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INTIMACY, MARITAL ADJUSTMENT, AND WELL-BEING IN LONG-TERM SURVIVORS OF CHILDHOOD CANCER

by

Sandra Marie Gallagher

A Dissertation Submitted to the Faculty of the

DEPARTMENT OF PSYCHOLOGY

In Partial Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

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As members of the Final Examination Committee, we certify that we have read the dissertation prepared by Sandra Marie Gallagher entitled Intimacy, Marital Adjustment and Well-Being in Long-Term Survivors of Childhood Cancer

and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy

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Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copy of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

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SIGNED: Sandra M Gallagher

ACKNOWLEDGMENTS

I would like to express my appreciation to the many people who supported me throughout this project. First, I would like to thank my primary advisor, Gary Schwartz, for his guidance, encouragement, and patience. I am also very grateful for the time and efforts of the other committee members: Lee Sechrest, John Allen, Dan Shapiro, and Al Kaszniak.

In addition to those at the University of Arizona, Mike Zevon at Roswell Park Cancer Institute deserves special thanks for providing me with an exciting new field of interest, the data for this study, and the computer programs used to analyze the data. His very tangible support has meant a great deal to me.

Finally, thank you to all my friends and family who have encouraged me throughout the years. Last, but definitely not least, to my husband, Shawn, and my daughter, Sedona, who's love and patient support have allowed me to reach this goal.

DEDICATION

This work is dedicated to all the generous individuals who gave their time and effort to helping us understand a little better, the experience of cancer survival. Thank you.

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ABSTRACT

The present study examined well-being and the contribution of intimacy and marital satisfaction to well-being in long-term survivors of childhood cancer (LTSCC). In addition, self-esteem, warmth and gregariousness were included to test for mediating effects. 207 adult LTSCC were assessed using the Rand Well-Being measure, Miller's Social Intimacy Scale, the Dyadic Adjustment Survey, Rosenberg Self-Esteem Scale, the NEO-PI Warmth and Gregariousness subscales, and the Marlowe-Crowne Social Desirability Scale (M-C) each of these is a well established and well validated self-report measure. Survivors scores on each of these measures were contrasted with those of a control group of adults who did not have a cancer history (N=169). Each of the variables, as well as several sociodemographic and medical variables, were utilized in regression and path analyses to determine their ability to predict well-being.

LTSCC reported significantly less overall well-being ($F=78.9$, $p<.000$), significantly more anxiety ($F=194.2$, $p<.000$) and depression ($F=1262.3$, $p<.000$), and significantly less positive well-being ($F=18.6$, $p<.000$), health ($F=137.0$, $p<.000$), and self-control ($F=88.3$, $p<.000$) than controls. Survivors reported significantly more

intimacy ($F=5.1$, $p<.01$), marital adjustment ($F=5.3$, $p<.01$), self-esteem ($F=216.8$, $p<.001$), warmth($F=65.2$, $p<.001$) and gregariousness ($F=113.3$, $p<.001$) than controls. LTSCC also had higher scores on the M-C ($F=26.7$, $p<.001$).

An omnibus stepwise multiple regression analysis accounting for 27% of the variance, revealed that self-esteem and the interaction of warmth and intimacy were the best predictors of well-being. Group membership was a nonsignificant predictor of well-being. Finally, path analysis was employed and different models "fit" the LTSCC and the controls. The best path model (NFI= .94) for the LTSCC indicates that well-being predicts intimacy. The best path model (NFI= .98) for the controls, on the other hand, indicates that intimacy predicts well-being. These results are discussed in terms of developmental and social support theories. Interpretations of these results, strengths and weaknesses of the study, and implications for theory, application, and future research are discussed.

Chapter 1

Introduction

The trauma of having had cancer and the difficult and painful diagnostic and treatment procedures it involves during the critical and vulnerable developmental periods of childhood and adolescence could have negative effects on well-being later in life. In addition, contemporary and continuing stressors in the lives of cancer survivors such as, fear of recurrence, shortened life expectancy, reproductive concerns, prejudice and discrimination, could detract from their well-being. Since past trauma and these current stressors cannot be erased, it becomes important to delineate positive inputs to well-being. As is shown in the literature review, intimacy and marital adjustment have the potential to influence positively well-being.

The review covers three literatures, the first sections will address the social support and intimacy literatures with an emphasis on the convergence of these two separate literatures on the critical healthful feature of relationships; namely, socioemotional support. A selective review of the social support literature will demonstrate that personal relationships provide healthful benefits by both "main effects" and by buffering one from stress. It will be shown, however, that it is not simply

having relationships per se, but rather that certain qualities of those relationships are crucial determinants of their healthful effects. Moreover, since marriage can be both a socially supportive and an intimate relationship, it will be given particular emphasis. The final section of this part of the review covers many alternative definitions of the concept of intimacy and supports the conclusion that emotional support provided in the context of our most important and intimate relationships can impact positively our health and well-being.

The second major section of the review serves both archival and didactic purposes for those not familiar with the cancer survivor literature. This section of the review traces the development of that literature as it has evolved in focus from achievement of basic life goals like employment, health and life insurance to determining the presence and extent of psychopathology, to the more recent focus on positive, relative adjustment, quality of life, and well-being. Generally speaking (with acknowledgment of the inconsistencies in the literature), individuals who have survived cancer and it's treatment in childhood or adolescence do not show more psychopathology than the norm and seem to completing the normative tasks of life. There are however, some findings to indicate that survivors may

have endured some more subtle insults to their adjustment. Thus, given the evolution of this literature, examining relative, normative adjustment with an emphasis on well-being and it's determinants, rather than pathology, is the approach adopted in this study.

Review of the Literature

This review begins by examining, in a highly selective manner, the literature on social support and well-being. The review will highlight theoretical work and empirical findings that suggest emotional support provided in the context of intimate relationships is a crucial determinant of the healthful effects of social support. Next, the literature on intimacy and well-being will be reviewed in a way that will make the parallels in these literatures apparent. This approach will serve to both clarify, differentiate, and integrate these concepts.

Social Support and Well-Being

The number of empirical studies on social support has increased exponentially since the seminal studies in the late seventies. Studies abound that demonstrate that being married and other indicators of social integration affect morbidity and even mortality (Berkman & Syme, 1979; House, et al, 1982). House, Landis, and Umberson (1988), for example, reviewed eight prospective studies that showed the

mere presence of relationships with others decreases mortality, even after controlling for other traditional medical risk factors thought to affect health.

In focusing on the positive aspects of life rather than morbidity or mortality, Argyle (1987) in *The Psychology of Happiness (1987)* concluded, "Social relationships are a major source of happiness, relief from distress, and health. The greatest benefits come form marriage and other close, confiding and supportive relationships" (pg.31). Beyond establishing that some relationship exists, however, these statements tell us little about why or how this effect occurs.

The empirical work and related theoretical development in this area have matured as they progressed from the demonstration that social connectedness is correlated with mortality (Berkman & Syme, 1979; House, 1981), to the current appreciation for the complex, multifaceted nature of the social support to health relationship. Moreover, the examination of psychosocial correlates of health and well-being (e.g., cognition, personality, and communicative transactions between people) offers a promising new direction. Having said this, there are two points I think most authors would agree upon: (1) there is no consensus regarding the definition of social support and, (2) social

support is not a unitary construct.

Definitions of social support have included measures of network size and density (labeled structural measures; Cohen & McKay, 1984), number of contacts with individuals in one's network, administered support, taxonomies of supportive behaviors (Barrera, Sandler, & Ramsay, 1981), perceived social support (Sarason & Sarason, 1985), satisfaction with social support, and functional components such as esteem or emotional, tangible, and informational support (Cohen & McKay, 1983; Cohen & Wills, 1985).

In contrasting two such definitions, Reis (1984) notes, "There is a distinction to be drawn between social support and social interaction. Social support refers to feelings of being cared for, esteemed, or otherwise closely involved with other people. Social interaction refers to descriptive aspects of the social events in which people participate. Both types of variables are important but likely have different impacts on health and thus, should be distinguished from one another." Many authors are using different definitions of social support to attempt to answer the same two questions, "Why, and how, does having contact with other people improve or protect our health?".

While most of the work in the social support arena has been atheoretical, Cohen & McKay (1983) proposed that

social support has its effect on health in one of two ways. These are either directly, called the "main effects" hypothesis, or by buffering the negative effects of stress, called the "stress-buffering" hypothesis. These hypotheses have been criticized as providing useful heuristics but not testable hypotheses (Cohen, 1988).

These hypotheses do, however, embody one question that has entertained social support researchers for many years. Do social support and the relationships it encompasses, have direct effects on well-being or does it confer benefits only in the face of stressful experiences? While some authors have chosen to focus on one or the other of the hypotheses, several authors (Reis, 1984; Thoits, 1985; Rook, 1984) have suggested that, as with many questions in this field, the answer is probably not a matter of "either/or" but rather "and."

In support of the opinion that both "direct" and "stress-buffering" effects are probably operating, Rodin and Salovey (1989) concluded in their review that,

> "At a more general level, social support via an integrated social network may have direct effects on health by providing the individual with a predictable set of role relationships, a positive social identity, and experiences of mastery and control (Thoits, 1983, 1985). In comparison, social support could play a role in buffering the impact of negative events and other stressors by eliminating or reducing the stressor itself, bolstering the ability of the

> individual to cope with the stressor, or by attenuating the experience of distress after it has already been triggered (Cohen & McKay, 1983; Gore, 1981; House, 1981). Direct effects are more likely to be obtained when support is defined as the degree to which an individual is integrated into social networks; buffering effects are typically found when support is operationalized as the social resources available to one undergoing stressful events (Cohen & McKay, 1983; Wethington & Kessler, 1986)."

In addition to asking how social support has its effects, some authors have defined social support by separating it into different components. S. Cohen and Hoberman (1982), for example, identified four types of support: self-esteem enhancement, appraisal support (someone to talk to about personal problems), tangible aid, and belongingness (someone to do things with). The results of their studies indicate that, although each of the components produced main effects on psychological (depressive) and physical symptoms, more extensive data analyses indicated that self-esteem and appraisal support were most likely responsible for the effect.

Thoits (1985) reviewed some of the social support research and highlights the lack of empirical and theoretical work regarding the processes by which social support has its effects. She states, "We know little about what aspects of support are really helpful, and from whom, through what mechanisms, and under what conditions support

can be beneficial (or harmful)."

In forming her opinion regarding the critical processes of social support, she emphasizes the research that demonstrates that something about being married (Eaton, 1978), having an intimate, confiding relationship, particularly with a spouse or lover (Brown & Harris, 1978; Lowenthal & Haven, 1968; Pearlin, Lieberman, Menaghan, & Mullan, 1981; Thoits, 1982b) have beneficial effects on health. In addition, socioemotional support from significant others appears to be the most powerful predictor of reduced physiological distress or disorder, whether stressful circumstances are present or absent, (Cohen & McKay, 1983; House, 1981; Turner, 1983).

Based on her review and integration of these findings, she suggests that, ". . . effective social support appears to consist primarily of emotional support from significant others." and that, "a key aspect of social support lies in its positive emotional functions." Similarly, House and Kahn, (1985) conclude, "*Within types of support, priority should go first to measuring emotional support*...emotional support has been most clearly linked to health, in terms of direct effects and buffering effects." Finally, Argyle (1987) also came to similar conclusions regarding the key role of emotion in the relationship between social ties and

well-being. He concluded, ". . . relationships increase happiness by generating joy, providing help, and through shared enjoyable activities. They buffer the effects of stress by increasing self-esteem, suppressing negative emotions and providing help to solve problems."

Others have conceptualized support as a perception that one is loved and esteemed by others, called perceived support. The view here is that a perception of being cared for is able, in and of itself, to promote health (Cobb, 1976; Lynch, 1977). Perceived support availability has been shown consistently to buffer the effect of stress on psychological outcomes (Kessler, McLeod,& Whethington, 1985). These findings have led some researchers to measure social support as the *perception* that support would be available if it were needed (Sarason, et al, 1983; Cohen, et al, 1985). Wethington and Kessler (1986), for example, showed that perceived support was, in general, a better predictor of adjustment to stressful life events than was actual support received. They also suggested that perceived support mediates the relationship between received support and adjustment.

In adopting an emphasis on perceived support, a study by Cutrona (1986) suggests that stress elicits specific behavioral events from others - listening, advice, and

caring - that produce feelings of social support, suggesting that support perceptions are rooted in actual interaction and not in global evaluations of a relationship.

Other authors have also focused on the correlates of, and mechanisms leading to, perceptions of support. Heller and Swindle (1983), for example, report findings from a set of studies that point to conversational intimacy and self-disclosure as the main determinants of perceived support. Finally, Wheeler, et al (1983) found that quantity of social contact did not predict loneliness but intimacy of interaction did. (They also identified five aspects of quality interaction: intimacy, self-disclosure, other-disclosure, pleasantness, and satisfaction.)

Some researchers have suggested that personality acts as a mediator of perceived support. The Sarasons (1985) for example, have said that perceived social support behaves more like a personality variable than a situational one. They found that anxiety, depression, hostility, extraversion, neuroticism, loneliness, and attachment style, were all correlated to perceived social support (more strongly for females). They then tie these findings to attachment theory in saying that perceived social support (conceived of as a personality style) reflects the

individual's attachment style and history.

In addition to the correlational studies, the Sarasons and their colleagues (Sarason, Sarason, & Shearin, 1986) have also looked at actual interactions to determine if being high or low in perceived social support was related to actual behavior. Those individuals high in social support were found to be more socially skilled than those low in social support across several measures including: self-evaluation, formal questionnaire/rating scale, partner's rating, experimenter's global assessment, a rating of videotapes, and a story completion task.

Taking a somewhat different approach, some authors have discussed different "mechanisms" by which social support has its beneficial effects on health. Cohen (1988) suggested that social support may have its effects through social (e.g., stress buffering), psychological (e.g., affective states), and behavioral (e.g., health-promoting) mechanisms. In addition, Argyle (1987) has suggested the following mechanisms as those by which social support confers its benefits: (1)increasing self-esteem and self-confidence, (2) generating some degree of positive affect suppressing depression and anxiety, and (3) because support and help are perceived to be available, perceptions regarding the stressfulness of situations are diminished.

Finally, I will mention briefly some of the works that have focused on the connection between social ties and physiology. Some researchers have chosen to examine the impact of social relationships on physiology because it provides the most plausible link to health. Physiology provides the most plausible link because, like other social animals, human physiology is influenced by both the physical and social environments. Our relationships and events in the social realm can affect (raise or lower) physiological arousal in a number of ways (e.g., changing perceptions of events and thus our emotional reactions).

Seeman, et al (1994) for example, examined the relationship between measures of both quantity and quality of social ties and several neuroendocrine parameters (epinephrine, norepinephrine, and cortisol). They found that "higher than average and maximal frequency of emotional support," which reflected the extent to which respondents felt loved and listened to when they had a problem, was associated with lower levels of the neuroendocrine chemicals (the effects were more consistent and positive for men, as has been found in other research).

