PERCEIVED SOCIAL SUPPORT IN YOUNG ADULTS WITH

CANCER AND THE CAMP EXPERIENCE

by

Stacy Marie Handley

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APPROVAL

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Stacy Marie Handley

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Wade Hill

Approved for the Department of Nursing

Jean Ballantyne

Approved for the College of Graduate Studies

Bruce McLeod

STATEMENT OF PERMISSION TO USE

Stacy Marie Handley

DEDICATION PAGE

I would like to dedicate my thesis to my husband, Mike, and my family for all of their support and guidance without which I would not be where I am today. I would also like to dedicate this to all children, adolescents, and young adults who have bravely faced an illness that has taken so many. I especially would like to dedicate my thesis to the memory of Sam, a young lady who was never without a smile or a joke while facing an uncertain future.

ACKNOWLEDGEMENTS

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ABSTRACT

During the years when a peer social support network should be formed, children and adolescents with cancer are in hospitals and are surrounded by protective parents and family. Literature suggests there are many benefits associated with formation of a social support network including improvement of health status but few childhood cancer survivors have had the opportunity to form these networks. The purpose of this study is to determine if there is an increase in reports of social support after attending an oncology camp. A non-random convenience sample of 18 to 25 year olds with a diagnosis of cancer attending a weeklong oncology camp were selected to participate in the research. Participants completed surveys containing the Medical Outcomes Study (MOS) Social Support Survey, RAND 36-Item Health Survey Questionnaire 1.0, and qualitative questions at the beginning and end of camp. Comparison of pre-camp and post-camp mean scores on the MOS Social Support Survey were statistically significant for one scale only, tangible support within a particularly vulnerable sub-sample of participants. An increase in all means was observed when pre-camp and post-camp results were compared. These results suggest that cancer camp may be an effective intervention for establishing a social support network and benefit overall health and wellbeing. The implications for nursing include implementation of interventions designed to increase social networks of children, adolescents, and young adults with cancer as well as encouraging camp attendance.

CHAPTER 1

INTRODUCTION

In 2001, 8,600 children under the age of 15 were diagnosed with cancer, and

1,500 died from this disease (National Cancer Institute (NCI), 2004). Cancer is the

leading cause of death by disease in young persons between the ages of one and 15 years

(NCI, 2004). The most common childhood cancers as reported by the National Childhood

Cancer Foundation (NCCF) include leukemia, brain tumors, lymphoma, soft tissue

sarcomas, bone tumors, and neuroblastomas (2003). Leukemia and cancers of the central

nervous system (CNS) including brain tumors accounted for more than half of all newly

diagnosed cases of cancer in 2001 (NCI, 2004).

The 5-year survival rate for all childhood cancers has steadily risen over the past

30 years according to the American Cancer Society (ACS) and the NCI. The NCI (2004)

estimates that in 1974-76 the 5-year survival rate for all childhood cancers was 55.7%

compared to a 5-year survival rate of 77.1% in 1992-1997. Some of the childhood

leukemia's are reaching cure rates upward of 80% (ACS, 2002). Survivors and their

families face a range of physical and psychological challenges imposed by the disease,

and some will suffer its long-term effects for the rest of their lives (ACS, 2002). An

overall increase in the 5-year survival rate for childhood cancer resulted in reintegration

with healthy peers and the need to form a social network.

During the formidable time prior to entering adolescence, children with cancer

can be confined to hospitals and home, relating more with doctors and nurses than peers.

It is during this time of emotional growth and development that they begin to move out of

their family unit into forming social networks and support systems with peers. These

initial social networks and support systems form the foundation upon which later social

support systems will be established as the adolescent enters young adulthood.

The presence of a social support system has been shown to be beneficial to the

recipient on multiple levels including physical, emotional, and health. Berkman and

Syme (1979) demonstrated a correlation between higher mortality rates and low levels of

social support. Research further suggests that a social support system is beneficial in

buffering the stress associated with illness and life changing events thus helping the

recipient of the support better cope with problems (Bliese & Britt, 2001; Caldwell,

Pearson, & Chin, 1987; Cohen & Willis, 1985; DeVries, Glasper, & Detillion, 2003).

Many researchers especially in the areas of healthcare and psychology have

studied the benefits associated with social support. Of particular interest is the effect of

social support on persons already coping with an illness, especially a life threatening

illness such as cancer. Social support can bolster the recipient's feelings of belonging

thus giving them strength on a psychological level. There is some evidence to suggest

that social support may also be beneficial in altering the disease process itself and

possibly amplifying the response of the immune system (Lutgendorf, Johnsen, Cooper,

Anderson, Sorosky, Buller, & Sood, 2002; Uchino, Cacioppo, & Kiecolt-Glaser, 1996;

DeVries, Glasper, & Detillon, 2003).

The ability to establish a social support system prior to diagnosis with a chronic

illness is advantageous. Children and adolescents diagnosed with a life threatening

disease have little time to comprehend their illness let alone navigate through the process

that is adolescence during which formation of social networks outside of the family

occurs. Cancer reaches far in wide in the life of the person diagnosed with it as well as

family members caring for and helping the person. It has been demonstrated that cancer

not only affects the physical but the psychological development of children and

adolescents grappling with this disease (Kazak & Meadows, 1989; Kliewer, 1997).

Milestones in social development may be delayed for the child with cancer while his or

her peer's progress into the world of young adulthood.

As children and adolescents with a diagnosis of cancer move toward adolescence

and adulthood they may find it difficult to relate to healthy peers and desire contact with

someone else their age that is "going through what they're going through." Camp

experiences can fill that void for young adults struggling with growing up and cancer at

the same time. There is limited research available that examines the implications of

social support from peers with cancer in young adults. Furthermore there is even less

information available examining the relationship between a camp experience and social

support. The purpose of the current study is to examine the perception of social support

as experienced by young adults diagnosed with cancer before and after a weeklong camp

experience.

<u>Background</u>

In 1999 and 2000, the ACS gathered representatives from 30 national organizations

working in the area of childhood cancer to identify issues to be addressed to improve

outcomes for children, adolescents, and young adults with cancer as well as their families

(ACS, 2003). The National Action Plan for Childhood Cancer was formulated at this

conference, a key factor identified in the plan was establishment of evidence-based

methodology and definition of the required components of social support (ACS, 2003).

To date there is little evidence available to determine the significance of a camp experience on perceptions of social support for young adults diagnosed with cancer. The existing literature available presents a significant source of anecdotal stories suggesting a positive affect on young adults both emotionally and physically after attending a camp experience with others their age with cancer. There is little to no data demonstrating quantification and evaluation of social support received during the camp experience.

Research Question

The research question to be addressed by this study is as follows: Is there a significant difference in perceived social support before and after a week long camp experience with other young adults diagnosed with cancer? The research hypothesis for this study is: Attendance at a week long camp for young adults diagnosed with cancer will increase perceived social support when pre-camp and post-camp means are compared.

CHAPTER 2

REVIEW OF LITERATURE

Social Support Definition and Theory

Social support is a burdensome term. In the early 1980's researchers were deep in

the initial examination of the concept of social support. The consensus of the time was a

definition that was both simplistic and concrete. Social support referred to an interaction,

person, or relationship (Veiel & Bauman, 1992). Over the last 20 years the concrete

definition evolved into a more abstract and complex explanation that encompassed more

than just interaction, person, or relationship. Today there is little agreement among

researchers and theoreticians in regards to an operational definition of social support.

However, there is some agreement in terms of characteristics that are found as a common

thread that is weaved through the multiple definitions apparent for social support. All of

the definitions imply some type of positive interaction or helpful behavior provided to a

person in need of support (Hupcey, 1998).

Categories of Defining Social Support

From the starting point of a common characteristic, further defining of social

support appears to fall into one of at least five categories of the following: 1) Type of

support provided 2) Recipients perceptions of support 3) Intentions or behaviors of the

provider 4) Reciprocal support and 5) Social networks (Hupcey, 1998).

Types of Support. The first of five categories proposed by Hupcey (1998) to

classify the types of definitions of social support is the type of support provided. The

type of support provided refers to the resources provided, what is actually given to the

person or persons. The support provided is tailored to the situation in which a person has

a perceived need. For instance, Sarason, Levine, Basham, and Sarason (1983) state that

examples of this include: psychotherapists try to provide their clients with acceptance

needed to pursue self-examination and soldiers develop strong mutually reinforcing

support with each other that contributes to their success and survival. The type of support

provided usually meets an emotional need of the recipient as demonstrated above. Cobb

(1976) states that social support can be instrumental where information is provided

leading a person to believe that they are cared for and loved, esteemed and valued, and/or

that they belong to a network of communication and mutual obligation. This information

serves to meet the needs of the survivor through a variety of means but mainly love and

belonging. Sarason et al (1983) furthers this notion by adding that social support

contributes to a positive adjustment and personal development. The type of support

provided involves an exchange between the provider and recipient. These authors do not

offer a concrete example of what the support is but note that it meets a need, thus the type

of support provided works to bolster adjustment and development. The type of support

provided is used to categorize definitions of support. Inherent in the type of support is a

source and recipient of such support. As previously mentioned the type of support is

dependent on the situation but also dependent upon the provider and the recipient. The

type of support can be physical or psychological but almost always meets an emotional

need of the recipient and often the provider. Defining social support as to its type offers

the researcher an opportunity to describe the support itself and briefly touch on the source

of the support and the recipient. The second category of definitions of social support is the recipient's perception of the support.

