ADOLESCENTS WITH CANCER:
SOCIAL SUPPORT, FAMILY ENVIRONMENT, AND COPING

Carol L. Decker

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James G. Daley, PhD- Chair

Margaret E. Adamek, PhD

Doctoral Committee

Carolyn Black, PhD

December 16, 2005

Joan E. Haase, PhD
DEDICATION

This dissertation is dedicated to all of the pediatric cancer patients and their families who allowed me the honor of being a part of their journey. You taught me more than you will ever know. It is also dedicated to my mother, who valued education above almost all else.
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The completion of this dissertation would not have been possible without the support and encouragement of my husband, who patiently listened without criticism to all of my concerns, insecurities and complaints. I am also grateful to my committee chair, James G. Daley, whose guidance and gentle prodding were vital in the dissertation process. My external minor advisor, Joan E. Haase, was also essential to the process both for her mentoring and generosity in sharing her research expertise and data. I need to also thank the other committee members, Margaret E. Adamek and Carolyn Black, for their help and encouragement. As the director of the social work doctoral program and my first research mentor, Dr. Adamek was a tremendous influence throughout my entire doctoral work. Many other social work professors were also supportive of my endeavors, including Cathy Pike, Barry Cournoyer, Bob Vernon, and Valerie Chang. A hardy thanks to all of you and I hope I can live up to your expectations and standards. My fellow doctoral students were also important supports to me throughout this process. Having encouragement and support from peers is vital to any major accomplishment. The faculty, students, and Angela McBride of the School of Nursing were also great supports to me in this process, treating me as one of their own in all ways.
ABSTRACT

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Research has shown that adolescents with cancer (AWC) face treatment that is complex, invasive, and onerous. Coming during a time with major developmental changes, it brings the potential of making high demands on the coping capacity of these adolescents. Using the theoretical frameworks of stress and coping, life-span development and Haase’s (1996) Adolescent Resilience Model (ARM), this study explored the influences of social support and family environment on coping for AWC.

This dissertation analyzed information on coping in AWC to determine the best coping model, analyzed the psychometric properties of the measures with this population, explored gender and age differences for each of the measures of social support, family environment and coping, and investigated the strength of the relationship of social support and family environment to coping in AWC using data from two ARM studies (ARM 1, N=74 newly diagnosed AWC and ARM 2, N=70 adolescent cancer survivors, ages 11-19). For the coping measure (Jalowiec Coping Scale-Revised), a two dimensional model of coping was derived using evidence from factor analysis, item analysis and Chronbach’s alpha. Examination of the items on these dimensions found them to theoretically match two of the three dimensions for a proposed adolescent model of coping derived from the literature. These two dimensions were also used in the subsequent analyses for this study.

For the other measures in the study (social support and family environment), Chronbach’s alpha was adequate, although the item analysis suggested some items to be less appropriate for use with this population. Using MANOVA, gender differences were significant for perceived social support from friends only with female AWC reporting significantly higher levels of support from friends than the males. There were no age group differences found for any of the dependent variables.
From the multiple regression analysis, none of the social support or family environment variables were significantly related to either coping dimension. Sources of error based on the assumptions of multiple regression are discussed along with other possible explanations for these findings. Based on these research findings, future research studies on social support, family environment and coping for AWC are proposed.

James G. Daley, PhD. Chair
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CHAPTER I
INTRODUCTION

Introduction

Coping with the demands of the diagnosis and treatment of cancer can be overwhelming at any time of life, but is particularly challenging for adolescents who face the multiple developmental changes of this life stage bridging childhood and adulthood. Many adolescents have limited experiences in dealing with stressors of this magnitude at a time when the need for effective coping is paramount. Effective coping is important not only to relieve short-term distress, but also for long-term social, cognitive, and personality development and adaptation (Skinner & Wellborn, 1994). Social support and family environment have long been recognized as important factors in the adaptation of adolescents faced with the demands of life changes such as chronic illness (Drotar, 1997; Hartup, 1993; Pelcovitz et al., 1998), yet few researchers have explored the relationship of social support and family environment to coping in adolescents with cancer (AWC). There is also limited knowledge of how adolescents cope with cancer-related stressors. Research exploring the relationship between these concepts can identify useful resources and potential risks for adolescents coping with the experience of cancer. Interventions can then be designed to facilitate effective development and long-term psychosocial adjustment for adolescents with cancer.

This study seeks to increase understanding of coping in AWC. It focuses on instrument and model testing of the external influences (social support from family, friends, and healthcare providers and family environment factors) on coping in AWC using data from two Adolescent Resilience Model (ARM) studies by Haase (2004). The ARM is the result of a series of qualitative and quantitative studies examining adolescents with chronic illness. The ARM components include individual, family, and social protective factors, individual and health-related risk factors, and outcome factors.

This chapter will provide an overview of the unique problems faced by AWC and describe the nature and purpose of the study. The assumptions underlying the study are outlined as well as
the significance of this study to social work practice and research. Conceptual frameworks of stress and coping, adolescent developmental theory, and the Adolescent Resilience Model will also be discussed.

Importance of the Problem

With the dramatic progress in the treatment of pediatric cancer in the past three decades, cancer is now considered a chronic illness with an uncertain prognosis and trajectory (Eiser, 1994). Children in the age group defined as “adolescents” (ages 15-19) by the National Cancer Institute develop cancer at a higher rate than in those in any of the younger ages groups and have the worst rates of mortality and morbidity (Smith, Gurney, & Ries, 1999). Each year approximately 3,800 adolescents are diagnosed with cancer with an additional 2,500 children aged 10-14. The rates for adolescents increased by 30% over the 20 year period from 1975-1995 (Smith et al., 1999) while the rates for younger children increased by only 10%. While the treatment for pediatric cancer overall is increasingly effective, adolescents continue to show the poorest improvement rate.

There is increasing recognition of the special needs and problems of adolescents diagnosed with cancer (Barr, 2001; Lewis, 1996). Unlike other major stressors, such as natural disasters, AWC face stress that is chronic in nature (Pelcovitz et al., 1998) with treatment that is complex, invasive, and onerous (Ellis, 2000). Adolescent cancers are multifaceted, presenting a unique epidemiology ranging from late onset of pediatric cancers, cancers unique to the adolescent period to the early presentation of adult cancers (Barr, 2001). Treatment for these cancers varies according to the type and staging and often includes multiple drugs, radiation, and surgery (Ellis, 2000). Treatment regimens often include painful procedures such as lumbar punctures and bone marrow aspirations, chemotherapy side effects, including nausea, and hair loss, multiple clinic visits or hospitalizations, radiation, and surgery resulting in physical discomfort, multiple school absences and a disruption in daily routines (Lewis, 1996). With treatment periods ranging from six months to several years, the numerous clinic visits and hospitalizations disrupt the daily routine of adolescent life over a long period of time.
In recent studies of posttraumatic stress disorder (PTSD) among adolescents and young adults with a history of cancer, the cancer survivors had significantly higher rates of lifetime PTSD than either physically abused or healthy non-abused adolescents (Hobbie et al., 2000; Pelcovitz et al., 1998). In a comprehensive review of the health status of long-term survivors of childhood cancer, Hudson and colleagues (2003) found moderate to severe impairment in some aspect of mental health across all types of childhood cancers.

The adolescents experience illness-related life disruption in addition to the emotional impact of the life-threatening disease and treatment. For adolescents diagnosed with cancer, the potential impact on their physical and psychological well-being is well documented (Keats, Courneya, Danielsen, & Whitsett, 1999). Common stressors include fear of treatments, the side-effects from treatment, loss of autonomy due to illness, changes in physical appearance, concerns about the future related to school and career, and the potential for being considered “different” (Bull & Drotar, 1991; Enskar, Carlsson, Golsater, & Hamrin, 1997b; Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997a; Konsler & Jones, 1993). Even after the active treatment phase is completed, the AWC faces the constant threat of recurrence of the disease (Pelcovitz et al., 1998). In addition, late effects of childhood cancer include complications, disabilities, or adverse outcomes resulting from the disease process or the treatment process (Institute of Medicine, 2003). Adding to the stressors of the cancer experience, adolescents also face the normal developmental tasks required for the transition from childhood to adulthood.

Adolescence is a complex period in life, serving as a transitional period from childhood to adulthood with all of the challenges inherent to such major transitions. Adolescence is a critical period in psychosocial development that can be disrupted by chronic illness (Bronheim, 1987) including cancer (Koocher, 1981). Adolescents are particularly vulnerable to the psychological effects of trauma due to the impact cancer may have on the major developmental tasks of this life phase (Pelcovitz et al., 1998). The life cycle phase known as adolescence, defined as ages 11-21 (Steinberg, 1999), represents a stage of intersecting biological, intrapsychic, and social forces that combine to contribute to a significant transformation in individual development (Hauser et al., 1991). In conjunction with the psychosocial effects of the cancer experience, AWC are faced with
the normal transitional adolescent developmental tasks. These specific developmental tasks of adolescence are related to psychological functioning and have an impact on social development, including gains in autonomy, self-identity, and the of beginning intimate relations with others (Baltes, Reese, & Lipsitt, 1980; Whyte & Smith, 1997). Research has shown chronic illness to complicate the achievement of adolescent developmental tasks (Stubler & Kazak, 1996; Weekes, 1995).

While none of these developmental tasks is unique to the adolescent with cancer, the demands of cancer and its treatment can result in the loss of self-esteem, personal control, and independence (Lewis, 1996) and concerns with body image and related changes in sexual identity (Kopel, Eiser, & Cool, 1998). Studies of adolescents with cancer demonstrate lasting psychosocial effects of cancer treatment such as social isolation, anxiety, and shyness (Noll, Bukowshi, Davies, Koontz, & Kulkarni, 1993) and problems in peer relationships (Pendley, Dahlquist, & Dreyer, 1997). Such disruption in social relations with peers is reported to increase the risk of long-term adjustment problems for adolescents with cancer (Katz & Varni, 1993) as studies have shown peer acceptance to be closely related to self-esteem in adolescents with cancer (Ellis, 2000). Additional long-term adjustment concerns for adolescents with cancer include academic problems, delayed marriage, health concerns, and worries about the long-term impact on their future with regards to lowered expectations for career and concerns for the impact on the health of their future children (Novakovic et al., 1996; Roberts & Feetham, 1982).

The combination of significant adolescent developmental tasks and the difficult treatment regimen for cancer makes AWC particularly vulnerable to long-term effects from the cancer experience. While the goal of cancer treatment is cure, there is increased understanding of the need to address the broader issues of the cancer experience in order to improve long-term outcomes in addition to cancer-related health issues.

Statement of the Problem

The study addressed two problems: 1) the lack of research on the development of models of coping for AWC and 2) the lack of research on the relationship of social support and family
environment to coping in AWC. Three types of social support (social support from friends, social support from family, and social support from health care providers) were examined. Family environment variables included family adaptability and cohesion, parent-adolescent communication, and family pride and accord.

This study contributes to the existing literature on social support and family environment in AWC by focusing on the relationship of these variables to strategies in coping with the experience of cancer. Many of the studies on social support in AWC have provided descriptive information on sources and levels of social support and satisfaction with the support received. No studies were found in the literature looking at the relationship of social support and coping in AWC.

There are few studies examining family environment in AWC. Studies with children with chronic illness have measured various aspects of family environment, such as adaptability, cohesion or expressiveness, with lower levels significantly related to depression (Bennett, 1994; Lavigne & Faier-Routman, 1993) and poorer social competence (Wallander, Varni, Babani, Banis, & Wilcox, 1989). Higher levels of family environment variables have been significantly related to better psychological adjustment (Kronenberger & Thompson, 1990; Rait et al., 1992; Wallander & Varni, 1989).

No studies were found examining the relationship of family environment to coping in AWC. While there are numerous studies on coping in AWC, most use a two-dimensional model of coping and provide mainly descriptive information such as the number of coping strategies used compared to norms and increased use of specific types of coping strategies, although not all studies were consistent in these findings. From the review of the literature on AWC, no studies were found focusing on the relationship of social support and family environment to coping in AWC.

Purpose of the Study

The purpose of this exploratory research study was to examine the relationship of social support and family environment to coping for AWC using data from the Adolescent Resilience Model (ARM) studies (Haase, 2004). Secondary data analysis is defined as the analysis of an
existing data set resulting in additional or different interpretations, conclusions, or knowledge from previous analyses of the same data (Krysik, 2001). In the original analysis of the ARM data, coping was conceptualized as two dimensional (defensive and courageous coping), combining selected dimensions from the Jalowiec Coping Scale-R (JCS-R) (Jalowiec, 2003). These two coping dimensions were proximal outcomes in the model with several latent variables influencing the two coping dimensions. Distal outcomes were resilience and quality of life. In the current study, an alternate model of adolescent coping was analyzed with this population in addition to the original eight dimensions of coping from the JCS-R. The resulting “best fit” model of coping dimensions was then used in the subsequent statistical analyses to determine the relationship of the social support and family environment variables to coping style for AWC. Figure 1 is an illustration of the variables in the study.

Figure 1 Variables in the Study

Research Aims:

1. To compare the eight dimension models of coping in the Jalowiec Coping Scale (JCS) (Jalowiec, 2003) with an alternate model with the JCS strategies.

2. To evaluate the psychometric properties of the social support, family functioning and coping instruments used in the study.
3. To determine the demographic group differences for each of the measures of social support, family environment and coping.

4. To determine the strength of the relationship of social support and family environment to coping in AWC.

Significance for Social Work

This research study on social support, family environment, and coping has several implications for social work practice in pediatric oncology. First, it is important that the validity and reliability of instruments used with this population be established. In research, valid and reliable instruments are needed to test the effectiveness of interventions to facilitate social support, family environment and coping. These instruments may also be useful in the clinical settings for assessment. This research also contributes to the knowledge base on social support, family functioning, and coping in AWC. Based on this knowledge, future intervention studies can be developed targeting the salient factors that are amenable to change.

This research may also further the development of theory on how social support and family environment influence coping in AWC. Examining two models of coping dimensions provides additional refinement of an existing model of coping for adolescents. While there have been studies looking at coping in AWC, most have used a two dimensional model of coping which recent research has shown to be less appropriate for the adolescent population (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000).

The fundamental goal of coping research is to identify those specific ways of coping which appear best for managing problems, distressing emotions, and relationships (Somerfield & McCrea, 2000). Increased understanding of what is most helpful for AWC would allow the social worker to focus interventions and education most effectively.

Few research studies on AWC provide an adequate sample size to evaluate differences in coping based on gender and age, although such knowledge is necessary to assist social workers in providing appropriate interventions and counseling. This information can also help with forming
and conducting groups for AWC. An understanding of the differences in gender may result in separate groups for boys and girls, discussions about the different ways of coping, or directed discussions with parent groups about these differences.

Assumptions of the Study

Assumptions identified for this study include:

- The experience of the diagnosis and treatment of cancer influences the psychosocial development of adolescents.
- The experience of the diagnosis and treatment of cancer represents a non-normative stressor for adolescents that may challenge their coping ability.
- Coping in adolescents should be conceptualized as multidimensional, although more research is needed to clarify the appropriate model.
- Coping in adolescents with cancer is influenced by social support from family, friends, and healthcare providers and family factors such as family functioning, communication, and family strengths.
- Quality of life and resilience in adolescents with cancer are influenced by the use and effectiveness of coping strategies.

Theoretical Frameworks

This section addresses the theoretical frameworks used in the study. These include a model of stress and coping, life-span developmental theory, and the Adolescent Resilience Model (Haase, 2004).

Stress and Coping Theory

While there are no theoretical models designed specifically for children’s stress and coping, the transactional model developed for adults by Lazarus and Folkman (1984) is widely used in research in children (Ryan-Wenger, Sharrer, & Wynd, 2000). Lazarus and Folkman (1984) describe the stress-coping process as a series of transactions beginning with a stressor from the environment, that results in an appraisal of the situation, an appraisal of the available coping
strategies, and the use of a repertoire of coping behaviors. This appraisal involves five important forms, all related to evaluation of a transaction with the environment: a) the relevancy to one's well-being; b) evidence of already produced harm requiring amelioration; c) threats of future harm; d) the presentation of a challenge; and e) the prediction of a positive outcome. These appraisals are all relevant for the experience of cancer for AWC.

While coping models vary in the weight given to antecedent factors such as personality (McCrae, 1984), resources (Holahan & Moos, 1991), and development through the life span (Alwin, 1994), there several unifying concepts (Folkman & Moskowitz, 2000). These include:

- Multiple functions of coping such as regulation of distress and the management of the problems causing this distress.
- Influences on coping by the appraised characteristics of the stressful situations, including controllability.
- Personality dispositions such as optimism, neuroticism, and extraversion.
- The influence of social resources on coping.

For looking at coping behavior in children, life span developmental theory provides additional insight.

*Life Span Developmental Theory*

Life-span developmental theory provides conceptual and methodological structure for the study of human behavior and change processes (Hultsch & Deutsch, 1981). According to Baltes, Reese and Lipsitt (1980), biological, environmental, and behavioral determinants, combined with specific developmental influences, serve to shape individuals and families. These developmental influences include:

- Age-related normative factors related to chronological age, person-related biological and environmental variables.
- Historical events and normative historical factors.
- Non-normative life events (such as the diagnosis of cancer in children or adolescents), described as events rarely experienced at that time in development.
This perspective views behavior as a change process with developmental change seen as ongoing and never-ending from the prenatal period through death, influenced by current and past events (Baltes et al., 1980). Over time, positive and negative changes occur in behavior. Along with these changes, new processes are mobilized that, in turn, affect the behaviors selected to enhance adaptation to the new circumstances. Thus, development is a complex phenomenon and not always uniform across the various developmental domains. This variation is influenced by the biogenetic processes as well as historical-cultural conditions and normative and non-normative events.

The life-span developmental perspective is particularly salient due to the social nature of human beings (Rutter, 1989) for whom social development results from interactions with the social environment. Development includes the concepts of emotions and social relationships as well as the capacities in these areas. While there are many important universals in human development, social development can follow many pathways with a variety of endpoints.

The timing of experiences are seen as equally important as the nature of the experiences (Rutter, 1989). On a biological level, experiences can have different effects on neural development depending on when they occur. These effects will also be regulated by the psychological processes emerging at the time, such as the developing identity and changes in autonomy. Timing is important because experiences will be felt differently or result in different societal responses if they occur at non-normative times.

It is also important to recognize the indirect effect of experiences. The impact of some factor in childhood or adolescence may not be reflected in immediate behavioral changes, but may begin a chain reaction which influences the developmental processes at a later time. Better understanding of the processes and mechanisms involved in both the indirect and direct effects provide knowledge to design interventions as needed to foster normal development.

The diagnosis of cancer represents a significant non-normative life event that will affect the development of adolescents during a significant transitional phase. The specific developmental tasks of adolescence related to biological and psychological functioning have an impact on social development, including the completion of puberty, gains in autonomy and self-identity as well as
beginning intimate relations with others (Baltes et al., 1980; Whyte & Smith, 1997). While none of these tasks is unique to the adolescent with cancer, the demands of cancer and its treatment can result in the loss of self-esteem, personal control and independence (Lewis, 1996) and concerns with body image and related changes in sexual identity (Kopel et al., 1998). One critical assumption of the life-span developmental framework is that life events (in this case the diagnosis and treatment of cancer) will not have the same effect on every individual. There is a need to develop intervention strategies that can modify both individual and shared developmental responses to illness once these responses are more fully understood.

*The Adolescent Resilience Model*

The framework for this study is based on the Adolescent Resilience Model (ARM) (Haase, 2004) seen in Figure 2. This model is the result of a series of qualitative and quantitative studies with chronically ill adolescents, especially cancer (Haase, Heiney, Ruccione, & Stutzler, 1999). The first series, for model generation, included seven qualitative studies, each contributing to the understanding of the cancer experience for adolescents. They included a variety of perspectives—the adolescents, their parents, and nurses. Several concepts were clarified for antecedent, critical attributes, and outcomes. In addition to the inductive approaches, four quantitative studies were conducted by Haase for the model evaluation phase to develop and test the psychometric properties of instruments to measure factors in the ARM. These studies included 1) Courage in Chronically Ill Adolescents; 2) Pilot Study of Instruments and Model Specification for the Becoming Courageous Model (BCM); 3) Factors Affecting Quality of Life Outcomes for Adolescents with Cancer: Cancer Support Interventions; and 4) The Adolescent Resilience Model: Model Development and Instrumentation (ARM 1). These studies provided support for the ARM-related instruments. All instruments had adequate reliabilities (α > .75) and evidence of concurrent and/or construct validity based on correlations and/or predicted factor structures. Stability in the model was evident for most, but not all of the factors. The indicators of defensive coping, courageous coping, and resilience significantly loaded together across the BCM and ARM 1 studies. Indicators for the family protective factors and severity of illness loaded as predicted in the exploratory model for the ARM 1 study, while the indicators of illness perspectives, derived
meaning, health care resources and social integration were unstable in exploratory measure model runs. While this instability may be attributed to small sample sizes and/or the lack of control for stages of illness, further model evaluation was needed. The longitudinal ARM study (ARM 2) was conducted to provide additional evaluation of the model.

The components of the ARM model include individual, family and social protective factors, individual and health-related risk factors and outcome factors (Haase, 2004). The model applies a developmental framework derived from the life-span development perspective (Baltes et al., 1980; Rutter, 1989) to the adolescent diagnosed with cancer, seen as a non-normative event with the potential to influence development. The model seeks to further the understanding of AWC through the examination of these “protective factors” and their influence on coping, resilience, and quality of life.
Figure 2

Adolescent Resilience Model

Illness Related Risk:
Illness Perception
Symptom Distress
Severity of Illness

Individual Risk:
Defensive Coping

Resilience

Quality of Life

Social Perspective:
Health Care Resources
Social Integration

Individual Protective:
Courageous Coping

Family Protective:
Family Atmosphere
Family Support/Resources

Individual Protective:
Derived Meaning

Summary

Adolescents diagnosed with cancer face a trauma that is chronic in nature with treatment that is complex, invasive, and onerous. This trauma comes at a developmental phase involving major developmental tasks, making them especially vulnerable to stress. Using the theoretical frameworks of stress and coping, life-span development, and Haase’s (2004) Adolescent Resilience Model, this study sought to explore the influences of social support and family environment on coping to better understand the experience of cancer for adolescents. From the studies on social support, family support is described as vital for these adolescents. Less clear is how the social support impacts the coping and adjustment of these adolescents. Additional knowledge is needed on appropriate models of coping for adolescents in general, and specifically for AWC. This additional knowledge would further theory development for future research studies as well as guide intervention studies to improve outcomes for AWC. Reliable and valid instruments are important both for use in future research studies as well as for assessment in the clinical setting. Finally, increased knowledge of which coping behaviors are most efficacious for AWC would also be useful for social workers working with these adolescents. Additional information on gender and age differences for these variables would enable social workers to better assess the strengths and potential needs of the adolescents.

Additional knowledge is needed to understand the relationship of social support and family environment factors to coping and adaptation both for the design of intervention studies as well as to assist the healthcare providers who seek to maximize the positive outcomes of the cancer experience for AWC.
CHAPTER 2
REVIEW OF THE LITERATURE

The literature review section summarizes and critiques the literature on social support, family environment, and coping in general and AWC in particular. This review will include an overview of the theoretical conceptualizations of each of these as well as a description of developmental aspects for adolescents. The findings and strengths and weaknesses of relevant research studies with AWC will also be presented.

Social Support

Conceptualization of Social Support

Social support in health and chronic illness has been one of the most frequently researched concept in the past decades, both as a coping resource (Thoits, 1985; Underwood, 2000) and as a protective factor related to stress and coping (Wortman, 1984). In spite of the voluminous research on social support, the numerous definitions remain vague and circular with the term social support widely used to refer to the mechanisms of interpersonal relationships by which people are protected from the effects of negative stress (Bertero, 2000).

Conceptualizations of social support have focused on the sources of support, the nature of what was available or provided, and unidirectional versus reciprocal function. Social support has also been viewed as an objective quantity and as a function of individual perception. The two conceptual models of social support used in research on social support represent these different views. Structural models consider the individual's social network of relationships (House, 1981; Kahn & Antonucci, 1980), while functional models assess the individual's perceptions of the types and qualities of relationships. Social support is also conceptualized as a metaconstruct with multiple dimensions including the type of relationship and social network size, the type and frequency of supportive behaviors, and the quality of support (Barrera, 1986; Vaux, 1990).

While most of the research has focused on the health-related benefits of social support for adults, the benefits of social support have also been observed in adolescents (Cohen, 1987; Daniels & Moos, 1990). Adolescents with higher levels of perceived support report fewer health
complaints (Geckove, Van Dijk, Steward, Groothoff, & Post, 2003), lower levels of depression (Dumont & Provost, 1999) higher positive health practices (Yarcheski, Mahon, & Yarcheski, 2003), higher optimism (Ayers, 2003), higher self-esteem (Dumont & Provost, 1999; Yarcheski, Mahon, & Yarcheski, 2001), fewer behavior problems (Gaines, 1997), and better adjustment to illness (O'Dell Mccollum, 1997; Yarcheski & Mahon, 1999).

Gender differences have been reported both in levels of perceived support (Tusaie-Mumford, 2002) and the relationship of social support to various outcomes in adolescents (Kliwer, Murrell, Mejia, Torres de, & Angold, 2001; Wilson & Ampey-Thornhill, 2001). Females report higher levels of support in general (Ayers, 2003; Geckove et al., 2003; Koubekove, 2001; Omi, 1999) and greater satisfaction with their support (Koubekove, 2001).

Most of the research on the role of social support in oncology has been conducted with adult cancer populations. This research shows a strong relationship between the availability of a caring person to confide in and successful emotional adaptation to the cancer experience (Blanchard, Albrecht, Ruckdeschel, Grant, & Hemmick, 1995). The adults preferred different types of support from family, friends, and health professionals with all of these sources indicated as necessary for the enhancement of self-esteem and assistance with decision-making and problem-solving. Inadequate social support has been linked to depressive symptoms in adults with cancer (Hann, Oxman, Ahles, Furstenberg, & Stuke, 1995; Lee, 1997; Mathieson, Logan-Smith, Phillips, MacPhee, & Attia, 1996).