The mechanisms suggested by Cohen (1988) provided the framework for a review and meta-analysis of 81 studies covering cardiovascular, endocrine, and immune system

functions. Uchino, Cacioppo, and Kiecolt-Glaser, (1996) concluded that their analyses of the mechanisms underlying the association between social ties and health suggested, "(a) potential health-related behaviors do not appear to be responsible for these associations; (b) stress-buffering effects operate in some studies; (c) familial sources of support may be important; (d) emotional support appears to be at least one important dimension of social support."

The following section will examine one of the most frequently studied sources of social, familial, and emotional support; namely, marriage.

Marriage as Social Support. I set aside a separate section for studies focusing on marriage because I will argue (and I think the literature supports) that marriage is a unique relationship that may or may not be supportive and thus, have healthful effects. The marital relationship is unique in that it has the potential to offer what I consider to be the key ingredients of "social support" - intimacy and emotional support - on the most regular basis.

Several major reviews have noted that married individuals enjoy better health and well-being than do non-married (Berkman & Syme, 1979; House, Landis, & Umberson, 1988; Burman & Margolin, 1992). Within the social support literature being married or the loss of such a relationship

(through divorce or death of a spouse) has been used as a proxy variable for the existence of a socially supportive relationship.

Marriage can be a source of great satisfaction and marital satisfaction has in fact, been shown to be highly correlated with overall satisfaction in life (Argyle, 1987). Denier (1984) found that satisfaction with one's marriage and family life is strongly correlated with one's overall sense of subjective well-being.

The following quote shows why marital status has often been used as a measure of social support and that, because of all the different concepts implicit in this one relationship, using it as such is problematic. "One of the main sources of satisfaction is the *quality* of relationships, the amount of affection, intimacy, acting as a confidant, providing reassurance of self-worth, which can generally be called 'social support'." (Argyle, 1987). This statement also conveys the importance of determining the quality of the marital relationship. Merely being married does not mean that the relationship is a supportive one.

Marriage can provide both positive experiences and conflict, which like positive and negative affect more generally, are relatively independent. Studies of happy

and unhappy marriages indicate that unhappy couples display less positive affect, more negative affect, and reciprocate negative affect to a greater degree than do happy couples (Margolin & Wampold, 1981). In addition, studies of marital interaction have shown greater discrepancies between the intent and impact of a communication in unhappy marriages than in happy marriages, presumably because underlying negative affect provides an interpretive context in which a given message is evaluated more negatively (Gottman, 1979; Noller, 1984).

Very few studies have measured marital quality as it relates to health. In a prospective study of coronary heart disease, Medalie & Goldbourt, (1976) found that men with high levels of anxiety, who perceived that their wives were loving and supportive, were less likely to develop angina five years later. Poor marital quality has also been related to diminished immune functioning (Kiecolt-Glaser, et.al., 1987,1988). Marital conflict has been shown to impact negatively on physiological parameters and health (Levenson & Gottman, 1983,1985; Kiecolt-Glaser, et al, 1987,1988). Wyke and Ford (1986) found that material resources (owning a car), stress, and perceived quality/intimacy of social support accounted the effect of marital status on health measures. Risky health behavior

(smoking and drinking) and "objective" levels of social support, however, did not.

In the most interesting work on the role of emotion in marital satisfaction, Levenson and Gottman (1985), found that the extent of "physiological linkage" (increasing physiological arousal in both partners during problem discussion) was greater in distressed couples and that 60 percent of the variance in marital satisfaction was accounted for by this linkage. In a follow-up study three years later, declining marital satisfaction was predicted by this linkage. Dissatisfaction and declines in satisfaction were also predicted by males emotional withdrawal and females' emotional involvement (for both positive and negative emotions). Studies like these provide a possible connection between marital communication, satisfaction and health. The constant physiological elevations such as those found in these studies could represent "wear and tear" on the system and potentially lead to breakdown.

To summarize, the literature on marriage and health suggests that the quality of the relationship - the amount of intimacy, emotional support, and lack of conflict - is critical to realizing the health benefits of being married. In their review, Burman and Margolin, (1992) concluded that

marriage per se has not demonstrated consistent effects on health because researchers have not considered the quality of the marriage - or what specifically about marriage is protective. Aggregate statistics in which all marriages, regardless of quality, are considered together muddy the water because poor or conflicted marriages - which have negative effects on health and well-being - are combined with good, supportive marriages thereby producing nonsignificant results.

Critique

I will at this point mention briefly three critical issues that must be addressed in research concerning social relationships and social support: 1) the multidimensional nature of social interaction, 2) methodological issues, and 3)the nature of the criterion measure. One or more of these issues are present either implicitly or explicitly in all of the works discussed in this review and thus should be addressed.

Social relationships are multidimensional phenomena possessing many characteristics, such as quantitative aspects like frequency of contact, number or partners or network density, as well as more qualitative aspects such as intimacy, emotional support, satisfaction, and perceived support. Although each of these factors may be relevant to

the study of relationships, it is likely that they operate via different mechanisms and thus, do not affect health in the same manner. To gain a more refined understanding of what is beneficial about social relationships, it is necessary to discriminate which variables add to our understanding of health from those that do not.

Some of the methodological issues relevant to the empirical works in this review are the same ones that operate in many other literatures. First, over-reliance on global scores can result in nonsignificant findings because many of the dimensions of social relationships mentioned above, are combined. This practice can obscure any significant relationship that might have been found if the analysis had focused on specific sub-scales (which requires theoretical specification of the important variables). Second, over-inference from unidimensional items is problematic because the reliability of single items is poor and often there is a tendency to overstate one's case and go beyond the data in ways that may or may not be valid. Third, the same criticism can be extended to method-bound results in that ecological validity is often not established nor had the call for multi-trait, multi-method (Campbell & Fiske, 1959) research been heeded. Finally, it cannot be determined whether the correlational findings in

this literature are spurious due to the failure to identify underlying "third" variables such as personality variables like negative affectivity (I would again highlight the need for better theoretical specification). These criticisms must be addressed if we are to move from the demonstration of the phenomenon (which is robustly established) to the more intricate questions of cause and mechanism.

In addition, there is a similar lack of specificity and agreement (thus affecting our ability to compare results of different studies) about the nature of the criterion measure, health. In Berkman & Syme's (1979) study the dependent variable was death. Cohen & Hoberman (1982) used a checklist of physical symptoms. Others have used a wide variety of psychological outcomes such as, Brown & Harris's (1978) study of depression, Barrera's (1981) use of general neurotic symptom checklist, and Beckman's (1981) research on general feelings of well-being. These outcome variables are not interchangeable entities, either in their etiology or in their consequences for the individual.

Summary and Conclusions. The literature supports the role of social ties in health and well-being. That has been robustly established. What has not been established is a consensus regarding the key components, mechanisms, or

processes that best explain this relationship. Emotional support, esteem support, and feeling cared for or loved by others have featured prominently in many analyses. In addition, intimacy or intimate relationships have been mentioned by many authors as the context in which this effect is demonstrated most strongly. Before we can say what it is about having an intimate relationship that provides benefits, we need to define intimacy and what constitutes an intimate relationship.

Intimacy

At least three reviews have likened intimacy to the "proverbial elephant" (Acitelli & Duck, 1987; Montgomery, 1984; and Reis & Shaver, 1988). Clark & Reis (1988) discuss three approaches to study of intimacy: processes involved in intimate interaction, the nature of intimate relationships, and individual differences in capacities and preferences for intimacy.

Several developmental theorists have offered their views on intimacy and its importance in normative development. Sullivan, (1953), Erikson (1963), Rogers (1961), and Bowlby (1973) have each made important theoretical contributions to our understanding of relationships and have offered unique perspectives on intimacy. Sullivan (1953, p.246) for example, emphasizes

the role of validation when he states, "Intimacy is that type of situation involving two people which permits validation of all components of personal worth (p.246). Intimacy is a collaboration in which both partners reveal themselves, and seek and express validation of each other's attributes and world views." Like Sullivan, Rogers' (1961) emphasizes validation as a critical component of intimacy. Rogers' also stresses that validation (and thus, intimacy) derives from a process of open communication characterized by unconditional positive regard, lowered defensiveness, and enhanced self-esteem.

Erikson (1963) defined intimacy as one of his "Eight Stages of Man" and argued that it becomes a major developmental issue early in adulthood, after the establishment of a secure identity and before the attainment of 'generativity'. Finally, Bowlby (1980) and other attachment and object relations theorists (e.g., Ainsworth, 1972), asserts that the establishment of the infant's sense of security is a prerequisite for normal curiosity, exploration and sociability with peers.

Some authors (Reis & Shaver, 1988) have criticized the developmentalists' research approach to intimacy, because intimacy is treated as a static variable whereas the theorists' formulations (e.g., Erikson) are of a dynamic

process. Thus, in contrast to the developmental approach, many authors have studied intimacy as a communicative process. In this vein, self-disclosure was for many years the focus of research on relationships and it has often been equated with intimacy (see works by Jourard; Cozby, 1973).

Schaefer and Olson (1981) disagree with the equation of these two concepts and offer an alternative definition. They state that, "Intimacy is a *process* and an *experience* which is the outcome of disclosure of intimate topics and sharing of intimate experiences." They emphasize the difference between "intimate experiences" and an "intimate relationship." According to these authors an "intimate experience is a feeling of closeness or sharing with another" which occurs in one of the seven domains they have conceptualized (emotional, social, intellectual, sexual, recreational, spiritual, and aesthetic).

In another criticism of the equation of intimacy and self-disclosure, Montgomery (1981) notes that the implicit assumption that "intimacy" as applied to topics corresponds to "intimacy" as applied to relationships is too simple (pg. 29), and I would add, probably inaccurate and misleading.

Tolstedt and Stokes (1983) offered verbal, affective,

and physical as three different types of intimacy and hypothesized that each would have its own impact on marital satisfaction. They defined verbal intimacy as a "combination of three classic self-disclosure variables: breadth, depth, and valence," affective intimacy as reflecting "feelings of closeness and emotional bonding, including intensity of liking, moral support, and ability to tolerate flaws in the significant other," and physical intimacy as "sex and other expressions of love."

Other authors have attempted to define intimacy according to more strict behavioral criteria. Some of those criteria are listed here. Hinde (1976), and Levinger and Snoek (1972), suggests that intimacy includes: frequent interaction, face-to-face interaction, diverse interactions across several behavioral and situational domains, substantial influence on each other's lives, repeated attempts to restore proximity during absence, alleviation of anxiety upon return of the partner, and unique communication systems, synchronized goals and behavior, mutual self-disclosure, seeing separate interests as inextricably tied to the well-being of the relationship.

Similarly, Walster, Walster & Berscheid (1978) suggest the following characteristics as defining intimacy: intensity of liking or loving; depth and breadth of

information exchanged, so that intimates know much more about one another's idiosyncrasies, personal histories, and vulnerabilities, actual and expected length of relationship,
value of resources exchanged, with partners increasingly willing to invest more of their resources, but also punish more keenly, particularly through termination of the relationship; interchangeability of resources; and "we-ness," the tendency for partners to define themselves as one unit in interaction with the external social world.

Dissatisfaction with the limitations of such reductionistic, behavioral criteria lead other authors to include more qualitative dimensions like that of Chelune, Robinson and Kommor (1984) who state that intimacy is "a subjective appraisal and an emergent property coming from a relational process of mutual self-disclosure." According to these authors, intimacy includes these six properties: knowledge of the innermost being of one another, mutuality, interdependence, trust, commitment, and caring.

Waring and his colleagues (1980) collected data reflecting lay conceptions of intimacy by asking their respondents, "What does intimacy mean to you?". They found that married couples mentioned these categories in the following order of importance: affection, expressiveness

(including self-disclosure), sexuality, cohesion (commitment), compatibility, autonomy (from parents), conflict (*not* arguing or criticizing), and identity (knowing oneself, knowing one's needs, and enjoying adequate self-esteem). In a similar approach, Helgeson, Shaver, and Dyer (1987) found that feelings and expressions of closeness, appreciation, and affection were central to both sexes' prototypes of intimacy. These two studies call attention to the importance of emotions, particularly affection, in everyday conceptions of intimacy.

Other studies highlight the importance of emotional self-disclosure. First, Fitzpatrick (1987) has argued that in marriage, once partners come to know each other, communication of feelings, rather than facts, is the key determinant of relationship satisfaction. Second, studies of therapeutic interactions demonstrate that emotional processes (e.g., elaborating emotional expression, accessing previously unacknowledged feelings, and restructuring emotions) are better predictors of therapy outcomes than are simple informational disclosures (Greenberg & Safran, 1987). Furthermore, research shows that informational and emotional self-disclosure are conceptually and empirically distinct (Morton, 1978, Pennebaker & Beall, 1986) and that emotional disclosure is

more important for well-being.

Some definitions of intimacy emphasize the role of nonverbal communication (Argyle & Dean, 1965). These researchers include as intimate a variety of behaviors that indicate heightened involvement in interactions (e.g., eye contact, proximity, forward leaning, touch). Some authors suggest (Clark & Reis, 1988) that emotional expression might lie at the heart of the disclosure component of intimacy. One should note that emotional communication often happens through nonverbal channels and that, even when individuals attempt to suppress affect, autonomic markers of emotional states are clearly identifiable (Buck, 1984). When intimate individuals are involved in an interaction their history and other contextual cues enhance the nonverbal communication of emotions so critical to establishing and maintaining intimacy.

Finally, Reis and Shaver's (1988) model of intimacy focuses on the interpersonal communicative process and emphasizes three key aspects that characterize it as intimate - understanding, validation, and caring. Understanding refers to one individual's belief that the other accurately perceives their "needs, constructs, feelings, self-definition, and life predicaments" and that this is a prerequisite for validation. Finally, caring as

the third aspect of intimate interaction, has both an immediate emotional impact and a facilitative role in that individuals who are unsure about a partner's regard are unlikely to disclose personal feelings that might lead to rejection, ridicule, or embarrassment (Altman & Taylor, 1973) The type of self-disclosure required for the intimacy process to proceed is unlikely to arise in the absence of caring.

Intimacy and Well-Being

Having reviewed many definitions of intimacy, I turn now to the research examining why intimacy should matter to us. Intimacy has been shown to have beneficial consequences for psychological or physical health. This is not however, the only justification for studying it. Intimate relationships, and the companionship and affection they provide, are inherently rewarding in and of themselves (I will return to this point later).

Recent studies have linked greater intimacy to absence of loneliness (Wheeler, et al, 1983 - loneliness was more closely related to lack of intimacy than to frequency of interaction), the perception of social support (Hobfoll et al, 1986), better psychosocial adjustment (McAdams & Valliant, 1982), fewer symptoms of illness (Pennebaker & Beall 1986, Reis et al, 1985). Some authors point out

however, that intimacy may have negative effects as well (Fisher & Stricker, 1982; Fitzpatrick, 1987; Hatfield, 1984; Rook, 1984, 1988).

Few studies have examined explicitly intimacy's effect on well-being; and of those that have, most have focused on psychological health. In reporting their development of a measure of intimacy, Miller & Lefcourt (1982) note that intimacy has received empirical support as an important predictor of individuals' response to stress "despite crude and global operationalizations of the variable." They offer marital status as an example of such an operationalization and cite research by Medalie & Goldbourt (1976), Berkman & Syme (1979), and Brown and associates (1978) in support of this conclusion.