Recipient's Perception of the Support. The second category of defining social support is the recipient's perception of the support. Procidano and Heller (1983) define social support as the extent to which an individual believes that their need for support, information, and feedback are fulfilled. There are many factors that impact the recipient's perception of support such as physical setting, attitudes, and actions of others, the recipient's attitude and actions, and the support provided.

Physical setting factors can greatly impact the recipient's perception of support to the extent that the recipient may not even be able to access the support needed or intended for the recipient. Physical setting can impose barriers on the social support provided thus limiting and/or prohibiting the person's access to support. The result of such barriers is a perception of not having social support and is usually deemed as a negative situation by recipient and possibly provider as well. Physical setting factors can include poor roads, lack of public transportation, bad weather, and poorly designed buildings (Pearson, 1990).

Attitudes and actions of others influence the recipient's perception of support as well. How the provider offers the support needed or deemed necessary to the recipient is as important as the support offered (Hupcey, 1998; Pearson, 1990).

Providers of support must first be able to appraise the situation and determine if help is needed, what actions to take and in what manner (Hupcey, 1998). During the appraisal and implementation of support attitudes and actions of the provider can greatly alter the support provided. The provider may greatly underestimate the need, the type of

support, and the length of time necessary to meet the need. The provider may also make

assumptions in regards to the support and the recipient. The provider may assume that

the support may make the person feel worse and they may also assume what they think is

needed instead of what the recipient may actually need (Hupcey, 1998). Finally the

provider may become tired, stressed, and or burned out if the time needed extends beyond

their ability to provide the support (Hupcey, 1998). The end result of the above factors

can lead the recipient to perceive an unmet need and overall dissatisfaction.

The recipient's attitudes and activities indubitably influence the perception of

support. Pearson (1990) identifies such factors as low self-esteem, fear, and suspicion of

others, fear of dependency, insensitivities of others, and a stigmatized status as personal

factors that can lead the recipient to perceive a lack of support. Other recipient factors

such as personality, social role, coping ability, independence, and history of supportive

actions can influence the potential availability of support and whether one request, needs,

or receives support (Hupcey, 1998).

Finally the support provided influences the individual's perception of support.

The support provided must meet the need of the recipient in terms of the type, amount,

and length of time (Pearson, 1990). If any of the above factors is not met the recipient

may perceive the support as not meeting their needs. The recipient's perception of the

support provided can determine whether or not the support is deemed as positive or

potentially negative. Defining support in terms of the recipient's perception allows for

further investigation of the potential of the support both in a positive and negative way.

How the recipient perceives the support can also be influence by the intentions or

behaviors of the provider of the support. Hupcey (1998) suggests that the third category

of defining social support focuses on the intentions or behaviors of the provider.

Intentions or Behaviors of the Provider. The third category of social support

definitions refers to the intentions or behaviors of the provider. Shumaker and Brownell

(1984) offer the definition social support as an exchange of resources between two

individuals perceived by the provider or the recipient to be intended to enhance the well

being of the recipient. The provider may perceive an obligation to provide support, they

may feel a need to provide support so when they are in need they will receive support

(Hupcey, 1998). Many of the factors mentioned above in regards to the recipients

perception of the support play into the intentions and behaviors of the provider. Social

support can occur in a bi-directional manner thus the provider can also be a recipient at

the same time. The models of social support will be further discussed later in the chapter.

Further examination of the reciprocating nature of social support is further explored in

the fourth category of defining social support, reciprocal support.

Reciprocal Support. The fourth category of definition is reciprocal support. This

category refers to the exchange of resources between the provider and recipient (Hupcey,

1998). Definitions focused on reciprocal support center themselves on the action of

exchange. Simply put the actual giving, receiving, and exchange of support is commonly

referred to as the function of social support (Antonucci, 1985). This category of

definition takes into account the interactions that occur between the provider and the

recipient and views both parties perception of the interaction. Definitions in this category

not only view the recipient's perception of support but also look at the actual support as

well as the perception of the provider of the support (Hupcey, 1998). Viewing the

perceptions of both parties involved in the exchange of support shows that there can be

an in congruence. Providers usually feel that they are giving more than recipients feel

they are receiving (Antonucci, 1985; Sarason, Sarason, & Pierce, 1990). This can lead to

dissatisfaction in both parties and the possibility of limiting or withdrawing the support

provided (Hupcey, 1998). Shumaker and Brownell (1984) note the importance of

reciprocity by stating that: "The value of the reciprocity model for social support derives

from its attention to factors that inhibit people's willingness to seek and accept help. By

being sensitive to situations in which the norm of reciprocity is salient investigators can

assess whether people lack access to support or are unwilling to become indebted to

others." (p. 15) The fear of becoming indebted to another can form a stressful

environment and further an individual's reluctance to ask for needed help (Hupcey,

1998). Reciprocity can indicate a mutual exchange relationship in which the members are

interdependent upon support given and received. A reciprocal relationship can also incite

a degree of discomfort from some in that they do not feel that they will be able to return

the favor and do not want to be indebted to another. In the fifth category, definitions are

in terms of the social network or the environment in which the support occurs.

Social Networks. The last category of definitions is social networks. The social

network is the milieu in which the support occurs. The social network can refer to an

individual, group, or large community (Hupcey, 1998). The social network can be

viewed as an environment in which the stage for the exchange of support is set. The

social network also refers to the individuals within that provide and receive the support

taking into consideration the characteristics of both parties as well as the characteristics

of the environment and the support itself (Hupcey, 1998).

Characteristics of the recipient of the support are the properties of the individual

that influence the structure and function of the social network (Antonucci, 1985). The

properties unique to the recipient are influenced by the cultural and social roles as well as

their demographic including age, sex, and education (Antonucci, 1985; Cohen & Willis,

1985). The person's requirements for support are determined by these properties and will

also influence their response to support received (Hupcey, 1998).

Characteristics of the provider are similar to that of the recipient but also include

an ability to appraise a situation (Hupcey, 1998). The provider of support must able to

assess a situation determine what they think is needed, how much is needed, and how to

give what is needed (Hupcey, 1998). The provider also must think beyond that situation

at hand and determine the aftermath of the support provided and what the lasting

implications may be (Shumaker & Brownell, 1984).

The environment and support are key components of the social network.

Although the size of the network would seem to be a key factor, there is little information

to support the notion that the bigger the environment the more support available (Sarason

et al, 1990). Hupcey (1998) states that many studies are based on the premise that the

number of individuals in the support network or presence of a particular person will

influence positive outcomes. This may not be the as the person in need of support may

be reluctant to ask for support (Hupcey, 1998; Sarason et al, 1990). Finally Cohen and

Willis (1985) suggest that there may be a threshold of support in which a increase in the

number of providers of support and/or the support provided does not result in a

proportionate increase in satisfaction or benefits associated with social support.

Defining Social Support on a Multifaceted Level

A multifaceted concept such as social support is problematic and isnot easy to

summarize into a single concise definition. Essential attributes of all definitions and to

the concept of social support is a provider, recipient, support, and an environment in

which the exchange can occur. Once these attributes are in place exchange of social

support can occur, how the exchange occurs is explained my models of social support.

SOCIAL SUPPORT APPLICATION AND MEASUREMENT

Models of Social Support

There are several proposed models for the exchange of social support as well as

proposed models of social support interactions (See Appendix D & E). The provider

recipient model suggests a flow of support from provider to recipient in which one

provider meets all needs of the recipient (Appendix D). The next model is the primary-

secondary provider model (Appendix D). In this model a secondary providers assists the

primary provider in meeting the needs of the recipient. The final proposed model is the

multiple provider model (Appendix D). This model consists of several providers

involved in meeting the needs of the recipient.

Within the models of support various social support interactions can occur. In an

example of this particular situation, the recipient can provide direct reciprocal actions

toward the provider instantaneously or the exchange can occur at a later time or because

of past relationships with the provider, there is no need to reciprocate (Hupcey, 1998)

(Appendix E). Another social support interaction involves a chain reaction type of

support where the initial provider provides to a recipient and the recipient in turn

providers to a second person in need (Hupcey, 1998) (Appendix E). Support can also

occur in ways that may not be positive or meet needs of recipient and provider. For

instance, the provider can provide more support than is reciprocated while the reverse can

also occur in which the recipient provides more support than is received (Hupcey, 1998)

(Appendix E). The final two proposed models of social support interactions occur in a

way that neither the provider nor recipients needs are met. In the first of these models the

interaction between the provider and recipient is stressful even though behaviors may be

intended to be supportive (Hupcey, 1998) (Appendix E). The last of these proposed

models in which neither the provider nor the recipients needs are met suggests the

support provided is negative, perceived as negative, and/or the outcome is negative

(Hupcey, 1998) (Appendix E).

