserman et al., (1987) found that only 66% of their sample had health insurance. Green et al., (1991), however, found that 79.3% of their sample had health insurance, and that the uninsured rate of 20.7% was not significantly different from the general population. Koocher and O'Malley (1981) reported that their adult survivors were able to obtain insurance from group plans, but that those who had obtained private insurance had to deal with exclusions of coverage.

Although most adult survivors of childhood cancers are able to obtain jobs and health insurance, sizable minorities in each of the studies reviewed above had experienced job and/or insurance discrimination. Employment and insurance are 2 important psychosocial facets of the life of any adult. Marriage and children are another. We will now explore studies concerning marriage and children of adult survivors of childhood cancer.

Koocher and O'Malley (1981) investigated 36 survivors

who were the age of 21 or older at the time of their study (mean age = 26 years). Koocher and O'Malley was one of the few studies to interview the spouses of childhood cancer survivors in-depth. Of these survivors, 20 were either engaged or married, and 2 were divorced. Thirteen of the 20 spouses or potential spouses were interviewed. Nine of the 13 said that their spouses' cancer histories had no effect on their decision to marry; the other 4 stated that they initially had reservations. While spouses cited sexuality and health of progeny as their main concerns going into the marriage, many of these issues had already been resolved within the relationship.

Other research simply cites incidence of marriage and divorce. Green et al. (1991) studied achievement of life goals of 227 adult survivors of childhood cancer. They found that marriage rates for both males and females who had a history of childhood cancer were lower than that of the normal population. Of those that were not married, 15.6% stated that their cancer history played a role in their decision not to marry. Of the married survivors, 79.3% reported that their decision to marry was unaffected by their cancer history. Green et al. found a greater incidence of divorce among older women in their sample (ages 40-45), while Wasserman et al. (1987) found an increased incidence of divorce among adult male Hodgkin's disease survivors. However, both of these studies found

that the overall incidence of marriage among adult survivors of childhood cancer did not differ significantly from that of the general population.

Teeter, Holmes, Holmes, and Baker (1987) compared marriage and childbearing incidence of 263 childhood cancer survivors with that of 369 adult siblings. Twenty-five percent of the survivors had not married, while only 16% of the siblings had not married. Of the 25% that had not married, one-third said that they had refrained from marriage for health reasons. Teeter et al. concluded that their sample of cancer survivors were less likely to marry than sibling controls, and they cite other studies (Holmes & Holmes, 1975; Byrne et al., 1985) that also drew this conclusion.

Depending on which research is reviewed, childhood cancer survivors either have a lower incidence of marriage or an incidence of marriage that does not differ from that of the general population. However, those studies that cited lower incidence of marriage among these survivors tended to be conducted earlier in time than the ones that cited no difference. The difference in results could be explained in terms of the fact that some of the survivors in these studies may have been treated before the advent of modern cancer treatment, and thus may have suffered more severe side effects, which, in turn, could have affected their decision to marry.

How is childbearing affected by a childhood cancer history? As mentioned previously, some adult survivors of childhood cancer are reluctant to confront their actual infertility, and put off having sperm counts or other confirmation of their reproductive status. Green et al. (1991) discovered that 20.4% of their sample who were married or lived as married had decided to either limit the amount of children they had or not have children altogether on the basis of their cancer history. Teeter et al. (1987) noted that 11% of their sample had been advised against having children by a doctor. However, of the 10 spouses who were interviewed in Koocher and O'Malley's (1981) work, most said that although they had had initial concerns about their spouses' fertility, doctors had urged them to try to have children.

Teeter et al. (1987) compared the reproductive status of 263 childhood cancer survivors with that of 369 sibling controls. They concluded that cancer survivors are more likely to have fewer or no children than their siblings. They also discovered that fertility problems (i.e., absence of menstruation, failure to become pregnant, and a diagnosis of infertility problems) occurred no more frequently in the survivor group than it did in the control group. Teeter et al. advised that survivors of childhood cancer should not assume that their treatment had made them sterile, and that survivors should seek a second opinion before

they decide whether or not to have children.