Several studies in the loneliness literature have shown that it is not the quantity of contact (e.g., frequency of interaction, time spent socializing, number of partners) with others that best predicts loneliness but rather the quality of that contact. Specifically, satisfaction with, and the perceived intimacy of, the interactions are associated with less reported loneliness (Wheeler, Reis & Nezlek, 1983; Cutrona, 1982; and Williams & Solano, 1983).

Intimacy has also been related to psychological health

and disorder. McAdams and Valliant (1982), for example, found better psychosocial adjustment in a sample of middle-aged men who has shown higher levels of intimacy motivation during their early twenties. Other studies demonstrate positive associations between intimacy and various dimensions of psychological maturity (e.g., ego development; Loevinger, 1976) and subjective well-being (e.g., positive mood; Reis, 1987). Intimacy problems are also closely linked to many mental health disorders (see Fisher and Stricker, 1982, for a review). Levitz-Jones & Orlofsky (1985), for example, found relatively more severe attachment and separation-individuation problems and heightened defensiveness in college women experiencing difficulties in attaining intimate relationships.

Summary and Conclusions. After reviewing the definitions of intimacy, several issues must be addressed. As with the definition of social support, intimacy is a multidimensional concept and must be measured and analyzed as such. Emotional expression, understanding, validation, and caring represent recurring themes and are most likely, the critical components of intimacy.

In addition, the following questions regarding intimacy must be answered, (Acitelli & Duck, 1987): (1) Is intimacy best conceived of as an intrapersonal or

interpersonal phenomenon, or both?; (2) Is intimacy static or dynamic, or both?; (3) How do different couples define intimacy in their relationship? A process or interactional model of intimacy (like that of Reis & Shaver, 1988) that accounts for what happens between and within the persons in a couple as they relate in different situations holds the most promise for furthering work in this area.

Integrating Social Support and Intimacy

As the literatures on social support and intimacy become more refined, these literatures are converging on a core social psychological process with distinct communicative and emotional features. It is this core process, I believe, that represents the critical component in the relationship between social interaction and health and well-being. As I have highlighted in the review thus far, both "main and stress-buffering effects" seem to explain the relationship between social ties and health. Intimate relationships may provide a backdrop of positive inputs to well-being and buffer one in stressful times (this point will be elaborated below). Furthermore, that relationships characterized by intimacy, emotional support, and caring seem to demonstrate most strongly these healthful effects. In addition, the process of emotional expression, caring and validation that is unique to

intimate relationships may lead to emotional regulation which could affect physiology and health.

Research supports the beneficial role of social ties and intimate relationships in health and well-being. In a review of ten studies correlating social support with mortality and psychological health, Reis (1984) speculates that, "well-being is most likely to stem from contact with affectively close or intimate partners." In fact, several authors agree that the critical component of social support lies not just in having relationships per se, but rather in quality of those relationships (Sarason & Sarason, 1985).

More specifically, intimacy has been offered as the critical concept differentiating supportive and nonsupportive relationships. The studies demonstrating that being married is associated with lower mortality (especially for men), that when facing stressful experiences, the presence of an intimate, confiding relationship (especially with a spouse or lover) is associated with a lower incidence of depression (Brown & Harris, 1978) are often cited to support this assertion.

Although there is little empirical work that discriminates explicitly intimacy and social support, two exceptions are found in Hobfoll, Nadler, and Leiberman (1986) and Reis (1989). The former study suggests that

intimacy is related positively to satisfaction with social support, over and above the effects of self-esteem and network size. In the latter diary study, interaction intimacy was the best predictor of social support. Additionally, as one might expect, intimacy was strongly correlated with several measures of psychological well-being, such as loneliness and life satisfaction.

As stated earlier, many studies indicate that the perception of social support buffers the impact of stress and facilitates psychological and physical health (Cohen and Syme, 1985). Recent research implicates intimacy as a central determinant of certain forms of social support. For example, Reis (1989), found that interaction intimacy was the best predictor of appraisal support (feeling useful advice and guidance is available) and belonging support (feeling integrated in a community of friends). As I mentioned in the section on marriage as social support, many authors have assumed incautiously that marriage *per se* provides social support, Gove, Hughes and Style (1983) demonstrated that only high quality marriages, which include intimacy, produce these effects.

In addition, of the studies that explicitly quantify the functional (versus structural) components of social support, most demonstrate that emotional caring and self-

esteem support, two concepts which overlap with intimacy, explain most of the variance in outcome measures such as health and well-being (S. Cohen and Hoberman, 1982; Schaefer, Coyne and Lazurus, 1981).

To summarize, intimate relationships, and the emotional and esteem support they can provide, are a subset, and some would argue the most important set (Reis, 1990, Sarason & Sarason, 1985), of concepts operating within the social support to health relationship. Moreover, supportive activities are most likely to occur in the context of intimate interaction and relationships, suggesting that intimacy and support are closely related processes (see Brown, Brolchain, & Harris, 1975, Hobfoll & Stokes, 1988, and Sarason & Sarason, 1985, for similar conclusions).

As stated earlier, there are few empirical studies that explicitly compare intimacy and social support as alternative explanations of the association between social ties and health or well-being. Several authors have, however, addressed explicitly the overlap between these concepts. The Sarasons and their colleagues (Sarason & Sarason, 1985; Sarason, Sarason, & Pierce, 1988), Reis (Reis, 1990), and Hobfoll (Hobfoll, 1985; Hobfoll, Nader, & Lieberman, 1986) have each mentioned that some aspects of

social support, and probably the most powerful aspects, bear considerable resemblance to some aspects of intimacy. In addition, in a most thoughtful review and synthesis, Rook (1985, 1988) integrated the literatures on social support, loneliness, and social isolation and came to similar conclusions. Each of these authors has touched upon the central issues in this section of this literature review and their contributions will be reviewed briefly below.

The Sarasons and their colleagues have stated the social support is best conceived of as the perception that support will be available is time of need. These authors have conducted several studies in which perceived social support explains most of the variance, over and above what is explained by quantitative indicators of social support, for a variety of outcomes. They have utilized, for example, outcome measures that indicate fewer psychological and physical symptoms among individuals reporting higher levels of perceived support.

Furthermore, they suggest that this perception is more like a personality variable in that it is stable over time and correlates substantially with other personality measures (e.g., introversion-extroversion, neuroticism, loneliness). The Sarasons and their colleagues (Sarason,

Sarason, & Pierce, 1990) use this data to place perceived social support within the context of attachment theory. These authors suggest that intimate adult relationships are attachment relationships and will parallel in type the attachments one formed in infancy. These authors' efforts are laudatory given the general atheoretical nature of most of the social support literature.

Reis (1984, 1989, 1990) has also given considerable emphasis to the integration of the social support and intimacy literatures. His work on the communicative process of social support and intimacy emphasizes the importance of emotional expression, caring, and validation and suggests that these are the active ingredients in socially supportive relationships. Interestingly, like the Sarasons, Reis had also mentioned attachment theory as a viable framework for studying both social support and intimacy (Reis & Shaver, 1988).

Similarly, Hobfoll (1988) has also given priority to intimacy in the social support - stress resistance relationship. He states, "... intimacy emerges as being of primary importance in social support, in warding off depression, and in avoiding loneliness." (Pg., 494). He and Stokes (1988) highlight the underlying feelings of caring and attachment one derives from intimate

relationships as being critical to effective social support.

Finally, although not specifically directed toward the intimacy literature per se, Rook (1985) integrated the social support, loneliness, and social isolation literatures and came to conclusions similar to those being suggested in this review. Specifically, that social relationships provide healthful benefits and she suggests that the literatures she reviewed converge on some central issues. In her review Rook concludes that social relationships provide 1) stress-buffering and main effects, and what is more important, 2) positive inputs to well-being all the time, not just help in times of need. She writes,

> "While sociable and intimate interactions may at times serve to provide distraction from stressful problems, they more typically serve to enhance mood and feelings of self-worth directly. . . .Thus companionship and intimate interactions represent centrally important contexts in which people reward themselves and each other by arranging mutually gratifying activities. . . . If we imagine psychological functioning to have a true neutral point, then companionship and intimate interaction serve to promote positive mental health by raising functioning above the neutral point, while receiving help with pressing problems serves to prevent impaired mental health by restoring disrupted functioning to the neutral point.

This is an important point, and highlights the inappropriate use of checklists of psychiatric or physical

symptoms as outcome measures in social support research. If, as Rook suggests, our relationships affect positively our well-being as well as buffering us in stressful times (probably a lesser function) then what is needed are outcome measures that reflect this emphasis (i.e., quality of life, positive affect checklists). Researchers tend to settle for bland definitions of well-being based on the absence of pathology. What is needed is greater attention to positive interpersonal experiences that enrich quality of life.

The next section of the review will cover the literature addressing the late-effects of childhood cancer and its treatment. While most of the empirical work has focused on medical late effects, psychosocial concerns are receiving increasing attention. In some ways, this literature is an example of what Lawton has observed in that most of the empirical work has been focused on finding pathology. This review will make apparent the need to focus on the quality of adjustment, especially in the interpersonal realm, when studying the sequelae of stressful or traumatic experiences such as childhood cancer and its treatment.

The Late Effects of Childhood Cancer and its Treatment

Cancer has changed, because of advances in detection

and treatment, from a nearly always fatal disease to an illness from which recovery is possible, and in some cases, even likely. It is often referred to now as a chronic illness due to greatly improved (and improving), survival rates. For these reasons, the individuals who survive cancer have become the focus of increasing research attention. The "late effects" of cancer can refer to any one of several categories of variables including: delayed medical or physical complications of treatment, psychosocial sequelae of the cancer experience, and practical consequences, such as insurance denial or job discrimination, that can result from having been a cancer patient.

Medical late effects have received the bulk of the research attention but growing emphasis is being placed on psychosocial late effects. After a very brief review of some of the medical late effects literature, this review will turn to the psychosocial research. This section of the review will be structured to follow the progression of the research from that which has addressed attainment of employment and insurance, to research designed to assess psychological status, to the current focus on more subtle indicators of relative adjustment and "quality of life" issues, and finally to the status of cancer survivors'

relationships and marriages.

Medical Late Effects

The literature on medical late effects has shown that while early detection and multimodal treatments improve the chances for survival, these treatments (which can include radiation, surgery, and various chemotherapy agents) may have several negative sequelae. The chances for a second malignancy as a result of treatment (oncogenesis) are increased; some estimate an increased risk as high as 20 times that of the general population (Byrd, 1985; Hawkins, Draper, & Kingston, 1987) which peaks 15-19 years post-treatment (Li, Cassady, & Jaffe, 1978). In addition, organ failure or impairment is possible, particularly in the cardiopulmonary and sexual/reproductive systems (Jaffe, 1987; Meadows & Silber, 1985). Cardiac dysfunction has been called the most significant contributor of morbidity in the 5-year period following treatment (Byrd, 1985) and sexual/reproductive problems represent a consistent source of concern for survivors (Zevon, Neubauer, & Green, 1990). Other side effects can include disfigurement, short stature, learning disabilities, and persistent fatigue. Increased risk of infection in the post 5-year period, possibly due to delayed effects of immunosuppression, has also been noted (Green, Zevon, & Hall, 1991; Koocher &

O'Malley, 1981). Finally, while estimates of survival time vary by type of malignancy and treatment, 20 year survival rates are lower for survivors of childhood cancer than for those in the general population (Li, Meyers, Heise, & Jaffe, 1978).

Moreover, in addition to the medical late effects just reviewed, modern cancer treatment can lead to cognitive dysfunction. For example, the combination of intrathecal methotrexate and full brain radiation, often used as CNS prophylaxsis for childhood acute lymphocytic leukemia (ALL), has been shown to be particularly problematic. This particular form of treatment has been associated with global decrements in intelligence test scores of up to 10 points. Other research indicates that neuropsychological testing results show deficits in the areas of attention, concentration, and memory (Mulhern, 1994).

In addition to the potential for serious medical late effects and cognitive impairment, most pediatric cancer survivors can expect continuous medical follow-up throughout their lives. These follow up appointments can be a source of considerable anxiety since they might involve painful diagnostic procedures such as bone marrow aspiration or lumbar puncture, the results of which are uncertain. Thus, even years after the diagnosis and

completion of treatment for childhood cancer, patients (and their families) must face continued medical and psychological issues. Some have suggested that when viewed from this perspective, childhood cancer can be considered a chronic medical condition that can be associated with long-term physical, psychological, and social consequences (Rait, et al, 1995).

For these reasons and others, the empirical literature has focused on describing the psychosocial repercussions that may result from surviving childhood cancer. There are many facets to examine when one asks the question, "How are these survivors doing?" Levine and Croog (1984), for example, have suggested that to answer that question an assessment should include at least the following elements: the physiological state, intellective functioning, the performance of social role, the emotional state and, general satisfaction or feelings of well-being. The following sections will review the empirical findings regarding cancer survivors' status in the areas of employment and insurance, the presence or absence of psychopathology, more subtle indicators of maladjustment, and finally, the data on marriage and relationships.

Employment and Insurance

Employment discrimination is a concern for cancer

survivors (Green, Zevon, & Hall, 1991). There are, however, some inconsistencies in the data regarding actual employment status. Some studies indicate a higher rate of unemployment for cancer survivors' than those in the general population (Koocher & O,Malley, 1981). Other studies have found a higher rate of unemployment for female cancer survivors, but not for males (Green, Zevon, & Hall, 1991).

In a study comparing a group of cancer survivors to their siblings Teta, et al, (1986) found that 80 percent of the male survivors had been rejected from the military, 13 percent from college and 32 percent from employment. These values were significantly higher than those of their male siblings. Female survivors were significantly more likely than their sisters to be denied entrance into the military ($p<0.05$), but no differences were found with respect to college or employment rejection.

In some instances, discrimination based on cancer survivor status is easy to ascertain as Koocher and O'Malley (1981) point out is the case with the armed services. Their policy regarding cancer survivors is straightforward - automatic rejection. In other cases, rejection from employment as a result of discrimination is sometimes harder to establish. One must rely on the self-

report of the cancer survivor since employers may be reluctant to say that rejection was based on the applicant having had cancer. Rejection is likely to be based on prejudice since there is no data to support the belief that having survived cancer would in any way detract from job performance (Koocher & O'Malley, 1981).

Nevertheless, figures ranging from 11 percent (Green, Zevon, and Hall, 1991) to 40 percent (Koocher & O'Malley, 1981) of cancer survivors report that they have experienced discrimination in the work environment based solely upon their having a history of cancer. As stated earlier, discrimination and rejection from employment are concerns for survivors and, as is the case for most people, can lead to lowered self-esteem. It has also been noted that in the case of someone with a history of cancer, rejection based on that history can lead to anxiety about disease prognosis (Koocher & O'Malley, 1981). Presumably, it communicates a lack of confidence in the future health of that individual. While the effect of these experiences will vary from person to person (and directionality of the effect is not established), Koocher and O'Malley noted that employment status was mediated by psychological adjustment. Those survivors rated as better adjusted were more likely to be employed.