Support is to be perceived as a positive experience however it can also occur in a

negative way and thus the needs of all parties involved may or may not be realized or

met. Models can be used to understand social support in a more concrete way. Social

support is influenced by multiple variables and differs from person to person. To better

examine and understand social support as it pertains to individuals a need to measure its

presence is essential. Through increased exploration of the concepts of social support,

researchers are striving to provide information to further the understanding of social

support and its role in human beings.

Social Support Measurement

As the knowledge related to the concept of social support has grown, applying a single simple definition has become more and more difficult. Even more cumbersome is development of a means to concretely measure the presence and associated outcomes of social support. There are many definitions for social support and even more means that attempt to measure this broad concept. Similar in the way Hupcey (1998) proposed categories of defining social support, Sarason et al (1990) have suggested three categories in which the measures of social support may be divided, these categories are as follows: a) the network model that focuses on the individuals social integration into a group and the interconnectedness of those within the group b) the received support model that focuses on what the person actually received or is reported to have received and c) the perceived support model that focuses on support the person believes to be available if he or she should need it. Of note there are few measures that address satisfactions with support, reciprocity, actual recipient needs, or the negative aspects of support with social interactions (Hupcey, 1998).

In assessing social support the many available tools attempt to address the multidimensional nature of social support. From these tools valuable insight to the perceived benefits of social support have been identified. One area of interest that is repeated identified in literature is the effect of social support on stress and stressful situations.

Social Support and Stress

The means in which social support affects stress and stressful situations is up to debate. Researchers have questioned whether the effect is related to a buffering or

protective mechanism for a person under stress or in a stressful situation or if the effects

of social support have a beneficial effect irregardless of whether the persons are under

stress or not (Cohen & Willis, 1985).

Examination of social support as a main effect suggest a generalized beneficial

effect of social support could occur because large social networks provide persons with

regular positive experiences and a set of stable, socially rewarded roles in the community

(Cohen & Willis, 1985). In this situation the person is immersed in a positive and

somewhat predictable environment allowing them to exert or feel as though they have at

least some degree of control.

Control and Stress. Control is also an important factor in consideration of the

effects of social support. Locus of control is a center of responsibility for one's behaviors

(Anderson, Anderson, & Glanze 1998). Individuals with an internal locus of control

believe they can control events related to their life, whereas those with an external locus

of control tend to believe that real power resided in forces outside themselves and

determines their lives (Anderson et al, 1998). The identified locus of control for an

individual greatly impacts their perception of support given as well as support received.

Caldwell et al (1987) found locus of control has an important impact on

perception of social support and stress moderating, where those that identified an external

locus of control reported receiving more social support than subjects classified as having

an internal locus of control. Even though persons with an internal locus of control

reported receiving less social support, they were found to make more effective use of the

support they did receive (Caldwell et al, 1987). This was noted because the stress

buffering effect of social support was found to be stronger for internal locus of control.

Caldwell et al (1987) found that locus of control orientation did not affect the impact of

stress on symptom formation for women, but it did have an important effect for men.

Men with an internal locus of control were more likely to develop psychosomatic health

symptoms under stress whereas external men were more likely to become depressed

(Caldwell et al, 1987).

Support as a Buffer. Viewing social support as a stress buffer suggests that social

support affords the person a degree of protection from potentially stressful events. Cohen

and Willis (1985) suggested that support might play a role at two different points in the

causal chain linking stress to the effects of stress on the person. They suggest that

support may intervene between the stressful event and the stress reaction by preventing a

stress appraisal response (Cohen & Willis, 1985). In other words it is possible that the

person will not perceive the potential threat as a stress due to the belief that they have

adequate resources upon which to draw and protect themselves from the threat. The

second notion is that adequate support may intervene between the experience of stress

and the adverse effect by reducing or eliminating the stress reaction or by directly

influencing physiological processes (Cohen & Willis, 1985).

Support can work in many ways to alter the perception of the stressor. Support

might provide a solution to the problem and thus reduce the potential of a response by the

person experiencing the stress. Bliese and Britt (2001) reiterate this notion in more

recent literature suggesting that social factors may ameliorate the negative effect of

stressors. They provide the example that factors such as cohesion were the reason the

German soldiers in the Wermacht were able to maintain morale and performance in the

face of intense combat stressors (Bliese & Britt, 2001). They tested this example in a

study designed to assess United States Army soldiers deployed to Haiti and their response

to a stressful situation. Bliese and Britt (2001) found that a positive social environment

helped individuals cope with stress.

Literature describes a link between the presence of social support and the nature

of the stress response is established. Another strong link is established in the literature in

regards to social support and illness response.

Social Support and Health

It has been suggested that social support may play a physiologic role in

modulation of health through the stress response system. Chronic exposure to

psychosocial stress may alter the hypothalamic-pituitary-adrenal axis function (Baum &

Poslenzky, 1999). Indirect effects of the central nervous system on immune function

involve the hypothalamic-pituitary-adrenal axis. Through this somewhat complex

mechanism of positive and negative feedbacks the central nervous system regulates the

activation and modulation of the immune system while at the same time stimulating the

stress response. The stress-induced alterations in equilibrium of various hormones

controlled by the hypothalamic-pituitary-adrenal axis have a significant effect on the

immune response. Whether this impact on immune function is suppressive or

potentiating depends on the type of immune modulating factors that are secreted, with

some factors known to have enhancing or suppressing activities, or both, depending on

the concentration and length of exposure, the target cell, and the specific immune

function (Shelby & McCance, 1998). The hypothalamic-pituitary-adrenal axis plays a

key role in functioning of physical and mental health in humans.

Social Support and Mortality. Evidence suggests that social support can have a

positive impact on health and decrease mortality from many different causes (DeVries et

al, 2003). In a review of a study on stress, DeVries et al (2003) noted the level of social

support significantly correlated with the rate of progression from asymptomatic to

symptomatic stages of human immunodeficiency virus (HIV) infection in men. These

researchers also found that stressful life events and increase serum cortisol concentrations

were associated with faster progression to acquired immune deficiency syndrome (AIDS)

in HIV positive men (DeVries et al, 2003). It has been noted that stressors increase the

level of strain thus leading to poor health and/or poor psychological well-being (Bliese &

Brett, 2001; Cohen et al, 1985; DeVries et al, 2003). These notions are reiterated

frequently throughout social support literature suggesting that social support is beneficial

to buffer the effects of stress and in the prevention of adverse health outcomes are

supported.

Social Support and Illness

Social support also appears to play a role in lessening the severity and/or

progression of present health problems. Persons that are more isolated and lack a social

network emerge as a group with high mortality and morbidity rates. Two key studies

demonstrate this notion, the first is a study that found less socially integrated people were

more likely to commit suicide than the more integrated persons (Durkheim, 1951). The

second study found a longer life expectancy in men who were married than in their single

counterparts (Carter & Glick, 1970). Authors House, Landes, and Umberson (1988)

point out that there is some difficulty in determining a casual interpretation and

explanation of these associations. They ask these poignant questions: Does a lack of

social relationships cause people to become ill and die? Or are unhealthy people less

likely to establish and maintain social relationships? Or is there some other factor, such

as a misanthropic personality, which predisposes people both to have a lower quantity

and quality of social relationships and to become ill? (House et al, 1988). These

questions are not easily answered even today. Researchers noted that there is a positive

correlation between social support and level of health. It would appear that social

support promotes adaptive behavior and modulates the hypothalamic-pituitary-adrenal

axis response in the face of stressful situations and the threat of ill health. However, it is

difficult to determine the significance of social support on health due largely in part to the

multidimensional nature of social support as previously discussed.

Benefits of Social Support on Illness. Social support has been linked to positive

impacts on health including reducing mortality rates and improving recovery from

serious illness (Berkman & Syme, 1979; Bliese & Brett, 2001; Carter & Glick, 1970;

Cohen & Willis, 1985; DeVries et al, 2003; Glass, Dym, Greenberg, Rintell, Roesch, &

Berkman, 2000; House et al, 1988). Social support also plays a role in specific disease

progression and coping (Berkman & Syme, 1979; Bliese & Brett, 2001; Carter & Glick,

1970; Cohen & Willis, 1985; DeVries et al, 2003; Glass et al, 2000; House et al, 1988).