Social support particularly from family members has been reported as a protective factor against stress for children (Garmezy, 1991; Rutter, 1989), including the experience of cancer (Barbarin, 1987; Varni, Katz, Colegrove, & Dolgin, 1994a). Higher levels of perceived stress have been predictive of higher anxiety and depressive symptoms in long-term survivors of childhood cancer (Varni, Katz, Colegrove, & Dolgin, 1994b). With the numerous stressors identified by adolescents with cancer, including multiple hospitalizations, lengthy treatment, significant side-effects in conjunction with the normal developmental demands, research to increase knowledge on social support for AWC is clearly important for improving understanding of outcomes such as well-being and decreased stress.
Social Support and Adolescents with Cancer

This review of literature on social support for adolescents with cancer examines support from the adolescent’s perception, including the types and sources of support and the adolescent’s satisfaction with this support. With limited studies on social support and children with cancer, very few are available that focus specifically on adolescents. Therefore, pediatric studies with an adolescent component have also been included. Table 1 outlines the social support studies with AWC. The table is followed with an extended review of the social support studies.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Design</th>
<th>Sample</th>
<th>Variables</th>
<th>Instruments</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Derevensky, Tsanos &amp; Handman (1998)</td>
<td>Descriptive</td>
<td>9 preadolescents ages 8-11 (M=10 SD=NA), 12 adolescents ages 12-17 (M=15) 57% female 91% Caucasian. Wide range of stage of treatment from newly diagnosed to 1 year off-treatment</td>
<td>Perceived social support</td>
<td>Social Support Scale for Children (Harter, 1985): levels of support from parents, teachers, classmates and close friends.</td>
<td>Compared to a normative group of children and adolescents: social systems similar to those in the normative group. Parental support was rated highest in the oncology sample. Peers increasingly more important in the older age group (ages 12-17).</td>
</tr>
<tr>
<td>Dunsmore &amp; Quine (1995)</td>
<td>Cross-sectional, exploratory and descriptive</td>
<td>51 Australian AWC (ages 15-24, M=18) Active to off treatment &gt; 5 years 53% male</td>
<td>Preferred sources of support-information and emotional</td>
<td>42 item self-administered questionnaire, current and retrospective data, open-ended and closed-ended items.</td>
<td>Illness related information- physician, then parents and other young persons with cancer. Peer interaction important. High need for someone to talk to- parents and friends, physician rated low for this.</td>
</tr>
<tr>
<td>Enskar, Carlsson, Golsater &amp; Hamrin (1997b)</td>
<td>Qualitative/ Descriptive</td>
<td>10 Swedish AWC (ages 10-20) &gt; 1 year from diagnosis</td>
<td>Interview guide- Domains: Problems due to the cancer and areas of life affected by the cancer.</td>
<td></td>
<td>Highest need for support from friends during the initial phase of treatment. Friends less available over time. Family (especially mother) provided greatest support. Often avoided the subject of cancer when talking with their family members. Health care providers support (early in the treatment period) provided by multiple disciplines: (nursing, social work, and psychology.)</td>
</tr>
<tr>
<td>Kyngas et al. (2001)</td>
<td>Qualitative</td>
<td>14 adolescents and young adults with cancer (ages 16-22) 43% male</td>
<td>Interviews on coping strategies</td>
<td></td>
<td>Major coping strategy: social support (emotional, material and informational). Sources of support: family, friends, and health care professionals.</td>
</tr>
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</table>

Table 1: Studies of Social Support in Adolescents with Cancer
<table>
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<tbody>
<tr>
<td>Rechner (1990)</td>
<td>Phenomenological qualitative</td>
<td>5 AWC (ages 13-17), on and off treatment</td>
<td></td>
<td>In-depth interviews</td>
<td>The establishment and maintenance of relationships with friends and classmates most important. Friendships had changed since the cancer diagnosis-restrictions on social lives and from the treatment and side-effects. Support from nurses both psychological and tangible (the provision of medical care related to the cancer treatment).</td>
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<tr>
<td>Trask, Paterson, Trask, Bares, Birt &amp; Maan, (2003)</td>
<td>Descriptive, comparative</td>
<td>28 adolescents ages 11-18 (M=13.6 SD=2) 1 month from diagnosis to 1 year off treatment (M=18 mo, SD=20 mo) 52% male</td>
<td>Perceived social support Child distress</td>
<td>Social support: Harter’s Social Support Scale for Children (Harter, 1985) Distress: The Child Behavior Checklist-Youth-Self Report (Achenbach &amp; Edelrock, 1987)</td>
<td>Parents were the major source of support. Friends were rated next, followed by teachers, and then classmates. Distress was not significantly correlated with social support.</td>
</tr>
<tr>
<td>Richie (2001)</td>
<td>Descriptive</td>
<td>45 AWC (ages 11-18, M=15, SD=1.7) 76% on active treatment 53% male</td>
<td>Perceived emotional support</td>
<td>Open-ended interview-sources of emotional support &amp; how helpful these were in dealing with the cancer and treatment.</td>
<td>Mothers primary source of emotional support. Additional significant sources other family members and friends. Developmental age groupings showed: Youngest age group (11-14) fewer resources for emotional support. Oldest (17-18) increasingly identified friends. Reported satisfaction with the level of support from family members.</td>
</tr>
<tr>
<td>Manne &amp; Miller (1998)</td>
<td>cross-sectional, exploratory</td>
<td>50 AWC and healthy adolescents (ages 12-20, M=16) 2 mo to 3 years (M=6 mo) from diagnosis 82% Caucasian 58% male</td>
<td>IV=social support-sources and types of received support DV=Psychological Distress</td>
<td>Social support: Researcher modified Network of Relationships Inventory (Furman &amp; Buhrmester, 1985) Psychological Distress: Psychological Distress scale of the Mental Health Inventory (MHI-18) (Weinstein, Berwick, Goldman, Murphy, &amp; Barsky, 1989)</td>
<td>AWC did not receive less support from friends or family members compared to other adolescents nor did this support change over time (from diagnosis). Positive support did not predict levels of distress.</td>
</tr>
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<tr>
<td>Nichols (1995)</td>
<td>Descriptive, exploratory</td>
<td>20 AWC (10-16 years old) 75% male</td>
<td>Perceived social support networks</td>
<td>Social Support: The Norbeck Social Support Questionnaire (Norbeck, Lindsey, &amp; Carieri, 1981) measures three types of support; affect, affirmation, and aid as well as the network characteristics (size, accessibility, duration of relationships and frequency of contacts).</td>
<td>AWC reported: High levels of perceived support from family, other relatives, friends, and healthcare providers. High levels of satisfaction with support for issues related to the cancer treatment from family, but not friends. Moderate satisfaction with support from classmates and teachers.</td>
</tr>
<tr>
<td>Neville (1998)</td>
<td>Cross-sectional, descriptive</td>
<td>60 AWC (ages 14-22, M=19 SD=2.2) with recently diagnosed cancer. 87% Caucasian 67% male,</td>
<td>IV: social support; uncertainty in illness DV: psychological distress</td>
<td>Social support: Personal Resource Questionnaire-84-Part 2 ((PRQ-85-2) (Weinert &amp; Tilden, 1990) Uncertainty:Uncertainty in Illness Scale (Michel &amp; Braden, 1988) Psychological distress: Brief Symptom Inventory, abbreviated version of the Symptom Checklist-90 (SCL-90) (Derogatis, 1977)</td>
<td>Social support was not significantly related to psychological distress when controlling for levels of uncertainty</td>
</tr>
<tr>
<td>Haluska, Jessee, &amp; Nagy (2002)</td>
<td>Cross-sectional, exploratory, descriptive</td>
<td>64 AWC attending a summer camp and 115 healthy adolescents (ages 12-19, M=15.6) 51% Caucasian, 55% male</td>
<td>Sources of social support, amount of perceived support &amp; level of satisfaction with support</td>
<td>Social Support Questionnaire(Sarason, Levine, Basham, &amp; Sarason, 1983), Perceived Social Support Family Scale (Procidano &amp; Heller, 1983) and Perceived Social Support Friends Scale (Procidano &amp; Heller, 1983)</td>
<td>AWC similar to the comparison adolescents on the amount of perceived support from friends with significantly higher levels of support from their parents than the healthy comparisons. AWC reported high levels of satisfaction with the support.</td>
</tr>
</tbody>
</table>

IV=Independent Variable  DV=Dependent Variable  M=Mean  SD=Standard Deviation
Dunsmore and Quine (1995) conducted an exploratory study of 51 adolescents with cancer to identify their preferences and needs for information and support. While the physician was the preferred source of illness-related information, parents and other young persons with cancer were rated nearly as high. In addition, involvement with peers with and without cancer was also seen as important. The adolescents indicated a high need for someone to talk to. Parents and peers were both seen as the preferred providers of this support. Parents and friends were also the preferred choice to share their feelings and concerns about the cancer, with healthcare professionals rated very low. The adolescents described supportive health care providers as those who were interested in the adolescents as individuals beyond their medical care. Honest communication with healthcare providers was also reported as important to a supportive relationship. While this study had a larger than average sample for a study of AWC, representativeness of the population of AWC cannot be assumed as the sample was obtained at an Australian camp for cancer patients. Social support in this study was limited to information about their cancer and treatment.

In a descriptive study using structured interviews with 10 adolescents with cancer (ages 10-20) at least 1 year from diagnosis, Enskar and colleagues (1997b) asked about problems due to cancer and the areas of life affected by the disease. The participants were also asked to respond to a list of 86 problems, symptoms or inconveniences from the disease using a five-point scale with the higher score indicating the greatest inconvenience. From the interview, the adolescents reported the highest need for support from friends in the initial phase of treatment. However, as the treatment period continued for an extended period of time, friends tended to be less available for this support. The adolescents reported the greatest support from family, especially the mother, yet often avoided the subject of cancer when talking with their family members. Support from health care professionals early in the treatment period was provided by multiple disciplines, such as nursing, social work, and psychology. The type of assistance changed over the course of treatment, with a stronger need for help from the social worker or psychologist reported later in the treatment period, especially when the treatment time was lengthy. One concern identified by
the researchers is the use of snowball sampling to obtain subjects in the study. Snowball sampling technique is most often used when members of a target population are difficult to find (Rubin & Babbie, 1997), but is questionable in this situation as AWC are available in clinics, hospitals, and other settings. While the age range is broad, the majority of AWC were 17-19 years old, making the sample less representative of AWC in general.

In a phenomenological study on the cancer experience of 5 AWC, the establishment and maintenance of relationships with friends and classmates was described as very important (Rechner, 1990). In fact, these relationships were identified as a part of what is essential to being an adolescent. The adolescents felt their friendships had changed since the cancer diagnosis due to restrictions on the social aspects of their lives from the treatment and side-effects. These adolescents also stressed the importance of being accepted by those in their social support network as the same people they were before the cancer diagnosis. While they saw themselves as unchanged, they felt others did not. These adolescents also identified supportive relationships with other adults, such as their nurses, teachers, and other parents. Support from nurses was seen as both psychological and tangible (the provision of medical care related to the cancer treatment).

While the findings in Rechner’s (1990) study were reported as themes identified in the interviews, the process of generating the themes was not explained. Social support was included as a part of the third theme “Redefinition of Social World” but the connection to the participants’ actual words was not clear, merely implied. Social support was discussed in terms of new relationships with support people, such as teachers, nurses, other parents, and youth workers. However, the author also describes the AWC’s efforts to keep their normal adolescent world separate from the world affected by cancer, making it difficult to understand how the AWC viewed social support from those outside the world of cancer. The author goes on to discuss social support in view of the unique culture of AWC and the influence of this culture on what constituted social support for them, who provided the support, and under what circumstances the support should be offered. The discussion of social support seems to be somewhat ambiguous and outside of the scope of the study.
In semi-structured interviews, 14 adolescents and young adults with cancer (ages 16-22) discussed how they coped with the cancer experience (Kyngas et al., 2001). The respondents reported social support (emotional, material, and informational) as the major coping strategy. Family, friends, and health care professionals were reported as the sources of this support. One concern about this study was the lack of description on how the data was analyzed. While the authors identified social support as the major coping strategy through the content analysis, it was not clear how many of the participants identified the different areas of social support discussed in the findings. An addition problem with this study is the lack of clearly identified themes.

Derevensky, Tsanos, and Handman (1998) measured perceived social support for 21 children and adolescents with cancer (ages 8-17) using the Social Support Scale for Children (Harter, 1985). This study examined levels of support from parents, teachers, classmates and close friends. This group was also compared to a normative sample of children and adolescents. Parental support was rated highest in the oncology sample with peers becoming increasingly more important in the older age group, which is consistent with developmental theory. The oncology group was found to have social systems similar to those in the normative group. While this study provided some descriptive information about social support and children and adolescents with cancer, the extremely small sample size makes it difficult to draw any general conclusions from the findings. This small sample (21 children/adolescents) was divided into three groupings of time-since-diagnosis, with these groups ranging from 4 to 10 children. Results were reported from an Analysis of Variance (ANOVA) for these 3 groups despite the small group sizes. While the instruments used to measure the variables of social support, coping, and behavior were standardized instruments with established reliability and validity, no research questions were stated in the article, making it difficult to connect the measured variables to the reported results. Generalizability is further hampered by the sample consisting of predominantly Caucasian families. A large percentage of these children also had received some type of supportive counseling prior to the study, a limitation recognized by the authors. Again, generalizability of the findings is hampered by this characteristic of the subjects in the sample.
Trask and colleagues (2003) also used Harter's Social Support Scale for Children (Harter, 1985) to measure social support for 28 adolescents with cancer (ages 11-18; 1 month from diagnosis to 1 year from the completion of treatment). Again, parents were described as the major source of support. Friends were rated next, followed by teachers, and classmates. Age was not significantly related to social support sources. Distress, measured by the Child Behavior Checklist-Youth-Self Report (Achenbach & Edelrock, 1987), was not correlated with social support. For the statistical analyses in this study, power was compromised by the small sample. Additional problems include using a broad range of cancer diagnoses with treatment that widely varies in intensity and duration and a broad range of time-from-diagnosis. Of those approached to participate in the study, fewer than 50% of those subjects agreed. Despite this, the authors did not include any information about possible differences between those who agreed to participate and those who declined. Generalizability of these results is limited due to methodological problems in the study.

In a descriptive study looking specifically at sources of emotional support for 45 adolescents with cancer (ages 11-18) ranging from currently on treatment to 4 months off treatment, the mother was reported as the primary source of emotional support (Richie, 2001). Additional sources identified as significant for the AWC were other family members and friends. These adolescents also reported satisfaction with the level of support from family members. Only one adolescent in this study identified a healthcare provider (physician) as a source of emotional support. The respondents were grouped into the development stages of early (ages 11-14), middle (ages 15-16) and late (17-18) adolescents. The early stage adolescents listed fewer resources for emotional support than the older adolescents who increasingly identified friends. This is consistent with developmental theory on the increasing importance of peers as adolescents mature. There were no significant gender differences for the number of resources or the kinds of supportive behaviors described. While the range of time-since-diagnosis was narrower in this study compared to some social support studies, the subjects were only grouped
for comparison by gender and age groupings and not into any time-since diagnosis. Since some studies have reported social support to change over treatment time, this would have been a useful comparison.

Manne and Miller (1998) compared the levels of the types of support from key social relationships (mother, father, closest sibling, and best friend) for 50 adolescents with cancer and healthy adolescents (ages 12-20) using a modified version of Furman and Buhrmester's (1985) Network of Relationships Inventory. There were no differences detected between the two groups. These adolescents had a variety of cancer diagnoses and ranged from 2 months to three years from diagnosis (Mean = 6 months). There were also no differences in the rating of levels of social support related to time-since-diagnosis for the AWC group. This finding is inconsistent with other research on adults with cancer showing the level of support to decrease over time. There was no significant relationship between decreased levels of social support from family and friends and levels of distress in this study. While the findings from this study described levels of social support from family and friends, the main purpose of the study was to compare social support with conflict in supportive relationships and to evaluate the influence of conflict and support on psychological distress. Despite an adequate sample size, the authors did not report any analysis to examine gender differences in social support. Information on gender differences might have provided additional descriptive information.

Nichols (1995) measured perceived social support for 20 adolescents with cancer (ages 10-16) using the Norbeck Social Support Questionnaire (Norbeck et al., 1981). This instrument is designed to measure three types of support (affect, affirmation, and aid) as well as the network characteristics (size, accessibility, duration of relationships, and frequency of contacts). The adolescents in this study reported high levels of perceived support from family, other relatives and friends. Satisfaction with support for issues related to the cancer treatment was also rated high from family members, but not from friends. While the level of satisfaction of support from healthcare providers was also high, the adolescents were moderately satisfied with support from classmates and teachers. This may be the result of less interaction with classmates and teachers with cancer due to decreased school attendance. Problems with this study included a small
sample size and unequal gender ratios (75% males). The age range of 10-16 years did not fit the accepted range for young adolescents, although the sample was labeled as such. While illness duration was one variable measured in the study, no information was given on the range of time-since diagnosis or even if all of the subjects were still on treatment.

The relationship between psychological distress and social support and uncertainty in illness, was examined in a study of 60 adolescents, ages 14-22, with recently diagnosed cancer (Neville, 1998). Social support was measured using the Personal Resource Questionnaire-84-Part 2 (PRQ-85-2) (Weinert & Tilden, 1990). The PRQ-85-2 is a global measure of perceived social support based on Weiss’ five dimensions of social support (Weiss, 1974) and has been used with adolescents in other studies. When controlling for uncertainty, social support was not significantly related to psychological distress in this study although the combined effect of uncertainty and perceived social support was a significant predictor of distress. While this study reported the sample as “adolescents”, the age range was not the accepted range for adolescence typically described as age 11-21 (Steinberg, 1999). The sample was primarily Caucasian (87%) with over-representation of males (66%). Despite evidence of gender difference in social support, the authors did not report any analysis for gender differences for either the independent variables (uncertainty, social support) or the dependent variable (psychological distress).

Haluska, Jessee, and Nagy (2002) measured the perceptions of support, the amount of support needed, and the satisfaction with this support of 64 adolescents (ages 12-19) with cancer and compared them to age-matched, healthy adolescents. The sample included cancer survivors from newly diagnosed to many years off treatment. Social support was measured using The Social Support Questionnaire (SSQ) (Sarason et al., 1983). The AWC were similar to the comparison adolescents on the amount of perceived support from friends and expressed high levels of satisfaction with the support. The AWC perceived significantly higher levels of support from their parents than the healthy comparisons. These findings were consistent with Manne and Miller (1998). It is unclear if this sample obtained at a camp for AWC with a participation rate of less than 50% can be considered representative of the population of AWC. No information was given on any analysis of potential differences between those who participated and those who
refused or between the adolescents who were able to attend the camp and those who were not. The authors speculated that the AWC who attended camp may have been more outgoing and confident with had higher levels of social support. They also stated those who agreed to participate tended to be more outgoing and confident.

As with many of these studies, the sample in Haluska and colleagues’ study lacked of ethnic diversity with 86% Caucasian participants. There were also significant differences between the sample of AWC and the comparison group for ethnicity and level of education for mothers and fathers. No information was given on the time-since-diagnosis range for the sample, but it can be assumed that many of the AWC were off treatment, perhaps several years, since the authors state that many of the subjects attended camp for several years. They may have had the additional benefit of peer support from this experience, making it difficult to generalize the findings of this study to AWC, particularly those who are newly diagnosed or still on treatment. The AWC in this study might have been better labeled as long-term survivors of childhood cancer.

Synthesis of the Social Support Literature

From these studies, parents, especially mothers, are reported to be the major source of support (Derevensky et al., 1998; Dunsmore & Quine, 1995; Kyngas et al., 2001; Richie, 2001; Trask et al., 2003). This is consistent with research showing mothers provide the majority of caregiving for these children and adolescents (Avison, Noh, & Speechley, 1991). Families in general have been identified as the major source of support for school-age children and adolescents (Enskar et al., 1997b; Rechner, 1990) with parents described as a source of illness-related information (Dunsmore & Quine, 1995). While described as vital for AWC, support from family was also described as difficult for the AWC due to the increased time spent with family and decreased privacy (Enskar et al., 1997b). AWC also reported a reluctance to discuss feelings about the cancer experience with their parents, especially parents (Enskar et al., 1997b).

Support from friends was also identified as significant to adolescents with cancer, including support from friends with cancer (Dunsmore & Quine, 1995; Enskar et al., 1997b) and healthy peers (Enskar et al., 1997b; Rechner, 1990; Richie, 2001; Trask et al., 2003). The AWC indicated a high preference for obtaining illness-related information from another young person.
with cancer (Dunsmore & Quine, 1995). Involvement with peers was also described as necessary to help the AWC develop a sense of identity and autonomy, both of which were seen as somewhat threatened by the illness (Dunsmore & Quine, 1995). Adolescents indicated a high need for support from friends during the initial phase of treatment, but also a decrease in friend’s support over time (Enskar et al., 1997b). AWC also reported changes in friendships due to the loss of time to socialize with friends from the demands of the illness (Dunsmore & Quine, 1995).

There was less information about support from healthcare providers. Some of the measures did not include healthcare providers as a choice. However, in those measures that included healthcare providers or with the option to identify anyone seen as supportive, healthcare providers were identified as supportive (Dunsmore & Quine, 1995; Enskar et al., 1997b; Kyngas et al., 2001; Rechner, 1990) although Dunsmore and Quine (1995) found this to depend on the type of support needed. The physicians were reported as preferred sources of illness-related information, but were rated very low to as a person to share the adolescents’ feelings or concerns (Dunsmore & Quine, 1995). Enskar (1997b) found the need for support from healthcare providers increased over the extended treatment time and was often more necessary after the treatment was completed. At that point, the AWC had more time to consider the serious implications of the disease and reflect on the treatment experience. The AWC considered having consistent primary nurses and physicians increased the feelings of confidence and safety and provided more opportunities to ask questions and discuss specific concerns (Kyngas et al., 2001).

Adolescents with cancer also expressed satisfaction with the level of support from family members (Haluska et al., 2002; Manne & Miller, 1998; Nichols, 1995), particularly emotional support (Richie, 2001) and also from healthcare providers (Enskar et al., 1997b; Kyngas et al., 2001; Rechner, 1990). They reported less satisfaction with support from friends, classmates, and teachers (Nichols, 1995).

While there were some age-related differences in perceived social support from these studies, there were no gender differences found. Due to the ethnic homogeneity of the samples, ethnic and cultural differences for social support were not analyzed.
Three studies examined the relationship of social support to distress (Manne & Miller, 1998; Neville, 1998; Trask et al., 2003). None of these studies found a significant correlation of social support with distress.

Many of these studies of AWC were limited by the small sample sizes (Derevensky et al., 1998; Rechner, 1990; Trask et al., 2003) making it difficult to interpret the true effect size due to low power. Sample size is also an issue in the studies using subjects at a broad range of time-from-diagnoses since this makes any differences over the time of the cancer experience difficult and any further analysis of time-from-diagnosis groupings difficult (Derevensky et al., 1998; Dunsmore & Quine, 1995; Manne & Miller, 1998; Rechner, 1990; Richie, 2001; Trask et al., 2003). Limited sample size also affects other groupings such as gender, ethnicity, or type of cancer diagnosis or treatment.

A variety of age ranges were used under the term of "adolescents" in these studies. While a difference of a year or two could be unimportant, it is difficult to synthesize the findings for these studies due to these age range differences.

The qualitative studies gave AWC the opportunity to speak about social support and provide some understanding of social support for AWC. These studies also provide some direction for future research, but by nature, do not lend themselves to generalizations. The quantitative studies used different types of measurement instruments representing a variety of social support conceptualizations, making it difficult to synthesize the results except as very broad generalizations. In those studies using social support as an independent variable, distress was the only outcome selected.

Some of the studies used interviews or surveys with open-ended questions probing for the adolescents' perception of the social consequences of having cancer, preferred sources of information about the cancer, and with whom they preferred to discuss their cancer-related feelings (Dunsmore & Quine, 1995; Enskar et al., 1997b; Kyngas et al., 2001; Rechner, 1990; Richie, 2001). Others looked at the type of support from the sources of support (Derevensky et al., 1998; Manne & Miller, 1998; Trask et al., 2003).
While these studies have helped to clarify the sources and perceptions of social support for AWC, additional research is needed to understand how this support is related to outcome variables beyond distress such as coping and adjustment. Measuring social support early in the cancer experience would provide information on the pattern of social support prior to the diagnosis as well as since the cancer diagnosis. Measuring social support from multiple sources would also increase understanding of each of the sources of social support for AWC.

Family Environment

*Conceptualizations of Family Environment*

From the literature on social support for adolescents with cancer, the family was clearly identified as the most important source of support. Therefore, examining the way a family communicates and functions could also provide additional information on coping in AWC. Family environment is a broad term to include the patterns of family functioning, communication and the perception of family strengths.

Research has shown families develop individual stable and predictable patterns of interacting with one another and with those outside of the family (Cornille & Boroto, 1992). These patterns, such as daily routines, roles, rituals, and rules, help promote stability and strengthen the families sense of identity (Steinglass, Bennett, Wolin, & Reiss, 1987) and are linked to the family’s perception of itself and the resources perceived as available (Cornille & Boroto, 1992). In turn, these patterns influence how the individuals in the family, in this case, the adolescent with cancer, copes with the stress of cancer.

Family environment defined as the way family members relate to one another, pursue goals, organize activities, and accept family routines and procedures (Moos, 1984). It can also be described as the adjustments and adaptations families experience as they move through the family life cycle (McCubbin, McCubbin, Thompson, & Huang, 1989). Beginning with the concepts of family cohesion and adaptability described in the early work of Angell (1936), the concept of family environment has been examined with a variety of measurement scales to detect differences among families.
Measures of Family Environment

There are multiple self-report measures to assess the characteristics of the family environment. Some of the family measures have one or two theoretically chosen dimensions (Epstein, Baldwin, & Bishop, 1983; Moos, 1986; Olson, Portner, & Bell, 1982) while others are multidimensional (Skinner, Steinhauer, & Santa-Barbara, 1983). Diverse concepts in these scales include problem-solving, communication, interpersonal and societal relationships, behavioral control, organizational properties, and support. Common to all of these instruments are the concepts of cohesion or emotional bonding and role adaptability or family organization.

Family cohesion is defined as the emotional bonding among family members including variables such as boundaries, friends, decision-making, coalitions, interests and recreation (Olson, 1993). Flexibility/adaptability is described as the amount of change possible in the leadership, role relationships and relationship rules including variables of control, discipline, and negotiation styles (Olson, 1993).

Most of the instruments examining family functioning include communication as a dimension or sub-dimension. Olson (1993) and Olson, Russel & Sprengle (1979) describe communication as the third dimension in their Circumplex Model of Marital and Family Systems. Communication is considered a facilitating dimension that influences movement on the other two dimensions of adaptability and cohesion and is measured by a separate scale, The Parent-Adolescent Communication Scale (PAC) (Barnes & Olson, 1982). In two other family instruments, The Family APGAR (Smilkstein, 1978) and The McMaster Family Assessment Device (FAD) (Epstein et al., 1983), communication is included as a separate dimension.

Family Environment and Adolescents With Chronic Illness (including cancer)

The majority of research on children with chronic illnesses examined family environment in relation to negative outcomes. Depression, for example, was found to be significantly related to family environment variables in children with chronic illnesses (Bennett, 1994; Lavigne & Faier-Routman, 1993). Variance in social competence levels were significantly related to family cohesion, conflict and control in children with chronic illness and disabilities (Wallander et al., 1989).
Studies examining the relationship of family environment to psychological adjustment in chronically ill children, adolescents, and their parents, high levels of cohesion and expressiveness had a positive relationship to better psychological adjustment (Kronenberger & Thompson, 1990; Wallander & Varni, 1989). Another study examining family cohesion and conflict in childhood arthritis measured by the Family Environment Scale (FES) (Moos, 1986) indicated the adolescents' self-worth was positively correlated and depression levels negatively correlated to higher levels of cohesion (Cuneo & Schiaffino, 2002).

Drotar (1997) reviewed studies examining the relationship between family environment variables and psychological adjustment of children with chronic illness. He found measures of family cohesion to be predictive of more competent psychological functioning. However, many of these studies were conducted at various times from diagnosis and included a wide variety of diseases, different treatment demands, and different courses of treatment with a variety of effects on the child’s functioning. The lack of similar conceptualizations, methods, and samples make it difficult to draw conclusions across the studies.