Perhaps the reason for this lower reproduction rate may be a belief in infertility, even when it is not documented. Another reason for limiting children may be fear of birth defects. Green et al. (1991) reported that there is no research to suggest that children of childhood cancer survivors have an increased risk for malformation or of childhood cancer themselves. Therefore, unless a survivor has experienced documented gonadal failure, there is nothing to indicate that they should not have children, if they so desire. In Green et al.'s study of 227 adult survivors of childhood cancer, 64 subjects reported 161 pregnancies, and 125 live born full-term infants resulted (77.2%). This figure is not different from that of the general population. The rate of minor congenital abnormality (8.1%) is also not different from that of the general population.

In conclusion, the research regarding adult survivors of childhood cancer, while not plentiful, has focused on the issues of employment, insurance, marriage, and progeny. Studies have shown, in general, that adult survivors of childhood cancer are able to achieve meaningful employment that they enjoy. Their health insurance is most often obtained when they delete their cancer histories from their medical information. While some studies show a higher rate of divorce among certain portions of the population,

many studies show that adult cancer survivors marry less frequently than controls. Survivors of childhood cancer also have less or no children compared with controls, and this finding may be based in part on the erroneous belief by the survivor that he or she is infertile, or that he or she will give rise to a child with birth defects. Several studies document that this is not so. Unless a survivor has experienced direct gonadal failure, say researchers, there is no evidence to suggest that he or she should assume that he or she cannot have children, or that these prospective children will have congenital abnormalities.

Conclusion. This chapter has focused on professional literature regarding the psychological consequences of childhood cancer for long-term survivors (i.e., those diagnosed before the age of 18). The earliest literature regarding childhood cancer assumed that there would be no survivors. Studies on the terminally ill, palliative care, and whether to tell the dying child his or her diagnosis were prevalent issues in the literature.

With the advent of "modern cancer therapy", studies in the mid-1970s focused on the question "Is the life saved worth living?" Psychological adjustment was high for the survivors in these early studies, and positive aspects of the cancer experience were highlighted. Modern cancer therapy's first success with childhood cancer survivors

was with acute leukemia. Studies focused on side effects of the treatment for this cancer, most often cognitive abnormalities as a result of radiation to the head. When other types of cancer began to be controlled by modern cancer therapy, studies appeared about how the side effects manifested themselves in the lives of childhood cancer survivors. Research with survivors of childhood brain tumors, and cancers bearing obvious impairments such as retinoblastoma and sarcomas focused on the secondary psychological effects of these impairments. While adjustment problems such as emotional difficulties and behavioral difficulties were documented for some childhood cancer survivors, most studies with survivors of various types of cancer show them to be functioning well and adjusting favorably to secondary aspects of their illness.

The youngest cancer survivors, those 12 and under, have frequently been studied with their families. Family reactions to illness and adjustment can influence later psychological functioning of the child. The under 12 survivors, while shown to score within normal limits on measure of psychological functioning, had a lower self-concept and more external loci of control than did peers. Children diagnosed in infancy or toddlerhood have the best potential psychosocial adjustment. Rehabilitation in the area of returning to school for those that have missed due to treatment is important to adjustment as well.

Adolescent survivors of childhood cancer have different issues with which to deal. Research with this population shows them to have minor difficulties with body image and opposite sex relationships, but a majority identified positive aspects of the illness. Transitions between grade school and high school often prove difficult for this population. Adolescent survivors rely more on their family for support than their peers, and family flexibility is an important factor in adjustment. Families of adolescent survivors need to be especially careful to check overprotectiveness in order to facilitate normal autonomy.