Social support plays a role in health promotion and disease prevention. It has

been shown to be influential in maintaining health and preventing disease for both men

and women as well as helping to cope and adapt to a variety of medical problems (Glass

et al, 2000).

The presence of a social support network has a positive impact on longevity and

decrease in mortality (Berkman & Syme, 1979 & Glass et al, 2000). Berkman and Syme

(1979) conducted a large-scale study in Alameda County in California on social support

and established that people with the lowest level of social contact had mortality rates

greater than those with strong social networks. These findings were reinforced even

when lifestyle factors such as smoking, alcohol, and physical activity levels were taken

into consideration.

Hurdle (2001) proposed that there was a significant increase in the utilization of

health promotion and disease prevention programs when the programs were introduced to

the intended recipients in the milieu of a group format. Other means such as the buddy

system and peer role models also increased social support and resulted in increased

utilization of these programs (Hurdle, 2001). Self-help programs such as Alcoholics

Anonymous (AA) also incorporates the notion of social support to increase health

promotion and disease prevention. Groups such as AA utilize designated sponsors or

buddies to help the individual progress through potentially difficult and stressful times.

Social Support and Chronic Illness

The existence of relationship between social support on stress, health promotion

and disease prevention results in an inability to ignore the likelihood of an association

between social support and a disease state. A great deal of research exists presenting

examination of how social support positively influences disease states including

HIV/AIDS, cardiovascular disease, endocrine disease, and cancer, as well as decreasing

mortality rates associated with many disease states.

Higher levels of social support have been related to a decrease in overall blood

pressure and decrease in mortality associated with adverse cardiovascular outcomes,

specifically myocardial infarct (Uchino et al, 1996). As previously mentioned, social

support is implicated as to having a buffering effect on stress response, which is closely

tied to the endocrine system through the hypothalamic-pituitary-adrenal axis (DeVries et

al, 2003). The progression of HIV to AIDS has been slowed through a strong social

support system as is demonstrated by several researchers (DeVries et al, 2003 & Uchino

et al, 2003).

Social Support and Cancer

Chronic disease and illness can be very stressful and the effects of social support

can have a many positive benefits on the recipients. A diagnosis of cancer carries a great

deal of emotion and fear of uncertainty. Social support in the face of a diagnosis

regarded as a life crisis can impact the course of the disease, positively or negatively.

Cancer patient's need for support is often extended beyond the initial diagnosis and well

into the treatment phase and frequently beyond remission.

Cancer and its associated treatments may require a fundamental change in

lifestyle, which, prompts the person to question their personal identity and self worth. It

is important to consider the amount and type of social support that will be available as

adjustment to this diagnosis is made (Price, 2003).

Models of Social Support in Cancer. Three theoretical models by which social

support may influence the impact of stressful life events on cancer patients psychological

state were described by researchers examining the impact of stressful life events in

women with breast cancer (Kornblith, Herndon, Zuckerman, Viscoli, Horwitz, Cooper,

Harns, Tkaczuk, Perry, Budman, Norton, & Hilland, 2001). The three models are as

follows: 1) the addictive model, in which social support and stressful life events each

directly influence concepts adjustment, irrespective of the magnitude of the other; 2) the

buffering hypothesis, previously discussed in which stressful events occurring in the

presence of social support should produce less distress than if the occurred in it's

absence; and 3) both addictive and buffering model (Kornblith et al, 2001).

In this study the researchers conducted phone interviews with 169 patients who

had Stage II breast cancer utilizing the MOS Social Support Survey, Life Experience

Survey, European Organization for Research on the Treatment of Cancer, Mental Health

Inventory, and the Systems of Belief Inventory (Kornblith et al, 2001). The authors

tested each of the models they identified explaining how social support may influence the

impact of stressful life events on women with breast cancer. When each model was

tested on women with breast cancer the addictive model was supported. Both stressful

life events and social support independently affected patient emotional state (Kornblith et

al, 2001). Of note, the level of social support needed to be very high to reduce the

likelihood of severe psychological distress (Kornblith et al, 2001).

Social Support on Psychosocial Well Being in Cancer. Social support plays a role

in adjustment to a life changing diagnosis of cancer (Kornblith et al, 2001). The

literature supports the notion of a positive affect of social support and psychosocial well-

being (Bliese & Britt, 2001; Cohen & Willis, 1985). Research currently is looking at the

physical effects of social support on cancer progression and indicators (Lutgendorf et al,

2002). One such study measured vascular endothelial growth factor (VEGF) and social

support in patients with ovarian cancer. Vascular endothelial growth factor is a key

cytokine that is capable of stimulating tumor angiogenesis and it has been associated with

poorer survival in patients with ovarian cancer (Lutgendorf et al, 2002). Researchers

compared results from a quality of life survey and a mood profile to serum VEGF levels.

Women with ovarian carcinoma who reported higher levels of social well-being had

lower levels of VEGF (Lutgendorf et al, 2002). Researchers noted that greater support

from friends and neighbors and less distance from friends were facets of social well-

being and were associated with lower VEGF levels while individuals who reported

greater helplessness or worthlessness had higher levels of VEGF (Lutgendorf, 2002).

Social Support as a Function of Gender and Cancer. Many studies have focused

on the effects of social support as they apply to women with cancer, there are fewer

studies recognizing the effects of social support as they apply to men. This phenomenon

may be related to recurrent findings that males report not needing or wanting as much

support as their female counterparts (Markwood, McMillan, & Markwood, 2003).

Goodwin, Samet, & Hurt (1996) briefly suggested that characteristics such as poor social

support, limited access to transportation, and impaired cognition can delay treatment and

increased the risk for inadequate treatment especially for older men with prostate cancer.

Other factors such as being uncomfortable in group or individual setting may hinder men

from participating in social support groups (Gotay & Bottomley, 1998). In such

situations other means of providing support may need to be explored such as providing

psychosocial support by telephone (Gotay & Bottomley, 1998).

A diagnosis of cancer can lead to feelings of anxiety as well as a lack of control

and feeling of uncertainty regarding the future. According to the literature a strong social

support network can buffer some of these feeling and successfully help the patient

diagnosed with cancer cope and progress through treatment and illness. Social support

has been shown exert a positive and important influence on a patient's adapting to the

changes in their life that accompany a diagnosis of cancer.

A large body of literature addresses social support and its positive attributes.

There is very little information addressing negative aspects associated with social

support, however it bears noting that these aspects do exist and can greatly impact a

persons ability to give and receive support. As previously noted in Hupcey's (1998)

article "Clarifying the Social Support Theory Research Linkage," there are several

models that have suggested a negative social support interaction. In these models the

recipient may receive more support than is reciprocated, the recipient may provide more

support than is received, and support may be provided in a negative way, perceived as

negative, or the outcome is negative (Hupcey, 1998). Social relationships can be viewed

as negative especially when the relationship threatens the individual's self-esteem,

autonomy, and ability to make choices (Bottomley & Jones, 1998). If the support

provided is more than is reciprocated the recipient may have feelings of dependency or

may feel as thought they are being treated as an infant and believed to be incapable of

doing anything for themselves (Bottomley & Jones, 1997). Social support relationships

can also have a negative effect in dealing with illness if the provider is unwilling or

unable to discuss the disease and or the treatment in fear of upsetting the person with

cancer (Bottomely & Jones, 1997). While the benefits affiliated with social support are

of significance it is also important to remember that good intentions may be perceived in

a negative light.

Social Support Development in Childhood and Adolescence

Social support can influence a person through their lifetime and is present before

the person may be cognitively aware of its presence. Social support plays a significant

role in emotional and psychological growth and development of the adolescent and young

adult. Adolescence has been viewed as a tumultuous time during which the adult to be

begins to emerge and be shaped. It is also during this time that social networks outside

the immediate family begin to form and become a central part of the adolescents and

young adults life. It has been suggested that the need for intimacy is one characteristic

that emerges in adolescence (Haluska, Jessee, & Nagy, 2002). Adolescents look

primarily to their peer groups, especially their best friends to meet their needs for

intimacy. It is through their peers that adolescents fulfill their needs for social support.

Erikson's Stages of Psychosocial Development. Psychologist and behaviorist

Erik Erikson (1950) believed that one of the most important tendencies we are born with

is the drive for identity. Erikson (1950) believed that personality developed gradually

over time as a result of interactions between physical maturation, inborn drives, and

experiences with the environment. Erikson defined eight unique stages of psychosocial

growth and development and concluded that a particular task or need must be met before

the person can move on to the next stage of development. The two stages that preoccupy

the adolescent and young adult years are formally titled identity versus role confusion

and intimacy versus isolation. The identity versus role confusion stage occurs from age

13 to18. During this stage the adolescent must adapt a sense of self to physical changes

of puberty, make occupational choices, achieve adult-like sexual identity, and search for

new values (Erikson, 1950). This phase continues from age 19-25 into the intimacy

versus isolation stage. During this time the person must form one or more intimate

relationships that go beyond adolescent love then marry and form a family group

(Erikson, 1950). Disruption in the progression of stages can promote difficulty forming

bonds and establishing identity.