Most studies on family environment and pediatric cancer looked at the impact of the cancer diagnosis of cancer on the family rather than how the family environment impacted the adjustment of these children. Therefore, this review includes only four studies: one descriptive study on the family environment and children with cancer (Brown et al., 1992); one that looked at the family functioning of adolescent cancer survivors (Rait et al., 1992); and two studies that specifically examined the influence of family environment on the adjustment of children and adolescents with cancer (Trask et al., 2003; Varni, Katz, Colegrove, & Dolgin, 1996).

In a study of adolescents who had completed cancer treatment, Rait and colleagues (1992) assessed the perceived family environment of 88 adolescents (ages 12-19) and its relationship to their adjustment. Using the Family Adaptability and Cohesion Scales-III (FACES-III) (Olson, Portner, & Lavee, 1985), the adolescents with cancer were compared to the normative sample for mean levels of cohesion and adaptability. There were no differences for adaptability, but significantly lower levels of cohesion for the adolescent cancer survivors. In fact, 40% of these adolescents saw their families as "disengaged" according to the instrument cutoff scores (Olson
et al., 1985). Both adaptability and cohesion were strong and consistent predictors of all the adjustment indicators—overall mental health, self-esteem, global competence, except total problem behaviors. Gender, current age, and age of diagnosis were not significant predictors of any of the adjustment indicators. However, when the variable of “time off treatment” was entered into the regression analysis, the groups looked very different. For those who were in the group of “recent” (less than 1 year off treatment), there is a strong association (50% of variance) between family environment and adjustment. For those subjects between 1 and 5 years off treatment, this association is much lower (10% of variance). For the final group of survivors more than 5 years off treatment, this relationship is again strong (34% of variance).

With the sample in this study at least 3 months off treatment and the majority of the subjects at least 1 year off treatment, many of the subjects were not adolescents when they received the diagnosis of cancer. This could also be a factor in the group differences of the association between family environment and adjustment. Despite the large sample, the sub-groups sizes (ranging from 21-45) make it difficult to generalize these findings to the larger population of AWC. Since this research was conducted after treatment was completed, it is not possible to determine if the family environment had changed since the adolescent was diagnosed with cancer or the influence of the family environment at diagnosis or during treatment on the adjustment of AWC.

In a study of 55 children (2-17 years old) with acute lymphocytic leukemia (ALL) and family environment, Brown and colleagues (1992) assessed the family environment for school-age children in the sample using the Children’s Version of the Family Environment Scale (FES) (Pino, Simons, & Slawinowski, 1984). Using a cross-sectional design, family environment was assessed at three specific times: 1) soon after the diagnosis; 2) one year from the diagnosis; and 3) at one year after the completion of treatment. There were no significant differences for the three groups for family environment, indicating that the family environment appeared to be stable over time despite the need for the family system to adapt to the experience of having a child with cancer. The sample used in this study were all children with mild to moderate risk ALL, making it difficult to generalize these findings to children with other types of cancer due to differences in treatment regimens and prognoses. As with many of the studies, the authors analyzed sub-
groups using time-since-diagnosis due to broad differences in this variable. However, the resulting sub-group sample sizes were small (ranging from 10-23 subjects/group) making the findings tenuous. No other groupings were analyzed such as age or gender groups, which might have resulted in different findings from this research.

Varni, Katz, Colegrove, and Dolgin (1996) analyzed the psychological and social adjustment of 77 newly diagnosed children and adolescents with cancer (ages 5-13) and their perceived family environment. Family environment was measured by the Family Environment Scale (FES) (Moos, 1986) looking at the domains of relationship, personal growth and system maintenance. Psychological and social adjustment were measured by the Children Behavior Checklist-parent report (Achenbach, 1991). The relationship dimensions of higher cohesion and expressiveness were associated with lower levels of psychological distress and higher levels of social competence at each of the measurement times: diagnosis, 6 months post diagnosis, and 9 months post diagnosis. The age range of subjects in this study included children and young adolescents, making it difficult to generalize the findings to adolescents in general, and older adolescents in particular. While the children with cancer were the subjects in this study, only parents completed the measures, perhaps in part due to the age of the children included. Including the children’s perception of family environment would seem to be important to examine in relation to their adjustment.

In a study of 28 AWC ages 11-18, Trask and colleagues (2003) examined the relationship of family environment and distress. Family environment was measured using the FACES II (Olson, Portner et al., 1982) with distress assessed using the Child Behavior Checklist-Youth-Self Report (Achenbach, 1986; Achenbach & Edelrock, 1987). Finding showed that AWC ratings of cohesion and adaptability were slightly higher than the normative sample, indicating an overall healthy level of family environment. Increased family cohesion was not associated with higher distress in the AWC. Due to the small sample size in this study, power is a concern. While a valid and reliable instrument designed for use with children and adolescents was used to measure family environment, results were limited to descriptive information in comparing the AWC to a normative sample and examining the correlation of family environment with the outcome of distress. An
additional concern is using a broad range of cancer diagnoses with treatment that widely varied in intensity and duration and a wide range of time-from-diagnosis (1 month from diagnosis to 1 year off treatment). With participation rates of less than 50% of those approached to participate, reporting on an comparison of the participants and those who declined to participate should have been included in the research report. Generalizability of these results is limited due to methodological problems in the study.

*Synthesis of the Family Environment Literature*

Based on the limited studies of family environment and AWC, family environment for cohesiveness and adaptability was similar to a normative sample. The relationship between family environment and outcomes such as distress is unclear. Both Varni and colleagues (1996) and Rait and colleagues (1992) found a significant relationship between cohesiveness and more positive outcomes while Rait and colleagues also found a significant relationship between adaptability and adjustment. There was a positive relationship between expressiveness and adjustment in Varni and colleague’s study. In other studies, there was no significant relationship between cohesiveness and adaptability and the adjustment of the children and adolescents with cancer (Brown et al., 1992) or to levels of distress (Trask et al., 2003).

The use of different instruments, different time-since-diagnosis and age groupings may account for some of the inconsistencies among these studies. The current research is too limited to provide adequate information about the relationship of family environment to outcomes such as adjustment for AWC.

While the descriptive studies have increased our knowledge on family environment and the AWC, additional research is needed to clarify the relationship of family environment to outcomes such as adjustment and coping in the AWC. Studies with larger sample sizes and more restrictive parameters on age or time-from diagnosis are also needed.
Coping

Conceptual Models of Stress and Coping

Lazarus and Folkman (1984) define stress as a relationship between the person and the environment appraised as relevant to his/her well-being which is taxing to the person’s resources. The relationship of stress, coping, and adaptation has been a topic of considerable research in the past 50 years (Lazarus, 2000). Chesler and Barbarin (1987) describe a range of stressors associated with childhood cancer, including understanding the diagnosis; prognosis; and treatment; adapting to the treatment and related side-effects; establishing a relationship with the medical staff; interaction with family and peers; and “dealing with two worlds, that of health and illness, of specialness and normalcy” (p.154). In addition to the stressors directly related to the cancer, the adolescents with cancer also have the everyday stress typical for this stage of development. This places extraordinary demands on children and adolescents and may necessitate specialized coping strategies such as the use of fantasy (Bull & Drotar, 1991).

In examining the research on adolescent coping, it is important to consider the conceptual models used. Coping has been conceptualized both as a trait and as a process. Viewed as a trait, coping has been connected to temperament, including reactivity and self-regulation (Compas, Malcarne, & Fondacaro, 1988). Individual temperamental differences can impact both the appraisal of the stressor and the ability to use coping strategies. Coping as a process is most commonly defined as the person’s constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). There are three main features to coping as a process. The first is the initial assessment of what a person is actually thinking or doing in a stressful situation. This is in contrast to looking at coping styles or traits, which describe what a person usually does in a stressful situation. Next, assessment of coping behaviors as process should be viewed in light of a specific context. The strategies used are determined in part by the demands of the situation. Finally, this process approach looks at the change in coping thoughts and acts as the stressful encounter occurs. The majority of the
research on coping in the past 30 years has used contextual models that emphasize coping by a person in a situation appraised as stressful (Lazarus, 1966; Lazarus & Folkman, 1984; McCrae, 1984).

*Dimensions of Coping*

Several conceptual models of the coping process derived from the research on coping in adults have been used in research on coping in children and adolescents (Ebata & Moos, 1991). The problem-focused versus emotion-focused coping models classify responses according to their function (Band & Weisz, 1988; Compas et al., 1988; Folkman et al., 1986). Emotion-focused coping is defined as responses used to regulate stressful emotions. These responses include expressing emotions, seeking solace and support from others, and attempts to avoid the source of stress. Problem-focused coping alters the troubled person-environment that causes the distress. These responses include seeking information, generating possible solutions to a problem, and taking actions to change the circumstances creating the stress. Cognitive appraisal of the stress is an integral part of this process.

This model has also been divided into primary and secondary control coping. Primary control coping is used to enhance a sense of personal control over the environment and the person's reactions where as secondary control is used to adapt to the environment (Randolph, Dennig, & Weisz, 1995). Weisz, McCabe, & Dennig (1994) categorized strategies directed toward influencing objective events or conditions and those that directly regulate one's emotions as primary control coping attempts. Secondary control coping describes efforts to fit with or adapt to the environment and typically may include acceptance or cognitive restructuring. These categories describe both the nature of coping responses and the goals underlying the responses. For example, a primary control response during a painful medical procedure (child to mother, "hold my hand") may reflect the secondary control goal- ("so I know she's with me").

An alternate theoretical framework to categorize coping is based on the focus of the coping, either towards or away from the stressful situation (Ebata & Moos, 1991). Approach coping can involve cognition or behaviors that focus on the stressful situation. Avoidant coping strategies
involve cognition or behaviors to either avoid thinking about the situation or to avoid the situation. Approach coping includes responses that are oriented either toward the source of stress or toward one’s emotions or thoughts, for example, those seen as seeking information or social support. Avoidant coping refers to responses that are oriented away from the stressor or one’s emotions or thoughts, such as the use of withdrawal or denial.

There are also models empirically derived from factor analyses of scales listing a variety of coping responses. Patterson and McCubbin (1987a) asked adolescents from the general population to indicate how often they used 95 coping responses. Factor analysis of the data resulted in 12 factors divided into those using direct actions, seeking family/peer support, and those using indirect or avoidant coping responses such as seeking diversions or ventilation of feelings. Additional studies with adolescents have resulted in three or more dimensions of coping, including categories of coping strategies such as cognitive coping, social support, palliative, and evasive (Ayers, Sandler, & Twohey, 1998; Connor-Smith et al., 2000; Frydenberg & Lewis, 1991; Jalowiec, 2003; Seiffge-Krenke & Shulman, 1990).

Both the problem/emotion-focused and the approach/avoidance coping models have been criticized as overly broad with the placement of a variety of types of coping into two general categories (Coyne & Gottlieb, 1996). For example, emotion-focused coping strategies include relaxation, seeking emotional support from others, writing about one’s deepest emotions, wishing that the problem might go away, emotion suppression and self-criticism. Other strategies, such as walking away, may be both problem-focused and emotion-focused. This framework does not include various forms of avoidance coping, such as avoiding the problem, denial, and wishful thinking. The approach-avoidant models include strategies that may not fit easily into one of the two dimensions. Cognitive distraction is described as avoidant due to the redirection of attention toward an alternative target, but this strategy also reflects an awareness and acknowledgement of the stressor that does not fit with the definition of avoidance.

Despite these criticisms, conceptualizations of the various dimensions serve as organizing principles that represent the overarching characteristics of responses to stress (Compas et al., 2001). In attempting to integrate these frameworks, Randolph and colleagues (1995) noted that
the approach-avoidant conceptual model is concerned with coping responses, the problem-focused versus emotion-focused dimension is concerned with coping goals and the primary versus secondary control dimension represents both of these. However these dichotomous frameworks appear to mask the complexity of different subtypes of coping that may differ significantly in their intentions and their effects.

Despite the differences in conceptualizations of coping for adolescents and the disagreement on the number of dimensions, theorists agree on several points:

- Coping has multiple functions, including the regulation of distress and management of the problems related to the stressor(s) causing the distress.
- Coping is influenced by appraisal of the stressful context, including the controllability of the stressor(s).
- Coping is influenced by personality dispositions such as optimism, neuroticism and extraversion.
- Coping is influenced by social resources, such as social support (Folkman & Moskowitz, 2000).

The Development of Coping in Children and Adolescents

At this time, there is little consensus about whether children use different types of coping strategies compared to adults (Schmidt, Peterson, & Bullinger, 2003). Research has shown coping skills change with children’s development with evidence of differentiation into several dimensions during adolescence (Kavsek & Seiffge-Krenke, 1996). Fournet, Wilson, and Wallander (1998) suggest a new taxonomy that distinguishes between technical and adaptive competence. Technical competence in coping is defined as the individual’s immediate concern to reduce stress (Fournet et al., 1998). These immediate concerns are based on:

1. The cognitive development of an individual such as the ability to identify stressful events and to link strategies of stress management to those events.
2. The emotional development of one’s ability to identify feelings.
3. Personality development related to the development of a unique coping style.
In contrast, adaptive competence reflects the individual's general capacities in response to situational stress. This is related to the potential fit between the cognitive appraisal of an event and the coping response, the developmental and contextual factors that influence how an individual copes with normal, everyday stressors, and the use of approach or active cognitive and behavioral efforts to produce adaptive changes. From a developmental perspective, the orientation of coping changes over time from the desire to develop skills in technical competence to adaptive coping. Adaptive coping is characterized by a match of the perception of situational demands on one hand and primary and secondary coping strategies on the other hand, based on their perceived effectiveness. Developmental changes in coping for adolescents reflects this ability to select effective coping strategies based on the perception of the match between the strategy and the controllability of the stressor.

Young children tend to orient towards palliating negative emotions through primarily behavioral means- seeking social support and soothing from others, behavioral withdrawal from threat, and use of tangible objects for soothing and security (Gunnar, 1994). More complex methods of achieving the goals of emotional palliation and problem-solving emerge in early to middle childhood with the development of more complex language and metacognitive capacities, including cognitive reframing or restructuring a problem, cognitive representations of absent caregivers, using self-talk to calm negative emotions, and generating alternative solutions to solve problems (Normandeau & Gobeil, 1998). Adolescents seem to have greater consistency in the use of coping, that is using similar strategies across different situations (Compas et al., 1988). Greater diversity and flexibility in the range of coping responses available to the individual is expected to develop during middle childhood and adolescence. In addition, with increasing metacognitive skills in early adolescence, a greater ability to match coping efforts to the perceived or objective characteristics of stress is expected. Ebata and Moos (1991) found older adolescents relying on a broader spectrum of coping responses. They also found adolescents with more psychological or behavioral problems used significantly more avoidant strategies than those without such problems while there was no significant difference in the use of approach coping.
Coping and Adolescent Development

Researchers examining coping in AWC should consider both the life transitional aspects of the developmental stage and the possible impact of the diagnosis of cancer on development. For adolescents, coping and development are interconnected with age-related factors strongly influencing adaptation to stress (La Greca, Siegel, & Wallander, 1992). Coping is a process shaped by development while, in turn, development is shaped by the coping process (Schmidt et al., 2003). From a developmental perspective, stressors are often divided into normative or non-normative (Steinberg, 1999). Normative stressors include those common to the adolescent developmental period such as physical changes, changes in family dynamics and friendships, and the transition to higher-level schools. For girls, the period of early adolescence often represents a higher level of stress due to the dramatic physical changes. In the middle adolescence period, stressors are largely related to friendships and family relationships. This age group typically begins spending more time with friends and may have increased disagreements with parents about issues like clothing, driving, personal space, and curfews. The middle to late adolescents begin dating and to develop romantic relationships. Stressors in this stage may involve fear of rejection and feelings of incompetence. In addition to these normative stressors, there is also stress if the timing of the transitions is clearly different from the norm, such as delayed or premature puberty. However, most adolescents cope with the normative stressors without major difficulty (Steinberg, 1999).

Non-normative life events occur rarely, but can be extremely stressful, increasing the risk of problems in adaptation. Onset of chronic illness in adolescence is considered a non-normative life event, since it afflicts a small number of the age group, is hard to predict, difficult to control, and extremely stressful, which places extraordinary demands on coping skills (Seiffge-Krenke, 2001). It may well be that puberty is the time when chronic illness has the largest impact on development, making the adolescent particularly vulnerable to problems due to the cumulative effects of changes in body shape, relationship patterns, and the demands of the school environment.
These normative and non-normative stressors do not occur or exert their effects independent of one another. In fact, they may interact and intensify the aversive effects (Lazarus & Folkman, 1984; Seiffge-Krenke, 1995). If individuals are especially vulnerable during transitional phases (Antonovsky, 1979), then the occurrence of a critical event, such as the diagnosis of cancer at these times becomes particularly significant.

In looking at the adolescent with cancer, there are several reasons for concern. The treatment of cancer generally results in increased absences from school, decreased ability to complete academic requirements due to fatigue, pain, or medications, and alteration or restriction of competencies or future perspectives. For example, the adolescent with cancer may be delayed in obtaining a driver's license, in starting college, or be required to change career choices due to physical impairments. Interactions with peers and a move towards autonomy may be delayed or limited for a significant period of time. For adolescents, the accumulation of stressors is even more significant since the number of normal developmental changes is greater during the adolescent period than any other age period. Therefore, the coping capacity of adolescents may be overtaxed in dealing with chronic illness since it occurs in conjunction with the normative stressors commonly present.

The risk of poor outcome rises exponentially with the number of major life stressors that an adolescent experiences (Seiffge-Krenke, 2001). Coleman (1978) studied healthy adolescents to discover how the adolescents coped with the number and diversity of developmental tasks. His theory of development described successful development occurring through a process of efforts where the focus was placed on the most relevant developmental task at the time. This focus changed as the adolescent worked sequentially through those tasks that seemed most important at each developmental stage. This process of adaptation in adolescence is extended over several years with a focus on different tasks at different times. However, illness-related stressors and developmental tasks occur simultaneously, not sequentially. Adolescents with chronic illness cannot wait until the illness is over to tackle important developmental tasks. Somehow they must strike a balance between following the normative developmental progression and dealing with their physical health (Seiffge-Krenke, 1998).
In addition to the developmental aspects of coping for adolescents, it is also important to consider gender and cultural differences. Cultural beliefs or values may have an effect on the perception of the event as well as the coping response (Copeland & Hess, 1995; Phinney, Lochner, & Murphy, 1990). In studies comparing the coping strategies of African-American and Caucasian adolescents, the African American adolescents used spiritual, peer, and family support more frequently than Caucasian adolescents (Chapman & Mullis, 2000; Maton et al., 1996) while the Caucasian adolescents reported ventilating feelings and the use of avoidance strategies more (Chapman & Mullis, 2000). The limited amount of research in this area makes it difficult to understand how ethnicity might affect coping in AWC.

There is some evidence of gender differences in the perception of the amount of stress and the subsequent coping resources used to deal with stress. Newcomb, Huba, and Bentler (1986) found females to perceive stressful events more extremely, both positively or negatively, than males. Female adolescents have reported relying on more peaceful, less aggressive methods of coping, such as social support, while males more often selected aggressive methods like ventilation of feelings through swearing and taking anger out on others (Bird & Harris, 1990). Several studies have reported a higher incidence of approach strategies from females while males tended to use avoidant strategies more often (Causey & Dubow, 1992, 1993; Phelps & Jarvis, 1994; Roecker, Dubow, & Donaldson, 1996). On the other hand, Reid, Dubow and Carey (1995) have reported significantly more avoidance coping by female adolescents with diabetes, although other studies found no gender differences (Causey & Dubow, 1993; Compas et al., 1988). It is not clear if these differences in coping strategies are associated with differences in overall outcomes. On one hand, females may have better adjustment due to the fact they typically can find and make use of social structures for dealing with their illness. However, from studies with young adolescents, females reported using more rumination, which is connected to overall higher rates of depression (Broderick, 1998).

There appear to be ethnic and gender differences in the perception of stress and the coping resources used to deal with that stress, such as differences in the perception of the type of
stressor or the use of avoidant versus approach coping strategies. With the limited amount of research on ethnic and gender issues in coping, it is difficult to hypothesize their impact on the coping of AWC.

Coping and Adjustment in Adolescents

A primary concern of research on coping in adolescents is the relationship between types of coping strategies and adolescents’ adjustment, psychological distress, or behavioral difficulties. A significant association between both disengagement or avoidant coping and emotion-focused coping with poor psychological adjustment has been reported (Causey & Dubow, 1992; Compas et al., 1988; Ebata & Moos, 1991; Lewis & Frydenberg, 2002; Reid et al., 1995; Wilkinson & Walford, 2000). These coping strategies include cognitive and behavioral avoidance, social withdrawal, resigned acceptance, emotional ventilation or discharge, wishful thinking, and self-blame or self-criticism. Compas and colleagues (2001) suggest that the emotion-focused coping itself is not the problem, but rather the consistent association of these strategies with more symptoms and lower competence. These responses may reflect inadequate skills in modulating and regulating the experience and release of negative emotions so the focus is not on the emotions per se. In addition, these responses blur the distinction between coping and symptoms of psychopathology and may be the result of confounds in measures of emotion-focused coping and symptoms.

Several studies found significant associations between disengagement and better adjustment when looking at uncontrollable stressors (Chaffin, Wherry, & Dykman, 1997; O’Brien, Bahadur, Gee, Balto, & Erber, 1997; Weisenberg, Schwarzwald, Waysman, Solomon, & Klingman, 1993). These patterns complement the findings that problem-focused coping is associated with better adjustment in response to controllable stressors and that coping responses are most effective when they match the controllability of the stressor. For example, adolescents used more approach than avoidant strategies when stressors were perceived as controllable, but for some types of uncontrollable stressors, there was an increase in the use of avoidance (Griffith, Dubow, & Ippolito, 2000). However, this was not consistent across all stressors seen as uncontrollable and appears to depend on the specific situation.
Compas and colleagues (2001) reviewed studies of the association of coping with psychological adjustment or psychopathology in adolescents. The majority of studies with statistically significant effects that examined engagement coping and problem-solving coping found these strategies to be associated with better psychological adjustment, using both simple correlations and multiple regression in which other types of coping and control variables were entered. The types of coping strategies consistently associated with better adjustment were problem-solving, cognitive restructuring, and positive reappraisal of the stressor. However, it is important to recognize that this association may instead indicate that adolescents who are more socially competent or less anxious or depressed are better able to generate solutions to problems and maintain a positive outlook when faced with stress. Studies that control for adjustment prior to the stress or those that were able to show the increase or decrease of these types of coping under controlled conditions would be the strongest test of this association.

Other studies found no significant association between the use of engagement or problem-focused coping with better adjustment or found the opposite to be true (O'Brien et al., 1997; Smith & Brodzinsky, 1994). These differences may point to the need to take the context of coping into account since engagement coping may not be effective in situations involving stressors that are subjectively or objectively uncontrollable, as was the case in several of these studies.

Current findings indicate the need to consider coping in adolescents as multidimensional (Compas et al., 2001; Connor-Smith et al., 2000), requiring models to conceptualize coping as more than two dimensions, e.g. problem-focused and emotion-focused or approach and avoidant coping. These two-dimensional models may be insufficient to capture the diversity and complexity of the ways in which adolescents cope. They may also disguise important differences in the nature and function of coping in adolescents. Using factor analysis of coping in children and adolescents, Ayers, Sandler, West, & Roosa (1996) identified four factors: 1) active strategies (problem solving, seeking information); 2) avoidance (avoidant action or cognitive avoidance); 3) distraction (distracting action, physical release of emotions); and 4) support seeking (seeking support for emotions or for problem-solving).
Using a similar analysis, Walker, Smith, Garber, and Van Slyke (1997) identified three types of coping with physical pain in children and adolescents. These were defined as active coping (problem-solving, social support), passive coping (isolation, avoidance), and accommodative coping (acceptance, distract-ignore). Compas and colleagues (2001) propose a model for adolescent coping, combining these models. This three-dimensional model of coping includes: 1) active strategies to achieve some level of personal control over the stressful aspects of the environment and their own emotions; 2) accommodative coping strategies to adapt to the situation using cognitive methods of reframing, acceptance, or distraction through positive thoughts or activities; and 3) avoidance/passive/disengagement coping strategies that attempt to avoid or disengage from the stressor or for one's emotions.

In summary, there appears to be some indication of an association of certain coping strategies with the psychological adjustment of adolescents exposed to stress. However, the causal role is less clear at this time and requires more rigorous research (Compas et al., 2001). Further research is needed to increase consensus on the conceptualization of coping in adolescence and for such research to incorporate models which reflect the developmental changes for this age period (Compas et al., 2001). It is also important for further research to include the broader social context in which stress and coping occur. This could be accomplished through the inclusion of adolescents from a more diverse ethnic and socioeconomic background and conducting observational research in natural settings.