Literature regarding psychological adjustment of adult survivors of childhood cancer is not plentiful, since many of the children first cured by modern cancer therapy are only now reaching adulthood. The areas most frequently studied within this population are employment, marriage, and children. While some studies show that this population is prone to job discrimination, others cite that the childhood history of cancer, which is often deleted on job applications by these survivors, does not prevent adults from reaching career goals. Health insurance coverage is problematic, however, with substantial minorities of each population not maintaining coverage. Adult survivors of childhood cancer tend to have lower marriage rates than the general population. Progeny of adult survivors of

childhood cancer have been shown to have no higher incidence of birth defects than the general population. However, childhood cancer survivors sometimes choose to have fewer or no children than siblings or other peers.

Childhood cancer survivors, no matter how long they have survived, have issues that they face as either a primary or secondary consequence of their illness. The literature that documents these consequences sometimes yields conflicting results, including varying degrees of psychological impairment. As mentioned previously, some studies focus on family variables, which have been shown to predict the child's coping with diagnosis and survivorship. Perhaps differences in the family variables studied contributed to the differences in results between the studies.

Koocher and O'Malley (1981) found that those children who were diagnosed with cancer early in their childhood were better adjusted than those who were diagnosed later. Some of the studies reviewed in this chapter focused on several different age groups of children who were diagnosed at various ages. Perhaps the variable of comparing survivors of different ages who had been diagnosed at different times also contributed to the conflicting research results evident in this literature.

The earliest childhood cancer survivorship literature spoke of the dangerous and mutilating effects of modern

cancer treatment. Since then, survival rates have risen dramatically, but treatment regimens have remained the same. Perhaps the fact that childhood cancer survivors are forced to undergo dangerous and mutilating treatment (often as infants or toddlers) prompts some researchers to make interpretations that focus on the positives in order to justify the suffering endured by the child. This phenomenon could also cause a discrepancy in results.

The amount of interpretation in the discussion sections of the psychological studies of childhood cancer survivors differs from that of the discussion sections of the literature regarding adult cancer survivors. This observation could be due to the fact that children are unable to articulate feelings in words as well as adults, and researchers are less sure how to interpret data. This phenomenon could be a reason why there is less psychological than medical research done on this population, and why there seems to be more research regarding the psychological consequences of adult cancer survivorship.

CHAPTER 5
CONCLUSION

The purpose of this thesis is to answer the question, What adjustment issues are associated with cancer survivorship? In order to answer this question, this thesis has reviewed psychological and medical literature involving cancer survivors who were thought to be free of disease for a minimum of two years.

The analysis of this literature shows that, overall, long-term cancer survivors show few, if any, permanent psychological effects as a result of the cancer experience. More common are adjustment problems, such as difficulties with interpersonal relationships and body image. After reviewing adult cancer survivorship literature, Welch-McCaffrey, Hoffman, Leigh, Loescher, and Meyskens (1989) stated that, although uncertainties persist for about three years after treatment, there is no overall evidence that psychopathology is a correlate of cancer survivorship.

Childhood cancer survivors have also been shown to have few permanent psychological side effects as well. Since many children are diagnosed and treated as infants or toddlers, for the recovery process, they seem to have

time on their side. However, due to the nature of childhood cancers and their treatment, survivors of childhood cancers may have more physical effects (e.g., the loss of limbs or organs such as the eye) than adult cancer survivors. These side effects result in adjustment problems for this population as well, including behavioral problems and difficulty with school absences. The childhood cancer survivorship literature yields conflicting results about psychological adjustment of these young survivors, possibly due to the fact that children are less verbal than adults and researchers find it more difficult to make interpretations.

An inherent limitation in this research is the fact that no pre-tests exist on cancer survivors before they became ill. Further, comparisons survivors are encouraged to make between themselves pre- and post-cancer are done retrospectively. There may not be a solution to this limitation, but it may affect results of research with this population.

Recommendations for future study include more research focusing on other types of cancers that yield survivors. There is much literature regarding survivors of testicular cancer and Hodgkin's disease, both of which affect young adults. The prevalence of this literature involves the high survival rates of both these cancers. However, as cancers such as non-Hodgkin's lymphoma and skin cancers

are rising in survival rates (American Cancer Society, 1994), these survivors need to be studied. Existing studies on types of adult cancers other than testicular cancer and Hodgkin's disease tend to lump groups of survivors of several different types of cancers together in the same research. As cancer survival rates increase for other types of cancer, a recommendation is to study survivors of particular types of cancer together.