Adolescence and Peers. During adolescence, peers become a major component of

the adolescent's social network. Adolescents may still turn to their family, specifically

their parents, to seek guidance and receive support.

Social support can have a great impact on development of the psyche in

adolescence. Preadolescents who reported low satisfaction with their social support had a

higher probability of having problems with anxiety, depression, and sleep disturbance

(Dumont & Provost, 1999). Researchers have also found that in adolescents and young

adults decreased satisfaction with social support was associated with depressive or

psychosomatic symptoms, anxiety, and interpersonal sensitivity (Burke & Weir, 1978;

Compas, Slavin , Wagner, & Vannatta, 1986; & Dumont & Provost, 1999).

During the period of adolescence the pre-adolescent begins to transition and form

a social network comprised primarily of family members to one that is centered around

peers. Of note this transition does not necessary signal the end of a relationship and a

disengagement of the adolescent from his or her parents. Researchers have suggested

that the stronger the relationship between parent and adolescent the stronger the identity

and development of autonomy experienced by the adolescent (Dornbusch, Peterson, &

Hetherington, 1991 & Haluska et al, 2002). Larson, Richards, Moneta, Holmbeck, and

Duckett (1996) along with Haluska et al (2002) suggest that although the adolescents

spend less time with their family members the time spent in communication with the

family members did not decline. Peer interactions play a significant role in personal

growth and development for the adolescent, however family support continued to be

important and played a significant role in the adolescents life. Burke & Weir (1978)

along with Haluska et al (2002) note that among the positive developmental outcomes

from this socialization with peers are self-understanding, emotional regulation, and

formation of relationships.

Social Support Development in Children, Adolescents, and Young Adults with Cancer

Adolescence has been shown to be a difficult time of transition. Formation of the

social identity occurs within the context of peer and family facilitated support. The

ability to cope and adapt to changes and life stressors is intimately related to the presence

and quality of a social support system. Support from family members played an

important role, however support from peers cannot be overlooked as a significant source,

especially for the adolescent. Past and current literature has established a connection

between psychological and physical health. The existence of this relationship is

essential; because of this it is important to recognize the significance of formation and

continuation of a social network. Adolescents who spend less time with family members

generally spend more time interacting with their peers; friendships are the principal

feature of adolescent social development (Hartup, 1993; Haluska et al, 2002).

Friendships are of the utmost importance during adolescence because these relationships

provide opportunities for interaction that are not otherwise available (Haluska et al,

2002). Disruption of the formation of peer support networks can likely affect the

psychological maturation of the individual and may have an impact on physical health.

Advancements in research and treatment have lead to an increase in survival rates for children and adolescents diagnosed with cancer. Historically, cancer was almost always fatal, but due to recent advances in treatment cancer is reaching curable rates up to 80% (Harvey, Hobbie, Shaw, & Bottomley, 1999; ACS, 2003). Survivors of childhood cancer and their families now are faced with a broad range of physical and psychological challenges imposed by the disease and treatment. Some survivors will suffer the long-term effects for the rest of their lives (ACS, 2003). Harvey et al (1999) report that the effects of cancer treatment can greatly impact the physical and psychological development of the survivor. The medical community can often trivialize the effects of cancer, especially when compared to the experiences the survivor may have faced while in treatment.

Late Effects Study Group. In the mid 1960s the Late Effects Study Group was formed to critically analyze the potential effects of cancer and cancer treatment (Harvey et al, 1999). The Late Effects Study group was a cohort of 1,380 children and adolescents diagnosed with Hodgkin's Disease between 1955 to 1986, all participants were 16 years of age or younger (Harvey et al, 1999). The study was initiated to determine the appropriate treatment necessary to maintain cure rates and minimize the potential for late effects of therapy (Harvey et al, 1999). A member of the research team Dr. D'Giulio D'Angio declared that "children cured of cancer must be followed for life, not so much because late recurrence of disease is feared as to permit early detection of the delayed consequences of radio and chemotherapy (D'Angio, 1975). The Late Effects Study group was the first formal attempt to gather information and analyze the possible effects associated with an organized and ongoing therapy (Harvey et al, 1999). The Late

Effects Study Group determined that multidisciplinary medical follow up was important but issues including psychosocial facets are also key so that the childhood cancer survivors of today will not become the chronically ill adults of tomorrow (Harvey et al, 1999). The results of the formal evaluation of the Late Effects Study Group are significant in light of the increasing population of childhood cancer survivors. The presence of a program in place to formally evaluate survivors of childhood cancer becomes as important a facet of treatment as chemotherapy and blood counts. Indeed a study conducted by the Children's Cancer Group and the Pediatric Oncology Group revealed that 96 institutions had some form of long term follow-up program for survivors of childhood cancer (Oeffinger, Eshelman, Tomlinson, & Buchanan, 1998).

Previous research has demonstrated a possible relationship between a healthy psychosocial being and positive health outcomes in light of this relationship and the suggestions of the Late Effect Study Group the importance of the formation of social ties cannot be undermined. Indeed the National Summit Meeting on Childhood Cancer sponsored by the American Cancer Society, recommended addressing the required component of psychosocial support, noting, "Meeting emotional, psychological, and spiritual needs of the patient enhances a positive response to treatment" (ACS, 2002).

Psychosocial Growth and Development. Growth and development on psychosocial level of the individual is a key component in care of adolescents and young adult survivors of cancer. Having problematic peer relationships during childhood and adolescence is of considerable concern given the importance of these relationships for health and emotional adjustment (Vannatta, Garsten, Short, & Noll, 1998). Peer relationships have been identified as playing a central role in children and adolescent's

social and emotional development (Sullivan, 1953; Vannatta et al, 1998). Hartup (1983)

notes peer relationships are fundamental for the development of adequate social skills and

for the emergence of healthy self-concept. Not only do peer relationships influence self-

concept but they also serve as predictive indicators of current adjustment as well as future

adaptation (Hymel et al, 1990; Vannatta et al, 1998). The nature of a diagnosis of cancer

and the treatment of cancer set the predisposes the child and/or adolescent to a potential

for isolation. During treatment, responses like neutropenia and extreme fatigue, may

require social isolation. Parents of the child and/or adolescent may instinctively choose

to "protect" them and in so doing may sever any social ties previously established.

One of the most common forms of childhood cancer are brain tumors, accounting

for approximately 1,200 new cases per year in the United States (Vannatta et al, 1998).

To evaluate the behavioral reputation and peer acceptance of children diagnosed and

treated for brain tumor Vannatta et al, (1998) compared 28 children surviving brain

tumors to 28 nonchronically ill peers. The researchers collected peer, teacher, and self-

report data from all participants in an attempt to study peer relationships. Vannatta et al

(1998) found that children treated for brain tumors were selected less often as a best

friend and were frequently viewed by teacher, peers, and self as socially isolated. They

also found that peers of children survivors of brain tumors perceived the survivor as

being sick, fatigued, and frequently absent form school even though these children were

no longer receiving active treatment (Vannatta et al, 1998). These results in addition to

finding on a formal questionnaire are suggestive of further difficulties in peer and social

relations later in life for children surviving brain tumors (Vannatta et al, 1998).

Social isolation experienced by children and adolescents with cancer is further compounded by the response of peers to the person. These responses can be amplified when evidence of the disease or it's treatment are obvious. In such cases others in the environment may alter their response to the child thus causing the child to feel different (Hymovich, 1995). Rejection by those who are not chronically ill can lead to feelings of self-consciousness, fear, maladjustment, and withdrawal (Gething, 1985). These findings may suggest an explanation for a typical response from cancer survivors in regards to peers "other people just don't understand" and "I've never met anyone like me that understands what I am going through."

It is undeniable that a diagnosis of cancer can greatly impact the physical and psychological well being of the individual. This notion is especially true when applied to children and adolescents with cancer. The period of time encompassing childhood and adolescence is essential for formation of peer social networks and psychosocial formation of the future adult. Disruption of this process is common with a cancer diagnosis and subsequent treatment, the result is a person with poor social networks, possible maladaptive behaviors, and potential adverse effects on later health status. These adverse reactions can potentially be averted if a strong social network can be achieved and maintained. Establishment of such a network and validation of feelings specific to those diagnosed with cancer and receiving treatment may have profound effects on the individual's psychosocial development. Forming these networks becomes a major focus of health care providers, family members, and the individual. One means to accomplish this may be bringing many individuals undergoing a similar experience together to meet,

discuss, and form bonds that may last a lifetime and provide the benefits clearly associated with a strong social support network.