*Coping and Adolescents with Cancer*

The developmental tasks of adolescents, developmental differences in coping strategies, and the potential impact of the diagnosis of cancer and treatment on the adaptation of AWC point to the need for research on coping specifically designed for the AWC. With limited studies of coping in adolescents with cancer, studies with samples of both adolescents and children with cancer are included in the literature review on coping. Table 2 provides a summary of the reviewed studies. An extended review of the AWC coping studies follows the table.
<p>| Reference          | Design                  | Sample                                                                 | Coping Model                                                                 | Variables                                                                                           | Coping Instruments                                                                                     | Findings                                                                                                  |
|--------------------|-------------------------|------------------------------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|
| Weekes &amp; Savedra (1988) | Qualitative             | 10 adolescents with cancer (ages 15-19, M=16) 70% female               | Emotion-focused and problem-focused coping                                    | Coping strategies specifically for treatment-related pain                                             | Structured interviews, field observation, and adolescent questionnaire                                 | Early adolescents used more emotion-focused, middle to late adolescents used a combination of both problem-focused and emotion-focused coping. |
| Weekes &amp; Kagen (1994)   | Qualitative, longitudinal | 13 children and adolescents, 31% females ages 9-18, (M=12)              | Symbolic interaction-integration of perception, meaning and cognition         | Perception and meaning of on-therapy/off-therapy experience. Coping strategies for treatment/off treatment | Semi-structured interviews, 4 points in treatment                                                      | Coping strategies used during treatment: 1) positive thinking; 2) avoiding thoughts of treatment; 3) keeping busy; 4) focusing on positive outcomes from the cancer experience; and 5) taking things as they come/staying calm. Off-therapy strategies: 1) negotiating to gain/regain levels of autonomy; 2) cognitive reliving of the cancer experience through volunteering as peer counselors/spending time with oncology providers/peers on treatment; and 3) focusing on resuming normal life while selectively forgetting &quot;bad&quot; aspects of treatment. |</p>
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<th>Reference</th>
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<td>Brown et al. (1992)</td>
<td>Cross-sectional Descriptive</td>
<td>55 children &amp; adolescents with cancer (ages 2-17) 80% Caucasian 3 groups: Newly diagnosed (M age=6.8 years, SD=4.2, 58% male) 1 year post diagnosis (M age=8, SD=4.2, 69% male) Off therapy (M age=7.6, SD=2.1, 40% male)</td>
<td>10 areas of coping: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem-solving and regulation.</td>
<td>IV= Time since diagnosis DV= coping, family functioning &amp; psychosocial functioning</td>
<td>Kidcope</td>
<td>No differences between the three diagnosis groups. Adolescents used more adaptive, behavioral and affective coping than younger children.</td>
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<tr>
<td>Burgess &amp; Heaga (1998)</td>
<td>Cross-sectional Descriptive</td>
<td>72 adolescents with cancer, ages 12-18 (M=15.2 SD=1.4), 49% female, 98% Caucasian</td>
<td>Emotion/problem-focused &amp; controllability of stressor-Lazarus' Model of coping attributions-Weiner's model of coping</td>
<td>IV=Coping strategies (which used and effectiveness of), appraisals of threat, &amp; attributions of causation DV=emotions (anxiety, anger, and depression), &amp; parental perception of adjustment</td>
<td>Coping Response Inventory-Youth form (CRI)</td>
<td>Gender differences- Females used wider repertoire of both types of strategies and more effectively. Males using more types of coping strategies had higher scores for negative moods and symptoms. Females using more types of strategies had lower scores for negative mood and symptoms. Controllability was not predictive of the type of strategy, but increased the use of both problem-focused and emotion-focused coping.</td>
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<td>Reference</td>
<td>Design</td>
<td>Sample</td>
<td>Coping Model</td>
<td>Variables</td>
<td>Coping Instruments</td>
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<td>Sorgen &amp; Manne (2002)</td>
<td>Cross-sectional, descriptive, correlational</td>
<td>76 children and adolescents on treatment, ages 8-18 (M=14.8 SD=3.3), 47% female, 76% Caucasian</td>
<td>Emotion-focused and problem focused coping &amp; controllability of stressor</td>
<td>IV=Appraisal of control and coping strategy, (cancer and non-cancer) stressors DV= distress (composite of behavior problems, depression, anxiety, &amp; adjustment to illness)</td>
<td>Children/adolescents: Open-ended, semi-structured interviews asking about cancer-related problems in 4 areas: friendships, school, family, and hospital treatment. Beck Depression Inventory, State Anxiety Inventory of State-Trait Anxiety Inventory, Parents: Child Behavior Checklist, single item adjustment questions</td>
<td>There was a significantly higher (p&lt;.001) use of emotion-focused coping when perceptions of controllability across the problems were low. Problem-focused coping was associated with perceptions of higher controllability and emotion-focused for low controllability for the adolescents (not younger children). The highest levels of distress occurred when there was a mismatch between controllability and the type of coping strategy for school and treatment at hospital stressors.</td>
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<td>Derevensky, Tsanos, &amp; Handman (1998)</td>
<td>Cross-sectional, descriptive</td>
<td>21 Children and AWC: 9 preadolescents ages 8-11 (M=10 SD=NA), 12 adolescents ages 12-17 (M=15 SD=NA), 57% female, 91% Caucasian. Wide range of stage of treatment from newly diagnosed to 1 year off-treatment</td>
<td>Approach, avoidant, and denial, &amp; coping behaviors-productive, active, flexible for 2 types of coping: coping with self and Coping with the environment</td>
<td>Social support, cancer treatment stage, behavior, &amp; coping</td>
<td>Biographical questionnaire, Assessment of Coping Style, Coping Inventory</td>
<td>Compared to norms, the children and adolescents with cancer used significantly (p&lt;.05) more adaptive and efficient coping. The adolescents used a wider repertoire of coping strategies than the pre-adolescents.</td>
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<td>Phipps, Fairclough &amp; Mulhern (1995)</td>
<td>Cross-sectional, descriptive</td>
<td>66 children with cancer ages 6-15, divided into 3 age groups ages 6-8, 9-11 and 12-15 (M=10 SD=3) 44% female, 82% Caucasian. Comparison group: a large sample of healthy children 5 time since diagnosis groups: • 0-6 months • 6-12 months • 1-2 years • 2-3 years • &gt; 3 years</td>
<td>Avoidant-approach coping</td>
<td>IV=children with cancer vs. healthy children, time since diagnosis, gender and age DV=Coping strategies (general and specifically for medical procedures)</td>
<td>Children's Behavioral Style Scale</td>
<td>There was a higher used of avoidance coping behaviors in the cancer group with the highest levels in those further from diagnosis. No differences in approach coping compared to norms. The older two age groups used less avoidant coping than the youngest group with difference for approach behaviors. No gender differences.</td>
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<td>Trask (2003)</td>
<td>Cross-sectional, descriptive, correlational</td>
<td>28 adolescents 1 month from diagnosis to 1 year off treatment, ages 11-18 (M=13.6 SD=2)</td>
<td>Engagement/ disengagement coping</td>
<td>IV=Coping, social support, behavior, symptoms, family environment DV=distress</td>
<td>Coping Strategies Inventory (CSI) The CSI divides engagement coping into 4 strategy groups: problem-solving, cognitive-restructuring, social support and expressing emotions. The disengagement coping groupings include problem avoidance, wishful thinking, social withdrawal, and self-criticism</td>
<td>Of the 8 strategy groups, only the use of cognitive-restructuring was significantly related to lower levels of distress. The adolescents reported higher use of engagement strategies compared to disengagement strategies. No gender differences on engagement strategies, but males used more disengagement strategies. No differences based on the type of cancer or time-since-diagnosis.</td>
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<td>Nichols (1995)</td>
<td>Cross-sectional, descriptive, correlational</td>
<td>20 adolescents, (ages 10-16) 75% male</td>
<td>12 coping patterns: Ventilating feelings Seeking diversions Developing self-reliance Developing social support Solving family problems Avoiding problems Seeking spiritual support Seeking professional support Investing in close friends Engaging in demanding activity Being humorous relaxing</td>
<td>DV=Coping, IV=social support</td>
<td>Adolescent coping orientation for Problem Experience (A-COPE), Norbeck Social Support Questionnaire (NSSQ)</td>
<td>No significant differences compared to norms. No gender differences. Higher social support related to family problem-solving strategies. Spiritual support and humor use decreased over treatment time.</td>
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IV=Independent Variable  DV=Dependent Variable  M=Mean  SD= Standard Deviation
Coping with procedure-related pain was examined in 10 AWC (ages 14-19) (Weekes & Savedra, 1988). This stressor was chosen because procedure-related pain was identified by AWC as the worst problem in treatment in a previous research study (Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980). Using a field note guide, a guide for structured observation of coping behavior, a structured interview guide, and an adolescent questionnaire, the data were analyzed, resulting in several themes. These were further refined through the use of a panel of nurse clinicians to culminate in a list of coping strategies divided into two categories: action and affective. The adolescents consistently used similar strategies before, during, and after treatments. The adolescents were also grouped into early, middle, and late adolescent periods for additional data analysis. This analysis showed early adolescents to consistently use affective coping strategies while the middle and late adolescents used more action-oriented and cognitive strategies.

With a sample of 10 subjects, the description of findings concerning coping differences for three age groupings seems unrealistic. Even for descriptive work, drawing conclusions for a group of one (younger adolescents, ages 12-14) or for the largest group of eight (middle adolescents, ages 15-17) seems to elevate the findings beyond the scope of the study. While a table of demographics was included in the research report, the table of age group differences omitted the number in each group, which served to mask this limitation. In addition, despite a higher percentage of males diagnosed with cancer during adolescence compared to females, there were only 3 males in the sample, all in the middle adolescent age group. Gender, rather than age may account for the reported age group differences. The sample also had a broad range of cancer diagnoses and time-since-diagnosis. The value of this qualitative study design is the use of observation as well as interviews, allowing for triangulation of the data and the opportunity for the AWC to freely express their opinions rather than indicate their preferences through the use of a standardized survey instrument. However, the findings should have been limited to description of coping for the sample as a whole.
Weekes and Kagan (1994) interviewed 13 AWC (ages 11-18) at four points in time (three to six months prior to completion of treatment, at completion, three months after completion, and six months after completion) to assess the adolescents’ perceptions of the experience. The adolescents identified five coping strategies prior to the completion of therapy. These included positive thinking, avoiding thoughts about treatment, keeping busy, focusing on the positive outcomes from the cancer experience, and keeping their cool/living one day at a time. After therapy was completed, the strategies were somewhat different. At this time point, the adolescents described the use of negotiation with parents as a coping strategy to regain a level of autonomy and responsibility within the family. In contrast to avoiding thoughts about the treatment, the adolescents off treatment wanted to relive the experience though discussions, peer counseling or other volunteer activities connected with the cancer center. The adolescents also described using a strategy of “selective memory” as they avoided thoughts about the worst parts of the experience and focused on achieving a normal life.

The subjects in this study were mostly young adolescents (mean age 12 years old) and included three children under 10 despite the inclusion criteria outlined in the sample section as ages 11 to 18. With the length of treatment and the longitudinal nature of the study, this may have been deliberate on the part of the researchers. However, these younger children were barely adolescents when their treatment was completed, which might have been important in their perceptions of the experience. The strength of this qualitative study is giving voice to the AWC on their coping with the cancer experience. Future studies might incorporate these findings when choosing instruments to measure coping or in the selection of variables to include in the study.

Emotion-focused and problem-focused coping strategies in 39 children and adolescents (ages 7-17) off treatment with cancer in remission were examined by Bull and Drotar (1991). Coping was measured by the Children’s Stress Inventory (CSI) (Wertlieb, Weigel, & Feinstein, 1987) and an interview developed by McCabe and Weisz (cited in Bull & Drotar, 1991) to assess children’s perceived coping strategies for specific cancer-related stressors. On both measures, the children were asked to identify strategies that helped, tell why they chose the coping strategy, and how it helped them. This study used statistical analysis of the data to calculate frequencies, correlations
among strategies and type of stressor, and ANOVA for gender differences from data coded by two independent raters to categorize the stressors as cancer and non-cancer related and coping strategies. The coping dimensions from the CSI were used to code both the measures for consistency. The coping strategies were then analyzed using a variety of dimensions including focus (self or environment), function (problem- or emotion-focused) and mode (information seeking, support seeking, direct action, inhibition of action, and intrapsychic). Compared to the younger children, adolescents used more emotion-focused and less problem-solving coping strategies for the cancer-related stressors, but not with other non-cancer-related stressors. This is consistent with a study by Band and Weisz (1988) who reported the use of secondary control strategies (such as emotion-management) for low control stressors by adolescents. This may be due to the increased ability of adolescents to recognize the futility of problem solving strategies in these situations, in this case, stressors such as hair loss or treatment side-effects. In this study, the females used significantly more emotion-management strategies than problem-solving while there was no difference in the use of the two types of strategies for males.

While the conceptualization of coping in children was described in the introduction as problem- or emotion-focused, the data was described using five coping dimensions for the frequency of strategy use by the subjects and in correlations between cancer and non-cancer stressors and coping strategies. These were also divided into problem-focused and emotion-focused coping to determine the relationship of age to coping strategy type. In this analysis, separate repeated measures ANOVA were conducted for two age groupings, 7-12 years old and 13-17 years old. To determine the relationship of gender to coping strategy type (problem-or emotion focused), separate repeated measures ANOVA were conducted. Finally, the dichotomous variable of diagnostic status, cured (remission >5 years) and remission (<5 years in remission and off treatment) was analyzed using repeated measures ANOVA for coping (problem-or emotion focused). Using different dimensions of coping in reporting the findings made the results confusing and required careful rereading to understand the differences among these coping conceptualizations. The analysis with age, gender and diagnostic status was somewhat
ambitious with a sample of 39 subjects although the significances reported were fairly robust: <.005 for age, <.001 for both gender and diagnostic status.

Brown and colleagues (1992) assessed coping strategies in 55 children and adolescents with leukemia (ages 2-17), using the Kidcope (Spirito & Williams, 1987). The Kidcope defines coping as multi-dimensional with 10 areas of coping strategies: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem-solving, emotional regulation, wishful thinking, seeking social support, and resignation. Using a cross-sectional design, coping was assessed soon after the diagnosis, one year from the diagnosis, and one year after the completion of treatment. There were no differences among the groups of time-from-diagnosis on the 10 dimensions of coping. In comparing the adolescents with the younger children, the adolescents reported using more adaptive, behavioral, and affective coping strategies than the younger children. Several areas of coping strategies increased with age including distraction, cognitive restructuring, emotional regulation, social support, and resignation. Problem-solving, wishful thinking, and emotional regulation were the three strategies used more often across the entire sample.

With the sample of children with mild to moderate risk ALL, generalization of these findings to children with other types of cancer is difficult due to differences in treatment regimens and prognoses. As with many of the studies, the authors analyzed sub-groups using time-since-diagnosis due to broad differences in this variable. However, it may not be possible to generalize the findings due to the small sub-group sample sizes.

Burgess and Haaga (1998) examined the relationship of two models of coping to the psychological outcomes of anger, anxiety, depression, behavior and adjustment in 72 AWC (ages 12-18). The first model used was Weiner’s (1985) attribution model, which proposes that the assessment of an event’s outcome determines the emotional response (negative or positive) and that this is further dependent on the perception of the perceived cause of the outcome. This includes the internal-external locus of control (for the cause of the stressor), controllability of the stressor, and the stability of the perceived cause. The second model tested in this study was Lazarus and Folkman’s (1984) stress and coping model. In this appraisal model, the negative
emotion from a stressor depends on cognitive appraisals and coping responses. Cognitive appraisals evaluate the relevance of a stressor to one's well-being and are divided into two types. Primary appraisal involves assessing the relevance, benign-positiveness and threat, challenge or harm-loss of the stressor. Secondary appraisals are concerned with the accountability (whose fault), problem-focused coping potential, emotion-focused coping potential, and future expectancy (the possibility of a change on its own). Coping was measured by the Coping Response Inventory-Youth Form (CRI) (Moos, 1992), modified to ask respondents to indicate how often specific coping strategies were used for coping with cancer and a cancer-related hassle (self-selected by the respondents).

Results of the analysis found no support for Weiner's attribution model, with the exception of a positive correlation (r = .30, p < .05) between anger and externality of attribution for cancer "hassles". In testing Lazarus's appraisal model, appraisals were limited to primary appraisals (harm/loss) and mainly for depressive symptoms for females, and trait anger for males. For the choice of coping strategies and how they related to appraisals of the stressor as changeable, the use of both problem-focused and emotion-focused strategies increased. Again there were gender differences in the relationship of the type of strategy and emotions. For the males, emotion-focused coping was positively correlated with trait anger but unrelated to anxiety or depression. For the females, total problem-focused scores were not related to emotion, but two specific strategies (problem-solving r = -.34, p < .05, and seeking alternative reward r = -.37, p < .05) were negatively correlated with depression. The females used more coping (emotion- and problem-focused) strategies and used them more effectively compared to the males. In addition, for the females, the coping strategies were non-significantly or negatively related to depression. For the males, the majority of the coping strategies had a positive relationship with negative moods and symptoms. The authors speculate that the use of deliberate coping, particularly emotion-focused coping by male AWC, may be an indication of distress rather than a way to effectively reduce it. A correlation analysis of the type of coping (problem-solving or emotion-focused) with the perception of the controllability of the stressor was also conducted. In this
study, the controllability of the stressor was not predictive of the choice of type of strategy. Instead, the perception of controllability of the stressor increased the use of both types of coping strategies. The findings did confirm the use of Lazarus and Folkman's model for this population.

This study used a large sample of AWC (n=72), allowing for analysis based on gender. However, limitations included a predominantly Caucasian (97%) sample and a wide range of cancer diagnoses, time since diagnosis, and treatment status. An additional concern is the fact that the CSI was not designed to divide the coping strategies into problem-and emotion-focused strategies, requiring interpretation by the researchers. The choice of Weiner's model may have been inappropriate in the case of cancer since the focus for AWC is not cause, but the treatment experience and potential for cure.

In a study of coping behaviors and perceived control, interviews were conducted with 76 children and adolescents with cancer, ages 8-18 (Sorgen & Manne, 2002). Using an open-ended, semi-structured interview based on Compas and colleagues (1988), the children were asked to identify specific cancer-related problems in areas such as friendship, school, family, and hospital treatment. They were also asked to identify one non-cancer related stressor. For each problem, they were asked to generate a list of coping strategies and to indicate how they felt each coping response helped make things better. These responses were then categorized into problem-focused and emotion-focused coping. Distress was measured using a composite score for five different instruments, (behavior, depression, anxiety, internalizing/externalizing behavior, and overall adjustment rating). There was a significantly higher use of emotion-focused coping (p<.001) compared to problem-focused coping when the children perceived low controllability of the problem. A significant association between problem-focused coping and the perception of higher controllability of cancer-related stressors was found for the AWC, but not for the younger children. In assessing the fit between coping and appraisals of control and psychological distress, mismatch for both school problems and treatment at the hospital problems showed a positive significant relationship, but not for the other problem areas. This may indicate stressors related to school or in-patient treatment are most disruptive to the children's lives with increased distress due to a mismatch in these areas.
One strength of this study was the large sample, allowing for analysis of the data for age groups. There was also a broader ethnic representation than in many other studies of AWC. Limitations included a very wide range of time-since-diagnosis (1 month to 12 years) with some of the subjects many years off treatment and the lack of a demographic table to help clarify this. While it was not discussed in this report, gender in addition to age might have been an important variable to examine. With some evidence of gender differences in coping strategies, appraisals and psychological outcomes, this might have resulted in different or additional findings.

Derevensky, Tsanos, and Handman (1998) examined the coping strategies of 9 preadolescents (ages 8-11) and 12 adolescents (ages 12-17). Using a cross-sectional design, the participants were grouped by time from diagnosis; first 6 months of treatment, 7-20 months of treatment, and 1 year off treatment. Based on evidence that children who use a broader repertoire of coping styles have more effective coping, the coping repertoire was assessed using two different measures. The Assessment of Coping Style (Boyd & Johnson, 1981) is a projective test dividing the responses into three major coping styles: approach, avoidance and denial. On this measure, responses were similar to those of the comparative sample of normal children. The AWC used a wider repertoire of coping types compared to the preadolescents, consistent with changes in cognitive capacities as children mature. The Coping Inventory (Zeitlin, 1985) divides coping behavior into three dimensions (productive, active, and flexible), resulting in a score for each dimension and a global Adaptive Behavior Index. The children and adolescents with cancer used significantly more adaptive and efficient coping than the comparison sample on each of these dimensions including the global Adaptive Behavior Index. There were no significant differences for the three time-from-diagnosis groups of the children/adolescents with cancer on the coping measures.

The sample in this study was fairly small for comparison by the two age groups, yet was again divided into three diagnostic groups—newly diagnosed, on treatment and off treatment for analysis. Gender differences were not analyzed for coping behaviors despite some evidence that gender does affect the type of coping strategy used by AWC.
Using the Children’s Behavioral Style Scale (CBSS) (Miller, Sherman, Roussi, Caputo, & Krus, 1995), Phipps, Fairclough, and Mulhern (1995) compared the coping strategies of 66 children and AWC and a normal comparison group. This instrument uses the coping dimensions of monitoring/information seeking and blunting/ information avoiding. Analysis of gender and age groupings (6-8, 9-11, and 12-15) found no differences between the cancer groups or between the cancer group and normative controls. There were significant differences in the use of blunting in the cancer group compared to the controls although differences between the groups in the use of monitoring did not reach significance level. There was also an increase of the use of blunting over time in the group with cancer. This finding was consistent with other studies reporting increased defensiveness and repression in this population (Canning, Canning, & Boyce, 1992; Worchel, Copeland, & Barker, 1987).

The researchers used a stratified convenience sample in this study to obtain approximately equal numbers of males and females in the age ranges making the gender and age effects more credible. The findings were limited to a descriptive analysis of coping and the comparisons to normative controls.

Trask and colleagues (2003) examined the coping strategies of 28 adolescents (ages 11-18) receiving treatment for cancer. Coping was assessed using the Coping Strategies Inventory (CSI) (Tobin, Holryod, & Reynolds, 1984) and is divided into engagement (4 factors: problem-solving, cognitive-restructuring, social support and expressing emotions) versus disengagement (4 factors: problem avoidance, wishful thinking, social withdrawal, and self-criticism) but due to an error, the CSI data was only available from one of the two sites for the adolescents. The use of engagement coping strategies was significantly correlated to lower levels of distress (measured by the Child Behavior Checklist-Youth-Self Report [(Achenbach & Edelrock, 1987)]. Of the engagement strategies, only cognitive restructuring was significantly related to lower levels of distress. Those adolescents that reported more active strategies and cognitive-restructuring in particular reported lower levels of distress. There was no significant relationship between disengagement coping strategies and distress. The adolescents reported using engagement coping strategies more often than disengagement strategies. There were no gender differences
in the amount of engagement coping, but males reported significantly more disengagement coping strategies. There were no differences in groups based on the type of cancer, cancer stage (in treatment or remission) or time since diagnosis.

Power was compromised by the small sample in Trask and colleague's (2003) study. Although coping was assessed using a valid and reliable instrument appropriate for use with children and adolescents, results for the adolescents were based on a sub-sample of 17. Descriptive results on coping strategies and the correlations with distress for the two coping strategy dimensions and their factors must be taken as tentative due to the small number of subjects for which coping data was available. Additional problems include using a broad range of cancer diagnoses with treatment that widely varies in intensity and duration and a broad range of time-from-diagnosis. Fewer than 50% of those subjects approached to participate in the study participated, but no analysis of differences between those who agreed to participate and those who declined was reported. Generalizability of these results is limited due to methodological problems in the study.

The coping patterns of 20 AWC were found to be similar to those of healthy adolescents using the Adolescent Coping Orientation for Problem Experiences (A-COPE) (Patterson & McCubbin, 1987b) in a study by Nichols (1995). The A-COPE divides coping responses into problem-focused, emotion-focused, and disengagement. In this study, there were no gender differences in the reported use of coping strategies. A positive relationship between social support and coping in adolescents with cancer was reported. Adolescents with higher perceived social support were more likely to use family problem-solving as a coping strategy which may be an indication of increased dependence on parents or decreased availability of peers. There was a difference in the types of strategies based on illness duration. Spiritual support was reported as more often used in the initial treatment period and less often as treatment time continued. The use of humor as a coping strategy also decreased over time. Nichols suggests this difference may be due to the decreased need for jokes and laughter or from difficulties in using humor as
the side effects of treatment and the impact of the disease on their body image increased. She also questions the adequacy of the coping repertoire of these adolescents in light of the stress from the cancer treatment.

This study used a small sample size and unequal gender ratios (75% males). While illness duration was one variable measured in the study, no information was given on the range of time-since diagnosis or even if all of the subjects were still on treatment. The positive correlation of higher social support to higher coping total scores seems to assume that the higher repertoire or use of a variety of coping strategies is always better than fewer without regard to the type of strategy or match with the problem situation.

Synthesis of the Coping Literature

From the studies on coping for children and adolescents with cancer, several studies reported a significant increase in the overall number of coping strategies used by the adolescents compared to the younger children (Brown et al., 1992; Bull & Drotar, 1991; Derevensky et al., 1998) although this appeared to be specifically for cancer-related stressors. Brown and colleagues (1992) reported the use of distraction, cognitive restructuring, emotional regulation, social support, and resignation increased with age. Bull and Drotar (1991) found AWC used more emotional management and less problem-solving strategies compared to school-aged children. This is consistent with research showing adolescents used more cognitive control and less behavior control coping strategies than younger children in dealing with stressful medical situations (Worchel et al., 1987). There also appears to be some evidence of increased use of problem-solving strategies for cancer-related stressors with high controllability for the adolescents compared to the younger children (Sorgen & Manne, 2002). However, in a study looking specifically at coping with invasive medical procedures, Phipps and colleagues (1995) found no significant differences between children and adolescents with cancer.

Children and adolescents with cancer also used different patterns or styles of coping compared to healthy peers (Derevensky et al., 1998; Nichols, 1995; Phipps et al., 1995). Derevensky and colleagues (1998) found the AWC used more adaptive and efficient coping based on the total adaptive behavior index for the Coping Inventory (Zeitlin, 1985). Nichols
(1995) reported the adolescents used different patterns of coping based on the A-COPE
(Patterson & McCubbin, 1987b) compared to their healthy peers, but found no significant
difference in the number of overall strategies used. For example, AWC used the patterns
"Solving family problems" which includes the behaviors of ventilating feelings and doing things
with the family and "Relaxing" significantly more than healthy peers. However, they used the
pattern of "Seeking spiritual support" less than healthy peers. Phipps and colleagues (1995)
found no differences in "monitoring" coping, but a significant increase in the use of
blunting/avoidant coping in the cancer sample.

In looking at the gender differences, there are also conflicting results. Burgess and Haage
(1998) found a significantly larger number of coping strategies used by the girls compared to the
boys. Trask and colleagues (2003) reported no significant differences on engagement coping
strategies, but a significantly larger number of disengagement strategies used by the males. In
another study, females used significantly more emotion-focused and less problem-solving than
the males (Bull & Drotar, 1991) while Nichols (1995) found no significant gender differences.

In comparing the types of coping strategies used by adolescents with cancer, the results are
unclear. Trask and colleagues (2003) found the adolescents used more engagement coping than
disengagement coping, while Phipps and colleagues (1995) found the opposite to be true. For
problem-solving versus emotion-focused, Bull and Drotar (1991) found the adolescents used
more emotion-focused strategies with cancer-related stressors. Weekes and Kagan (1994) found
this to be true for the younger adolescents while Sorgen and Manne (2002) found the choice
between the types of strategies to depend on the controllability of the stressor. In contrast, Brown
and colleagues (1992) found no differences at all.

There are several possible explanations for the conflicting results from these studies on coping
in AWC. For example, to measure coping, Weekes and Kagan (1994) used interviews with open-
ended questions such as "When you come in to have your treatments, what kinds of things do
you do and think about that help you deal with them?" In contrast, Sorgen and Manne (2002)
asked the participants to identify specific cancer-related problems in areas such as friendships,
school, family, and hospital treatment and then to generate a list of coping strategies used to
cope with these problems. Other studies used a variety of standardized coping instruments with the range of conceptualizations of coping from two dimensional (problem/emotion-focused coping or avoidant/approach coping styles), three dimensional (approach, avoidant, and denial) and those with 12 different coping styles, making it difficult to draw conclusions among the studies. With some indication that two dimensional models may not be appropriate in measuring coping in adolescents compared to multidimensional models, the dimensionality differences might explain these conflicting results.

Sample sizes in these coping studies varied from 20 to 76, making the comparison of groups (age or gender) within the smaller sample studies difficult to interpret. Each of the studies used different inclusion criteria for the adolescent and children, with a range of “more than five years off treatment” to those with newly diagnosed disease. Again, these differences make it difficult to draw any conclusions across the studies.

There is a need for additional studies on coping in AWC using adequate samples to allow for analysis across age, gender, and ethnicity groupings. While some of the studies used an ethnically diverse sample, no analyses compared the groups while several stated the sample consisted almost entirely of Caucasian adolescents and children.

Based on the literature on coping for adolescents in general, future studies should incorporate multidimensional conceptualizations of coping instead of those with two dimensions. This broader view of coping strategies may provide a better analysis of the differences within the group of AWC as well as how they differ from adolescents in other stressful situations.