Studies involving survivors of other types of cancers may target cancer survivors who are in the age range of 40-55, which is another area where survivorship research is lacking. In years to come, there will most likely be more studies conducted on adult survivors of childhood cancer, since many of these survivors are just reaching adulthood now and are not abundantly available for study.

In most cancer survivorship literature, the psychological variables (e.g., depression) of the survivors studied are compared to either "normal" controls or to a psychiatric population. Analysis of this literature seems to indicate that long-term cancer survivors do not fit neatly into either of these groups, but that their adjustment falls somewhere in between these two populations. Thus, while cancer survivors are not disturbed enough to be diagnosed with psychiatric disorders, nor are they pronounced "normal". This phenomenon was captured by Koocher and O'Malley (1981) when they coined the term "Humpty-Dumpty Syndrome". This

term refers to the fact that cancer survivors often report feeling not quite like their old selves after being "put back together" with cancer treatment. Another recommendation is for researchers to conduct more research comparing cancer survivors against other cancer survivors in hopes of acquiring a more homogeneous sample.

A final recommendation involves the theoretical nature of research involving cancer survivors. Effects of the cancer experience often involve a loss of some kind, such as the loss of a body part or the loss of fertility. Therefore, it would be helpful to study these survivors within the framework of psychological theories of loss.

How can mental health professionals best help this population that is not truly disturbed but has adjustment problems as a result of the cancer experience? Studies show that some adult cancer survivors experience difficulties with interpersonal relationships. These difficulties may be related to issues such as infertility or diminished body image as a result of cancer treatment. The resolution of these issues could take place in individual psychotherapy.

For those that have issues regarding infertility or marital disruption, couples psychotherapy would be beneficial. Those experiencing employment problems could benefit from career counseling. Literature shows that parents of childhood cancer survivors sometimes have lingering fears about their children's health. These fears

sometimes manifest themselves in the form of failure to discipline and overprotection of their children. These parents could also benefit from either individual or family psychotherapy.

Large cancer research centers such as university hospitals employ social workers, psychologists, and psychiatrists who help cancer patients and survivors deal with adjustment problems. However, since many cancer patients are now treated in smaller community hospitals, community counselors play a role in assisting cancer survivors. This assistance is particularly needed when long term cancer survivors return to the community and discover lingering psychological adjustment problems due to the cancer experience. Community counselors may encounter these survivors in community mental health centers, hospitals or in centers designed specifically to provide support to cancer survivors and their families. Community counselors may be able to provide very effective interventions for cancer survivors experiencing psychological adjustment problems. These counselors and the centers at which they are frequently employed may offer a safer "close to home" environment which may reduce anxiety and foster a more productive therapeutic atmosphere. As the amount of cancer survivors is expected to increase, community counselors will most certainly encounter long term cancer survivors in practice.

Cancer survivors of all ages and races are affected by their cancer experience, whether positive or negative. It remains the task of psychologists and researchers to continue to conduct research designed to ease cancer survivors back to living until, one day, there is a cure.

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THESIS APPROVAL SHEET

The thesis submitted by Lesley J. Widmer has been read and approved by the following committee:

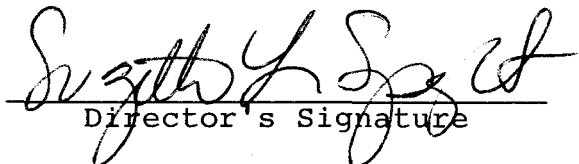
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The final copies have been examined by the director of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the committee with reference to content and form.

The thesis is, therefore, accepted in partial fulfillment of the requirements for the degree of Master of Arts in Community Counseling.

4/3/95
Date


Director's Signature