<u>Social Support and the Camp Experience</u>

A camp experience for children, adolescents, and young adults diagnosed with cancer may offer an environment in which social networks can be formed and strengthened. A medically supervised camp has the potential to provide a positive milieu in which cancer survivors could meet, discuss their experiences, and form social support networks. The literature examining the effects of a camp experience on children and adolescents with cancer in regards to social support is limited. There is very little information available to quantitatively measure the effects of a camp experience most information available is primarily anecdotal in nature.

It has been suggested that attendance at an oncology camp can enhance self esteem, improve communication about cancer especially among family members, and contribute to the person's knowledge of the disease and it's treatment even in the absence of formal educational programs (Benson, 1987; Smith, Gotlieb, Gurwitch, & Blotcky, 1987; Bluebond-Langer, Perkel, Goertzel, McGeary, & Nelson, 1990). Through shared experiences children, adolescents, and young adults have a similar foundation upon which a peer relationship can be established. The amount of time available to establish peer relationships is also an important factor. One study suggested that an inability to spend time with peers plays a major role in an inability to develop peer relationships (Bluebond-Langer, Perkel, & Goertzel, 1991). Parents that limit their child's access to peer groups, as parents of handicapped and ill children and adolescents often do, further exacerbate problems for themselves and their child (Bluebond-Langer et al, 1991).

The above results were found in a study conducted by researchers Bluebond-Langner et al (1991) over two years at a summer oncology camp in Pennsylvania. Researchers used a case-study quasiexperimental design including detailed, structured, open-ended interviews with children and adolescents with cancer before and after camp (Bluebond-Langner et al, 1991).   A questionnaire was also administered to parents before and after the session (Bluebond-Langner et al, 1991). The investigators also conducted field observations at the camp and affiliated treatment centers during the study (Bluebond-Langner et al, 1991). Using 50 children and adolescents age 7 to 16 years, researchers found that the children and adolescents formed relationships that extended beyond the seven-day camp experience and had difficulty separating at the end of the camp session (Bluebond-Langer et al, 1991). The researchers also found that the relationships did not end with camp. Aside from the contact provided during the camp reunion, clinic visits, and hospitalization, 27 children and/or adolescents (54%) also staying in touch through letters and phone calls (Bluebond-Langer et al, 1991). Not surprisingly the researchers found that the relationships formed at the camp were unlike any established with healthy peers in that they shared a common experience upon which a significant relationship was built (Bluebond-Langer et al, 1991). However the researchers noted that the relationships established with peers with cancer helped the survivor develop and maintain relationships with healthy peers (Bluebond-Langer et al, 1991). These finding suggest the potential for further study in the effect of camp on children, adolescents, and young adults diagnosed with cancer.

Objective on Oncology Camp. Research and anecdotal narratives have suggested that there are many benefits associated with a camp experience for the cancer survivor

and the family. Swensen (1988) suggested six important objectives of oncology camp in meeting the goal of providing a positive camp experience, including: 1) emphasizing the normalcy of each camper, that is although the campers may be undergoing some painful experiences they are still normal, the emphasis becomes what each camper can do, not what they cannot 2) alleviating at least in the short term, the anxiety and depression experienced by the campers 3) ameliorating the sibling's sense of isolation and neglect, much of the attention of the family is directed toward the child, adolescent, or young adult with cancer thus inevitably resulting in some anger and resentment of the well sibling toward the cancer patient 4) providing opportunity for a sense of mastery and efficacy in peer relationships, physical changes in appearance and frequent school absences can serve as catalysts to deterioration in any child, adolescent, or young adult with cancer resulting in an inability to establish successful peer relationships, the fostering of friendship and intimacy within camp may help the cancer patient establish health relationships with healthy peers 5) elevating self-esteem among cancer patients, it is clear that self-esteem can greatly impact psychological well being, increasing self-esteem can have a positive impact on the long-term psychological well being 6) edifying those of us who do not know the experience first hand, cancer is a far-reaching disease that can potentially affect one in every five individuals. A greater understanding of the total emotional and physical experience can lead to better understanding and better care. Through these objectives a positive camp experience can be realized for the camper as well as the staff members.

     <u>Anecdotal Benefits of Camp</u>. Attending camp as a child or adolescent is considered to be a "normal" experience and in many ways a right of passage. Children

and adolescents with medical conditions may be denied entrance to camps. Specialized

camps like oncology camps can offer the camper a chance to be normal and provides a

positive environment and ultimately a positive experience for all involved. Campers with

cancer attending an oncology camp can benefit from exposure to other children,

adolescents, and young adults with problems and issues similar to their own and from the

challenges that camp provides, all of which facilitate peer interaction and support

(Johnson, 1990). Camp offers an opportunity for growth and acceptance. Fochtman

(1993) notes in an editorial, a week at camp can have it's highs and lows but by the end

of the week the campers have a mutual understanding and concern for each other as well

as a sense of love, sharing, and togetherness. It is a chance for everyone to be normal,

grow, and challenge boundaries. Kline (2001) in her editorial recounts some of her

fondest memories of camp, "a wheelchair bound teen aged girl, paralyzed since the age of

two by a spinal tumor, who had her first dance at camp" and the "12-year-old with the

posterior fossa syndrome who finally began to eat at camp and for the first time in six

months did not require total parenteral nutrition when she got home". Kline (2001) also

tells of the "19 year old who was in the terminal stages of illness but wanted to come and

have the opportunity to be a junior counselor." Finally, Feeg (1989) notes in her editorial

that while attending an oncology camp the campers will live and share experiences with

other children and adolescents with similar problems and needs, the very act of sharing

will be of enormous psychological benefit. There are many more anecdotal stories

extolling the benefits of oncology camps in forming and maintaining social interactions.

Although one cannot ignore the presence of these first hand accounts it is worth noting

that there is very limited research into the area to quantify or even qualify the benefits

associated with a oncology camp experience or any other medical camp experience.

Summary. Limited quantitative and qualitative research is available exploring the

camp experience and its impact on illness. Through anecdotal recounting of camp

experiences it has been suggested that a camp experience can have a positive impact on a

person with cancer. The benefits appear to be associated with the development and

fostering of peer relationships with others having a shared experience like cancer as well

as with healthy peers. There is a significant gap in the literature addressing these issues.

The potential for research to explore the phenomena that is camp and its impact on social

support is great. It is for this reason it appears reasonable to address the question, is there

a significant difference in perceived social support before and after a week long camp

experience with other young adults diagnosed with cancer?

CHAPTER 3

METHODS

Population and Sample

A non-random convenience sample of 18 to 25 year olds with a diagnosis of cancer attending a weeklong oncology camp at Camp Mak-A-Dream in western Montana, were selected to participate in the research. All participants in the camp are able to attend the camp free of charge, and there were also funds available to help with travel cost if needed. Most referrals for camp attendance came from recommendations from previous campers; campers are also referred to attend camp through social workers at their home treatment centers. The average camp size is 30 –40 participants per session and most campers come from areas outside of Montana.

Setting

The camp is located in a rural area of Montana, approximately 70 miles from a population center of Missoula, MT. The camp was specially designed to meet most medical needs of campers including administration of chemotherapy when needed, laboratory sampling for blood counts, and ability to access blood products for administration if necessary. The camp is also able to care for most needs that arise at any camp, skinned knees, cuts, scrapes, and bug bites. All activities are optional and are supervised by trained staff members.

Sampling Procedures

The study and survey material were reviewed with all of the campers on arrival to camp during medical check in procedures. Campers willing and able to participate were asked to read and sign an informed consent form prior to completing the survey. The survey and procedure were reviewed and discussed with counselors and research assistants prior to the arrival of campers. The counselors and research assistants were available during the pre-test and post-test to answer questions and assist the participants as needed.

Design

The study design is quasi-experimental due to the lack of a control group consisting of young adults not attending camp. The dependent variable to be tested is report of perceived social support. The dependent variable was measured by comparing means for the pretest and the posttest on the MOS Social Support Survey utilizing the subscales and the overall index of support. The identified subscales on the MOS Social Support Survey include Tangible support, Affectionate support, Positive interaction support, and Emotional/Information support. The overall index of support was calculated using each of the subscales scores and one additional item (Sherbourne & Stewart, 1993). The dependent variable was assessed based on scores obtained from the MOS Social Support Survey in the pretest then compared to the posttest MOS Social Support Survey results. The comparison was made by calculating the mean score on each subscale of the MOS Social Support Survey as well as the overall support index, which is calculated by obtaining the mean score from all items on the scale including the subscales and the one

additional item. The pre-test and post-test scores were compared using a paired t-test in

SPSS. The independent variable is time, with the pre-test occurring prior to the camp

experience and the post-test occurring after the experience.

Instrument

A four-part survey was designed for this study utilizing pre-existing tools

accessed through the Rand Corporation and other sources. The first section asked

participants to provide demographic information. The questions for the demographic

information were obtained from the United States Census Bureau so as to be worded in

an understandable way. The other three sections addressed current health and social

support with the final section consisting of open-ended questions about the participants

experience prior to and after camp (See Appendix A).