Gaps in Research

While research on social support and adolescents with cancer has provided useful knowledge on the sources and types of support and on the levels of satisfaction with the perceived support, there is limited information about how social support is related to either family functioning or coping in AWC. Models of coping and stress include personal and social resources as independent variables on adaptive coping strategies, but lack information on the relationships between these variables. Lazarus, for example, describes primary relationships as having an
effect on perceived available support, which in turn, influences individual coping (Lazarus & Folkman, 1984). Lazarus (1984) and Holahan and Moos (1991) group these variables under personal and social resources described as having a direct effect on both adaptive coping and psychological adjustment.

While there is clear evidence that the experience of cancer treatment coming at a time of major developmental changes can be taxing on resources for coping with stress, research on coping with the cancer experience during adolescence is limited. Little is known about gender differences or how the repertoire of coping strategies compares to healthy adolescents. Studies on coping in adolescence are also needed to understand the relationship of coping to outcomes such as adjustment, resilience, and quality of life. Further research on the relationships between and among social support, family environment, and coping adolescents with cancer would provide additional knowledge.

While models of adolescent coping continue to be refined, additional research is needed to improve understanding of the multidimensional model that appears to best fit this developmental life stage. Studies to compare models of coping specific to the AWC will be helpful to understand adolescent coping in the context of a life-threatening disease with a difficult and onerous treatment course.
CHAPTER 3

METHODOLOGY

In this section, the data collection procedures and sample characteristics are described for each of the ARM studies. Ethical considerations for the studies are then discussed. Next the conceptual definitions and instruments for each of the variables are outlined. Finally, the statistical procedures used to address the research aims briefly described.

Data Collection and Design

This study used a secondary analysis of data from two studies based on Haase’s Adolescent Resilience Model (ARM) (Haase et al., 1999). Secondary data analysis has the economic advantage of both cost and time by using an existing data base (Rubin & Babbie, 1997). However, it is important to assess the validity of the data in addressing the research questions for the secondary data study. Some evidence of this comes from the use of existing instruments with established reliability and validity with adolescents whenever possible for the ARM studies. In addition, the ARM studies were specifically designed for AWC. Further information on the development of the ARM also provides some evidence of validity for the data.

The ARM model is the result of a series of qualitative and quantitative studies looking at adolescents with chronic illness (Haase et al., 1999). Using the perspectives of adolescents, parents, and nurses, seven qualitative studies contributed to the understanding of the cancer experience for adolescents. From these studies, several concepts were clarified for antecedent, critical attributes and outcomes. In addition, four quantitative studies were conducted by Haase for model evaluation to develop and test the psychometric properties of instruments to measure factors in the ARM and provide support for the ARM-related instruments. All instruments had adequate reliabilities and evidence of concurrent and/or construct validity based on correlations and predicted factor structures.

The first of adolescent resilience studies providing data for this study, ARM 1, was conducted at multiple sites in the United States and Canada (Haase et al., 1999) serving a culturally diverse population. Institutional Review Board approval for the protection of human subjects was
obtained for each site. A convenience sample of subjects was recruited through the clinics and hospital units at each of the sites. Data were collected from 1992-1993. Characteristics of those who declined to participate in the study were not available so it was not possible to compare the participants and non-participants to determine if there were differences between the two groups. Completion rates for those who consented to participate in the study were not available. The study used a cross-section design and included adolescents with cancer from the ages of 11 to 21.

Potential subjects were contacted by the clinic nurse or social worker in the outpatient clinic or the inpatient unit and given a brief explanation of the study. After consent was obtained from the adolescent and parent, the Clinical Nurse Specialist or social worker explained the instruments in the booklet to the adolescent. Completion of the booklet took about 1 hour and the adolescents were encouraged to take breaks as needed. If participants were unable to finish the booklet during the clinic visit or hospitalization period, the booklet was taken home and returned by mail, using a stamped envelope. The ARM 1 booklet contained 19 instruments and a demographic section. In this study, data from the Jalowiec Coping Scale-Revised (Jalowiec, 2003) and selected demographics were used in the data analysis for Research Aim 1.

ARM 2 was conducted at multiple sites in the United States including Arizona, California, Oklahoma and Indiana from 1997 to 2003. Institutional Review Board approval for the protection of human subjects was obtained at each site. A convenience sample of subjects from these sites was recruited though the clinics and hospital units at each of the sites. The study used a longitudinal design and included adolescents with cancer with 3 data collection times, approximately 1 month from diagnosis, at 4 and 9 months from diagnosis. Information on the characteristics of those who declined to participate in the study was not available. Data from the initial data collection time for this study from the social support, family environment and coping instruments were used in the study analyses as well as the same demographics used in ARM 1. The completion rates of those who agreed to participate in the initial data collection time were approximately 70%.
Potential subjects were identified in the inpatient unit or the outpatient clinic and given a brief explanation of the study. Consent was obtained from the adolescent and parent by the nurse, social worker or the site study coordinator. The booklets were then presented to both the parent and adolescent. The adolescent was given an explanation of each of the instruments in the booklet and had the opportunity to ask questions and begin each instrument to clarify understanding. The adolescent booklet contained 21 instruments and a demographics section at the end. The parent was given the opportunity to ask any questions after looking over the parent booklet, containing nine instruments and a demographic section. The adolescent was given $10 for each of the three data collection times, beginning with the initial consent session and at each subsequent data collection meeting. Subjects were contacted by phone to verify clinic appointments, to provide the data collection booklets and to give the payment for the second and third data collection times.

Completion of the booklet took 2 hours on average and the adolescents were encouraged to take breaks as needed. A parent also completed the parent booklet for each collection time. If participants were unable to finish the booklet during the clinic visit or hospitalization period, the booklets were taken home and returned by mail, using a researcher provided stamped envelope.

Sample

For ARM 1, the sample of 125 adolescents included a variety of cancer diagnoses (excluding CNS involvement) and time-since-diagnosis ranged from newly diagnosed to adolescents who had been diagnosed for more than 5 years. A sub-sample (n=73) of those subjects from ARM 1 who were eleven years or older when diagnosed with cancer was used in combination with the ARM 2 sample in the data analysis for Research Aim 1. The ARM 2 sample included 74 adolescents ranging in age from 11 to 19 years of age with a variety of cancer diagnoses (excluding those with brain involvement). Since the initial data collection time was used for this analysis, all of the subjects in the ARM 2 study were within two months of diagnosis. Table 3 summarizes the characteristics of each of the samples from the ARM studies.
Table 3
Demographic Characteristics of the Participants in ARM I (N=73) and ARM II (N=74)

<table>
<thead>
<tr>
<th>ARM I Characteristics</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at time of survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young adolescent (11-13)</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Middle adolescent (14-16)</td>
<td>29</td>
<td>40</td>
</tr>
<tr>
<td>Young adult (17-19)</td>
<td>31</td>
<td>43</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39</td>
<td>53</td>
</tr>
<tr>
<td>Female</td>
<td>33</td>
<td>45</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>37</td>
<td>51</td>
</tr>
<tr>
<td>Black</td>
<td>17</td>
<td>10</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>17</td>
<td>23</td>
</tr>
<tr>
<td>Native Am</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

| ARM II Characteristics         |    |    |
| Age at time of survey          |    |    |
| Young adolescent (11-13)       | 18 | 25 |
| Middle adolescent (14-16)      | 41 | 57 |
| Young adult (17-19)            | 13 | 18 |
| Gender                         |    |    |
| Male                           | 44 | 60 |
| Female                         | 30 | 40 |
| Ethnicity                      |    |    |
| White                          | 46 | 62 |
| Black                          |  3 |  4 |
| Asian                          |  4 |  5 |
| Hispanic                       | 10 | 13 |
| Native Am                      |  5 |  7 |
| Other                          |  2 |  3 |

Ethical Considerations

Ethical considerations for research studies included protection of the human rights of participants; evaluating the risk/benefit ratio for study participation; securing written informed consent; and submission of the proposal to the Institutional Review Boards for each institution.
prior to data collection. This study was also granted approval by the Indiana University Institutional Review Board (IRB) for the secondary data analysis.

Protection of human subjects in scientific research includes: a) voluntary participation and informed consent to determine both potential risks as well as benefits; b) protection from harm; and c) anonymity and confidentiality (Thyer, Padgett, & Logan, 2001). Children and adolescents are defined as a vulnerable population due to concerns about their ability to fully understand the consent process and questions of true voluntary participation with the possibility of undue influence from adults (Broome, Richards, & Hall, 2001). Despite these concerns, the National Institutes of Health (National Institutes of Health (NIH), 1998, March 6) published a position paper mandating that children be offered the opportunity to participate in clinical trials or for the researcher to provide a written explanation for the reason to exclude them. The goal of this mandate was to increase the opportunity for participation and benefits. However, the protection of children and adolescents as a vulnerable population remains of concern with responsibility for oversight delegated to the individual research institutions Institutional Review Board.

In a study of the ability of children to understand the purpose of research, what they will be actually doing in the study, and the risk and benefits, Lewis, Lewis, and Ifekwunigwe (1978) found children as young as 6 years old asked appropriate questions during the consent process. Another study gave participants 4 hypothetical treatment dilemmas followed by interviews for understanding, choice, reasoned outcome, and rationale. In these areas, adolescents were similar to the adults, but there were differences in the younger children on understanding and reasoning, but not on choice and reasoned outcome (Weithorn & Campbell, 1982). Age and length of illness influenced children and adolescents’ (ages 8-22) understanding of the research process and the consent process (Broome et al., 2001). There was some evidence that the children were influenced to consent to the study by their parents desire for them to participate (Abramovitch, Freedman, Thoden, & Nickolich, 1991) as well as by the financial incentives, ease of participation, and a sense of altruism (Broome et al., 2001). While it seems clear that children and adolescents can fully participate in the informed consent process, the choice of voluntary participation should be emphasized throughout.
In the ARM studies, voluntary participation was addressed by providing thorough information about the study to the adolescents and parent(s) and allowing them the choice to decline participation at several points in the consent process. The informed consent statements provided information about the study procedures and timelines, potential risks and benefits and the right to withdraw or refuse participation at any time during the study. Both the adolescents and parents were given ample opportunity to ask questions prior giving consent. Written consent from both the adolescents and parents was obtained for the study.

Risks identified for these studies were minimal. Anxiety was a potential risk due to an emotional reaction to the content or questions on the measures. More serious risks such as depression would be rare. While no harm was anticipated from participation in these studies, participants were given contact phone numbers for the researchers so appropriate referrals could be made as needed.

Potential benefits for participation outweighed the risks. Participants often expressed appreciation for the opportunity to increase the knowledge about the experience of AWC (Haase, personal communication, September 15, 2004). Participation may increase the awareness of feelings and personal strengths resulting from the cancer experience. Increased understanding of the research process may also benefit participants.

Although total anonymity is not possible unless it is impossible for even the researcher to identify a given response with a given respondent, confidentiality is maintained when the data cannot be linked to the participants except as needed by the researchers (Rubin & Babbie, 1997). Confidentiality was maintained in the ARM studies through the use of identification numbers on all study materials, access to the master identification file limited to the researchers, and the storing of all data in a locked cabinet.

Conceptual Definitions and Instruments

Table 4 outlines the individual instruments used to measure each of the variables (social support, family environment and coping). The conceptual definition for each variable is given along with a complete description of the instruments.
Table 4

<table>
<thead>
<tr>
<th>Variable</th>
<th>Instrument (Author)</th>
<th># of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Perceived Social Support-Family (PSS-FA) (Procidano &amp; Heller, 1983)</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Perceived Social Support-Healthcare Provider (PSS-HP) (Haase)</td>
<td>20</td>
</tr>
<tr>
<td>Family Environment</td>
<td>Family Adaptability and Cohesion (FACES II) (Olson, Portner et al., 1982)</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Parent-Adolescent Communication (Olson, 1993)</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Family Strengths (Olson, Portner et al., 1982)</td>
<td>12</td>
</tr>
<tr>
<td>Coping</td>
<td>Jalowiec Coping Scale -Revised (JCS-R) (Jalowiec, Murphy, &amp; Powers, 1984; Jalowiec, 2003)</td>
<td>60</td>
</tr>
</tbody>
</table>

**Social Support**

Social support is defined as information that leads the subject to believe that he is cared for, esteemed and valued and that he or she belongs to a network of communication and mutual obligations (Cobb, 1976). Perceived support refers to the appraisal of these social activities by the recipient as esteem enhancing, providing stress-related interpersonal aid, such as emotional support or cognitive restructuring, or some type of instrumental aid (Heller, Swindle, & Dusenbury, 1986; Procidano & Heller, 1983).

Three instruments in the ARM studies were used to measure perceived social support: Perceived Social Support-Friends (PSS-FR) (Procidano & Heller, 1983), Perceived Social Support-Family (PSS-FA) (Procidano & Heller, 1983), and Perceived Social Support-Healthcare Provider (PSS-HP) (Haase, personal communication, August 5, 2003). Each of these instruments consists of a series of statements to assess the subject's perception of the fulfillment of support needs. PSS-FR and PSS-FA were validated with undergraduate college students (mean age=19). The subjects responded to 20 statements such as "My friends give me the moral support I need" with either "Yes", "No", or "Don't Know". High reliability was demonstrated both with a test-retest reliability of $r = .88$ test-retest and Chronbach's Alpha for PSS-FR = .88, and PSS-FA= .90. Separate factor analyses with orthogonal factor rotation indicated that each scale was composed of a single factor. For construct validity, relationships between PSS, life stress,
and symptomology were significantly and predictably correlated. Haase modified the original scales for use in the ARM studies by expanding the responses from 1=totally disagree to 5=totally agree with the midpoint 3=unsure. The PSS-FA and PSS-FR are scored through summation of the item scores (reverse coding of several items on each instrument) with the higher total score indicating higher perceived social support. For the ARM 1 study, the alpha was .87 for the PSS-FA and .88 for the PSS-FR.

PSS-HP is adapted from the Procidano and Heller scales using the words “healthcare providers” to replace the words “friends” for the ARM study (Haase, personal communication, August 5, 2003). The subjects respond to the 20 statements using a scale of 1=totally disagree to 5=totally agree with the midpoint 3=unsure. Chronbach’s alpha for the ARM I was .94 for the PSS-HP.

Family Environment

Family environment includes family functioning, communication and family strengths. Family functioning is the way family members relate to one another, pursue goals, organize activities, and accept family routines and procedures (Moos, 1984). Olson and colleagues (1982) define family functioning as consisting of three dimensions: cohesion, adaptability, and communication. Family cohesion is defined as the emotional bonding in a family. Family adaptability is the ability of the family system to change the power structure, roles, and rules in response to developmental or situational stress. Communication between family members is described as the amount of openness, the extent of problems or barriers to communication within the family, and the extent to which family members are selective in their discussions with family members. Family strengths are defined by Olson, Larsen & McCubbin (1982) as the dimensions of pride and accord in the family.

Family environment in the ARM studies was measured with three instruments from the Family Inventories developed by Olson and colleagues (1983). These inventories were developed to provide a comprehensive view of marital and family dynamics using data from more than 1,000 families across the family life cycle. This sample included over 1,120 couples and 412 adolescents. National norms are available for each of the inventories.
The Circumplex Model (Olson et al., 1979) represents the three central dimensions incorporated in the concept of family behavior from family theory and family therapy literature: cohesion, adaptability and communication. Family Adaptability and Cohesion and Parent-Adolescent Communication (FACES II) (Olson et al., 1979) are the scales developed to measure these dimensions in the Circumplex Model. The Family Strengths scale is an additional scale used to assess family environment, but is not included in the Circumplex model.

Family Adaptability and Cohesion Scale (FACES II) is a 30-item, self-report questionnaire with 2 subscales: Adaptability (14 items) and Cohesion (16 items). The adolescents rate their level of agreement with statements about their perceptions of their family on a 5 point Likert-type scale. The choices range from 1= "almost never" to 5= "almost always". Test-retest reliability coefficients for Cohesion and Adaptability were reported as .83 and .80, respectively (Joanning, 1985). Cronbach’s Alpha was calculated using a split sample for the total scale and each of the subscales. Internal consistency for Cohesion was high at .87 with internal consistency moderate at .78 for Adaptability. For the overall scale, Cronbach’s alpha was .90 for the sample (Olson et al., 1985).

The Parent Adolescent Communication Scale (PACS) (Barnes & Olson, 1982) is designed to measure both positive and negative aspects of parent-adolescent communication from the view of adolescents and their parents. There are 40 items (20 asking about communication with the mothers and 20 about communication with the fathers) for the scale with three dimensions measured: Open family communication (10 items); Problems in family communication (6 items); and Selective family communication (4 items). Cronbach’s alpha was calculated using a split sample for the total scale and each of the subscales. Internal consistency for the subscale open family communication was high at .87 with internal consistency moderate at .78 for the subscale problems in family communication. For the overall scale, Cronbach alpha was .88 for the sample (Barnes & Olson, 1982).

Family Strengths is a 12-item, self-report scale of two family dimensions, Pride and Accord (Olson, Larsen, & McCubbin, 1982). The Pride subscale consists of seven items about respect, trust and loyalty in the family. The additional 5 items make up the Accord subscale that includes
family conflict, support, and accomplishments. Each adolescent rates his/her level of agreement
with each of the statements about his/her family on a 5-point Likert-type scale, ranging from 1=
"strongly disagree" to 5= "strongly agree". Reliability was in the acceptable range with an overall
scale alpha coefficient of .83 (Olson, Larsen et al., 1982).

Coping

Coping is "defined as the person's constantly changing cognitive and behavioral efforts to
manage specific external and/or internal demands that are appraised as taxing or exceeding the
person's resources" (Folkman et al., 1986, p 993).

Coping was measured using the Jalowiec Coping Scale-Revised (JCS-R) (Jalowiec et al.,
1984; Jalowiec, 2003). Respondents rate the use of 60 coping strategies on a scale of 0= "never"
to 3= "often" and their perception of the effectiveness of the strategy from 0= "not helpful" to 3=
"very helpful". The JCS-R measures both frequency of use and perceived effectiveness for 60
strategies. The original JCS divided coping strategies into problem-focused and emotion-
focused; the revised scale was expanded to reflect a multidimensional conceptual framework
(Jalowiec, 2003). Using sequential thematic clustering, related clusters of similar coping
strategies were derived to generate a multidimensional model of coping behavior. This
multidimensional model of coping grouped the 60 responses into eight coping styles: Confrontive,
Evasive, Optimistic, Fatalistic, Emotive, Palliative, Supportant, and Self-Reliant ranging from 4-13
items for each style. The JCS-R can be scored in a variety of ways. Ratings of the individual
items can be summed for each of the coping styles both for frequency of use and perception of
effectiveness. A total use by effectiveness score can also be obtained by multiplying these two
scores for each coping style. The JCS-R has a sixth grade reading level as determined by the
Grammatik Computer Program (Jalowiec, 1995). Reliability for each of the dimensions was
originally established in a population of adults with pending or past heart transplantation resulting
in Cronbach's alphas for internal consistency ranging from .47 to .80. The JCS-R has been used
with populations of adolescents who had some type of illness and those who were considered
healthy. Reliabilities for the JCS-R coping dimensions from these studies were not available.
Further information on the development of the JCS-R is available on page 77.
Data Analysis

To address Research Aim 1: To compare the eight dimension models of coping in the Jalowiec Coping Scale-Revised (JCS-R) (Jalowiec, 2003) with an alternate model with the JCS strategies, a combined sample of ARM 1 (sub-sample of AWC diagnosed at age eleven or older) and ARM 2 was used. Exploratory factor analysis was conducted on this combined sample.

To address Research Aim 2: To evaluate the psychometric properties of the social support, family functioning and coping instruments used in the study, item analysis was used to determine the correlation of items within each scale and Chronbach’s alpha calculated for each scale using the sample of ARM 2.

To address Research Aim 3: To determine the demographic group differences for each of the measures of social support, family environment and coping, Multivariate Analysis of Variance (MANOVA) were conducted to determine group differences for gender and age groups were conducted for each of the social support, family environment, and coping variables. This analysis also used the ARM 2 sample only.

To address Research Aim 4: To determine the strength of the relationship of social support and family environment to coping in AWC, multiple regression analysis was conducted using the sample from ARM 2.
CHAPTER 4

RESULTS

The results section first describes the data screening procedures performed on the data prior to the data analysis. Next the statistical analysis procedures and results for each of the research aims will be described separately. All of the data analyses were conducted using the Statistical Package for the Social Sciences 12.0 (SPSS).

Data Screening

Prior to conducting any of the analyses, the data were examined for outliers, normality, missing data, linearity, and homoscedasticity. Univariate descriptive statistics were inspected for accuracy of data input, looking for out-of-range values, credible means and standard deviations, and univariate outliers. From this analysis, one case was eliminated due to the subject's indicating "0's" on each item of the JCS-R. Missing data included an occasional random missing item, but these were a small number of data points. When less than 5% of the data is missing and appears to be in a random fashion, it should not seriously affect the analyses (Tabachnick & Fidell, 2001). Therefore, the missing data were addressed as appropriate for each type of statistical analysis.

Multivariate outliers can be identified through Mahalanobis distance, which is the distance from the centroid of the remaining cases with the centroid calculated as the intersection of the means for all of the variables (Tabachnick & Fidell, 2001). A conservative interpretation of the Mahalanobis distance for an outlying case is $p<.001$ for the Chi Square value and can be conducted using the case ID as the dependent variable in a regression analysis. No outliers for the predictor variables were identified in this analysis. This was assessed again in the regression analysis with the coping dimensions outcome variables.

Univariate normality was examined through histograms for each of the variables. Due to positive skewness for the three social support measures (PSS-FR, PSS-FA, and PSS-HP), the
data were transformed to attempt to achieve normality. However, transformation did not correct
the abnormality of the distributions so normality was reassessed in the regression analysis
through the residual scatterplots.

Homoscedasticity is related to linearity, both of which can be assessed through bivariate
scatterplots (Tabachnick & Fidell, 2001). While none of the bivariate scatterplots showed
curvilinear relationships between the sets of variables, the plots tended to be grouped towards
the high end of the plot. Although homoscedasticity is desirable, this is not vital when analyzing
ungrouped data (Tabachnick & Fidell, 2001), as was the case of the regression analysis in this
study. For the MANOVA, where the data are grouped, the homogeneity of variance was
assessed to determine homoscedasticity.

Addressing the Research Aims

Research Aim 1

To compare the eight dimension models of coping in the Jalowiec Coping Scale-revised (JCS-
R) (Jalowiec, 2003) with an alternate model with the JCS strategies.

To determine the best fit model of coping for AWC, factor analysis was performed on the items
on the Jalowiec Coping Scale-R (JCS-R). Although the original JCS used a two dimensional
(problem and emotion-focused) coping model, the scale was later revised after exploratory and
confirmatory factor analysis indicated the inadequacy of the two dimensional model. Additional
items were added to the scale and a multi-dimensional conceptual approach was examined
resulting in a revised scale of 60 items and eight coping dimensions. This was accomplished
through generating descriptions of coping behavior types or styles and creating coping strategies
to fit into each of these coping themes (Jalowiec, 2003). Face validity for the eight dimensions
was then assessed through the use of expert opinion of 25 nurse researchers familiar with the
literature on stress and coping. Additional support for the eight dimensions came from another
panel of three different judges. The dimensions were described and the panel asked to indicate
how well the items fit each dimension. Despite the importance of construct validity when there is
no accepted criterion that adequately defines the concept to be measured (Carmines & Zeller,
1990), there was no evidence of an attempt to establish construct validity for the revised instrument. Also of concern is the lack of theoretical basis for the eight dimensions, described as important for establishing scale validity (Carmines & Zeller, 1990).

Due to the problems outlined above with the eight dimensional conceptualization of coping used in the JCS-R and evidence from studies of adolescent coping demonstrating some theoretical evidence for three or four coping dimensions (Ayers et al., 1998; Compas et al., 2001; Connor-Smith et al., 2000; Walker et al., 1997), the first aim of the research study was to determine the best model for the coping outcome variables. This was accomplished through factor analysis conducted for the items on the JCS-R (Jalowiec, 2003) “Use” scores with the combined sample of AWC from ARM 1 and ARM 2. This sample included the subjects from the ARM 1 study who were diagnosed with cancer at age 11 or older (N=72) and all of the subjects in the ARM 2 study (N=74). Prior to conducting the factor analysis with the combined samples, gender, age and ethnicity were compared for the two samples and were found not to differ significantly (p<.01). Factor analysis was selected to analyze the dimensionality of the JCS-R in this sample because it is considered one method in assessing construct validity (Carmines & Zeller, 1990), lacking in the initial instrument testing of the revised scale. Theoretical direction for construct validity in the interpretation of the factors resulting from the factor analysis came from the coping literature supporting a three or four dimensional model of adolescent coping (Ayers, 2003; Compas et al., 2001; Connor-Smith et al., 2000).

Factor analysis is a statistical technique applied to a single set of variables to determine groupings of variables, to determine which variables belong to which group and how strongly they belong, and to explore the number of dimensions needed to explain the relations among the variables (Nunnally & Bernstein, 1994). The goals of factor analysis include reducing a large number of variables to a smaller number of latent variables, succinctly describing the relationships among observed variables, and testing theory about the underlying processes (Tabachnick & Fidell, 2001). These are also goals of this analysis. Questions to be answered through this analysis include:
- How many reliable factors (or latent variables) of adolescent coping are represented in this data set?
- What is the underlying meaning of these factors?
- How well do they fit with current theory on adolescent coping?

This factor analysis was conducted to determine the “best fit” model of coping to be used in the analyses to address research aims two, three and four and to examine adolescent coping in this population of AWC for additional testing of the proposed three or four dimensional model of adolescents coping.

Since factor analysis is very sensitive to correlation sizes, it is vital that reliable correlations be used (Tabachnick & Fidell, 2001). Therefore, prior to performing exploratory factor analysis, it is important to examine the data for outliers, missing data, and poorly distributed variables. This was accomplished through the data screening prior to the analysis and described in that section.

Sample size adequacy continues to be an issue of debate in factor analysis (Sapnas & Zeller, 2002). While power analysis is appropriate when the research design evaluates the likelihood of a null hypothesis, in factor analysis there is no null hypothesis, making such an analysis inappropriate (Sapnas & Zeller, 2002). The rule of thumb generally recommends a large sample size with a minimal number of items for testing valid and reliable instruments. Tabachnick and Fidell (2001) recommend more than 100 subjects with 300 seen as more desirable. Kerlinger (1986) suggests a ratio of 10 subjects per item while Bryant and Yarnold (1995) advise a ratio of 5 subjects per item. Others have suggested the analysis can be performed reliably using samples below 100 with as few as 2 subjects per item (Hughes-Hammer, Martsof, & Zeller, 1998; MacCullam, Widaman, Zhang, & Hong, 1999). Using a Monte Carlo simulation, Sapnas and Zeller (2002) demonstrated the adequacy of a sample of 50 subjects in the factor analysis of a scale of 9 items with 100 subjects described as fully adequate. While a large sample size would be desirable in the factor analysis of the data, the difficulty of obtaining large samples of AWC would make any such analysis extremely difficult. Therefore, the sample of subjects in this study can be seen as adequate with the caution that the small sample size may preclude replication of the factor analysis without additional analyses of larger samples.
After selecting and measuring a set of variables, the next step in exploratory factor analysis recommended by Tabachnick and Fidell (2001) is to begin with a visual examination of the correlation matrix. If there are only a few correlations > .30, factor analysis is not appropriate. Examination of this data showed an adequate, although not large, number of correlations > .30 as can be seen in the communalities column in Table 5.