Finally, some have noted suboptimal performance at school and work (Lansky, List, & Ritter-Sterr, 1986, Fobair, et al, 1986). Teta, et al (1986), on the other hand, found that the cancer survivors' educational levels exceeded those expected for sex-, age-, and state-matched populations.

Obtaining health and life insurance presents another difficulty for cancer survivors and discrimination and denial of coverage has been established. Individual health insurance policies are nearly impossible to obtain and if they are purchased, they contain many exclusionary clauses related to the cancer history. Thus, most adult survivors are covered under group insurance policies (Koocher & O'Malley, 1981). Moreover, while cancer survivors may be able to obtain life insurance coverage, their policies will be different than those of the general population. They may have to endure waiting periods, pay higher premiums, and many have been denied coverage at least once (Koocher & O'Malley, 1981).

Psychological Status

The stressful nature of diagnosis, treatment, and later, the survival and chronicity of childhood cancer has lead researchers to examine the psychological impact of these experiences. As Hammond (1986) noted, despite the

spectacular successes in developing treatments capable of enabling complete recovery from illness as well as long-term survival, achieving the "restoration of health, including physical, developmental, functional, and psychological" often fails (p. 412)." While early epidemiological studies suggested that survivors were psychologically well-adjusted (Li & Stone, 1976, Holmes & Holmes, 1975), subsequent works, especially that of Koocher and O'Malley (1981), raised doubt about that conclusion and inconsistencies and disagreement still exist today.

In Koocher and O'Malley's (1981) landmark study of 117 long-term survivors of childhood cancers, these authors concluded that approximately half of the sample showed some maladjustment. They based their conclusions on the results of observations during personal interviews and on survivors' self-descriptive responses to objective measures. These measures included a variety of self-report personality and mood measures (verbal IQ, self-esteem, satisfaction with self, self-minus-ideal discrepancy, death anxiety, depression, manifest anxiety scale) the scores of which were all in the more favorable direction in well-adjusted survivors.

From their interview data these authors concluded that approximately half of the survivors had some psychiatric

symptoms, resulting in mildly to severely impaired functioning. Of the survivors that showed some adjustment problems (47%) the percentages and descriptions of the categories were as follows: 25.6%, mild - no impairment in functioning, 10.2%, moderate - no apparent interference with life adjustment, 8.5%, marked impairment - moderate symptoms, impaired functioning, 2.7%, severely impaired - severe symptoms yet functioning with some difficulty, 0%, incapacitated.

Koocher and O'Malley (1981) concluded, "It seems evident from the data presented in this chapter that survivors of childhood cancer are at substantially greater psychological risk than are the survivors of other chronic, but not life-threatening, childhood illnesses." I will turn next to subsequent works that indicate some adjustment difficulties but, as will become apparent, findings across studies are inconsistent.

Cella, et al (1988) found that nearly a third (13 of 42) of the survivors in their sample were rated as having experienced significant maladjustment in one of the four major psychosocial areas assessed: psychiatric disorder, marital status, education, or employment. Mulhern and colleagues (1989) documented significant deficits in social competence and increased behavior problems in their sample

of adolescent survivors. Others have also found increased emotional and behavioral disturbances (Danoff, et al, 1982, Bamford, et al, 1976). Finally, in a study of adult survivors, Fobair, et al (1986) uncovered significant problems in sense of well-being, employment, and marital and family relationships.

So, while some studies have shown a consistent pattern of negative psychosocial late effects, others have not. Not only have results between studies been inconsistent, one can find seemingly inconsistent results even within studies. Fritz and Williams (1988), for example, found that 61% of the adolescents in their sample reported good or excellent global adjustment while also reporting persistent illness-related concerns such as negative body-image, disruption in dating and somatic preoccupation. Similarly, Greenberg, Kazak, and Meadows (1989) found that cancer survivors reported significantly poorer self-concept and more external locus of control than a matched sample of healthy children. Their responses were, however, within normal range. These authors also found there were no differences in reported depression. Madan-Swain, et al (1994), found that the survivors' teachers reported no major psychopathology, and the survivors reported no major difficulties in social competence, overall coping, and

family communication. The cancer survivors did, however, report body image disturbances and adjustment difficulties. Finally, Ostroff, Smith, and Lesko (1989) found that the adolescent cancer survivors in their sample reported significantly greater levels of emotional distress. These authors also found, in contrast to the findings of Mulhern and his colleagues (1989), that when compared to healthy peers, there were no significant differences in school achievement, social competence, or problem behaviors in their group of survivors.

Teta et al (1986) report that on indicators of serious psychological maladjustment, survivors did not differ significantly from their siblings or the general population. They employed indicators such as frequency of lifetime major depression (male survivors, 15%; male siblings, 12%; female survivors, 22%; female siblings, 24%). In addition, these authors reported that there were no differences in the reported frequencies of suicide attempts, running away or psychiatric hospitalizations for either sex.

The long-term survivor's self-concept has received a good deal of attention in the empirical literature and, although not consistent, some researchers have reported positive findings. Anholt, Fritz and Keener (1993) for

example, found that cancer survivors had similar global self-concept scores to a comparison group and both were within normal limits. Furthermore, the survivors' scores on five of six subscales were actually higher and reflected significantly more positive feelings about intellectual, school, and behavioral functioning, and overall happiness and satisfaction.

One could conclude from this research that major psychosocial disruption and distress among cancer survivors is rare. On most measures of psychological dysfunction, survivors are not significantly different from comparison groups such as siblings or the general population. Indeed, several researchers have noted that survivors report positive psychological effects resulting from their experience with cancer (Anholt, Fritz, & Keener, 1993). Many survivors report that having survived cancer has changed the way they view life, given them a new perspective, and increased enjoyment of the small pleasures in life. Therefore, research attention has shifted from assessment tools designed to find diagnosable psychopathology to other, sometimes more subtle, indicators of psychosocial adjustment.

Other Indicators of Adjustment

A methodologically rigorous study by Gray and his

colleagues (1992) provides an excellent example of the information to be gained from a non-pathological focus. These authors used a screening questionnaire which covered demographic information and included ratings of satisfaction with relationships, standardized self-report inventories (POMS, Desirability of Control Scale, Control Belief Scale, Rosenberg Self-Esteem Inventory, Impact of Event Scale), a projective technique, and experience sampling via pager (7 times per day for 7 days).

The results of this study indicated that survivors report significantly more positive affect, less negative affect, higher intimacy motivation, more perceived control, and greater satisfaction with control in life situations. In contrast to these positive findings, the authors found several specific problems. Survivors were more likely to have repeated school grades, to be worried about issues of fertility, and to express dissatisfaction with important relationships. The authors suggest that the survivors' dissatisfaction may be related to their high expectations for interpersonal relationships. Post-treatment relationships may be somewhat disappointing when compared to the intensity of those experienced during illness and treatment.

Cella and Tross (1986) also found evidence for subtle,

nonimpairing psychological distress in their sample of childhood cancer survivors. Specifically, they found decreased intimacy motivation, increased avoidant thinking about illness, diminished work capacity, subjective somatic distress, and a variety of illness-related concerns. These authors note that their findings are consistent with those of other studies (Koocher & O'Malley, 1981; Fobair, et al, 1986; Zevon, Green, & Hall, 1991; Gray, et al, 1992) in which subtle adjustment problems suggest that the cancer experience may leave residual effects.

Finally, Zevon, Neubauer, and Green (1990) studied 55 ALL survivors and found that, consistent with other studies, survivors were well-adjusted and leading essentially normal lives. These authors found however, that the women in their sample tended to become upset and experience anxiety in stressful situations and were considered a potential at-risk group.

Interestingly, many of the studies reviewed this far have focused, at least in part, on the interpersonal aspects of adjustment. The emphasis on interpersonal relationships makes sense when one considers the developmental stage at which many survivors were when they were diagnosed and received treatment. By virtue of their being children or adolescents, their relationships with

parents, and later, peers, are an important aspect of their lives. Wasserman, et al (1987) found for example, that the survivors had missed an average of six months of school and 40% reported unpleasant school experiences. These unpleasant experiences resulted mainly from being teased about baldness, thinness, and being avoided because they might be 'contagious', or generally treated as outcasts. This finding suggests that there is potential for maladjustment in interpersonal relationships because of the critical role they play in the survivors' developmental course.

Other authors have echoed these thoughts when suggesting that a cancer history may set survivors apart from peers by increasing their sense of alienation and social isolation. The disturbances in interpersonal relationships during treatment may lead to the lower intimacy motivation noted in survivors. As a result, the cancer experience may constrict the survivors' availability for warm interpersonal relationships.

It has also been suggested that the extended disruption in role functioning and the dependency forced by the patient role may lead to difficulties in interpersonal relationships during the survival period. In support of this, some have noted that, in addition to disturbances in

peer relationships, excessive dependency on parents (Lansky, 1978, Links & Stockwell, 1985), is another potential outcome of cancer diagnosis and treatment.

To summarize, the long-term survivor of childhood cancer is no more likely to experience major psychopathology than someone in the general population. They have, however, shown a tendency to experience some negative psychological sequelae. Somatic preoccupation and distress are common, and several researchers have reported a tendency for survivors to show lowered interest in or dissatisfaction with interpersonal relationships (Koocher & O'Malley, 1981; Cella & Tross, 1986; Gray, et al, 1992; Mulhern, et al, 1989; Corn, 1995). Barbarin (1988) stated, "...consistent with our clinical observations of survivors, particularly young adults, who even a dozen years after a single course of cancer treatment report feeling as though they are sitting on a powder keg and waiting for it to go off. The question that remains unanswered is how often and in what ways do these forms of uncertainty influence the cancer survivor's life and relationships."

Marriage and Family Relationships

Several studies reviewed in the previous section found some difficulties with intimacy, decreased intimacy motivation, and decreased interest in and dissatisfaction

with interpersonal relationships. Koocher and O'Malley (1981) found that when they interviewed the parents of the survivors, they were concerned less with the physical effects than with the psychosocial effects of having had cancer. Specifically, the parents reported that while their child was functioning well in general, they appeared to have some difficulty forming lasting relationships with members of the opposite sex.

Results such as these have lead researchers to focus on marriage and the family relationships of long-term survivors of childhood cancer. Several studies have found that survivors are marrying at a lower rate than comparison groups (siblings or general population) (Byrne, 1985; Green, Zevon, & Hall, 1991; Holmes & Holmes, 1975; Koocher & O'Malley, 1981; Meadows, McKee, & Kazak, 1989; Teeter, et al, 1988). In addition to marrying at a lower rate, although the findings are less consistent, some studies have found an increase in divorce rate for survivors (Green, Zevon, & Hall, 1991; Wasserman, et al, 1987).

Koocher and O'Malley (1981) found that marital status was dependent upon the interaction of several variables. The marital status of survivors was related to sex, the extent of physical impairment, and the visibility of the impairment. Specifically, if the survivor was female with

more physical and visible impairment, she was less likely to be married. This was not the case for male survivors. In fact, the more marked the males' impairment, the more likely they were to be married. In addition, the never married survivors tended to show more psychological symptoms than the married ones, but the two groups did not differ significantly in overall psychological adjustment.

In addition to marital status, some researchers have focused on the quality of survivors' marriages. While some studies indicate that there is no overall decrease in marital satisfaction (Cella, 1983; Holland, 1982), the findings of other studies indicate that health concerns (fear of recurrence, sexual functioning, health of progeny) played a role in survivors' decision to delay marriage or not marry (Byrne, 1985; Holmes & Holmes, 1975; Teeter, et al, 1988). These health concerns may have other ill effects on relationships such as occasional tension, emotional withdrawal, temper, anxiety (Chang, 1991), and may even play a role in the decision to dissolve relationships (Green, Zevon, & Hall, 1991).

One could conclude from these studies and those reviewed in the previous section that survivors may be experiencing some difficulties in the interpersonal realm. This may be one of the only consistent findings suggesting

negative psychosocial late-effects of childhood cancer. These difficulties are troubling given that relationships with others play an important role in well-being (marriage; Schmale, et al, 1983) and in facilitating coping with cancer (Koocher & O'Malley, 1981; Taylor, 1982). Thus, families, and the quality of the relationships within them, provide another potential area in which psychosocial late-effects might be expressed.

The characteristics of the survivors' families and how they adapt and cope have also been examined. Spinetta, et al (1981), for example, found that positive family adjustment was related to three factors: (1) the family's ability to resolve questions about cancer and focus on family matters unrelated to the disease, (2) the family system was adaptive, healthy, and supportive of its members, (3) family members were able to seek help when needed. Some studies have focused on cohesion (closeness in the family) and flexibility (ability to adapt to change) within the family. Rait, et al (1992) found that survivors rated their families as less cohesive and Madan-Swain, et al (1994) reported that the survivors in her sample rated their families as less flexible. In most studies, the family is considered a coping resource and family variables are then related to the survivor's adaptation.

Family cohesion, for example, has been shown to be positively associated with survivors' mental health, self-esteem, and global competence (Rait, et al, 1992). In addition, other social/ecological variables such as family support, coping of other family members, intactness of the family, quality of the parent's marriage, peer support, lack of concurrent stressors, socioeconomic status, and open communication within the family have also been to be related to the survivor's adaptation (Fritz, et al, 1988; Kupst & Schulman, 1988; Mulhern, 1994; Zeltzer, 1993).

Two family variables that have received considerable attention and are correlated with adjustment or coping in long-term survivors include openness in family communication (Fergusson, 1976; Koocher & O'Malley, 1981; Spinetta & Deasy-Spinetta, 1981; Spinetta, Swarmer & Sheposh, 1981) and emotional support (Futterman & Hoffman, 1978; Kaplan, Grobstein, & Smith, 1976; Koocher & O'Malley, 1981; Morrow, Carpenter, & Hoagland, 1984).

Fritz, Wiliams, & Amylon, (1988), for example, found that direct communication during treatment was an important predictor of global adjustment (11% of the variance explained). Direct communication also explained 9% of the variance in school functioning, 31% in social/peer interaction, 14% in activity level, and 11% in current

openness. Sincere self-disclosure by family members and responsiveness to the child's expressions of emotion also make an important contribution to the adjustment of the child who survives (Benjamin, 1978; Green & Solnit, 1964). Barbarin (1988) states, "Empathic communication is a form of social support related to healthy psychological adaptation of the child with cancer. . . . Candor and encouraging the expression of feelings contribute specifically to the ill child's self-esteem."

Interestingly, several studies have reported that although open communication is vitally important to adjustment, it is often a scarce commodity. Adult patients who had been treated for cancer reported that, although treatment was completed, cancer represented an ongoing and inescapable threat. Family and friends, who had been supportive during the immediate postdiagnostic period, discouraged patients from talking about these concerns (Taylor, 1982). Furthermore, ongoing support and open lines of communication can be important for the long-term adjustment of the survivor. Northouse (1981) found that patients in remission experienced less fear of recurrence if they had support from significant others in their lives. This phenomenon has also been reported in adolescent survivor samples. The need for closure at the end of

treatment is often strong and families may discourage open communication. Discussions about cancer often become taboo during the subsequent post-treatment period (Ostroff, Smith, & Lesko, 1989).