Although data were collected utilizing the RAND 36-Item Health Survey 1.0

Questionnaire the data were not analyzed or compared for the participants in this study.

The RAND 36-Item Health Survey was utilized as a means of gathering health status

information about the campers. Data collected for the scale however was incomplete due

to an input error in formation of the instrument. These data were subsequently not used

in analysis of results

The Medical Outcome Study (MOS) Social Support Survey is a brief,

multidimensional, self-administered survey that was designed to be comprehensive of the

various dimensions of social support (Sherbourne & Stewart, 1993). The four functional

support scales measured emotional/informational, tangible, affectionate, and positive

social interaction. Participants responded to statements representing the four functional

support areas by selecting a response that best corresponded to their experience.

Responses corresponded with a 5-point Likert scale ranging from one (none of the time) to 5 (all of the time). These support measures are distinct from structural measures of social support and from related health measures (Sherbourne & Stewart, 1993). The reliability for the subscales and overall support index is reported in Table 1. Items from the MOS Social Support Survey were randomized within the survey participants completed. The survey utilized in this study is included in Appendix A.

Table 1. Published Alpha Reliability Scores for MOS Social Support Survey
(Sherbourne & Stewart, 1991)

Measure	Alpha	N of Cases	N of Items
Emotional/Informational Support	0.96	2987	8
Tangible Support	0.92	2987	4
Affectionate Support	0.91	2987	3
Positive Social Interaction	0.94	2987	3
Overall Support Index	0.97	2987	19

Table 1 reports alpha reliability scores from the MOS Social Support Survey as reported by Sherbourne and Stewart (1991). These scores can be compared to the alpha scores found in this study as reported in Table 2. The current study's alpha reliability scores are similar to those reported by Sherbourne and Stewart thus suggesting the instrument performed well with the sample and internal consistency was appropriate.

Table 2. Alpha Reliability Analysis of MOS Social Support Survey Current Study

Measure	Alpha	N of Cases	N of Items
Emotional/Informational Support	0.929	39	8
Tangible Support	0.885	39	4
Affectionate Support	0.799	39	3
Positive Social Interaction	0.978	39	3
Overall Support Index	0.934	39	19

Procedures

Data was gathered from young adults who were attending the week long camp at Camp Mak-A-Dream held in western Montana for young adults diagnosed with cancer. Institutional Review Board Exempt approval was obtained from Montana State University and the camp administration (See Appendix C). Participants were asked to read and sign a informed consent form prior to completing the survey. A copy of the consent form is included in Appendix B.

An explanation of the instrument and the consent form was given to campers interested in participating as identified by a research assistant and or counselors familiar with the instruments and procedure on the first day of camp as participants were being checked in with the medical staff upon arrival. Participants were given the time necessary to complete the survey and a quite environment in which to complete the survey. Several camp counselors familiar with the instrument and procedure were present to answer questions and collect materials. The survey included demographics, the Rand 36-Item Health Survey, the MOS Social Support Survey, and the pre-test

qualitative questions. The participants were asked to fill out a similar survey on the last

full day of camp prior to attending the closing ceremony. Participants were given ample

time and a quite environment in which to complete the survey. Several camp counselors

were present to answer questions and collect materials. The survey included the Rand

36-Item Health Survey, the MOS Social Support Survey, and the post-test qualitative

questions.

Treatment of Data

MOS Social Support Survey

Scores from the MOS Social Support Survey were calculated by averaging the

scores for each item in the subscale. An overall support index was calculated by

averaging the scores for all 18 items included in the four subscales and the score for the

one additional item. Responses to the MOS Social Support Survey were assigned

numerical value; ranging from 1, none of the time to 5, all of the time. The results from

each subscale and the overall index were tested for reliability using SPSS software.

Definitions

There are several terms associated with the study requiring definitions to further

understanding of the data. The following table contains the definitions using both a

conceptual definition and operational definitions.

Table 3. Definitions

Term	Conceptual Definition	Operational Definition
Young Adult	The stages of life from 22 to 65 years of age (young and middle adult) (Anderson, Anderson, & Glanze, 1998).	A person between and including the ages of 18 years of age to 25 years of age.
Cancer	A neoplasm characterized by the uncontrolled growth of anaplastic cells that tend to invade surrounding tissue and to metastasize to distant body sites (Anderson, Anderson, & Glanze, 1998)	Leukemia, Lymphoma, Brain Tumor, Osteosarcoma, and Kidney Tumor
Social Support	Social support is the perceived availability of functional support wherein functional support refers to the degree to which interpersonal relationships serve particular functions (Sherbourne & Stewart, 1991). The functions served by support include emotional support which involves caring, love and empathy, instrumental support and information, guidance or feedback that can provide a solution to a problem, appraisal support which involves information relevant to self evaluation, and social companionship, which involves spending time, with others in leisure and recreational activities (Sherbourne & Stewart, 1991).	A score on the MOS Social Support Survey so that the lowest possible score was 0 and the highest possible score was 100, indicating more frequent availability of different types of support, if needed (Sherbourne & Stewart, 1991).

CHAPTER 4

RESULTS

Sample Demographics

The sample contained 42 participants. Pre-test and post-test data were compared

and participants who did not complete both portions of the survey were eliminated from

the data analysis. There were 29 participants that completed both pre and post tests of the

survey, Table 3, 4, and 5 contain demographic data for the sample.

Table 4. Age, Sex, Race, and Educational Level of Sample

Response	Number of Cases Reported	% of Total Sample
Age*		
18 years old	4	13.8
19 years old	6	20.7
20 years old	5	17.2
21 years old	6	20.7
22 years old	1	3.4
23 years old	3	10.3
25 years old	2	6.9
Gender**		
Male	9	31
Female	18	62.1
Race***		
White	22	75.9
Black or African American	3	10.3
Asian	3	6.9
Education****		
Grade 12 or GED (high school graduate)	12	41.4
College 1-3 years (some college or tech sch)	12	41.4
College 4 years or more (college graduate)	3	10.3

* 2 participants did not indicate their age.
** 2 participants did not indicate their gender.
***1 participant did not indicate race.
****2 participants did not indicate education level.

Of these participants there were 18 or 62% were females and 9 or 31% were

males and 2 participants that did not indicate their gender. The mean age of the

participants completing both sections was 22 years of age. Most participants reported

their race as white (75.9% or 22), black or African American (10.3% or 3), or Asian

(6.9% or 2) one participant did not indicate their race. The highest educational level

obtained was college graduate with most participants reporting that they were high school

graduates or had some college or technical experience, two participants did not indicate

their educational level.

Table 5. Marital Status, Living Arrangement, and City/Town Population for Sample

Response	Number of Cases Reported	% of Total Sample
Marital Status		
Never Married	26	89.7
A member of an unmarried couple	3	10.3
Living Arrangement		
Live alone	3	10.3
Live with spouse of significant other	1	3.4
Have a roommate	5	17.2
Live with parents or other family member	20	69
City/Town Population		
< than 5,000 people	3	10.3
5,001- 10,000 people	4	13.8
10,001-30,000 people	10	34.5
30,001 – 50,000 people	1	3.4
50,001 – 10,000 people	4	13.8
>100,000 people	7	24.1

The majority of participants (69% or 20) reported that they were single and had

never been married. Twenty (69%) participants reported that they lived with their parents

or other family member. Ten (34%) participants reported living in a town with a

population of 30,001-50,000 people.

Table 6. Camp Attendance, Cancer Type, Treatment, and Support Group Attendance of the Sample

Response	Number of Cases Reported	% of total Sample
Camp Attendance		
Yes	17	58.6
No	12	41.4
Times at Camp (if responded yes to Camp Attendance) *		
Only once	8	47.1
More than once	11	64.7
Type of Cancer		
Leukemia	6	20.7
Lymphoma	6	20.7
Brain Tumor	5	17.2
Osteosarcoma	6	20.7
Other	6	20.7
Age at Diagnosis**		
15 years of age or <	12	41
16 years of age or >	16	55.1
Currently In Treatment		
Yes	7	24.1
No	22	75.9
Currently Attending a Support Group		
Yes	5	17.2
No	24	82.8

* 10 participants did not indicate if they had attended a camp.
** 1 participant did not indicate age at diagnosis.

Of the participants responding 41.4% (12) had never attended camp before. The

most commonly reported cancer diagnoses were leukemia (20.7% or 6), lymphoma

(20.7% or 6), osteosarcoma (20.7% or 6), and other (20.7% or 6). Most participants

reported being diagnosed with cancer between the ages of 16 and 17 years of age and of

the sample 75.9% currently not receiving treatment. Of the participants responding only

17.2% (5) currently participate in a support group, all reported being in a cancer support

group.