Table 5
Summary of Retained Items and Factor Loading for Varimax Orthogonal Two-Factor Solution for the Jalowiec Coping Scale-Revised (N=124)

<table>
<thead>
<tr>
<th>Items Dimension 1</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Communality</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Tried to get out of the situation</td>
<td>.680</td>
<td>.091</td>
<td>.049</td>
<td>.473</td>
</tr>
<tr>
<td>20. Told yourself that the problem was someone else's fault</td>
<td>.526</td>
<td>-.135</td>
<td>.160</td>
<td>.321</td>
</tr>
<tr>
<td>23. Resigned yourself to the situation because things looked hopeless</td>
<td>.670</td>
<td>-.114</td>
<td>.120</td>
<td>.477</td>
</tr>
<tr>
<td>25. Tried to change the situations</td>
<td>.677</td>
<td>.090</td>
<td>.077</td>
<td>.473</td>
</tr>
<tr>
<td>34. Took a drink to make yourself feel better</td>
<td>.536</td>
<td>-.063</td>
<td>.069</td>
<td>.296</td>
</tr>
<tr>
<td>40. Put off facing up to the problem</td>
<td>.671</td>
<td>.010</td>
<td>.207</td>
<td>.493</td>
</tr>
<tr>
<td>46. Did something impulsive or risky that you would not usually do</td>
<td>.629</td>
<td>.055</td>
<td>.007</td>
<td>.399</td>
</tr>
<tr>
<td>48. Tried to ignore or avoid the problem</td>
<td>.590</td>
<td>-.084</td>
<td>.128</td>
<td>.372</td>
</tr>
<tr>
<td>51. Blamed yourself for getting into such a situation</td>
<td>.662</td>
<td>-.005</td>
<td>.007</td>
<td>.441</td>
</tr>
<tr>
<td>53. Took medications to reduce tension</td>
<td>.554</td>
<td>.119</td>
<td>.018</td>
<td>.321</td>
</tr>
<tr>
<td>55. Told yourself that this problem was really not that important</td>
<td>.621</td>
<td>.207</td>
<td>-.091</td>
<td>.437</td>
</tr>
<tr>
<td>56. Avoided being with people</td>
<td>.499</td>
<td>.017</td>
<td>.052</td>
<td>.437</td>
</tr>
<tr>
<td>Items Dimension 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Thought out different ways to handle the situation</td>
<td>.205</td>
<td>.580</td>
<td>-.011</td>
<td>.378</td>
</tr>
<tr>
<td>13. Tried to look at the problem objectively and see all sides</td>
<td>-.032</td>
<td>.510</td>
<td>.122</td>
<td>.276</td>
</tr>
<tr>
<td>16. Tried to keep the situation under control</td>
<td>-.067</td>
<td>.579</td>
<td>.104</td>
<td>.351</td>
</tr>
<tr>
<td>27. Tried to find out more about the problem</td>
<td>.022</td>
<td>.518</td>
<td>.267</td>
<td>.340</td>
</tr>
<tr>
<td>29. Tried to handle things one step at a time</td>
<td>-.088</td>
<td>.628</td>
<td>.117</td>
<td>.404</td>
</tr>
<tr>
<td>31. Thought about how you had handled other problems in the past</td>
<td>.208</td>
<td>.628</td>
<td>-.026</td>
<td>.439</td>
</tr>
<tr>
<td>32. Told yourself not to worry because everything would work out fine</td>
<td>-.165</td>
<td>.523</td>
<td>.108</td>
<td>.312</td>
</tr>
<tr>
<td>37. Told yourself that you could handle anything no matter how hard</td>
<td>.012</td>
<td>.562</td>
<td>-.025</td>
<td>.317</td>
</tr>
<tr>
<td>38. Set up a plan of action</td>
<td>.318</td>
<td>.540</td>
<td>-.065</td>
<td>.397</td>
</tr>
<tr>
<td>45. Learned something new in order to deal with the problem</td>
<td>.181</td>
<td>.507</td>
<td>.211</td>
<td>.334</td>
</tr>
<tr>
<td>50. Tried to think positively</td>
<td>-.275</td>
<td>.542</td>
<td>.300</td>
<td>.460</td>
</tr>
<tr>
<td>54. Tried to see the good side of the situation</td>
<td>-.196</td>
<td>.637</td>
<td>.145</td>
<td>.466</td>
</tr>
</tbody>
</table>
Examination of the matrix of the partial correlations through an anti-image correlation matrix is also recommended and is a slightly more stringent test than the previous one. The partial correlations should be small, opposite to the previous test. These data also met this criteria. Other recommended tests include the Bartlett Test of Sphericity and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA) (Norman & Streiner, 2000). The Bartlett Test (yielding a chi-square statistic) should be statistically significant at the p<.05 or lower (Norman & Streiner, 2000). The Bartlett Test for this analysis was statistically significant at the p<.00. Sampling adequacy is also determined using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA) with scores ranging from 0-1 (Field, 2000). Scores below .5 indicate factor analysis is likely inappropriate with score of .5-.7 as mediocre, and values from .7-.8 as good. MSA gives you a value for each variable (diagonal on the antiimage correlation matrix) and a total MSA score. Of the 60 JSC-R variables, the MSA range was .525 to .881 with a total MSA of .74.

All of the factor analyses were performed using principal component factor extraction with varimax rotation. In exploratory factor analysis, the correlations matrix is decomposed into its constituent factors or dimensions (Bryant & Yarnold, 1995). The principal component analysis (PCA) method estimates communalities in the positive diagonal of the observed correlation matrix through an iterative procedure with squared multiple correlations (SMCs) as the starting values for the iterative process (Tabachnick & Fidell, 2001). The goal of PCA is to extract the maximum orthogonal variance from the data set for each factor. In the initial iteration, the diagonal numbers (typically 1) are replaced by the communality of the variables. In each iteration, the communalities are estimated on the basis of the factors identified in the previous iteration, replace the original numbers on the diagonal of the correlation matrix and PCA is performed again (Bryant & Yarnold, 1995). This iterative process is continued until there is minimal change in the communality estimates in two successive steps. This solution is then rotated and interpreted.

The initial factor analysis was interpreted using the three methods for determining the number of factors. Kaiser's eigenvalue rule (Nunnally & Bernstein, 1994) is based on retaining those factors that explain more variance than the average amount explained by one of the original items
and is recommended when there are at least 250 observations and the communalities are at least .60. When the data do not meet these qualifications, Cattell’s (1966) scree test is then suggested for selecting of the number of factors to interpret (Bryant & Yarnold, 1995). The scree test is a graphic representation of the eigenvalues where the substantial change in variance explained appears as an “elbow” in the graph (DeVellis, 1991). The eigenvalue rule generally results in extraction of too many factors while the scree plot provides an acceptable starting point to determine the maximum number of factors to extract from the data (DeVellis, 1991; Hair, Anderson, Tatham, & Black, 1998). From this analysis, 16 factors had eigenvalues >1 with the scree plot indicating 3 factors. Neither the eigenvalue or scree plot verified 8 dimensions as suggested by Jalowiec.

The parallel analysis method also uses the eigenvalues to determine the number of components (Lautenschlager, 1989). For parallel analysis, the appropriate eigenvalue is determined by the number of variables and sample sizes using a Monte Carlo simulations. Based on tables generated from this technique, a sample size of 100-150 and 60 variables (items), factors with eigenvalues over 2.5 should be retained (Lautenschlager, 1989). Based on these guidelines, three factors were indicated.

To test the original eight dimensions through factor analysis, a second factor analysis was performed using the extraction method of “forcing” the data on eight factors. The resulting factors did not verify the item groupings among the eight dimensions as was proposed in the original revision of the scale. A similar analysis was then performed forcing on three dimensions (consistent with the scree plot and the parallel analysis eigenvalue criteria). The factors were then analyzed using the model of the three coping dimensions suggested by Compas and colleagues (2001).

The greater the loading factor, the more the variable is a pure measure of the factor so generally only variables with loading of .4 and above are interpreted. For the interpretation of factors, Comrey and Lee (1992) suggest the following rating: excellent = .71+ (50% overlapping variance), very good = .63 (40% overlapping), good = .55 (30% overlapping), fair = .45 (30% overlapping), and poor = .32 (10% overlapping). However, the choice for cutoff is a matter of
research preference and not a hard and fast rule. For this analysis, a cut-off of .5 was used with the additional criteria of more than .2 difference in item loadings across the factors.

Table 5 lists the items and factor loadings. Factor loadings for retained items for each factor are in bold type. Factor 1 loaded 13 items >.5 on the rotated component matrix and with one failing the >.2 difference of loadings for the other two dimensions. The retained items that loaded on Factor 1 seemed to fit with avoidance, passive, or disengagement coping strategies that attempt to avoid or disengage from the stressor or one’s emotions (Compas et al., 2001).

For the second factor, 14 had loadings >.5 with two items having <.2 item loadings differences on the other two dimensions. These items appeared to fit the definition of active coping strategies described as strategies to achieve some level of personal control over the stressful aspects of the environment and one’s own emotions (Compas et al., 2001).

With only two items on the third dimension meeting the retention criteria, there was little evidence for three factors from this data. An additional factor analysis was performed designating 2 factors by forcing the 24 retained items from the first two factors with these two factors accounting for 40% of the variance. These resulting two dimensions of coping (active and avoidant) were used in the rest of the analyses.

Reliability and item analysis were also calculated for each of the separate dimensions using the item groupings from the JCS-R and the two dimension item grouping for use in the decision-making process for the best fit model of coping. This is described in the next section.

Research Aim 2

To evaluate the psychometric properties of the social support, family functioning and coping instruments used in the study.

To evaluate the psychometric properties of the measures used in the study, item analysis was used to determine the correlation of items within each scale and Chronbach’s alpha calculated for each scale. There are two types of item-scale correlations which provide information about how well each item correlates with the rest of the items as a whole (DeVellis, 1991). The corrected item-scale correlations provide the correlation of each item with all of the other scale items, excluding itself. Those items with high correlations (> .30) are viewed as more desirable items
(DeVellis, 1991). Another way to determine the relationship between the items and the total scale is to try to predict a person’s score on an item by using the scores on the other items (Norusis, 2003). This is calculated by multiple regression analysis of each item as the dependent variable and all the other items as independent variables, resulting in an R squared for each item, called the Squared Multiple Correlation. Table 6 shows the corrected item-scale correlations, the number and percentage of items <.30, and the Squared Multiple Correlations for each of the measures or dimensions. For each of the social support instruments the determinant of the covariance matrix was 0 or approximately 0. The Squared Multiple Correlations are based on its inverse matrix so this could not be computed, resulting in missing values in that column.

Table 6
Summary of Item Analyses

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Corrected-item-Total Correlation Range</th>
<th>Number and percent of items &lt; .30</th>
<th>Squared Multiple Correlation Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSS-FR</td>
<td>106 - .616</td>
<td>6/20 30%</td>
<td></td>
</tr>
<tr>
<td>PSS-FA</td>
<td>157 - .670</td>
<td>3/20 15%</td>
<td></td>
</tr>
<tr>
<td>PSS-HP</td>
<td>234 - .505</td>
<td>3/20 15%</td>
<td></td>
</tr>
<tr>
<td><strong>Family Environment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACES-II</td>
<td>.072 - .764</td>
<td>4/30 20%</td>
<td>.465 - .851</td>
</tr>
<tr>
<td>PAC-Open</td>
<td>.430 - .763</td>
<td>0/20 0%</td>
<td>.936 - .941</td>
</tr>
<tr>
<td>PAC-Unproblematic</td>
<td>.283 - .675</td>
<td>2/20 10%</td>
<td>.485 - .828</td>
</tr>
<tr>
<td>Family Strengths</td>
<td>.321 - .793</td>
<td>0/12 0%</td>
<td>.382 - .791</td>
</tr>
<tr>
<td><strong>Coping</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jalowiec Coping Scale-R</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active Coping Dimension*</td>
<td>.417 - .586</td>
<td>0/12 0%</td>
<td>.268 - .361</td>
</tr>
<tr>
<td>Avoidant Coping Dimension*</td>
<td>.379 - .640</td>
<td>0/12 0%</td>
<td>.288 - .452</td>
</tr>
<tr>
<td>Confrontive Coping Dimen</td>
<td>.184 - .544</td>
<td>1/10 10%</td>
<td>.136 - .392</td>
</tr>
<tr>
<td>Evasive Coping Dimension</td>
<td>.151 - .572</td>
<td>2/13 15%</td>
<td>.127 - .399</td>
</tr>
<tr>
<td>Optimistic Coping Dimen</td>
<td>.208 - .588</td>
<td>1/9 11%</td>
<td>.145 - .412</td>
</tr>
<tr>
<td>Fatalistic Coping Dimen</td>
<td>.179 - .366</td>
<td>2/4 50%</td>
<td>.035 - .143</td>
</tr>
<tr>
<td>Emotive Coping Dimen</td>
<td>.245 - .508</td>
<td>2/5 40%</td>
<td>.118 - .306</td>
</tr>
<tr>
<td>Palliative Coping Dimen</td>
<td>.206 - .444</td>
<td>3/7 42%</td>
<td>.066 - .331</td>
</tr>
<tr>
<td>Supportant Coping Dimen</td>
<td>.229 - .536</td>
<td>3/5 60%</td>
<td>.066 - .313</td>
</tr>
<tr>
<td>Self-Reliant Coping Dimen</td>
<td>.305 - .544</td>
<td>0/7 0%</td>
<td>.171 - .310</td>
</tr>
</tbody>
</table>

* Coping Dimensions determined by factor analysis of this sample

For the social support instruments, particularly the PSS-FR, the corrected–item total correlations indicate that some items may be less appropriate for this population. On the PSS-FR, the items "My friends get good ideas from me on how to do things or make things", "I've recently gotten a good idea about how to do something from a friend", "Most other people are
closer to their friends than I am”, “My friends give me the moral support I need”, and “My friends enjoy hearing what I think” had correlations below .30. Fewer items on the PSS-FA were below .30. Some of these items were similar to the low correlation items on the PSS-FR scale including “Members of my family get good ideas from me”, “I get good ideas from my family about how to do things or make things”, and “I don’t have a relationship with a member of my family that is as close as other people’s relationship with family members”. An additional item with low correlations was “I wish my family were much different”. In a similar way, the PSS-HP low correlations items were “Most other people are closer to their health care providers than I am”. My health care providers want to hear what I think”, and “My health care providers get good ideas from me about how to do things”.

The Family Environment instruments had fewer items with low correlations. The FACES II, for example, had 30 items with 4 items below .30. These items were “We shift household responsibilities from person to person”, “It is hard to know what the rules are in our family”, “It is difficult to get a rule changed in our family”, and “Family members say what they want”.

The two dimensions on the Parent Adolescent Communication (PAC) were evaluated separately. The Open Communication dimension items were all above .30. The Unproblematic Communication dimension had 2 of the items <.30. All of the items on the Family Strengths Scale had correlations above .30.

For the coping instrument, both the eight dimensional and two dimensional models were examined in a similar way. The eight dimensions show a lower range of Corrected-Item-Total Correlation Range and Means and Squared Multiple Correlation Ranges when compared to the two dimensions. The eight dimensions also had more items <.30. Due to the factor analysis and item evaluation, those items on the two dimensional model that had low correlations were not included in the final dimensions of active and avoidant coping. Therefore, there were no items on these dimensions with low correlations.

Chronbach’s alpha gives a unique estimate of the expected correlation of one test with an alternate form containing the same number of items (Carmines & Zeller, 1990) and is considered equal in value to the alternate form reliability estimate. Reliability determined by Chronbach’s
alpha gives the lower bound of the reliability of an unweighted scale providing a conservative estimate of a measure's reliability (Novick & Lewis, 1967). A satisfactory level of reliability for widely used scale should be > .80 (Carmines & Zeller, 1990). Reliability was assessed using the Chronbach's alpha for each of the study variables and are displayed in Table 7. All of the social support and family environment scales had acceptable Chronbach alphas (> .80). Chronbach's alpha for the two coping dimensions have reliabilities > .80 with Active coping = .83 and Avoidant coping .86. The eight dimension model alphas range from .511 to .797. This finding should also be taken with some caution since the most of the eight dimensions contained fewer items compared to the two dimensional model, which would result in lower alphas.

The analysis to determine the psychometric properties of the measures in this study demonstrated adequate Chronbach's Alpha for the social support and family environment instruments, and for the two dimensional coping model resulting from the factor analysis. From the item analysis, some items seemed to be less appropriate for use with this population.

Table 7  Chronbach's Alpha Based on Standardized Items for the Measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>( \alpha )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
</tr>
<tr>
<td>Perceived Social Support-Friends (PSS-FR)</td>
<td>.81</td>
</tr>
<tr>
<td>Perceived Social Support-Family (PSS-FA)</td>
<td>.84</td>
</tr>
<tr>
<td>Perceived Social Support-Healthcare Provider (PSS-HP)</td>
<td>.83</td>
</tr>
<tr>
<td><strong>Family Environment</strong></td>
<td></td>
</tr>
<tr>
<td>Family Adaptability and Cohesion (FACES II)</td>
<td>.92</td>
</tr>
<tr>
<td>Parent-Adolescent Communication-Open</td>
<td>.94</td>
</tr>
<tr>
<td>Parent-Adolescent Communication-Unproblematic</td>
<td>.87</td>
</tr>
<tr>
<td>Family Strengths</td>
<td>.88</td>
</tr>
<tr>
<td><strong>Coping Jalowiec Coping Scale-R (JCS-R)</strong></td>
<td></td>
</tr>
<tr>
<td>Active Dimension*</td>
<td>.83</td>
</tr>
<tr>
<td>Avoidant Dimension*</td>
<td>.86</td>
</tr>
<tr>
<td>Confrontive</td>
<td>.75</td>
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<tr>
<td>Evasive</td>
<td>.80</td>
</tr>
<tr>
<td>Optimistic</td>
<td>.76</td>
</tr>
<tr>
<td>Fatalistic</td>
<td>.51</td>
</tr>
<tr>
<td>Emotive</td>
<td>.61</td>
</tr>
<tr>
<td>Palliative</td>
<td>.61</td>
</tr>
<tr>
<td>Supportant</td>
<td>.58</td>
</tr>
<tr>
<td>Self-reliant</td>
<td>.67</td>
</tr>
</tbody>
</table>

* Coping Dimensions determined by factor analysis of this sample
Research Aim 3

To determine the demographic group differences for each of the measures of social support, family environment and coping.

Group differences for gender and age groups were conducted for social support, family environment, and coping variables in the ARM II study using Multivariate Analysis of Variance Analysis (MANOVA) statistical analysis. MANOVA is used to assess the effect of one or more independent variables on a set of two or more dependent variables (Howell, 1997). In this case the independent variables were gender and age groups and the dependent variables were social support, family environment, and the two coping dimensions. MANOVA is preferable to ANOVA when there are multiple intercorrelated dependent variables since MANOVA takes the intercorrelations into account, providing a richer multivariate analysis of the data (Weinfurt, 1995). MANOVA also allows detection of group differences on the whole group of dependent variables which may not be significant when each dependent variable is examined individually using ANOVA (Weinfurt, 1995).

MANOVA is based on the following assumptions:

- Multivariate normality
- Homogeneity of the covariance matrices
- Independence of observations (Weinfurt, 1995)

Underlying univariate ANOVA is the assumption of normal distribution for the variables for each group defined by the independent variables (Tabachnick & Fidell, 2001). Normal distribution is assessed through statistical or graphical methods. Multivariate normality is a more difficult assumption to meet as this requires normal distribution of the individual variables, normal distribution of any linear combinations of the dependent variables and that all subsets of the variables have a multivariate distribution (Weinfurt, 1995). As there is no test for multivariate normality, most researchers use the univariate normality test since univariate normality generally assures that any problems with multivariate normality are inconsequential (Hair et al., 1998). Univariate normality was examined through histograms for each gender and age group resulting in normal distributions for each group on each variable.
Univariate ANOVA requires similar variance on the dependent variable for each of the groups defined by the independent variables (Tabachnick & Fidell, 2001; Weinfurt, 1995). For multivariate analysis, the variances for all dependent variables should be equal for each group defined by the independent variables. Univariate homogeneity of variance is assessed with Levene’s Test of Equality of Error Variances and is especially important when there are unequal sample sizes (Howell, 1997) as was true with the age group data. None of the variables were significant (p<.01) for Levene’s Test of Equality of Error Variances, although PSS-FR approached significance at p=.018. In addition, MANOVA requires that the covariances (variance shared between two variables) for each pair of dependent variables be equal for all experimental groups and can be tested though the Box’s M Test (Weinfurt, 1995). Since the sample sizes for the age groups are unequal, robustness of significance should be examined for significance <.001 (Tabachnick & Fidell, 2001). In this analysis, Box’s M Test was nonsignificant (F=1.13, p= .163), allowing the acceptance of the null hypothesis of homogeneity of the variance-covariance matrices.

Independence of observations assumes each subject’s score on the dependent measures are not influenced by the other subjects in the group (Weinfurt, 1995). In this study, the instruments were administered individually with no subject interaction and the data are grouped for demographics only.

Means and standard deviations for the variables are presented by gender and age group in Table 8. Table 9 shows the correlations among the variables. There were high correlations among the social support variables, among the family environment variables and between social support from family and open communication between parent and adolescent. Avoidant coping was significantly negatively correlated with FACES II and Family Strengths. Active coping was significantly correlated with open communication.
Table 8
Mean Scores and Standard Deviations for Measures of Social Support, Family Environment, and Coping as a Function of Gender and Age

<table>
<thead>
<tr>
<th>Group</th>
<th>FACES II</th>
<th>PAC-Open</th>
<th>PAC-Unproblematic</th>
<th>Fam. Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.5</td>
<td>.6</td>
<td>3.8</td>
<td>.8</td>
</tr>
<tr>
<td>Female</td>
<td>3.6</td>
<td>.5</td>
<td>3.8</td>
<td>.7</td>
</tr>
<tr>
<td>Age Groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>3.5</td>
<td>.7</td>
<td>3.7</td>
<td>.9</td>
</tr>
<tr>
<td>15-16</td>
<td>3.5</td>
<td>.5</td>
<td>3.9</td>
<td>.7</td>
</tr>
<tr>
<td>17-19</td>
<td>3.5</td>
<td>.3</td>
<td>3.7</td>
<td>.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group</th>
<th>PSS-FR</th>
<th>PSS-FA</th>
<th>PSS-HCP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2.7</td>
<td>.2</td>
<td>2.8</td>
</tr>
<tr>
<td>Female</td>
<td>2.8</td>
<td>.1</td>
<td>2.8</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>2.7</td>
<td>.2</td>
<td>2.8</td>
</tr>
<tr>
<td>15-16</td>
<td>2.8</td>
<td>.1</td>
<td>2.8</td>
</tr>
<tr>
<td>17-19</td>
<td>2.8</td>
<td>.1</td>
<td>2.7</td>
</tr>
</tbody>
</table>
Table 8 (Con't)

<table>
<thead>
<tr>
<th>Group</th>
<th>Active M</th>
<th>Active SD</th>
<th>Avoidant M</th>
<th>Avoidant SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.9</td>
<td>.6</td>
<td>.9</td>
<td>.7</td>
</tr>
<tr>
<td>Female</td>
<td>2.1</td>
<td>.6</td>
<td>.6</td>
<td>.6</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>2.0</td>
<td>.7</td>
<td>.9</td>
<td>.7</td>
</tr>
<tr>
<td>15-16</td>
<td>2.0</td>
<td>.5</td>
<td>.6</td>
<td>.6</td>
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<tr>
<td>17-19</td>
<td>2.2</td>
<td>.4</td>
<td>.5</td>
<td>.2</td>
</tr>
</tbody>
</table>

Table 9
Correlation Coefficients for Relations Among Social Support, Family Environment and Coping Variables

<table>
<thead>
<tr>
<th>Measure</th>
<th>PSS-FA</th>
<th>PSS-HP</th>
<th>FACES II</th>
<th>PAC-Open</th>
<th>PAC-Unproblematic</th>
<th>Fam. Strengths</th>
<th>Active</th>
<th>Avoidant</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSS-FR</td>
<td>.62**</td>
<td>.46**</td>
<td>.07</td>
<td>.03</td>
<td>.01</td>
<td>-.05</td>
<td>.09</td>
<td>-.16</td>
</tr>
<tr>
<td>PSS-FA</td>
<td>--</td>
<td>.65**</td>
<td>.43**</td>
<td>.40**</td>
<td>.23</td>
<td>.33</td>
<td>.03</td>
<td>-.23</td>
</tr>
<tr>
<td>PSS-HP</td>
<td>--</td>
<td>--</td>
<td>.20</td>
<td>.19</td>
<td>.2</td>
<td>.16</td>
<td>.16</td>
<td>.00</td>
</tr>
<tr>
<td>FACES II</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.66**</td>
<td>.55**</td>
<td>.82**</td>
<td>.24</td>
<td>.25*</td>
</tr>
<tr>
<td>PAC-Open</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.39**</td>
<td>.62**</td>
<td>.28*</td>
<td>.16</td>
</tr>
<tr>
<td>PAC-Unprob</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.60**</td>
<td>.09</td>
<td>-.20</td>
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<td>Fam.Str.</td>
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<td>--</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>.14</td>
<td>-.32**</td>
</tr>
<tr>
<td>Active</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.02</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01
After testing the assumptions, MANOVA was executed for the gender and age groups on the dependent variables of social support, family environment and coping. In interpreting MANOVA, it is important to consider Type I error, the inequality, effect size and statistical power (Weinfurt, 1995). The Type I error rate, expressed as alpha, is the probability of rejecting the null hypothesis when it is true (Weinfurt, 1995). There are two types of alphas: actual and nominal. The actual alpha levels is the true probability of making a Type I error while the nominal alpha is the Type I error level chosen by the researcher, $\alpha < .05$, for example. This should be equal to the actual alpha if the assumptions for the analysis are not violated. The Bonferroni Inequality is important for familywise and experimentwise alphas when multiple levels of an independent variable or several tests are conducted in the same study (Weinfurt, 1995). Calculating the Bonferroni–corrected alpha level using the formula: $\alpha (0.05)$ divided by the number of analyses (3) results in a significance level requirement of $\alpha < .017$.

Table 10 shows the results of the multivariate and univariate analyses for gender and age group. The multivariate analysis found no significant main effects for the groups (p<.01) using the Pillai’s Trace statistic.

Effect size is related to the magnitude of the findings, indicated in MANOVA as eta-square, and is equivalent to the R square in multiple regression (Weinfurt, 1995). In this analysis, each of the partial eta-squared are .20 or lower, considered a small effect. Power is the probability of detecting a significant effect when there is a true effect and is a function of sample size, effect size and the alpha level selected by the researcher (Weinfurt, 1995). For this analysis, Pillai’s Trace indicated low power (<.8) ranging from .334 to .411.