Summary

Generally speaking, the long-term survivor of childhood cancer has shown relatively few serious psychosocial late effects. According to the results of many studies they do not appear to be experiencing significantly more major psychopathology than comparison groups. They may experience discrimination in employment and insurance, and they report more somatic preoccupation and symptoms. They may be marrying at a lower rate and divorcing at a higher rate, and several studies suggest that they are experiencing difficulties with intimacy and relationships.

Critique

Several factors have been shown to mediate or moderate the relationships between survivor status and psychosocial outcomes such as those just reviewed. Medical variables such as age at diagnosis, type of cancer and treatment, duration of treatment, permanent side-effects, relapse or recurrence, and time since treatment have all been related to adjustment (again, results are not completely

consistent).

The prevalent use of denial as a coping mechanism or defensiveness about having a history of cancer has been mentioned repeatedly in the late-effects literature (Cella & Tross, 1986, Greenberg, Kazak, & Meadows, 1989; Koocher & O'Malley, 1981; Madan-Swain, 1992; Wasserman, et al, 1987; Zevon, Neubauer & Green, 1991). Higher levels of defensiveness has been related to decreased well-being and heightened stress reactivity in survivors (Zevon, Neubauer, & Green, 1991). Adolescents in Madan-Swain, et al's study were "eager to present themselves favorably" and reported that they are "overly compliant in social and interpersonal situations and that they avoid interactions that involve conflict." An extensive literature has addressed the potential for denial or defensiveness to act as a moderator variable on measures of psychological adjustment (Paulhus, 1986).

Several other intrapersonal factors have also been mentioned as potential moderators of psychosocial late-effects. In particular, self-esteem has been related to adjustment of long-term cancer survivors and has been called a resistance or resilience factor (Fritz, et al, 1989; Koocher & O'Malley, 1981; Kupst, et al, 1995; Kupst & Schulman, 1988; Mulhern, 1994; Zeltzer, 1993).

Finally, several researchers have stated that it is time to abandon null hypothesis testing and comparisons of cancer survivors to "normal" populations, and instead focus within the survivor group to determine factors associated with relative adjustment (Greenberg, Kazak, & Meadows, 1989). Thus, future research should include within subjects analyses and consider the potential mediating or moderating effects of the medical variables as well as those of more personologic variables like denial/defensiveness and self-esteem.

Statement of the Problem

The stress of having had cancer and having endured difficult and painful diagnostic and treatment procedures during the vulnerable periods of childhood and adolescence may have contributed to decrements in well-being. In addition, contemporary issues such as fear of recurrence and reproductive concerns represent ongoing stressors that could impact negatively survivors' well-being. It becomes important therefore, to examine variables such as intimacy and marital adjustment that might provide positive inputs to well-being. Secondarily, it is necessary to examine the potential for variables such as personality, defensiveness, and self-esteem to impact that relationship.

Research Questions

1)Are total well-being scores lower for those individuals in the survivor group than for those in the control groups?

2) Do intimacy and marital adjustment represent significant positive inputs to the well-being of individuals who have survived cancer and it's treatment? Does the same hold true for those individuals in the control groups?

3) Are exogenous variables such as age, sex and age at diagnosis significant predictors of intimacy? Do

defensiveness or personality variables like warmth and gregariousness mediate those relationships? Finally, does self-esteem in turn mediate the relationships between the personality variables, intimacy, and well-being?

Chapter 2

Method

Roswell Late Effects Project

The Roswell Late Effects Project (LEP) was initiated in 1980 by Dr. Daniel Green and is an ongoing investigation of the long-term sequelae of cancer in childhood or adolescence and it's treatment. Demographic and medical data was abstracted from the charts of 1,239 untreated individuals who were diagnosed between 1960 and 1986 and were less than twenty years of age at diagnosis. A subgroup of this overall population (n=370) met the inclusion criteria for the LEP, namely, being 18 years of age or older and five or more years post-diagnosis.

These participants continue to be evaluated annually on a wide range of global and specific factors related to their current functioning. As was noted in the literature review, the findings regarding the psychological and psychosocial functioning of long-term survivors has been quite mixed. One possible explanation for this heterogeneity of findings was the emphasis on examining more severe psychopathological sequelae and the associated use of measures developed on psychiatric populations. Therefore, most investigators agree that the evaluation of psychosocial treatment sequelae or late-effects must focus

on normative functional domains, subtle effects, and more complex psychosocial contexts (e.g., relationships). The LEP was designed therefore, to reflect this emphasis which could lead to more relevant and generalizable findings. The present study, one of several "off-shoots" of the LEP, represents a new emphasis and extension of the project into the realm of survivors' functioning in their intimate/marital relationships and their impact on overall well-being.

Participants

Patient Sample. Of the 370 patients eligible for inclusion in the LEP, 254 were enrolled (68.6%) and of those 207 (81.5%) completed the questionnaires for this study. The remainder had received the questionnaire but neither returned it nor formally declined participation. To test the representativeness of those participants who returned completed questionnaires, they were compared with those individuals who did not return the questionnaire on several variables. No significant differences were found in age, sex, race, age at diagnosis, time since diagnosis, diagnosis, occurrence of metastatic disease, type of treatment, history of relapse, or occurrence of secondary malignancy (see Table 1).

Control Sample. A sample of control participants

(N=231) who did not have a history of childhood cancer were recruited from three different community settings in Buffalo, NY: (1) a state college adult education class, (2) a parochial middle school, and (3) a university-affiliated Catholic church.

Procedures

Patient sample. A letter describing the study was sent to each of the survivors enrolled in the LEP (see Appendix A). The letter requested that the individual contact the principal investigators only if they wished to withdraw from further participation in the LEP. After a brief waiting period, the survivors were sent a packet including a cover letter describing the nature of the project, an instruction sheet, and a pre-addressed, stamped envelope for the return of the materials to the Project Director. Two questionnaires (see Appendix B) were included in the packet with a request for the spouse or partner of the survivor (if available) to complete the second questionnaire. The questionnaire, which took approximately one and one-half hours to complete, included measures of well-being, social intimacy, marital adjustment, personality, self-esteem, adult attachment, parental warmth and satisfaction. A supplementary data form was used to elicit demographic data such as sex, age, education, occupation, income, religion, marital history, current living arrangements, and parents' marital status during childhood. The survivors were then contacted by phone to review the materials, to respond to any questions, and to encourage them to return their completed

questionnaires within two-weeks. Over the next six months, follow-up phone calls were made on a bi-weekly basis to those survivors who had not yet returned the packet.

All study procedures were approved by the Institutional Review Board at Roswell Park Cancer Institute and all of the participants of the LEP had signed consent forms at the time of their enrollment.

Control sample. The participants recruited from the state college were enrolled in an adult education research and statistics class. These participants were offered extra course credit for their participation and for recruiting four other individuals. They were asked to recruit one male and one female from the 18-24 and 25-29 age categories.

The LEP was also presented to a group of parents attending a PTA meeting at a parochial middle school and they were asked to participate. They were told that the purpose of the study was to investigate the relationship between stressful medical events and adult/family relationships. Each of these families was then sent a letter and a self-addressed, stamped postcard which was to be returned to the Project Director only if they wished to decline participation. Questionnaire packets, including two copies of the questionnaire to be filled out by both

parents if possible, were sent within two weeks of the orientation letter and a prompt return was encouraged.

In addition, an overview of the study was presented to the members of a university-affiliated Catholic church. Identical (except for the orientation letter) questionnaire packets were sent only to those individuals who had expressed their interest and had provided their names and addresses. Once again, both parties (individual and spouse/partner) were asked to complete the questionnaire and return it in a timely manner.

In an ANOVA with age as the dependent variable, the survivor's spouses and the control participants were found to be significantly older (see Table 2). This difference may due to the survivor sample including both married and unmarried individuals with the unmarried individuals tending to be younger. In addition, there are more females in the control group and more males in the survivor group (see Table 2). Given these results, the analyses presented in the results sections controlled statistically for any influence of age and sex.

Measures

Miller Social Intimacy Scale. Miller and Lefcourt (1982) designed a 17-item questionnaire said to measure the maximum amount of intimacy currently experienced in an individual's closest relationship. This scale has high Cronbach's alpha (alpha = .86 or higher) and high test-retest reliability (r = .84 to .96 over a one- to two-month period). The authors provided some evidence for convergent, discriminant, and construct validity. This measure correlated strongly with Guerney's (1977) measure of trust and intimacy (r=.71, p<.001) and it was correlated inversely with the UCLA Loneliness Scale (r=-.65, p<.001). In addition, mean scores were significantly higher for married than unmarried (t=8.17, p.<.001) respondents indicating "known group validity."

The Dyadic Adjustment Survey (Spanier, 1976). The DAS is one of the most popular and well-researched self-report inventories of relationship functioning and adjustment. It is comprised of 32 items and yields an overall adjustment score and four subscale scores (Dyadic Consensus, Dyadic Satisfaction, Dyadic Cohesion, and Affectional Expression). Alpha reliabilities of .90 and higher have been reported by the author and many other investigators. Test-retest reliability is also high, .96 after 11 weeks. There is

some disagreement about the independence of the subscales and some suggest that the DAS be used as only a measure of overall relationship adjustment.

The author and other researchers have established the convergent validity of the DAS. It correlates with the Locke-Wallace Marital Adjustment Scale (Locke & Wallace, 1959). In addition, the author suggests that the results of many studies have established the predictive validity by showing that lower scores on the DAS are related to domestic violence, family dysfunction, depression, and poor communication. Generalizability from the norm group (109 white couples from Pennsylvania and 90 divorced individuals - only 22.5% of those contacted) may, however, be somewhat limited. Finally, the T-scores for determining cutoff scores reflecting "well-adjusted" and "maladjusted" couples is somewhat arbitrary which may be concern for clinical applications.

Rand Well-Being Measure (RW-B) is a 22-item measure, originally designed by Dupuy (1969) to assess perceptions of mental health primarily in psychological terms, although two of the subscales include items reflecting physiological symptoms. There are six response choices for each item, ranging from extemely positive to extremely negative evaluations of the individual's mental state during the

previous month. In addition, the scale contains both positively and negatively worded items for the same construct (i.e., From the vitality subscale - How much energy, pep, or vitality did you have or feel?, and Have you felt tired, worn out, used up, or exhausted?).

The scoring of the RW-B results in eight summated rating scales: four mental health constructs (Anxiety, Depression, Positive Well-Being, and Self-Control); two somatic health constructs (Vitality and General Health); the Mental Health Index (MHI; a composite score using all items on the four mental health constructs); and the RW-B Total (a summary score representing all 22 items). Items are scored so that higher scores indicate the presence of the construct, for example, higher scores on the Anxiety scale indicate a greater degree of anxiety.

The Rand corporation, through a series of psychometric studies, has shown the RW-B to be a reliable and valid instrument. Internal consistencies for each of the six subscales and the two combined indexes are as follows: anxiety (r= .88), depression (r= 84), positive well-being (r= .83), self-control (r= .72), general health (r= .73), vitality (r= .81), mental health index (r= .93), and RW-B total (r= .94). Test-retest reliabilities were only available for the anxiety (r= .70), positive well-being (r=

.74), and the mental health index (r= .80).

Construct validity was examined by correlating scores on each of the subscales and overall scales of the RW-B with other "mental health related variables". Specifically, RW-B scores were correlated with self-reported stress at home, stress on the job, stressful life events, recognition of mental health problems, use of mental health care, and life satisfaction. The manual also indicates that men, married individuals, younger individuals, and those with higher education levels report greater well-being. Thus, sex, marital status, age (although this might reflect negative age-related changes in physiological items only), and education level should all be considered potential covariates in the relationship between psychosocial variables and well-being.

NEO Personality Inventory - Warmth and Gregariousness subscales. The complete NEO-PI is a 181-item scale designed by Costa and McCrae (1985) and is a measure of the "Big 5" personality traits. The complete scale, as well as each of the subscales, has good internal consistency and test-retest reliabilities. Respectable alpha coefficients for the Warmth (.76 for men, .69 for women, and test-retest of .77 over 6 months) and Gregariousness (.65 for men, .66 for women, .92 over six months) subscales have been

reported.

The validity of the NEO-PI has been tied to the 5-factor model of personality and the authors of this scale are to be commended for submitting the studies of the development of their measure to peer-reviewed journals rather than just publishing them in the manual. Convergent validity was established by correlating the NEO-PI subscales with the appropriate subscales from the Eysenk Personality Inventory, the Guilford-Zimmerman Temperament Survey, part of Tellegen's Differential Personality Questionnaire (absorption scale), and the Washington University Sentence Completion Test. In addition, two studies using spouse and peer rating were conducted to obtain "other" ratings of personality and substantial (all correlations of self to other ratings were significant) agreement was demonstrated. Finally, scores on the NEO-PI (couched in terms of the 5-factor model of personality) have been related to psychological well-being, vocational interests and behavior, health perceptions, and coping mechanisms.

Interestingly, when the authors attempted to measure the impact of socially desirable responding (using Eysenk's lie scale and the Marlowe-Crowne Social Desirability Scale) they found that partialling the scores on these measures

did not improve the correlation between self- and spouse-reports. Presumably, if the responses were an attempt to lie on the NEO-PI the correlation (accuracy) between the self- and spouse-ratings should improve after the effect of the response set was removed. This was not the case; in fact, the correlations went down. A complete discussion of the issues surrounding socially desirable responding is not possible (or appropriate) here, it does, however, suggest that considerable thought be given to any analyses involving this construct.

Marlowe-Crowne Social Desirability Scale - Reynold's Short Form. Reynolds (1982) developed a short form containing 13 of the original 33 items from the Marlowe-Crowne Social Desirability Scale (MCSDS; 1960). The short form has internal consistency reliability similar to the original scale (Kuder-Richardson 20 = .76, short form; r= .73-.88, original form). Concurrent validity was established by correlating the short form to the original, full-length MCSDS (r= .93), the Edwards Social Desirability Scale (r= .41), and other short forms of the MCSDS. Reynolds concluded that the short form provides a reliable and valid substitute with 1/3 the items of the original MCSDS.

Rosenberg Self-Esteem Scale. The Rosenberg Self-

Esteem Scale (RSES; Rosenberg, 1965) is a 10-item, unidimensional, self-report scale designed to assess general self-esteem. Reliability is good with reported internal consistencies of .77 to .88 and test-retest correlations of .82 to .85.

Convergent and discriminant validities have been established with the RSES correlated positively with other measures of self-regard, self-confidence, and self-esteem (correlations ranging from .65-.78) and negatively or no correlation with measures of anxiety (-.64), depression (-.54), GPA (.01, .10), and vocabulary (-.04) to name a few (see Blascovich & Tomaka, 1992, for a review).

Chapter 3

Results

To the first research question, do survivors differ in their self-reported level of well-being? The answer is yes. Long-term survivors report significantly less total well-being compared with controls (all Tables in Appendix C). A one-way ANCOVA controlling for the effects of age, sex and Marlowe-Crowne scores (which, in one-way ANOVAs were found to be significantly different for the groups - see Tables 2 and 3), revealed a significant main effect for group ($F= 78.9$, $p < .001$). The means, standard deviations, counts, F and p-values for all the variables are shown in Table 3.