In looking at the tests of between subjects effects, the only significant difference was for gender ($F [1,65]=8., p=.006$) on the variable PSS-FR with moderate power (.65) and a small effect size (.05).
Table 10
Multivariate and Univariate Analyses of Variance for Social Support, Family Environment, and Coping

<table>
<thead>
<tr>
<th>Source</th>
<th>Multivariate F (5,59)</th>
<th>Univariate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>PSS-FR</td>
</tr>
<tr>
<td>Gender(G)(^{a})</td>
<td>1.41</td>
<td>8.20*</td>
</tr>
<tr>
<td>Age Group (AG)(^{b})</td>
<td>.77</td>
<td>2.33</td>
</tr>
<tr>
<td>G X AG(^{b})</td>
<td>1.2</td>
<td>2.07</td>
</tr>
</tbody>
</table>

Note. Multivariate F ratios were generated from Pillai’s statistic.
\(^{a}\) df = (1,59)  \(^{b}\) df=(2,59)
\(^{*}_{p} < .017\)
Because of the problems with power in the MANOVA, a factor analysis of the social support and family environment instruments was conducted to see if power could be increased through combining the separate measures into fewer latent variables. For the factor analysis, each of the variables (PAC-Open, PAC-Unproblematic, Family Strengths, Faces Total, PSS-FR, PSS-FA, and PSS-HP) was analyzed using principal component analysis/Promax rotation. Promax rotation rotates an orthogonally rotated solution again to allow correlations among factors and was selected due to prior knowledge of moderate to strong correlations between some of the variables.

Proceeding through the steps in factor analysis recommended by Tabachnick and Fidell (2001), the correlations matrix showed an adequate number of correlations >.30, an MSA statistic = .752, and the Bartlett’s Test of Sphericity p<.001. In this analysis, despite the relatively small sample size, the eigenvalues indicated that more than 72% of the variance was explained by two factors with similar confirmation from the scree plot, which showed a distinct “elbow” at component 3, indicating two factors. Loadings on the Structure Matrix (Promax oblique rotation) were strong with the family environment variables loading on one factor with loadings from .734-.912 and social support variables loading on the other factor from .827-.896, all within the "excellent" range (Tabachnick & Fidell, 2001). With the strong indication for two factors, the family environment variables were combined into a single total score and the social support variables into a second total support score and used to conduct a 2nd MANOVA.

The MANOVA using the total family environment and total social support scores resulted in non-significance for Box’s Test of Equality of Covariance Matrices (p=.135) and for Levene’s Test of Equality of Error Variances on all variables. However, power in this analysis was reduced over the first model (.057-.145) and was non-significant on the multivariate and univariate tests for gender, age group, and interaction between gender and age group. This analysis also resulted in lower partial squared for Pillai’s Trace (.030-.085). Therefore, the model using summed variables to represent family environment and social support variables in the MANOVA for gender and age group differences did not show improvement over the one using the entire set of social support, family environment and coping variables as individual variable.
There were no significant demographic group differences (age group or gender) determined by this analysis. Therefore, the regression analysis for Research Aim 4 was conducted using the entire sample from ARM II.

**Research Aim 4**

*To determine the strength of the relationship of social support and family environment to coping in AWC.*

Multiple regression is used to determine the value of a set of predictor variables for predicting another event or behavior described as the outcome variable (Licht, 1995). Multiple regression analyses were conducted for each of the two coping dimensions (active and avoidant) as outcome variables with all of the predictors (FACES II, PAC-Open, PAC-Unproblematic, Family Strengths, Perceived Social Support-Family (PSS-FA), Perceived Social Support-Friends (PSS-FR), Perceived Social Support-Healthcare Providers (PSS-HP) entered simultaneously. This method assesses each predictor as if it had entered the regression after all of the other predictors had been entered so that each predictor variable is evaluated for its unique contribution in the prediction of the outcome variable (Tabachnick & Fidell, 2001).

The regression analysis was used to try to address the following questions:

- What is the strength of the relationship between the outcome variable and the predictor variables as a whole (How good is the regression equation?)
- What is the importance of each of the predictor variables (Which predictor variables are important in the equation?)

Prior to conducting regression analysis, several issues should be addressed (Tabachnick & Fidell, 2001). These include:

- the ratio of cases to predictor variables
- outliers among the predictor and outcome variables
- multicollinearity and singularity
- normality, linearity, homoscedasticity of residuals
- independence of errors
- outliers in the solution
To detect a medium-size relationship between the predictors and outcome variables, Tabachnick and Fidell (2001) recommend the formula of \( N > 50 + 8m \) where \( m \) = the number of predictor variables for testing the multiple correlation and \( N > 104 + m \) for testing the individual predictors. In this analysis, the sample of 69 subjects does not meet either of these requirements for sample size. Therefore the analysis can only be considered suggestive for any significant relationship in predicting the outcomes variables or in the strength of the relationship for each of the predictors.

The other issues are addressed in the multiple regression analysis itself. Outliers were assessed through Mahalanobis distance for multivariate outliers with no indication of outliers from this analysis. Multicollinearity and singularity are also assessed in the regression analysis. Multicollinearity and singularity occur when variables are too highly correlated (.9 and above). Singularity occurs when one of the variables is a combination of two or more other variables (Tabachnick & Fidell, 2001). Singularity should not be a problem in this analysis since each variable was independent of the other ones.

The multiple regression program in SPSS has default values for tolerance (1- squared multiple correlations) to prevent the inclusion of multicollinear predictors (Tabachnick & Fidell, 2001). The collinearity diagnostics for this analysis had tolerances from .356-.749. According to Field (2000), the general rule for tolerance is to consider scores <.20 as indications of potential problems while those <.10 indicating a serious problem. The tolerances for this analysis were all in the acceptable range. The Variance inflation factor (VIF) measures the effect of other predictor variables on a regression coefficient. It is inversely related to the tolerance so those larger than 10 (corresponding to a tolerance of .10) indicate a high degree of collinearity. The VIF scores for this data range from 1.6-3.6.

Residual scatterplots test the assumptions of normality, linearity, and homoscedasticity between the predicted outcome scores and errors of prediction. The scatterplots in this analysis demonstrated acceptable meeting of the assumptions although they show some clustering at the higher end of the plot scores.
Independence of errors is also examined through the residual analysis using the Durbin-Watson test statistic which examines correlations between errors (Field, 2000). The statistic ranges from 0-4 with 2 indicating that the residuals are uncorrelated. Scores below 2 indicate a positive correlation and those above 2, a negative correlation. In this analysis, the Durbin-Watson test for the model was 1.99 for Active Coping and 1.35 for Avoidant Coping. While SPSS does not provide the significance value for this test, the general rule is to be concerned about those scores below 1 and above 3 (Field, 2000). For this data, the assumption of independence of errors was met.

Three tests to measure the influence of individual cases on the model are Cook’s distance, leverage, and Mahalanobis distances (Field, 2000). Cook’s distance considers the effect of a single case on the entire model with values above 1 as concerning. Neither of the regression analyses had scores on Cook’s distance above 1 for the two outcome variables (avoidant and active coping). Leverage measures the influence of the observed value of the outcome variable over the predicted value. Average leverage is defined as 1 + the number of predictors divided by n with a recommended cut-off point for investigating cases with large leverage values using this average leverage multiplied by three. Average leverage for this analysis is 0.072, so the cut-off in this analysis was 0.22. Three cases were above the cut-off point for leverage on the Active Coping outcome. The analysis was rerun with these deleted resulting in a slightly better model fit so they were omitted in the analysis. Mahalanobis distances were also evaluated for the two regression analyses. Using the accepted p<.001 from the Chi-square (degrees of freedom) table, none of these were significant.

In interpreting the regression model, each of the coping dimension models (active and avoidant coping) will be described separately. The active coping dimension was the outcome variable in the first regression analysis using predictor variables of FACES II, PAC-Open, PAC-Unproblematic, Family Strengths, PSS-FA, PSS-FR, and PSS-HP.

Table 11 displays the means, standard deviations and correlations between the variables. The unstandardized regression coefficients (B), the Standard Error of B, the standardized regression coefficients (β), the 95% confidence intervals, the semi-partial correlations (sr²) and
R² are shown in Table 12. R for the model was .435 indicating the multiple correlations among all of the predictors and the outcome variable of active coping. The comparison of the R² (.189 or approximately 19% of active coping predicted by the predictor variables) to the Adjusted R² (.09) shows a fair amount of shrinkage (.099 or 10%). Shrinkage indicates the loss of variance in the outcome variable expected if the model were derived from the population rather than a sample. This model would account for about 10% less variance in the outcome based on the shrinkage estimate. The standard error is also an indication of how the regression coefficient would vary between samples of the same size taken from the same population and is also used in the estimation of the confidence interval for the predictions (Hair et al., 1998). This should be small if prediction is reliable. The standard error of the estimate is .529 for this regression coefficient.

Table 11
Means, Standard Deviations, and Intercorrelations for Active Coping and Family Environment and Social Support Predictor Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<tr>
<td>Active Coping Predictor Variable</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td>.6</td>
<td>--</td>
<td>.66**</td>
<td>.55**</td>
<td>.82**</td>
<td>.07</td>
<td>.43**</td>
<td>.20</td>
</tr>
<tr>
<td>2. PAC-Open</td>
<td>3.8</td>
<td>.8</td>
<td>--</td>
<td>.39**</td>
<td>.62**</td>
<td>.03</td>
<td>.40**</td>
<td>.19</td>
<td></td>
</tr>
<tr>
<td>3. PAC-</td>
<td>3.3</td>
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<td>--</td>
<td>.60**</td>
<td>.01</td>
<td>.23</td>
<td>.12</td>
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<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Family Strengths</td>
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<td>.7</td>
<td>--</td>
<td>.05</td>
<td>.33</td>
<td>.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. PSS-FR</td>
<td>2.8</td>
<td>.2</td>
<td>--</td>
<td>.62**</td>
<td>.46**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. PSS-FA</td>
<td>2.8</td>
<td>.1</td>
<td>--</td>
<td>.65**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. PSS-HP</td>
<td>2.7</td>
<td>.2</td>
<td></td>
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</tbody>
</table>

**p<.001 *p<.017

Table 12
Standard Multiple Regression of Perceived Social Support and Family Environment Variables Predicting Active Coping.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>95% Lower Bound</th>
<th>95% Upper Bound</th>
<th>sr² (unique)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACES II</td>
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<td>.22</td>
<td>.32</td>
<td>-.129</td>
<td>.742</td>
<td>.03</td>
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<tr>
<td>PAC-Open</td>
<td>.24</td>
<td>.12</td>
<td>.33</td>
<td>-.003</td>
<td>.483</td>
<td>.06</td>
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<td>.12</td>
<td>.05</td>
<td>-.260</td>
<td>.219</td>
<td>.00</td>
</tr>
<tr>
<td>Family Strengths</td>
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<td>.18</td>
<td>-.18</td>
<td>-.498</td>
<td>.217</td>
<td>.01</td>
</tr>
<tr>
<td>PSS-Friend</td>
<td>.75</td>
<td>.52</td>
<td>.24</td>
<td>-.289</td>
<td>1.791</td>
<td>.03</td>
</tr>
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<td>PSS-Family</td>
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<td>.79</td>
<td>-.50</td>
<td>-.3489</td>
<td>.331</td>
<td>.08</td>
</tr>
<tr>
<td>PSS-HP</td>
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<td>.50</td>
<td>.29</td>
<td>-.090</td>
<td>1.920</td>
<td>.04</td>
</tr>
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</table>

Note. R² = .189  (N=66)
The Analysis of Variance (ANOVA) tests if the model is significantly better at predicting the outcome than using the mean as a "best guess" (Field, 2000). The ANOVA F-ratio represents the ratio of the improvement in prediction as a result of fitting the model relative to the inaccuracy that still exists in the model. This was also non-significant (F(7,58) = 1.9, p=.08) indicating that the model is not significantly better than using the mean to predict active coping, although the F value is >1 which indicates some small level of improvement using the predictors.

None of the individual predictors were significantly related to active coping with values as follows: FACES II (t=1.41, p=.17), PAC-Open (t=1.97, p=.05), PAC-Unproblematic (t=-.17, p=.87), Family Strengths (t=-.79, p=.44), PSS-FR (t=1.45 p=.15), PSS-FR (t=-2.42, p=.02) and PSS-HP (t=1.82, p=.07). Both Family Strengths and PSS-FA were negatively related to active coping, but not at a significant level.

The 95% confidence interval for the unstandardized B values gives the range within which 95% of the B values of the sample fall (Tabachnick & Fidell, 2001). Larger ranges and confidence intervals that cross zero indicate that for some subjects the predictor has a negative relationship to the outcome while for others, there is a positive relationship. In this model, there are fairly broad ranges and all cross zero except PSS-FA. The lower bound of the 95% confidence intervals for PAC-Open approaches 0 at -.003.

The semi-partial correlations represent the unique relationship between each predictor and the outcome, controlling for the effect the other predictors have on the outcome (Field, 2000). These values squared indicate how much the R² would be reduced if a predictor variable were omitted from the analysis and are shown in the table as sr².

For the outcome variable of avoidant coping, Table 13 displays the means, standard deviations, and correlations between the variables. Table 14 shows the unstandardized regression coefficients (B), the Standard Error of B, the standardized regression coefficients (β), the 95% confidence interval, the semi-partial correlations (sr²), and R². R for the model was .414 with an R² of .171 (about 17% of the variability in avoidant coping predicted by the predictor variables. In comparing the R² to the Adjusted R² (.071), there is a fair amount of shrinkage (.1 or 10 %). The standard error of the estimate is .632 for this regression coefficient. The Analysis of
Variance (ANOVA) was not significant (F (7,58) = 1.714 p=.124) indicating that the model is not an improvement over using the mean to predict avoidant coping.

Table 13
Means, Standard Deviations, and Intercorrelations for Avoidant Coping and Family Environment and Social Support Predictor Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
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<td>Avoidant Coping</td>
<td>.74</td>
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<td>-.25</td>
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<td>-.20</td>
<td>-.32*</td>
<td>-.16</td>
<td>-.23</td>
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<td></td>
</tr>
<tr>
<td>1. FACES II</td>
<td>3.5</td>
<td>.6</td>
<td>--</td>
<td>.66**</td>
<td>.55**</td>
<td>.82**</td>
<td>.07</td>
<td>.43**</td>
<td>.20</td>
</tr>
<tr>
<td>2. PAC-Open</td>
<td>3.8</td>
<td>.8</td>
<td>--</td>
<td>.39**</td>
<td>.62**</td>
<td>.03</td>
<td>.40**</td>
<td>.19</td>
<td></td>
</tr>
<tr>
<td>3. PAC-</td>
<td>3.3</td>
<td>.7</td>
<td>--</td>
<td>.60**</td>
<td>.01</td>
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<td>.12</td>
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<td></td>
</tr>
<tr>
<td>4. Family Strengths</td>
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<td>.7</td>
<td>--</td>
<td>.05</td>
<td>.33</td>
<td>.16</td>
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<tr>
<td>5. PSS-FR</td>
<td>2.8</td>
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<td>--</td>
<td>.62**</td>
<td>.46**</td>
<td></td>
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</tr>
<tr>
<td>6. PSS-FA</td>
<td>2.8</td>
<td>.1</td>
<td>--</td>
<td>.65**</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. PSS-HP</td>
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<td>.00</td>
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<td></td>
<td></td>
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</tr>
</tbody>
</table>

**p<.001 *p<.017

Table 14
Standard Multiple Regression of Perceived Social Support and Family Environment Variables Predicting Avoidant Coping.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>95% Lower Bound</th>
<th>95% Upper Bound</th>
<th>sr² (unique)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACES II</td>
<td>.16</td>
<td>.26</td>
<td>.14</td>
<td>- .357</td>
<td>.666</td>
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<tr>
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<td>.281</td>
<td>.00</td>
</tr>
<tr>
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<td>.14</td>
<td>-.03</td>
<td>-.310</td>
<td>.253</td>
<td>.00</td>
</tr>
<tr>
<td>Family Strengths</td>
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<td>.21</td>
<td>-.39</td>
<td>-.781</td>
<td>.058</td>
<td>.04</td>
</tr>
<tr>
<td>PSS-FR</td>
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<td>.61</td>
<td>-.18</td>
<td>-1.88</td>
<td>.555</td>
<td>.02</td>
</tr>
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<td>.94</td>
<td>.59</td>
<td>.26</td>
<td>-.236</td>
<td>2.123</td>
<td>.04</td>
</tr>
</tbody>
</table>

Note. R² = .171 (N=65)

All of the predictors are negatively related to avoidant coping with the exception of Faces II and PSS-HP. The t-test values were as follows: FACES II (t=.61, p=.55), PAC-Open (t=.03, p=.98), PAC-Unproblematic (t=.02, p=.84), Family Strengths (t=-1.73, p=.09, PSS-FR (t=-1.09, p=.28), PSS-FA (t=-.95, p=.35), and PSS-HP (t=1.6, p=.12), with none of the predictors of avoidant coping at the significant level. The 95% confidence interval for the unstandardized B values all cross zero with moderate to large ranges. The upper bound of the 95% confidence interval for Family Strengths approaches 0 at .058.

From the regression analysis for Research Aim 4, none of the predictors of social support or family environment in the regression model significantly predicted avoidant or active coping.
CHAPTER 5
DISCUSSION

Overview

This dissertation reported the findings of a study on coping in AWC. The purpose of the research was to determine a "best fit" model of coping for AWC, to explore gender and age group differences in social support, family environment and coping in AWC, and to analyze the relationship of social support and family environment to coping in newly diagnosed AWC.

In the present dissertation, the literature on social support was reviewed. Methodological problems in these studies included the use of large age ranges, subjects with large ranges of time-since-diagnosis, and small sample sizes. These problems make it difficult to detect any differences in social support due to age, gender, or treatment experience. While these studies have helped to clarify the sources and perceptions of social support for AWC, little information was available on how support is related to coping and adjustment in AWC. This review of literature showed the need for measuring social support early in the cancer experience to provide information on the pattern of social support prior to the diagnosis, rather than later after several months or years have passed. Measuring social support from specific sources would also increase understanding of any differences in each of the sources of social support for AWC.

There were few studies in the literature on family environment and AWC. As with social support, these descriptive studies have provided some knowledge on family environment and the AWC. However, little information was available to help clarify the relationship of family environment to outcomes such as adjustment and coping in the AWC. This literature review pointed to the need for additional studies with larger sample sizes and more restrictive parameters on age or time-from diagnosis.

The review of literature on coping highlighted several problems in the current literature on coping in AWC. Many of the studies used a variety of two-dimensional models of coping derived from adult studies. Based on the literature on coping for adolescents in general, future studies should continue to explore multidimensional conceptualizations of coping in addition to two
dimensions. As with the social support and family environment studies, most of the studies on coping in AWC had samples too small to allow analysis across age, gender, and time-since-diagnosis.

Due to methodological problems in many of the studies in this literature, the findings would be difficult to generalize to the larger population of AWC. On the basis of this comprehensive literature review of research with AWC on social support, family environment and coping, it was concluded that there is limited information on the relationships between these variables. With clear evidence that the experience of cancer treatment coming at a time of major developmental changes can be taxing on resources for coping with stress, additional research on adolescents coping with the cancer experience is required. Information on gender differences or how the repertoire of coping strategies compares to healthy adolescents is lacking. While models of adolescent coping continue to be developed, additional research is needed to improve understanding of the multidimensional model that is suggested as the best fit for adolescents. Studies to compare models of coping specific to the AWC will be helpful to understand adolescent coping in the context of a life-threatening disease with a difficult and often length treatment course.

This research study was conducted to provide some of the additional information needed to clarify the relationship of social support, family environment to coping in AWC. The specific research aims addressed by this study were as follows:

1. To compare the eight dimension models of coping in the Jalowiec Coping Scale-Revised (JCS-R) (Jalowiec, 2003) with an alternate model using the JCS strategies.
2. To evaluate the psychometric properties of the social support, family functioning and coping instruments used in the study.
3. To determine the demographic group differences for each of the measures of social support, family environment and coping.
4. To determine the strength of the relationship of social support and family environment to coping in AWC.
The next section provides a summary of the data collection procedures and the outcomes from each of the analyses. Results are first discussed for each of the four research aims separately followed by possible explanations for the results. Advantages and limitations of the methodology are then explored. Finally, suggestions for the use of the present findings and recommendations for future research are presented.

In order to address the research aims, data from the ARM 1 and ARM 2 studies were analyzed. In ARM 1, AWC at various times-since-diagnosis completed a booklet of 19 instruments with data from the coping scale used in this study for Research Aim 1. For the ARM 2 study, newly diagnosed AWC completed a booklet with 21 instruments, including the social support, family environment, and coping measures. Data from these measures for the ARM 2 sample were used for this study to address Research Aims 2-4.

Research Aims

Research Aim 1

The present research demonstrated that the data best fit a two dimensional model of coping for AWC, based on the factor analysis and scale dimension reliabilities. This two dimensional model of coping for AWC fits the definitions of active coping and avoidant coping (Compas et al., 2001). Exploratory factor analysis based on Eigenvalues, the scree plot and parallel analysis failed to confirm the eight dimensions suggested by Jalowiec (2003). An additional factor analysis "forcing" the data onto eight factors also failed to provide evidence for the item groupings on the eight dimensions. While the scree plot and parallel analysis methodology indicated three factors, examination of the third factor found only two items meeting the retention criteria. Based on this, an alternate model of two dimensional coping was explored. The interpretation of the factors was generally consistent with the theoretical definitions of the two of the three coping dimensions for adolescents (Compas et al., 2001). Reliability for each of the two dimensions was higher than for any of the eight coping dimensions.

These results failed to support the findings of Ayers and colleagues (1994) and Walker and colleagues (1997) or the suggested multi-dimensional model proposed by Compas and
colleagues (2001) as models of coping for adolescents. While the items loading on the three factors in the initial three factor model of coping seemed to fit with Compas and colleagues’ proposed coping dimensions (active, avoidant, accommodative), the third factor was not well supported. The fourth dimension suggested by Ayers and colleagues “seeking support” was also not supported by this data. There were several items on the JCS-R representing social support as a separate dimension (“Talked the problem over with family and friends”, “Talked the problem over with a professional person”, “Talked the problem over with someone who had been in a similar situation”), but these did not load on the same factor or as items on a separate fourth factor.

Factor 1 items seemed a good fit with the definition of avoidant coping dimension, defined as coping strategies that attempt to avoid or disengage from the stressor or one’s emotions. These included items such as “Tried to get out of the situation”, “Tried to ignore or avoid the problem”, “ Took a drink,” and “Avoided being with people”.

In looking at the items that loaded on Factor 2, the items appeared to fit the active coping strategies, described as taking action to achieve some level of control over the situation. Most of the Factor 2 strategies implied action in approaching the situation (“Thought out different ways to handle the situation”, “Tried to find out more about the situation”, “Set up a plan of action”) or in controlling emotions (“Told yourself not to worry because everything would work out fine”, “Tried to think positively”, “Tried to keep the situation under control”).

Despite the factor analysis resulting in two dimensions rather than multiple dimensions, it is important to consider the unique situation of the AWC. The third dimension proposed by Compas and colleagues (2001) involves adaptation to the situation. It is possible that coping strategies indicating adaptation to the situation might not be as feasible for AWC.

Another possible explanation for the lack of confirmation of multidimensional coping might be due to the fact that this scale was not theoretically based on these models. In addition, the items on this scale designed for adult coping, not adolescent coping. They may not capture the range and specific types of coping strategies used by adolescents. Further testing of a
multidimensional model using an alternate scale with this population might result in three factors matching the proposed model of adolescent coping.

The second purpose of the factor analysis was to determine how the outcome variables of coping would be conceptualized. The factor analysis indicated two factors rather than the eight dimensions used by Jalowiec (2003). The reliabilities for the two dimensions were also higher than those for the eight dimensions. Multiple regression requires separate analyses for each outcome variable, in this case, each of the coping dimensions. Therefore the two dimensional model was selected based on the factor analysis, comparison of the reliability analysis between the eight dimensional models and the alternate two dimensional model, and for parsimony.

Research Aim 2

The analysis for Aim 2 evaluated the psychometric properties of the social support, family functioning and coping instruments used in the study. All of the social support and family environment scales had acceptable Chronbach alphas (> .80). The corrected–item total correlations indicated that some items may be less appropriate for this population, but additional data is needed to verify these findings. Chronbach’s alpha for the two coping dimensions had reliabilities > .80 with Active coping = .83 and Avoidant coping .86. The eight dimension model alphas ranged from .511 to .797.

Item analysis for the social support instruments showed some of the items to have low item-total correlations and low squared multiple correlations (SMC), indicating these items were not consistent with the subject’s ratings for the other statements on the measures. These low correlations could reflect current changes in the life of the AWC due to the diagnosis of a life-threatening illness. These life changes might include fewer options for time with friends, a more rigid schedule, increased parental oversight, decreased flexibility in rules, and a monitoring by the AWC of what is said (particularly thoughts and feelings about the cancer diagnosis), treatment, and prognosis. Avoiding these topics is a common theme among AWC since they often avoid discussions that might upset their parents even more (Palmer et al., 2000).

The item-total correlations and SMC for the family environment instruments indicated higher correlations among the items. The four items on the FACES-II that had item to total correlations
<.30 were all on the adaptability dimension and may also reflect the life changes that are occurring due to the recent cancer diagnosis. The JCS-R item-total correlations and SMC for the eight dimensional model were consistently lower than the two dimension model. The eight dimensions also had more items <.30. However, this last finding is somewhat skewed because in the factor analysis to determine the alternate coping model, those items that loaded poorly on the two factors were dropped from the final item groupings for each of those dimensions. If these items had been included despite their poor loadings, there would have been more items in each dimension and some of these dropped items would have been reflected in the <.30 column.

The instruments in the study demonstrated adequate reliability. From the analysis, some of the scales could be revised to make them more appropriate for use with AWC but additional research with other samples is needed before this is confirmed.

Research Aim 3

A MANOVA analysis was conducted to determine any gender and age group differences for each of the social support and family environment variables. Only PSS-FR was significant for gender in the analysis with females reporting significantly more social support from friends. However, in this analysis, the sample size resulted in low power, making interpretation of the findings difficult. The sample size also affected the age group analysis with very different cell sizes, with the oldest age group only containing 5 subjects compared to 25 and 40 in the other age group cells.

The non-significant findings for age group differences for social support conflicts with those of Richie (2001) who reported that the younger AWC had fewer sources of support while the older AWC had more friend support. However, Richie measured emotional support in her study while this study measured perceived support, a broader concept of social support.

The only norms available from other healthy adolescents to compare AWC to healthy adolescents for the PSS-FR and PSS-FA were provided by Haluska and colleagues (2002). In this study, means were calculated for PSS-FR and PSS-FA for AWC and healthy norms. Haluska and colleagues reported significantly higher levels (t=2.08; p=.04) of PSS-FA for the AWC (M=3.6) than the healthy norms (M=3.4) with no significant differences (t=.56; p=.58) for
friend support (AWC $M=3.7$). The measures ask adolescents to rate their level of agreement with a statement of some type of support using a scale: 1=totally disagree, 2=sort of disagree, 3=unsure, 4=sort of agree, and 5=totally agree. The means for this study sample of newly diagnosed AWC in this study on each of the social support measures (PSS-FR $M=2.8$, $SD=.2$, PSS-FA $M=2.8$, $SD=.1$ and PSS-HP $M=2.7$, $SD=.2$) are much lower than the means reported by Haluska and colleagues. They were also inconsistent with Manne and Miller (1998) and Nichols (1995), who also reported high levels of support from friends and family by AWC. The means on these measures for this sample would fall between the responses “sort of disagree” and “unsure”. The small standard deviations indicate AWC rated the items very similarly.