The Rand Well-Being measure also provides sub-scales that allow one to break the total well-being score into six categories. ANCOVAs on each of the sub-scales revealed that survivors report significantly more depression and anxiety while also reporting significantly less positive well-being, self-control and health. The means, standard deviations, counts, F, and p-values for each of the Rand Well-Being subscales are shown in Table 4.

Two different correlational approaches (see the correlation matrices for each group in Tables 5 and 6) were employed to answer the second research question. Namely,

do intimacy and marital adjustment represent significant, positive inputs to well-being in long-term survivors of childhood cancer and controls? The answer is somewhat less clear.

First, an omnibus regression equation was constructed using six blocks of variables (age, sex = first block, personality - NEO subscales and MC = second block, self-esteem = third block, intimacy - DAS and MSI = fourth block, and the interaction of personality and intimacy = fifth block, four, dummy-coded groups: survivor, spouses, control A, and control B = sixth block) to predict well-being. Computing interaction (product) terms and including them in regression equations allows one to test whether particular variables interact to produce stronger effects than when used individually. Each of the blocks was entered with stepwise selection within each block allowing for the strongest predictors to emerge within each block. This omnibus regression accounted for 27% of the variance (multiple R = .52, r-square = .27) and self-esteem and the interaction of NEO warmth and intimacy (Miller Social Intimacy) emerged as the only significant predictors of well-being (see table 5). The group variable was non-significant.

Multiple regression equations were then constructed for,

and tested on, the survivors and controls separately. With well-being as the dependent variable, age, sex, and Marlowe-Crowne scores were entered first allowing them to account for any variance due them before the other variables were entered. Intimacy, marital adjustment, self-esteem, gregariousness, warmth, and the interaction terms were entered in the final block using the stepwise selection technique. The stepwise technique was chosen to allow the strongest predictor of well-being to emerge from this group of variables.

For the survivors, an equation accounting for 18% of the variance (r=.42, r-squared = 17.7) in well-being included intimacy (B =.26, p< .01), and self-esteem (B =.23, p< .01) as significant predictors. For the controls, the same equation accounted for 16% of the variance in well-being (r=.40, r-squared=.16) included marital adjustment (B = -.35, p < .01) as the only significant predictor. None of the other variables, including age, sex, or Marlowe-Crowne scores, carried significant beta weights. In addition, several sociodemographic variables for both the survivor and control groups (income, education, religion, number of children, number of girls, and number of boys) and, for survivors, the medical variables (radiation, chemotherapy, surgery, age at

diagnosis, and relapse) were entered in separate regressions with well-being as the dependent variable. None of the sociodemographic or medical variables was a significant predictor of well-being. The regression equations are presented in Table 7.

For the third, and final, research question regarding the existence of any mediating effects of age, sex, or personality (Marlowe-Crowne, NEO Gregariousness and Warmth) on the relationship between intimacy, marital adjustment, and well-being were tested using path analysis (Bentler's EQS program). A model, conceived a priori (see Figure 1), was tested on the long-term survivor's data first and then the control data to determine whether the same model fit the data from both samples. It did not fit for either group.

Several other models were then tested to determine whether they fit the data. The model that fit (independence model chi-square = 196 (21 d.f.), $p < .001$; model chi-square = 11.2, $p < .02$; NFI = .94, CFI = .96, Robust CFI = .97) the long-term survivor's data is presented in Figure 2.

The model that fit the survivor's data was then tested on the control group's data and it did not fit. The model that fit (independence model chi-square = 59 (10 d.f.), p<

.001; the model chi-square = 1.5, p <.69; NFI = .98, CFI = 1.0) the control group's data is presented in Figure 3.

Chapter 4

Discussion

Summary and Integration

Long-term survivors of childhood cancer report less overall well-being than controls. They report more depression and anxiety, and less positive well-being, self-control, and health. The significant predictors of well-being (keeping in mind that they differ, depending on the analysis, and the groups) include self-esteem, intimacy, marital adjustment, and the interaction of a warm personality with high levels of intimacy in one's primary relationship. Finally, the pattern of relationships among these variables (as shown in the path analyses) differ for the groups. This finding, and the resulting path analyses, seem to indicate that the explanation of reported feelings of well-being is more complex for long-term survivors of childhood cancer than for controls.

In the regression analyses self-esteem emerged as a significant predictor of well-being for survivors but not for the controls. Moreover, the path analyses indicate that in the survivor group well-being predicts intimacy rather than intimacy predicting well-being, as was hypothesized. These findings might indicate that for survivors positive self-esteem must be present before

intimate relationships can flourish. This finding could be taken as support for Erikson's (1969)theory of development which asserts that the developed sense of self precedes intimacy concerns. It is possible that having had cancer as a child or adolescent may have influenced their developing sense of self and self-esteem. Indeed, previous research has consistently supported the critical role of self-esteem in positive adaptation to cancer survival (Berry-Sawyer, 1992; Koocher, et.al., 1980; Spinetta, 1977).

In the control group, on the other hand, intimacy and marital adjustment predict well-being, which is what social support or social ties researchers would predict (i.e., that intimate relationships increase our well-being and health). The regression analysis showed that marital adjustment was the only significant predictor of well-being for the controls. However, the beta-weight was negative. This is curious, and in the opposite direction from what was predicted. One can only speculate about why when well-being decreases, marital adjustment increases. It may be that there is a certain balance between negotiating self-concerns with relationship-concerns and that this requires a trade-off of personal well-being for the sake of the relationship. One could speculate that the composition of

the control group (i.e., a higher proportion of women than in the survivor group) had some influence on this result. Women tend to focus more on defining themselves within relationships than do men (Gilligan, 1982). This focus might lead to the sacrifice of personal well-being for the improvement of the relationship. This finding may parallel in some way the research that finds health benefits of marriage for men but not for women (House, Landis, & Umberson, 1988).

The significant difference between groups with survivors reporting less overall well-being, more depression and anxiety, and less health, positive well-being, and self-control converge with the findings of some late-effects researchers (Koocher & O'Malley, 1981; Fobair, et.al., 1986; Cella, et.al., 1988; Ostroff, Smith & Lesko, 1989). Because this study used measures intended to tap more normative differences in well-being, rather than measures designed to test for more serious psychopathology, it may have been more sensitive to and therefor more able to detect subtle decrements in well-being. This focus on more normative levels of distress is similar to that adopted in the studies mentioned above in which the findings of less well-being and more distress were also noted. Koocher and O'Malley's (1981) study, for example,

utilized interviews, as well as objective measures increasing the likelihood that more subtle differences would be found.

Survivors' reports of significantly higher self-esteem than controls is consistent with some previous findings (Gray, et.al., 1992; Anholt, Fritz, & Keener, 1993) and inconsistent with others (Greenberg, Kazak, & Meadows, 1989). As stated earlier, positive self-esteem has been found by several researchers to be the best predictor of adaptation and well-being. It has also been suggested as a "buffer" against psychological distress from trauma and other negative life events (Garmezy & Rutter, 1983; Rutter, 1987).

Survivors' reports of significantly higher levels of intimacy in their primary relationship and better overall marital adjustment are inconsistent with previous findings (Koocher & O'Malley, 1981; Cella & Tross, 1986; Fobair, et.al., 1986; Gray, et.al., 1992). The survivors' elevated Marlowe-Crowne (M-C) scores provide one possible explanation for the significantly higher self-esteem, intimacy, and marital adjustment scores. High M-C scores have been found in other survivor populations and have been interpreted as defensiveness, denial, or self-presentational concerns by several authors (Koocher &

O'Malley, 1981; Cella & Tross, 1986; Wasserman et.al., 1987; Greenberg, Kazak, & Meadows, 1989; Zevon, Neubauer, & Green, 1991; Madan-Swain, 1994). This self-presentational set is widely recognized as a possible contaminant, especially in measures of positive or desirable characteristics (e.g., intimacy, marital adjustment).

One alternative explanation of the significantly higher levels of self-esteem, intimacy, and marital adjustment in long-term survivors is the increased appreciation of life and change in priorities that they (and others, e.g., AIDS patients) sometimes report following their experience with life-threatening illness (Anholt, Fritz, & Keener, 1993). This change in priorities or gaining of perspective may lead to a shift of focus to increased appreciation of relationships and the support they provide.

One implication of these findings is that one must include measures like the M-C (or other better measures of socially-desirable responding) that allow for statistical control of self-presentational set. To test the second explanation, one could design questions to tap survivors' values and priorities, especially focusing on the importance of relationships and significant others in their lives. One could attempt to differentiate "defensive"

self-presentational concerns from genuine valuing or prioritization of relationships and intimate connections with others.

While I think this study raises more questions than it answers, it contributes to the resolution of some current issues. First, the findings of this study indicate that survivors are reporting less overall well-being. This finding supports the assertion that researchers need to abandon their search for serious pathology and focus instead on detecting differences in well-being or more normative levels of distress. Second, survivors' reports of higher levels of self-esteem, intimacy, and marital adjustment indicate that (once the influence of self-presentational concerns is controlled) overall, long-term survivors have adjusted well in several important areas of their lives. These results also indicate that there is still much work to be done in determining the relevant contributors to well-being.

Implications

Theoretical Implications. The findings of this study have implications for theoretical development specific to long-term cancer survivors as well as for clinical and health psychology more generally. First, a better theory of well-being is needed. Is well-being the same as absence

of pathology?; probably not. What then, influences well-being? Are there individual differences in the well-being "set-point"? Can this be raised? If so, how? What contributes to positive well-being? Are relationships with others one possibility? If yes, we need to develop a theory of intimacy or social ties that spells out the critical components related to well-being.

Finally, we need to determine what contributes to well-being, or lack thereof, for long-term survivors of childhood and adolescent cancer. None of the medical variables, nor age, sex, income, education, religion, or number of children was correlated to well-being. Other researchers have found repeatedly that psychosocial variables are better predictors than medical or sociodemographic variables which have little if any power to predict long-term adjustment (Anholt, et.al., 1993; Berry-Sawyer, et.al., 1992; Fritz, et.al., 1988; Koocher, et.al., 1980; Lesko, 1990; Rait, et.al., 1992).

Ideally, theoretical development would lead directly to development of better measures of intimacy using more items (to increase reliable variance) across several domains of intimacy (e.g., affect expression, companionship, tolerance of expressed emotion, feedback that allows for reality checks without injuring, knowing

that one is accepted and cared for). Measures based in theory could potentially provide more satisfying explication of the critical components in the intimacy-well-being relationship. In addition, a more exploratory, microanalytic research approach could be adopted to allow one to look for the ways in which intimacy is expressed in daily interactions and whether, and in what forms, they correlate with well-being.

Applied Implications. Some of these findings could be applied in clinical settings by encouraging health care providers to attend to the well-being of survivors. Some clinicians have observed that survivors' are experiencing diminished well-being (Zevon, personal communication). Research, however, has not always born this out. While there could be any number of reasons for this (like the ones mentioned earlier), this study is one more on the side of the ledger supporting clinicians' perceptions. Further theoretical development and a body of consistent research findings are required before any intervention is designed. It seems prudent at this time, however, to conclude that self-esteem is critical to positive adjustment and it should be targeted for ongoing assessment and possibly, intervention. Long-term cancer survivors can be encouraged to focus on the strengths that helped them cope and adjust

to their diagnosis and treatment. They might also be encouraged to develop stronger self-concepts (or alternate selves, see works by Markus and Higgins) that are not organized around their cancer experience but rather other positive qualities they possess.

It remains to be seen whether future research will support the role of intimacy, or marital adjustment as critical to well-being. If a body of research supports this connection, relationship counseling, especially given survivors' relapse and reproductive concerns, could be provided to those survivors' having adjustment difficulties, relationship problems, or experiencing diminished well-being.

Limitations and Recommendations for Future Studies

This study has several strengths which include, (1) a large sample of long-term survivors, (2) a control group without a history of childhood cancer, and (3) use of well-established and validated instruments. Nevertheless, there are limitations that pose threats to both internal and external validity. Future work could be improved by careful attention to these issues.

First, the all self-report, correlational design is problematic. The significantly higher M-C scores found in the survivor sample are one possible concern. Furthermore,

the survivors' M-C scores are correlated significantly with all the measures except well-being, while the M-C correlated significantly only with age and self-esteem for the controls. These significant correlations were the reason M-C scores were forced into the regression equations where they emerged as nonsignificant predictors of well-being. Future work could benefit from a multi-trait, multi-method approach which would include multiple measures of each trait (e.g., well-being and intimacy), and some observational (e.g., interview and observation of behavior in interactions) and collateral (significant other, family, friends, and health care workers) reports. This approach would allow for triangulation of measures and methods allowing one to reduce the impact of any self-presentational set.

In addition, with correlational data, one cannot make any statements about causation. In other words, it is possible that intimacy causes increased well-being, but it is also possible that positive well-being causes increased intimacy. With correlational data there is no way to rule out the possibilities of reverse causation, third-variable explanations, or circular causation. Regression and path analytic analyses can address some of this by changing specification of the dependent and independent variables.

Only through experimental manipulation and control can one begin to make statements of causality. One could, for example, treat one group of survivors with intimacy-focused relationship therapy (e.g., Waring, et.al.'s , 1994) and collect data to determine if changes in intimacy parallel changes in well-being.

Cross-sectional data does not allow one to detect changes in well-being or intimacy over time. It is very likely that well-being fluctuates (perhaps around some individual set-point) as would intimacy levels in one's relationship. One might expect intimacy levels to be higher or lower depending on the developmental phase of the relationship.

Second, to increase external validity or generalizability one should obtain a more representative "non-survivor" control group. It is likely that the control samples in this study were not representative of the entire "non-survivor" population. External validity could also be strengthened by including survivors of other illnesses with possible life-threatening relapse (e.g., multiple sclerosis) as comparison groups to improve one's ability to say something unique about long-term cancer survivors. Moreover, dividing the survivor sample by diagnosis would decrease the contamination of differences

in prognosis, likelihood of recurrence, and treatment variables inherent when survivors of all diagnoses are treated as one group. This would require consideration of power when determining whether one has sufficient numbers of survivors of each diagnosis (which is often not the case, but could be if national data bases were constructed and available to all researchers).

One must also consider the data analytical and statistical limitations of one's work. The data analytic strategy employed in this study used different approaches to answer two basic questions: "Is there a difference?", and "Can we explain that difference?" One must be careful when doing multiple significance tests (as computed in the ANCOVAs) to use corrections to prevent alpha slippage. The results of the two different regression approaches also highlight the importance of how different data analytic strategies allow one to maintain as much variability in the data as possible. When the regressions were run on the groups separately, the interaction terms were not significant. When the groups were treated as a dummy-coded variable in the omnibus equation, variance was maximized and the interaction of warmth and intimacy emerged as a significant predictor.

Finally, while a correlation of 0.2 might be

statistically significant it indicates the two variables share only 4% of their variance. This begs the question, "Is this a "real" significant relationship?". Similarly, is a difference of 3 or 4 points on a questionnaire an "important" difference.

Measurement limitations in this study are a combination of theoretical specification and definitional issues as well as the pragmatic decisions that enter into the design of questionnaire-based research. The measure of marital adjustment, for example, has only a few items in each subscale which can lead to lowered reliability and limits the usefulness of these subscales in some analyses. The measurement of intimacy could benefit from attention to different components of intimacy as they may differ in their relationship with well-being. In other words, all types of intimacy may not be equally important for well-being. This is a theoretical and definitional problem as well as an instrumentation problem.

This study supports the shift away from measures designed to tap serious psychopathology and toward more subtle measures of well-being and normative distress. It is probably the case that, just as positive affect is not the opposite of negative affect, well-being is not simply the opposite of doing poorly. Focusing on those

individuals who seems to be doing well, rather than only on those experiencing difficulties, would allow one to discover the correlates of well-being. The ways in which these individuals are coping that allow them to experience positive well-being, despite (or maybe because of) their cancer history and ongoing stressors, would be informative and would aid in theory development. One would ask, "What are their strengths and do relationships with others contribute to them?" In other words, an approach like that adopted in the resilience research and literature might provide new insights (e.g., the work of Garmezy and colleagues) into the progression from adaptation, to adjustment, to well-being.

These findings speak not only to the case of long-term survivors of childhood cancer, but to all individuals. The explanation of well-being for the control groups is not any more compelling than that for the survivors. This study highlights the need for further development of a theory specifying the critical contributors to well-being. In addition, if the importance of social ties for well-being is to be promoted, we must have increased specification of the critical components of intimate relationships or social ties that affect well-being (e.g., affect expression, companionship, tolerance of expressed emotion). An

exploratory, integrative, and microanalytic approach examining day-to-day interactions with significant others and the effect (or lack thereof) they have on changes in well-being would be informative. A naturalistic, observational study could be designed in which a couple records their interactions, the situation, behaviors during the interactions, level of intimacy experienced, and their well-being. One could then determine whether and which behaviors are correlated with increased experience of intimacy and whether this correlates with increased well-being. This approach would also generate interesting data allowing one to examine the convergence or divergence of each partner's ratings. One could also determine the durability of these influences over the short and long-term. I suspect that the events, behaviors, and interactions that affect short-term well-being may be different from those which affect a more global or long-term sense of well-being.

In closing, this study represents another small increment in the knowledge of long-term cancer survivors' experiences and provides interesting new questions and avenues of research.

Appendix A

Introductory Letter to Survivors

Dear Name,

We would like to express our appreciation to you for your participation in our ongoing follow-up study. Our work to date has resulted in a number of important findings, and we plan on sharing this information at a later date with those of you who are interested. Your continued involvement in this project has been extemely helpful in planning support and educational programs.

We would also like to let you know that we are beginning a new phase of our program during which we are interested in gathering information about you and your relationships with others. We are planning two mailings in this phase. The first packet of materials will be mailed our within the next week. Shortly thereafter, we will contact you by telephone to answer any questions you might have about the included materials.

As before, you participation is voluntary, and your answers will be help in strict confidence. We would be happy to discuss this study or any other questions you might have; feel free to contact Dr. Green at (716)845-2334 or Dr. Zevon at (716)845-3052. If your call is long distance, use our toll free number: 1-800-726-2220. If you do not wish to be included in this phase of our program, please call and let us know that you would prefer not to participate.

Once again, Name, thank you for helping us with this study. Based on your participation we hope to be able to provide better care based on more complete understanding of the problems encountered by former patients.

Sincerely,

Daniel M. Green, M.D.
Department of Pediatrics

Michael A. Zevon, Ph.D.
Department of Psychology

Appendix B

Questionnaires

NEO Personality Inventory Warmth and Gregariousness Subscales

In the blank provided, please write the letter of the answer which best represents your opinion. There are no "right" or "wrong" answers.

Mark SD if you *strongly disagree* or if the statement is *definitely false*.
Mark D if you *disagree* or if the statement is *mostly false*.
Mark N if you are *neutral* on the statement, you *cannot decide*, or if the statement is about *equally true and false*.
Mark A if you *agree* or the statement is *mostly true*.
Mark SA if you *strongly agree* or believe that the statement is *definitely true*.

1. I really like most people I meet.
2. I shy away from crowds of people._____
3. I don't get much pleasure from chatting with people.___
4. I like to have a lot of people around me._____
5. I'm known as a warm and friendly person._____
6. I usually prefer to do things alone.
7. Many people think of me as somewhat cold and distant.__
8. I really feel the need for other people if I am by myself for long._____
9. I really enjoy talking to people._____
10. I prefer small parties to large ones._____
11. I find it easy to smile and be outgoing with strangers._____
12. I'd rather vacation on a popular beach than an isolated cabin in the woods._____
13. I have strong emotional attachments to my friends._____
14. I prefer jobs that let me work alone without being bothered by other people._____
15. I take personal interest in the people I work with.____
16. I would rather watch an event on television than be there in the audience._____

Marlowe-Crowne Social Desirability Scale - Short Form

Listed below are a number of statements concerning personal attitudes and traits. Read each item and mark in the space provided *T for true* or *F for False* as it pertains to you personally.

1. It is sometimes hard for me to go on with my work if I am not encouraged._____
2. I sometimes feel resentful when I don't get my way._____
3. On a few occasions, I have given up doing something because I thought too little of my ability._____
4. There have been times when I felt like rebelling against people in authority even though I knew they were right._____
5. No matter whom I'm talking to, I'm always a good listener._____
6. There have been occasions when I took advantage of someone._____
7. I'm always willing to admit it when I make a mistake._____
8. I sometimes try to get even rather than forgive and forget._____
9. I am always courteous, even to people who are disagreeable._____
10. I have never been irked when people expressed ideas very different from my own._____
11. There have been times when I was quite jealous of the good fortune of others._____
12. I am sometimes irritated by people who ask favors of me._____
13. I have never deliberately said something that hurt someone's feelings._____

Rosenberg Self-Esteem Scale

Using the scale below, please record the appropriate answer for each item.

4 = Strongly Agree, 3 = Agree, 2 = Disagree, 1 = Strongly Disagree

1. On the whole, I am satisfied with myself._____
2. At times, I think I am no good at all._____
3. I feel that I have a number of good qualities._____
4. I am able to do things as well as most people._____

5. I feel i do not have much to be proud of._____
6. I certainly feel useless at times. _____
7. I feel that I'm a person of worth, at least on equal plane with others._____
8. I wish I could have more respect for myself.
9. All in all, I am inclined to feel that I am a failure._____
10. I take a positive attitude toward myself.

Rand Well-Being

The following questions ask how you feel and how things have been going for you. For each question, *place a check in the blank provided for the answer which best applies to you.* Please give only *one choice* for each question.

1. How have you been feeling in general (during the last month)?
   1. In excellent spirits___
   2. In very good spirits___
   3. In good spirits mostly___
   4. I have been up and down in spirits___
   5. In low spirits mostly___
   6. In very low spirits___
2. Have you been bothered by nervousness or your "nerves" (during the past month)?
   1. Not at all___
   2. A little___
   3. Some - enough to bother me___
   4. Quite a bit___
   5. Very much so___
   6. Extremely so - to the point where I could not work or take care of things___
3. How often were you bothered by any illness, bodily disorder, aches, or pains (during the last month)?
   1. None of the time___
   2. Rarely___
   3. Now and then, but less than half of the time___
   4. About half of the time___
   5. Almost every day___
   6. Every day___
4. How much energy, pep, or vitality did you have or feel (during the past month)?
   1. Very full of energy - lots of pep___
   2. Fairly energetic most of the time___
   3. My energy level varied quite a bit___

4. Generally low in energy, pep___
5. Very low in energy or pep most of the time
6. No energy or pep at all, I felt drained, sapped___

5. How happy, satisfied, or pleased have you been with your personal life (during the past month)?
   1. Extremely happy - could not have been more satisfied or pleased
   2. Very happy most of the time___
   3. Generally satisfied, pleased___
   4. Sometimes fairly satisfied, sometimes fairly unhappy___
   5. Generally dissatisfied, unhappy___
   6. Very dissatisfied or unhappy most or all of the time___

6. Have you been under or felt you were under any strain, or pressure (during the last month)?
   1. Not at all___
   2. Yes - a little___
   3. Yes - some, but about normal___
   4. Yes - some, more than ususal___
   5. Yes - quite a bit of pressure___
   6. Yes - almost more than I could stand

7. Have you been in firm control of your behavior, thoughts, emotions, or feelings (during the past month)?
   1. Yes, definitely so___
   2. Yes, for the most part___
   3. Generally so___
   4. Not too well___
   5. No, and I am somewhat disturbed___
   6. No, and I am very disturbed___

8. Did you feel depressed (during the past month)?
   1. No - never felt depressed at all___
   2. Yes - a little depressed now and then___
   3. Yes - quite depressed several times___
   4. Yes - very depressed almost every day___
   5. Yes - to the point that I did not care about anything___
   6. Yes - to the point I felt like taking my life___

9. Have you been anxious, worried, or upset (during the past month)?
   1. Not at all___
   2. A little bit___
   3. Some - enough to bother me___
   4. Quite a bit___
   5. Very much so___

6. Extremely so - to the point of being sick or almost sick___

10. Did you feel healthy enough to carry out the things you like to do or had to do (during the past month)?
    1. Yes - definitely so___
    2. For the most part___
    3. Health problems limited me in some important ways___
    4. I was only healthy enough to take care of myself___
    5. I needed some help in taking care of myself
    6. I needed someone to help me most or all of the time___

11. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory (during the last month)?
    1. Not at all___
    2. Only a little___
    3. Some - but not enough to be concerned or worried about___
    4. Some, and I have been a little concerned___
    5. Some, and I am quite concerned___
    6. Yes, very much and I am very concerned___

12. Did you feel relaxed and at ease or high strung, tight, or keyed-up (during the past month)?
    1. Felt relaxed and at ease the whole month___
    2. Felt relaxed and at ease most of the time - seldom or never felt high strung___
    3. Generally felt relaxed but at times felt fairly high strung___
    4. Generally felt high strung but at times felt fairly relaxed___
    5. Felt high strung, tight, or keyed-up most of the time - seldom or never felt relaxed___
    6. Felt high strung, tight, or keyed-up the whole month___

13. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile (during the past month)?
    1. Not at all___
    2. A little bit___
    3. Some - enough to bother me___
    4. Quite a bit___
    5. Very much so___
    6. Extremely so - to the point that I have just about given up___

14. Have been concerned, worried, or had any fears about your health (during the past month)?
    1. Not at all___
    2. Practically never___
    3. Some, but not a lot___
    4. Quite a bit___
    5. Very much so___
    6. Extremely so___
15. Were you generally tense or did you feel any tension (during the past month)?
    1. I have never felt tense or any tension at all___
    2. My general tension level was quite low___
    3. I felt a little tense a few times___
    4. Not generally tense, but did feel fairly tense several times___
    5. Yes - very tense most of the time___
    6. Yes - extremely tense most or all of the time___
16. Did you feel active and vigorous or dull and sluggish (during the past month)?
    1. Very active, vigorous every day___
    2. Mostly active, vigorous - never really dull, sluggish___
    3. Fairly active, vigorous - seldom dull, sluggish___
    4. Fairly dull, sluggish - seldom active, vigorous___
    5. Mostly dull, sluggish - never really active, vigorous___
    6. Very dull, sluggish every day___
17. Have you felt downhearted and blue (during the past month)?
    1. None of the time___
    2. A little of the time___
    3. Some of the time___
    4. A good bit of the time___
    5. Most of the time___
    6. All of the time___
18. Have you felt tired, worn out, used up, or exhausted (during the past month)?
    1. None of the time___
    2. A little of the time___
    3. Some of the time___
    4. A good bit of the time___
    5. Most of the time___
    6. All of the time___
19. Has your daily life been full of things that were interesting to you (during the past month)?

1. All of the time___
2. Most of the time___
3. A good bit of the time___
4. Some of the time___
5. A little of the time___
6. None of the time___

20. Have been waking up feeling fresh and rested (during the past month)?
    1. All of the time___
    2. Most of the time___
    3. A good bit of the time___
    4. Some of the time___
    5. A little of the time___
    6. None of the time___
21. Have you been feeling emotionally stable and sure of yourself (during the past month)?
    1. All of the time___
    2. Most of the time___
    3. A good bit of the time___
    4. Some of the time___
    5. A little of the time___
    6. None of the time___
22. Have you been cheerful and lighthearted (during the past month)?
    1. All of the time___
    2. Most of the time___
    3. A good bit of the time___
    4. Some of the time___
    5. A little of the time___
    6. None of the time___

SECTION B

If you are not married, or romantically involved with someone, please skip to the bottom of page 4 in section B (marked with an arrow), otherwise continue.

Miller Social Intimacy Scale

For the next 17 items, please keep in mind either your partner or spouse. For each statement below, please select a number from 1 to 10 with 1 (very rarely) and 10 (almost always) that best describes your relationship.

Very Rarely				Some of the Time				Almost Always	
1	2	3	4	5	6	7	8	9	10

1. When you have leisure time how often do you choose to spend it with him/her alone?_____
2. How often do you keep very personal information to yourself and do not share is with him/her?
3. How often do you show him/her affection?_____
4. How often do you confide very personal information to him/her?_____
5. How often are you able to understand his/her feelings?_____
6. How often do you feel close to him/her?_____

Please use the following scale for questions 7-17.

Not Much				A Little				A Great Deal	
1	2	3	4	5	6	7	8	9	10

7. How much do you like to spend time alone with him/her?_____
8. How much do you feel like being encouraging and supportive to him/her when he/she is unhappy?_____
9. How close do you feel to him/her most of the time?_____
10. How important is it you listen to his/her very personal disclosures?_____
11. How satisfying is your relationship with him/her?
12. How affectionate do you feel towards him/her?_____
13. How important is it to you that he/she understands your feelings?_____
14. How much damage is caused by a typical disagreement in your relationship with him/her?_____
15. How important is it to you that he/she be encouraging and supportive to you when you are unhappy?_____
16. How important is it to you that he/she show you affection?_____
17. How important is your relationship with him/her in your life?_____

Dyadic Adjustment Survey

Most persons have disagreements in their relationships. Please indicate below the approximate *extent of agreement or disagreement between you and your partner* for each item on the following list.

5 = Always Agree, 4 = Almost Always Agree, 3 = Occasionally Agree, 2 = Frequently Disagree, 1 =

Almost Always Disagree, 0 = Always Disagree

1. Handling family finances_____
2. Matters of recreation_____
3. Religious matters_____
4. Demonstrations of affection_____
5. Friends_____
6. Sex relations_____
7. Conventionality (correct of proper behavior)_____
8. Philosophy of life_____
9. Ways of dealing with parents of in-laws_____
10. Aims, goals, and things believed important_____
11. Amount of time spent together_____
12. Making major decisions_____
13. Household tasks_____
14. Leisure time interests and activities_____
15. Career decisions_____

Please use the following scale for the next set of items.