One possible explanation for the differences between these findings and the other research studies may be the time-since-diagnosis. The other studies used AWC at a variety of points from diagnosis while the subjects in the current study were all newly diagnosed AWC. The findings in this study suggest that adolescents recently diagnosed with cancer feel less supported by their family and friends than their healthy norms and AWC further from diagnosis.

From the coping literature, Bull and Drotar (1991) reported female AWC used more emotion-focused coping than males. Trask and colleagues (2003) also reported males used more avoidant coping strategies, but found no gender differences for engagement coping strategies. Using a different conceptualization of coping dimensions, this study found no gender differences for either coping dimension, consistent with the findings of Nichols (1995).

This study found no significant age group differences in coping, contrasted with the findings of Weekes and Savadra (1988), who reported younger adolescents used more emotion-focused coping strategies than the older adolescents. However, the samples (ranging from N=10-39) used in these studies were too small to generalize to other AWC.

Research Aim 4

From the factor and reliability analysis for the eight dimensional JCS-R coping model and the alternate two dimensional model, the two dimensions of coping, active and avoidant, were used as the outcome variables for the analysis for Aim 4. Therefore, the outcomes used in the analysis
for Aim 4 were active coping and avoidant coping, each using the mean of the 12 retained items. From the MANOVA, separate regression analyses were not indicated for gender or age groups.

The multiple regression analysis, FACES II, PAC-Open, PAC-Unproblematic, Family Strengths, PSS-FR, PSS-FA, and PSS-HP did not significantly predict either of the coping dimensions. This was evident from the low $R^2$ values, the non-significant ANOVA and non-significant relationship for each of the predictors to the outcomes. Although not at a significant level, social support from family and family strengths were negatively related to Active Coping. There were negative relationships for all of the predictors except for FACES II and PSS-HP with avoidant coping, although again not at a significant level. This would suggest that higher levels of family environment and family and friend support are related to the use of fewer Avoidant coping strategies.

Alternate Explanations for the Regression Analysis Findings

Since regression analysis is based on several important assumptions, it is helpful to consider these assumptions to evaluate potential problems of the model (Schroeder, Sjoquist, & Stephan, 1986). The first assumption is specification, which means the selection of the correct variables used for the regression analysis. It is possible that one or more relevant variables were omitted from this analysis or that irrelevant variables were included. In considering specification error in this coping model, a major concern is the omission of relevant variables. There is evidence from the literature on coping that individual personality traits may be important to consider in predicting coping style. Since coping is a reflection of an individual's response to a particular class of actions, coping as a response to stress should be consistent with responses to different events (non-stressful) and experiences (Watson & Hubbard, 1996). Research has shown extraverts are very motivated to interact in social situations and spend more time socializing than do introverts (Watson & Clark, 1992; Watson, Clark, & Harkness, 1994). In a similar way, those with high conscientiousness tend to act in a cautious and highly organized way (Costa & McCrae, 1992; Watson et al., 1994). It would seem that these individuals might use similar responses when coping with stress.
Dispositional differences are also linked to intrapsychic and interpersonal resources (Watson & Hubbard, 1996). For example, those who tend to be more pleasant and agreeable may have larger social support networks available during stressful times. Individuals with high levels of openness tend to have more flexibility and imagination than those who score low on this trait so more open individuals may be better able to develop new and creative ways to cope with stressful events when they occur.

The five-factor model of personality has been linked to stress appraisal, clusters of coping strategies and to outcomes that are often used to evaluate coping effectiveness (Watson & Hubbard, 1996). This model of personality includes five traits: 1) neuroticism (also called negative emotionality); 2) extraversion or positive affect; 3) conscientiousness; 4) agreeableness and; 5) openness. Neuroticism has been linked to negativistic appraisals of the environment (Costa & McCrae, 1990; Watson & Clark, 1984) and individuals who tend to be easily upset and overreact to minor hassles (Costa & McCrae, 1989; Hooker, Frazier, & Monahan, 1994). In fact, neuroticism is highly correlated to many of the criteria used to measure coping effectiveness such as distress, anxiety, and depression (Clark, Watson, & Mineka, 1994; Watson et al., 1994).

Studies based on the five-factor model of personality have linked the individual personality traits to coping effectiveness. Neuroticism has been associated with passive and ineffective coping (Costa & McCrae, 1989; Costa, Somerfield, & McCrae, 1996; Fikova, 2002) including increased use of wishful thinking, avoidance, emotion-focused coping and decreased use of problem-focused coping, positive appraisal and support seeking. Extraversion has been consistently associated with increased use of problem-focused coping, positive reappraisal, and support seeking and negatively related to emotion-focused coping (Costa et al., 1996; Fikova, 2002; Hooker, Monahan, Shifren, & Hutchinson, 1992). Conscientiousness was a strong predictor of problem solving and positive reappraisal (McCrae & Costa, 1986) and positively related to problem-focused coping and negatively related to emotion-focused coping (Hooker et al., 1994). The other two personality factors of openness, and agreeableness have also been related to some aspects of coping, although these relationships were much weaker.
Two other aspects of temperament (reactivity and regulation) have also been linked to coping (Compas et al., 2001). Reactivity includes individual differences in physiological and emotional responses to stress and can affect an individual’s initial automatic response to stress as well as inhibit or facilitate certain types of coping responses. Self-regulation is also related to coping (Compas et al., 2001). Individuals vary in their capacities for regulation of physiological arousal, behavior and emotions which in turn, will affect social behavior skills. These skills affect the ability to use social resources in coping with stress. Other characteristics suggested to influence regulation include self-esteem, goals, needs and values (Eisenberg, Fabes, & Guthrie, 1997).

Other individual characteristics have been suggested to affect coping and adaptation in adolescents with chronic illness. These include cognitive abilities, social competence, and confidence (Moos, 2002). Also missing from this analysis were any disease related variables such as type of cancer, prognosis, or projected length, intensity, and scope of treatment.

A measure of the appraisal of the stressor is another variable excluded in the multiple regression model in this study. The concept of appraisal is considered an important part of the stress and coping model of Lazarus and Folkman (1984). Variability in coping has been shown as partially a function of a person’s judgment about what is at stake and what options there are for coping (Folkman et al., 1986). The appraisal of the stressor by the individual subjects was not assessed in this study so could not be included in the analysis.

Perhaps a more basic specification error is the selection of coping as the outcome or dependent variable. If coping is seen as an outcome influenced by one or more predictor variable, there is an assumption of unilateral control of each individual’s behavior outside of any environmental influence. If a person's behavior is to some degree influenced by the environment, then the particular situation would influence the coping response. It is also possible that coping behaviors reflect a consistent pattern that occurs without any conscious choice by the individual or without regard to the particular stressor. It is difficult to determine which of these is the case and if it is in fact some combination of these three possibilities, it would be also difficult to determine the individual influences of any proposed predictor variables.
The other type of specification error is the use of an incorrect functional form that occurs when there are nonlinear relationships among the variables. This assumption was tested using the plots of residual error defined as the difference between the actual value of the dependent variable and its value estimated in the equation. While some of the P Plots showed an unusual pattern, none suggested a non-linear relationship between any of the predictor variables and the dependent variables of active coping or accommodative coping.

While the low $R^2$ resulting from each of the multiple regression analyses could indicate specification error, there are also other explanations, including multicollinearity and measurement error (Berry & Feldman, 1985). The assumption of multicollinearity for the predictor variables was assessed through the VIF and Tolerance statistics in each regression analysis and did not appear to be a problem with these variables. Violation of the second assumption, that the variables are accurately measured, is seen as a major problem in social science research with the potential for having a major impact on the estimation of the regression coefficients (Berry & Feldman, 1985). While no measurement is perfect, it is important to consider how much error is present and how this error will affect the data analysis.

One source of error is the use of indicator rather than true variables. A true variable is the theoretical concept to be measured while indicators are empirical observations designed to measure this concept. Both of these can occur in the two distinct types of measurement error: random and nonrandom. In nonrandom measurement error, the indicator is also measuring one or more additional variables in addition to the true variable and is an issue of validity of the indicator. If this is the case, the coefficient estimates will be inaccurate and difficult to interpret.

As discussed in the literature review section, there are various conceptualizations for each of the true variables in this study. Coping, for example, has been described as strategies, responses, cognitions or behavior (Schwarzer & Schwarzer, 1996). In addition, coping viewed as a process requires consideration of the stability of coping strategies over time and across different situations. For the coping scale used in this research, the subjects were asked about how they coped with the stress of having cancer. Therefore, one strategy selected might have been used for one particular stressor in the cancer experience, while another one might have been used for
a different stressor. There is no way to know if the subjects used the same stressor when responding to the use of different coping strategies, the cancer experience overall without regard to a particular aspect of their experience or if they evaluated their use of coping strategies beyond the cancer experience. Differences in how the subjects interpreted the directions could have resulted in very different responses.

Social support can be viewed in terms of network size, sources of support, the nature of what was available or provided, or as unidirectional versus reciprocal function. It may also be seen as a meta-construct incorporating multiple dimensions including the type of relationship and social network size, the type and frequency of supportive behaviors, and the quality of support. Similar problems exist with the concept of family environment. While this study used established instruments tested for reliability and validity, random error could still occur for the true variables of social support, family environment and coping.

Random error in this analysis is a possible source of measurement error and should be carefully considered. Random error may occur for several reasons (Berry & Feldman, 1985). With self-report instruments, guessing may occur due to poorly defined response categories, subject inattention or because of vague or confusing items. It may also occur because of data entry or coding errors. Random error may occur because the concept to be measured is abstract and unobservable requiring the use of indicators in place of true variables. In any case, random error may have a significant impact on the estimate of the regression coefficient.

In a linear regression analysis with one predictor variable, random error in the outcome variable will be absorbed into the error term in the regression equation, resulting in a lower $R^2$ (Berry & Feldman, 1985). If the measurement error occurs in one or more predictor variables, the result will be a biased coefficient estimate. Using the accepted cut-off of .8 for a reliable instrument, the slope coefficient could still be as much as 20% inaccurate. With lower reliability, this percentage increases. With multiple predictors, the effect of random error is much more unpredictable. The amount of bias due to random error is both a function of the reliabilities of each of the predictor variables and the correlations among them. If the predictors are uncorrelated, the impact is the same as it would be for a bivariate analysis. While random error
will always bias the estimated regression coefficient, it is not possible to predict the direction and magnitude of the bias. What is known is that measurement error will decrease the goodness-of-fit of the regression.

Measurement error related to data quality for responses from children faces similar concerns to those in adults (Scott, 1997). These include context effects, social desirability, and acquiescence bias. While these have been relatively well researched in adults, there is less evidence that these findings can be generalized to children. Children have been described as less susceptible than adults to social desirability, for example, but this depends on how social desirability is defined and the context (Scott, 1997). Both context effects and acquiescence bias will be influenced by developmental stage and the subject matter of the instrument. For social support and family environment, some of the adolescents may feel less inclined to be critical of their family or friends during the first months after diagnosis with a life-threatening disease. Coping strategies are less likely to be influenced by social desirability, but the general belief that maintaining hope improves the chances of cure could influence the ratings of those strategies that describe a pessimistic or optimistic view. This might include the statements: “Tried to think positively” or “Resigned yourself to the situation because things looked hopeless”. In a different context from being diagnosed with cancer, social desirability might take a different form in a coping scale. Acquisition bias would seem to be a possibility for these instruments if adolescents behave similar to adults as it is known that adults tend to use similar responses for contiguous questions (Schulman & Presser, 1981), although Hershey and Hill (1976) found little evidence of this among older school-age children.

Measurement error can be minimized in several ways (Berry & Feldman, 1985). Data collection and coding should be carefully designed to reduce the possibility of error. Multiple indicators of a concept will provide some information on improved reliability. In this study, subjective self-report measures were used to measure all of the variables-social support, family environment and coping in this study. The advantages of self-reports include the low cost and versatility of content while the main limitation is their reactivity (Beehr & McGrath, 1996). Additional forms of measurement might have been used to reduce measurement error, including
interviews, observation, and physiological measures. For this analysis, while established instruments were used as indicators of social support, family environment, and coping, they were not designed for or tested extensively in this population. While the correlations among the indicators were not large enough for concern, having some degree of correlation will also introduce some level of measurement error into the analysis.

Due to the various sites used to recruit the research participants and the individual situations of the subjects, the conditions under which the data collection occurred also varied. Some of the participants completed the booklet in the clinic or hospital, while other took them home and returned them by mail at a later date. Despite instructions to take breaks while completing the booklet, some of the participants completed all of the measures quickly without a break while others completed the various instruments several days apart. Their present mood and intervening experiences could have influenced how they responded to the items in the instruments. In addition, the preceding instrument may have also influenced their responses to later instruments since all of the booklets used the same order of instruments.

In summary, the factor analysis of the JCS-R provided some evidence for a two dimensional model of adolescent coping in AWC. There were no significant gender or age group differences detected for any of the family environment variables, the social support variables or the two coping dimensions. The predictor variables of FACES II, PAC-Open, PAC-Unproblematic, Family Strengths, PSS-FR, PSS-FA and PSS-HP did not significantly predict either of the outcome variables of active or avoidant coping.

Strengths and Limitations

The major strength of the study is the size of the sample from newly diagnosed AWC. The homogeneity of time-since-diagnosis should make it possible to generalize to other AWC at this same time in their cancer experience. Although too small to allow for analysis based on ethnicity, both samples represented a broader range of ethnicity for AWC than many of the previous research studies.
With the exception of the PSS-HP, all of the instruments had established reliability, although the reliabilities for the eight dimensions of the JCS-R were not all above the recommended cut-off of .80. The two dimensions derived from the factor analysis and used in the MANOVA and regression analysis demonstrated good reliability (α=.83 & .86). While the JCS-R was not designed to be a two dimensional measure of coping, the use of factor analysis to determine the factor structure for this sample of AWC makes the instrument more “customized” for this population.

The Adolescent Resilience Model is based on a strengths perspective than a deficit model. This study described the relationship of coping to potential predictor variables, but did not categorize the coping dimensions as effective or ineffective. Rather than using a deficit adaptation model with the outcome variable of psychological distress or depression, the focus of this study was to examine the relationship of family environment and social support to various coping dimensions.

The sample size used in this study was large for a study on AWC. However, it was still somewhat limited for the number of items used for the factor analysis and the number of predictor variables in the multiple regression analyses.

Another limitation of this study was the use of a non-experimental cross-sectional design. The lack of a comparison group restricts generalizability and does not assess causal relationships. Another limitation was the lack of any variables measuring individual personality characteristics, with demonstrated relationships to the use of particular coping strategies or coping styles. An additional limitation in the measurement of coping were the instructions asking the subjects to refer to the general stress from the cancer experience without determining the appraisal of these stressors. Missing from this measurement of coping is the view of coping as a process involving an appraisal of the meaning of the stressor for the individual. A coping measure that includes a rating of the appraisal of the threat for specific stressors that links this appraisal to specific strategies would be more consistent with Lazarus’ Stress and Coping Model (Lazarus & Folkman, 1984).
Summary

With the limited research on social support, family environment, and coping in AWC, little is known beyond the descriptive findings. Much less is known about the relationship among these three variables. The purpose of this study was to determine the best fit model of coping, to explore gender and age differences in social support, family functioning, and coping and to examine the relationship of social support and family environment to coping in AWC. A two dimensional model of coping was determined to best fit the data for these AWC and to partially replicate the theoretical models of adolescent coping from other research studies. Examination of the variables for significant demographic differences, only PSS-FR for gender was significant with female AWC reporting significantly higher levels compared to the males. There was no significant overall relationship of the variables of social support and family environment to either of the two coping dimensions. In addition, none of the individual measures of social support or family environment were significantly related to the coping dimensions.

Recommendations for Future Research

The essential contribution of this study is the evidence of the two dimensional model of coping for AWC. To better understand how coping is related to other variables in AWC, additional research studies are needed. Future studies using coping measures designed for adolescents may provide additional knowledge on the appropriate coping model for AWC.

With no significant relationship between social support, family environment and the outcome variables of active and avoidant coping, future research is needed to determine the best way to measure social support, family environment and coping for AWC. While the social support measures were validated on undergraduate university students just a few years older than the AWC in this study, they were not adolescents with a chronic illness. The diagnosis of cancer has a large impact on many aspects of an adolescent’s life and may require specialized instruments. Similarly, the family environment instruments have been used with a variety of samples of adolescents, but the majority of these were adolescents with depression, eating disorders or behavioral disorders. In fact in a search using the key words “family environment” and
"adolescents" resulted in 44 references only one was used in a sample of chronically ill adolescents. This study looked at the relationship of social learning to family environment in adolescents with diabetes. Despite the results from the factor analysis using the JCS-R, the scale was not theoretically designed to test a three dimensional model and may not be the best measure of coping for AWC. For all of these variables, this population may require measures more specific to the experience of cancer. Future studies should continue to assess the appropriateness of established instruments for use in this population as well as provide additional validation of researcher-designed instruments created specifically for the special situation of AWC. Instruments created specifically for use with AWC would provide opportunities for analysis across research studies using the same measures and assist with the sample size problems prevalent in the research with this population. Sample will continue to be an issue for research with AWC. Replication of research using similar designs and instruments would allow for analyses across studies for gender, age group, and ethnic differences.

Additional studies are needed to determine the effect of the experience of cancer on adolescent's perceptions of social support and family environment. This may require comparison groups of other adolescents to determine differences between the two groups. This would require larger samples of AWC, which would be difficult to achieve unless the studies are conducted in multiple sites with large numbers of adolescents diagnosed with cancer. There should also be multiple methods to assess the variables such as interviews, observation, and multiple instruments to measure each concept.

Future studies on social support, family environment, and coping might benefit from the inclusion of additional predictor variables. Assuming the coping dimensions are appropriate for AWC, selecting additional predictor variables should help determine other variables with a larger influence on the coping style of AWC. For example, individual personality traits might also be included since studies have shown the effect of temperament and stress reactivity on biological responses to stress. Disease-related variables such as symptom distress, length and intensity of treatment and prognosis may also influence the perception of social support, family environment and coping.
Future studies should also include assessment of the adolescents' social and economic contexts as well as the specific stressful event for which the coping strategy was selected. In addition, the measurement of coping should include both an assessment of the stressful situation and the individual's appraisal to be consistent with Lazarus' stress and coping theory. This could be accomplished through interviews in addition to measurement with an established coping instrument or by using an instrument that gives examples of stressful situations often experienced by AWC when asking the AWC to rate different coping strategies. It may also be helpful to assess coping at various stages in a stressful situation. For example, AWC might be asked about coping during the first hospitalization for chemotherapy, preparation for surgery, returning to school and also for additional experiences such as coping with repeated hospitalizations, coping during recovery from surgery, or coping with school in the long-term after the initial return time when the attention from other students, teachers, and staff returns to a more normal level. Additional information about the intention of coping behaviors and perception of controllability would also provide useful information about the choice of coping strategies.

Research based on developmental changes in cognition and social relationships would provide better information on how developmental changes affect the resources that are available for coping such as social support from various sources, the use and effectiveness of different types of coping responses as well as differences in coping at various developmental stages. The influences of temperament and reactivity may also vary with the developmental changes of adolescence.

Longitudinal studies of AWC would clarify patterns or changes in the perceptions of social support and family environment through the treatment period and the post treatment time. Measuring coping over time would also provide better information about how coping changed during the adolescents' cancer experience. While individual traits are not subject to major alteration, social support and family environment might change significantly over time. Such studies could not only identify patterns of change but also those individuals who might be more at risk for long-term problems resulting from the cancer treatment and the resulting changes in the life of the adolescents. Prospective designs can provide knowledge on the directional effect
between coping and adjustment. This additional information on coping in AWC will provide a basis for intervention studies designed to enhance the psychosocial functioning of AWC.

Looking at the cancer experience over time will allow analysis of the impact of specific stressors and the role of development in coping unavailable with cross-sectional research. Research of this type would also provide information on how coping affects several aspects of the cancer experience such as coping with procedures, symptoms, social interactions, and long-term adjustment to cancer as a chronic illness that requires unique follow-up and health vigilance compared to other adolescents and young adults.
APPENDIX A

Social Support Instruments
PERCEIVED SOCIAL SUPPORT-FRIENDS

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are five possible answers. Please circle the answer you choose for each.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Totally Disagree</th>
<th>Sort of Disagree</th>
<th>Unsure</th>
<th>Sort of Agree</th>
<th>Totally Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My friends give me the moral support I need.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Most other people are closer to their friends than I am.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. My friends enjoy hearing about what I think.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Certain friends come to me when they have problems or need advice.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I rely on my friends for emotional support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I feel that I'm on the fringe in my circle of friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. There is a friend I could go to if I were just feeling down, without feeling funny about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. My friends and I are very open about what we think about things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. My friends are sensitive to my personal needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. My friends come to me for emotional support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. My friends are good at helping me solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I have a deep sharing friendship with a number of friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. My friends get good ideas from me about how to do things or make things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. When I confide in friends, it makes me uncomfortable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. My friends seek me out for companionship.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I think my friends feel that I'm good at helping them solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I don't have a relationship with a friend that is as intimate as other people's relationship with friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I've recently gotten a good idea about how to do something from a friend.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. I wish my friends were much different.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Permission received from Procidano to include the complete measure.
PERCEIVED SOCIAL SUPPORT-FAMILY

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with families. For each statement there are five possible answers. Please circle the answer you choose for each.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Totally Disagree</th>
<th>Sort of Disagree</th>
<th>Unsure</th>
<th>Sort of Agree</th>
<th>Totally Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family gives me the moral support I need.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I get good ideas from my family about how to do things or make things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Most other people are closer to their family than I am.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. When I confide in the members of my family who are close to me, I the idea that it makes them uncomfortable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. My family enjoys hearing about what I think.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Members of my family share many of my interests.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Certain members of my family come to me when they have problems or need advice.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I rely on my family for emotional support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. My family and I are very open about what we think about things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. My family is sensitive to my personal needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Members of my family come to me for emotional support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Members of my family are good at helping me solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I have a deep sharing relationship with a number of my family members.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Members of my family get good ideas from me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. When I confide in members of my family, it makes me uncomfortable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Members of my family seek me out for companionship.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I think that my family feels that I am good at helping them solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I don’t have a relationship with a member of my family that is as close as other people’s relationship with family members.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. I wish my family were much different.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Permission received from Procidiano to include the complete measure.
PERCEIVED SOCIAL SUPPORT-HEALTHCARE PROVIDERS

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with doctors, nurses, or other health care workers. Once more, please circle the answer you choose for each item.

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My health care providers give me the moral support I need.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Most other people are closer to their health care providers than I am.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. My health care providers want to hear about what I think.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I have certain health care providers I can go to when I have problems or need advice.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I rely on my health care providers for emotional support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. If I felt that one or more of my health care providers were upset with me, I’d just keep it to myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I feel that my health care providers are interested in me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. There is a health care providers I could go to if I were just feeling down, without feeling funny about it later.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. My health care providers and I are very open about what we think about things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. My health care providers are sensitive to my personal needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Health care providers share things about themselves with me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. My health care providers are good at helping me solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I have a deep sharing friendship with a number of health care providers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. My health care providers get good ideas from me about how to do things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. When I confide in my health care providers, it makes me uncomfortable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I have fun with my healthcare providers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I think my healthcare providers feel that I'm good at helping them solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I don’t have a relationship with a healthcare provider that is as intimate as other people's relationship with their health care providers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I’ve recently gotten a good idea about how to do something from a health care provider.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. I wish my health care providers were much different.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Permission received from Haase to include the compete measure.
APPENDIX B

Family Environment Instruments
FAMILY ADAPTABILITY AND COHESION SCALE-II

Directions: For each statement, place an “X” in the space that best describes what you think about your family.

Example Items:

<table>
<thead>
<tr>
<th></th>
<th>Almost never</th>
<th>Once in a while</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Family members are supportive of each other during difficult times.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. In our family, it is easy for everyone to express his/her opinion.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. It is easier to discuss problems with people outside the family than with other family members.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Permission received Olson to include examples of items from the FACES-2.
**PARENT ADOLESCENT COMMUNICATION SCALE**

**Directions:** Answer each question first as it applies to your mother, and then as it applies to your father. If you are living in a single-parent family, please answer only for the parent you live with. If you are not living with parents, please answer for the person(s) who are your guardians. Read each statement and place an (X) in the box that describes how much you agree with that statement.

Example Items:

<table>
<thead>
<tr>
<th>Questions about your mother</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I can discuss my beliefs with my <strong>mother</strong> without feeling restrained or embarrassed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Sometimes I have trouble believing everything my <strong>mother</strong> tells me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My <strong>mother</strong> is always a good listener.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questions about your father</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. I am sometimes afraid to ask my <strong>father</strong> for what I want.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. My <strong>father</strong> has a tendency to say things to me which would be better left unsaid.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. My <strong>father</strong> can tell how I'm feeling without asking.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Permission received Olson to include examples of items from the Parent-Adolescent Communication Scale.
FAMILY STRENGTHS

Directions: Please rate the following items as they apply to YOUR family.

Example Items:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. We can express our feelings.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. We really do trust and confide in each other.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. We have the same problems over and over.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Family members feel loyal to the family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. We share similar values and beliefs as a family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Permission received Olson to include examples of items from the Family Strengths Scale.
APPENDIX C

Coping Instruments
Examples of the items for the eight coping dimensions in the Jalowiec Coping Scale-Revised
Directions for Part A
How often have you used each coping method?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Seldom</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>Used</td>
<td>Used</td>
<td>Used</td>
<td>Used</td>
<td></td>
</tr>
</tbody>
</table>

1. Confrontive Coping Style
Learned something new in order to deal with the problem

2. Evasive Coping Style
Tried to put the problem out of your mind and think of something else

3. Optimistic Coping Style
Compared yourself with other people who were in the same situation

4. Fatalistic Coping Style
Resigned yourself to the situation because things looked hopeless

5. Emotive Coping Style
Worried about the problem

6. Palliative Coping Style
Blamed yourself for getting into such a situation

7. Supportant Coping Style
Depended on others to help you out

8. Self-Reliant Coping Style
 Tried to keep your feelings under control

Permission received from Jalowiec to include examples of items for each of the dimensions.
Revision Of JCS-R Dimensions From The Factor Analysis In This Study

Active Dimension
Tried to get out of the situation
Told yourself that the problem was someone else’s fault
Resigned yourself to the situation because things looked hopeless
Tried to change the situations
Took a drink to make yourself feel better
Put off facing up to the problem
Did something impulsive or risky that you would not usually do
Tried to ignore or avoid the problem
Blamed yourself for getting into such a situation
Took medications to reduce tension
Told yourself that this problem was really not that important
Avoided being with people

Avoidant Dimension
Thought out different ways to handle the situation
Tried to look at the problem objectively and see all sides
Tried to keep the situation under control
Tried to find out more about the problem
Tried to handle things one step at a time
Thought about how you had handled other problems in the past
Told yourself not to worry because everything would work out fine
Told yourself that you could handle anything no matter how hard
Set up a plan of action
Learned something new in order to deal with the problem
Tried to think positively
Tried to see the good side of the situation
REFERENCES


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