5 = All the time, 4 = Most of the time, 3 = More often than not, 2 = Occasionally, 1 = Rarely, 0 = Never

16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?_____
17. How often do you or your mate leave the house after a fight?_____
18. In general, how often do you think that things between you and your partner are going well?_____
19. Do you confide in your mate?_____
20. Do you ever regret that you married (or lived together)?_____
21. How often do you and your partner quarrel?_____
22. How often do you and your mate "get on each other's nerves"?_____
23. Do you kiss your mate? (Check only one.) ___ Every Day ___ Almost Every Day ___ Occasionally ___ Rarely ___ Never
24. Do you and your mate engage in outside interests together? (Check only one.) ___ All of them ___ Most of them ___ Some of them ___ Very few of them ___ None of them

How *often* would you say the following events occur between you and your mate/partner?

0 = Never, 1 = Less than once a month, 2 = Once or twice a month, 3 = Once or twice a week, 4 = Once a day, 5 = More often

25. Have a stimulating exchange of ideas _____
26. Laugh together _____
27. Calmly discuss something _____
28. Work together on a project _____

These are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no.)

	Yes	No
29. Being too tired for sex	___	___
30. Not showing love	___	___

31. Which words below best describe the degree of happiness, all things considered, of your relationship? (Check only one.) ___ Extremely Unhappy ___ Fairly Unhappy ___ A Little Unhappy ___ Happy ___ Very Happy ___ Extremely Happy ___ Perfect

32. Which of the following statements best describes how you feel about the future of your relationship? (Check only one.)

___ I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.

___ I want very much for my relationship to succeed, and *will do all I can* to see that it does.

___ I want very much for my relationship to succeed, and *will do my fair share* to see that it does.

___ It would be nice if my relationship succeeded, but *I can't do much more than I'm doing now* to help it succeed.

___ It would be nice if it succeeded, but *I refuse to do any more than I am doing now* to keep the relationship going.

___ My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

Appendix C

Table 1

CHARACTERISTICS OF RESPONDENTS AND NON-RESPONDENTS

Characteristic	Respondents (N=207)	Non-Respondents (N=47)
Sex		
Male	114 (55.1%)	22 (46.8%)
Female	93 (44.9%)	25 (53.2%)
Race		
White	202 (97.6%)	46 (97.9%)
Non-White	5 (2.4%)	1 (2.1%)
Mean age at evaluation	28.85	29.56
Mean age at diagnosis	11.58	12.37
Mean time since diagnosis	17.02	17.20
Diagnosis		
ALL	45 (22.3%)	11 (24.4%)
Hodgkin's Lymphoma	52 (25.7%)	14 (31.1%)
Non-Hodgkin's Lymphoma	24 (11.9%)	7 (15.6%)
Sarcomas	38 (18.8%)	7 (15.6%)
Wilm's Tumor	9 (4.5%)	1 (2.2%)
Other	34 (16.8%)	5 (11.1%)
Presence of Metastatic Disease		
Yes	10 (4.8%)	3 (6.4%)
No	197 (95.2%)	44 (93.6%)
Treatment		
Surgery		
Yes	118 (57.0%)	27 (57.4%)
No	89 (43.0%)	20 (42.6%)

Radiation		
Yes	121 (58.5%)	26 (55.3%)
No	86 (41.5%)	21 (44.7%)
Chemotherapy		
Yes	166 (80.2%)	34 (72.3%)
No	41 (19.8%)	13 (27.7%)
Occurrence of Relapse		
Yes	41 (19.8%)	9 (19.1%)
No	166 (80.2%)	38 (80.9%)
Occurrence of Second Cancer		
Yes	11 (5.3%)	2 (4.3%)
No	196 (94.7%)	45 (95.7%)

Note. There were no significant differences between respondents and non-respondents with respect to these variables.

Table 2

MEANS, STANDARD DEVIATIONS, COUNTS,
F, AND P - VALUES FOR AGE AND SEX BY GROUP

	Survivors	Spouses	Controls	F,p-value
Age	28.1 6.3 207	29.3 6.5 122	31.1 10.6 251	6.8 p< .001
Sex	M = 114 F = 93	M = 72 F = 54	M = 111 F = 142	4.2 p< .05

Table 3

MEANS, STANDARD DEVIATIONS, COUNTS,
F AND P VALUES FOR ALL VARIABLES

	Survivors	Spouses	Controls	F,p-value
Marlowe-Crowne	7.6 3.2 203	7.4 3.0 122	5.8 2.7 254	26.7 p< .001
NEO - Warmth	31.4 4.6 207	23.2 4.1 124	27.3 8.4 253	65.2 p< .001
NEO - Gregari-ousness	24.5 4.7 204	15.9 5.1 125	23.7 6.0 251	113.3 p< .001
Self - Esteem	32.3 4.5 202	32.1 4.4 123	20.9 1.3 69	216.8 p< .001
Intimacy	143.0 18.1 144	146.6 17.5 125	137.8 19.3 64	5.1 p< .01
Marital Adjust-ment	96.0 9.1 122	96.7 8.8 111	92.3 8.5 62	5.3 p< .01

Table 4

MEANS, STANDARD DEVIATIONS, COUNTS,
F, AND P VALUES FOR THE WELL-BEING SUBSCALES*

	Survivors	Controls	F, p-value
Anxiety	20.1 3.3 206	15.2 4.1 253	194.2 p< .000
Depression	15.3 2.8 205	6.3 2.6 253	1262.3 p< .000
Health	10.3 1.8 206	13.1 3.0 253	137.0 p< .000
Positive Well-Being	14.0 1.4 207	15.1 3.4 254	18.6 p< .000
Self-Control	15.3 2.7 205	11.9 4.5 253	88.3 p< .000
Vitality	15.5 2.2 207	15.1 3.5 254	1.7 p = n.s.
Total Well-Being	79.1 5.1 204	89.2 16.9 253	78.9 p< .000

* Sub-scales are scored such that higher scores indicate more of the attribute in the title of the sub-scale

Table 5

CORRELATION MATRIX FOR SURVIVORS

	Age	Sex	M-C	NEOg	NEOw	RSES	DAS	MSI	RW-B
Age	1.0								
p<									
Sex	.05	1.0							
p<	n.s.								
M-C	.04	.01	1.0						
p<	n.s.	n.s.							
NEOg	-.18	.23	.15	1.0					
p<	.01	.00	.05						
NEOw	-.07	.24	.30	.61	1.0				
p<	n.s.	.00	.00	.00					
RSES	.00	-.06	.33	.17	.34	1.0			
p<	n.s.	n.s.	.00	.05	.00				
DAS	-.14	-.08	.22	.16	.25	.35	1.0		
p<	n.s.	n.s.	.01	n.s.	.01	.00			
MSI	-.19	.19	.17	.18	.34	.34	.58	1.0	
p<	.05	.05	.05	.05	.00	.00	.00		
RW-B	-.07	.13	.12	.22	.35	.29	.30	.38	1.0
p<	n.s.	n.s.	n.s.	.01	.00	.00	.01	.00	

M-C - Marlowe-Crowne
NEOg - NEO Gregariousness subscale
NEOw - NEO Warmth subscale
RSES - Rosenberg Self-esteem scale
DAS - Dyadic Adjustment Survey
MSI - Miller Social Intimacy
RW-B - Rand Well-Being

Table 6

CORRELATION MATRIX FOR CONTROLS

	Age	Sex	M-C	NEOg	NEOw	RSES	DAS	MSI	RW-B
Age	1.0								
p<									
Sex	-.03	1.0							
p<	n.s.								
M-C	.18	.01	1.0						
p<	.01	n.s.							
NEOg	-.44	.05	-.08	1.0					
p<	.00	n.s.	n.s.						
NEOw	-.44	.12	-.06	.73	1.0				
p<	.00	n.s.	n.s.	.00					
RSES	-.07	.02	.33	-.09	.10	1.0			
p<	n.s.	n.s.	.01	n.s.	n.s.				
DAS	.04	.10	-.10	-.26	.15	-.25	1.0		
p<	n.s.	n.s.	n.s.	.05	n.s.	.05			
MSI	-.22	.21	.09	-.41	.21	-.08	.63	1.0	
p<	n.s.	n.s.	n.s.	.01	n.s.	n.s.	.00		
RW-B	-.16	.10	.10	.37	.49	.29	-.40	-.21	1.0
p<	.01	n.s.	n.s.	.00	.00	.01	.01	n.s.	

M-C - Marlowe-Crowne
NEOg - NEO Gregariousness subscale
NEOw - NEO Warmth subscale
RSES - Rosenberg Self-esteem scale
DAS - Dyadic Adjustment Survey
MSI - Miller Social Intimacy
RW-B - Rand Well-Being

Table 7

REGRESSION EQUATIONS

Omnibus

Well-Being=-.10*Age+.04*sex-.06*M-C +.31*RSES+.42*NEOWxMSI
(n.s.) (n.s.) (n.s.) (p<.02) (p<.05)

Survivors

Well-Being= -.07*Age +.06*Sex -.01*M-C +.26*MSI +.23*RSES
(n.s.) (n.s.) (n.s.) (p<.01) (p<.01)

Controls

Well-Being= -.08*Age + .13*Sex -.13*M-C - .35*DAS
(n.s.) (n.s.) (n.s.) (p<.01)

M-C - Marlowe-Crowne
NEOW - NEO Personality - Warmth subscale
RSES - Rosenberg Self-Esteem Scale
MSI - Miller Social Intimacy
DAS - Dyadic Adjustment Survey

Figure 1

A Priori Path Model

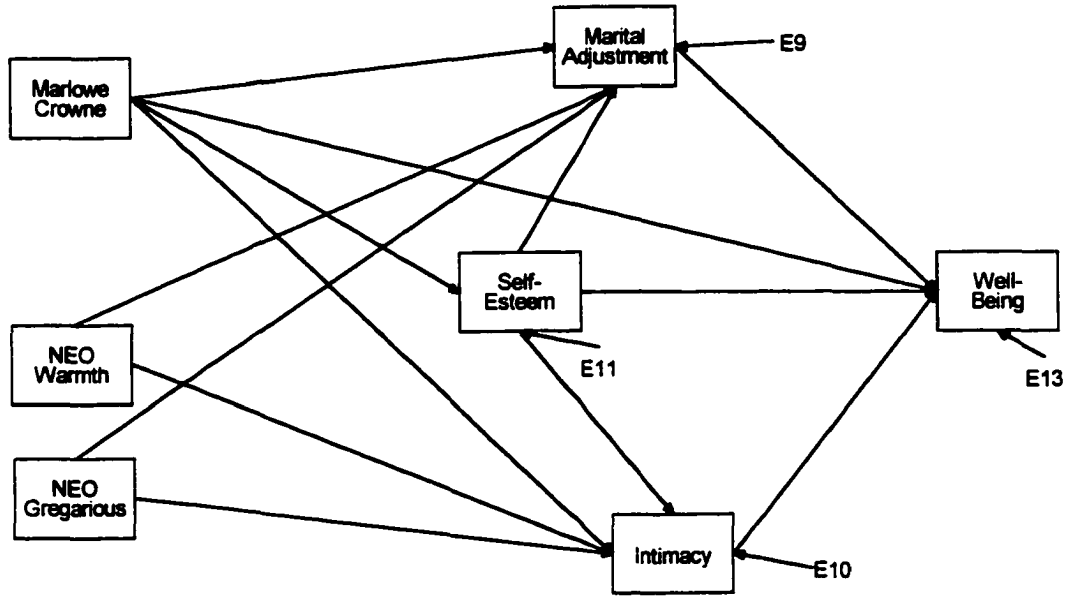


Figure 2

Path Model for Survivors

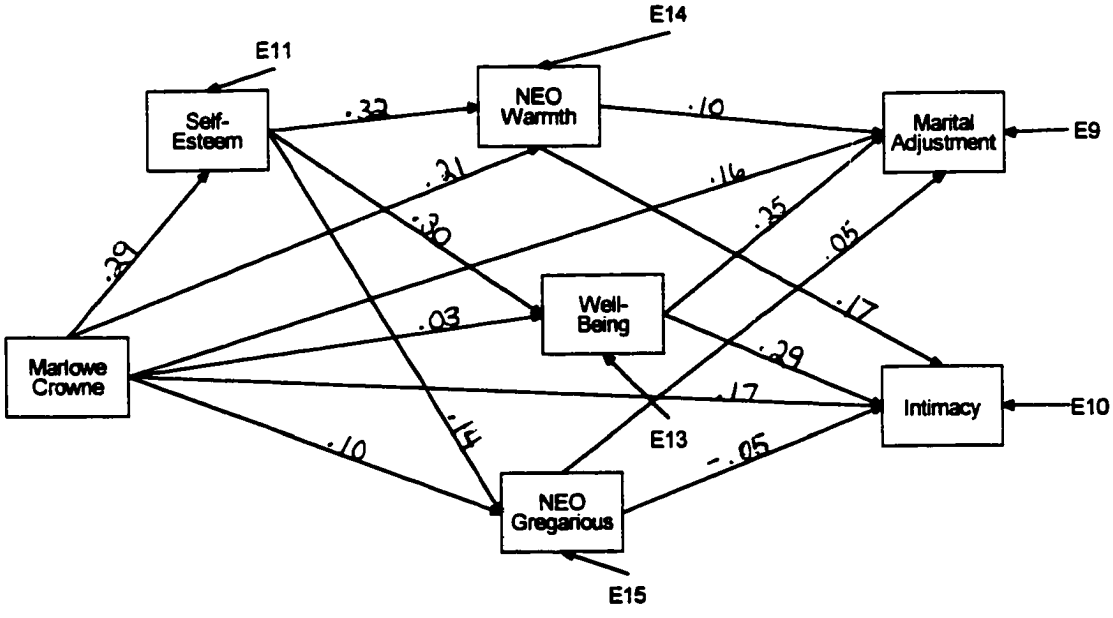
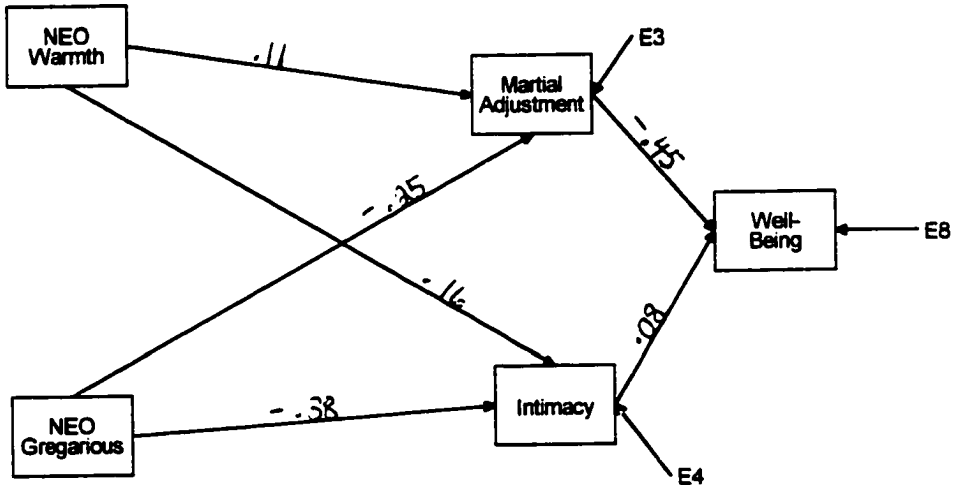


Figure 3

Path Model for Controls



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