Tests of Effects of Camp Experience on Social Support

Scores recorded on the MOS Social Support Survey were calculated to yield

means for both pretest data and posttest data. The means are reported in Table 6. The

means were compared using a paired t-test to determine differences between pretest and

posttest scores on the MOS Social Support Survey.

Table 7. Comparison of Pre-Test and Post-Test Means and Standard Deviations for MOS
Social Support Scores

	Pre-Test Mean	Standard Deviation	Post-Test Mean	Standard Deviation
Overall Support Index	4.027	.642	4.18	.715
Emotional/Informational Support	3.84	.855	4.09	.734
Affectionate Support	4.28	.817	4.33	1.04
Positive Social Interaction	4.09	.996	4.07	1.04
Tangible Support	4.16	.851	4.41	.769

A comparison of the pre-test and post-test means as reported above shows an

increase in the means for overall support index, emotional/informational support,

affectionate support and tangible support. The mean for positive social interaction

showed as slight decrease. The reported pre-test means and post-test means on overall

support index, emotional/informational support, affectionate support, positive social

interaction, and tangible support were then used to compute a paired t-test score to test

for statistical significance these findings are reported in Table 8.

Table 8. t-Tests Comparing Pre-Test and Post-Test Data on MOS Social Support Survey

Pre-Test Post-Test Paired Comparison	Paired Differences (n=28)					t	P*
	Mean	Std. Deviation	Std. Error mean	95% Confidence Interval of the Difference			
				Lower	Upper		
Overall Support Index	-.156	.572	.106	-.374	.061	-1.47	.153
Emotional/Informational Support	-.246	.889	.165	-.584	.093	-1.49	.148
Affectionate Support	-.057	.782	.145	-.355	.240	-.396	.695
Positive Social Interaction	.022	.584	.108	-.199	.245	.212	.834
Tangible Support	-.241	.676	.126	-.499	.016	-1.92	.065
* Two-tailed p values, df=28							

Calculated means for overall support index, emotional/informational support, affectionate support, positive social interaction, and tangible support on pre-test and post-test were compared utilizing a paired t-test. Initial results yielded no significant difference in pre-test and post-test means for overall support index and the subscales including emotional/informational support, affectionate support, positive social interaction, and tangible support. The possible scores for the subscales and overall support index ranged from 1 to 5. As previously reported there was an observed increase in the mean for overall support index, emotional/informational support, affectionate support, and tangible support. These increases in mean did not result in statistically significant differences. The investigators also wanted to explore possible effects of the camp experience on a vulnerable sub-sample of camp attendees. Vulnerability is defined as participants that had scores reported as a mean score in the lower 50th percentile and completed both the pre-test and post-test. Table 9 reports these results.

Table 9. Comparison of Pre-Test and Post-Test Means and Standard Deviations for
Participants Reporting MOS Social Support Scores in Lower 50th Percentile

	Pre-Test Mean	Standard Deviation	Post-Test Mean	Standard Deviation
Overall Support Index	3.433	.413	3.794	.838
Emotional/Informational Support	3.269	.844	3.740	.839
Affectionate Support	3.564	.699	3.795	1.33
Positive Social Interaction	3.641	1.21	3.641	1.24
Tangible Support	3.442	.701	4.078	.932

The results showed an overall increase in the means from pre-test to post-test for

the subscales including emotional/informational support, affectionate support, positive

social interaction, and tangible support as well as the overall support index. The mean

scores were used to calculate statistical significance using a paired t-test.

Table 10. t-Tests Comparing Pre-test and Post-test Data on MOS Social Support Survey
for Participants Reporting MOS Social Support Scores in Lower 50th Percentile

Pre-Test Post-Test Paired Comparison	Paired Differences (n=13)					t	P*
	Mean	Std. Deviation	Std. Error mean	95% Confidence Interval of the Difference			
				Lower	Upper		
Overall Support Index	-.360	.753	.209	-.815	.095	-1.726	.110
Emotional/Informational Support	-.471	1.226	.340	-1.212	.270	-1.386	.191
Affectionate Support	-.230	1.117	.310	-.906	.444	-.745	.471
Positive Social Interaction	.000	.544	.151	-.328	.325	.000	1.00
Tangible Support	-.635	.740	.205	-1.082	-.187	-3.091	.009
* Two-tailed p values, df=12							

Scores from camp attendees in the lower 50th percentile were calculated to yield means for overall support index, emotional/informational support, affectionate support, positive social interaction, and tangible support on pre-test and post-test and were compared utilizing a paired t-test. Statistically significant results were observed for the subscale of tangible support with a calculated t score of -.3.091 and a p value of 0.009. These results suggest attendance at camp had a positive effect on young adults perceptions of received tangible support. Statistically significant results on comparison of pre-test and post-test means for overall support index and the subscales including emotional/informational support, affectionate support, and positive social interaction were not observed. The possible scores for the subscales and overall support index ranged from 1 to 5. As previously reported there was an observed increase in the mean for overall support index, emotional/informational support, affectionate support, and tangible support. There was no change in the mean for the subscale positive social interaction. These increases in mean did not equate to statistically significant results except for the subscale of tangible support.

The findings of this study showed no statistical significance for overall support index, emotional/informational support, affectionate support, positive social interaction, tangible support on initial examination of data. An observed increase in means was demonstrated on comparison of means for overall support index, emotional/informational support, affectionate support, and tangible support for pre-test and post-test scores. A decrease was found in the pre-test and post-test means for positive social interaction. Similar results were reported when the investigators explored the possible effects of the camp experience on a vulnerable subpopulation of camp attendees with exception of

statistical significance in the sub scale tangible support. In this vulnerable subpopulation

there was no statistically significant change in pre-test and post-test means for overall

support index, emotional/informational support, affectionate support, and positive social

interaction. A statistically significant increase in mean was observed in the vulnerable

subpopulation for tangible support. These results suggest that attendance at camp had a

positive effect on camper's perception of tangible support. Again an increase in means

was observed for overall support index, emotional/informational support, affectionate

support, and tangible support.

CHAPTER 5

DISCUSSION

In this small study there was no significant change in the overall social support

index, emotional/informational support, tangible support, positive social interaction

support, or affectionate support on the pre-test post-test paired t-test within a sample of

29 participants aged 18-25 attending a week long camp for young adults with a diagnosis

of cancer. When the data for an identified vulnerable population were compared there

was a statistically significant increase in the mean for the subscale tangible support. Of

note is the size of the vulnerable population, n-13. Finding a statistically significant

increase in pre-test to post-test means for the subscale of tangible support is an important

finding. It is unlikely that the observed increase in tangible support is due to an anomaly

in the population or the study. The is can be said with a degree of confidence due to the

fact that the mean change in pre-test to post-test means for the tangible support subscale

in the vulnerable population falls within the 95% confidence interval. The 95%

confidence interval does not contain the value 0 suggesting that the results of this finding

are due to treatment effect. Although statistically significant results were found only in

the tangible support subscale for the vulnerable sub-sample, an overall increase in the

observed means from pre-test to post-test was demonstrated. This trend was observed in

the means for all campers completing both the pre-test and post-test surveys as well as

the data set examining only those campers that scored in the lower 50th percentile of

social support on the pre-test. These results together with the testimonials of campers

about the value of the experience certainly suggest that further evaluation studies with a larger sample would be very worthwhile.

Comparison of pre-test and post-test means showed an increase in overall social support as well as each individual subscale with the exception of positive social interaction which remained the same on both pre-test and post-test means. It seems likely that the means on this subscale would increase after a camp experience however this was not found in this study.

Comparison of the pre-test and post-test means showed in increase in the emotional/informational support, tangible support, and affectionate support. Items on the emotional/informational support subscale contained items addressing the presence of a person or persons to talk and confide in that understand the individual experience. The overall mean on this subscale increased in both evaluations of data. The initial comparison of means showed an increase in pre-test post-test means in the overall support index from 4.02 to 4.18, emotional/informational support from 3.84 to 4.09, affectionate support from 4.28 to 4.33, and tangible support from 4.16 to 4.41. There was an observed decrease in overall means for positive social interaction from 4.09 to 4.07. In the exploratory analysis of an identified vulnerable population and increase in pre-test post-test means was observed in the overall support index 3.433 to 3.794, in emotional/informational support from 3.269 to 3.740, in affectionate support from 3.564 to 3.795, and in tangible support from 3.442 to 4.078. The increase observed for tangible support was statistically significant. These results indicate that attendance at camp had a positive influence in camper's perception of received tangible support. There was no observed change in pre-test post-test means in positive social interaction, the pre-test and

post-test means were reported as 3.64. These results were supported with qualitative data collected on pre-test and post-test surveys for the overall support index as well as the individual subscales. In terms of overall support one participant reported "My friends are great to me, but most of them don't and can't understand what this experience has done or why things are so different for me". The same participant reported the following on the post-test survey, "Friends from camp understand and have gone through similar experiences". Another camper reported a poor relationship with his family on the pre-test survey noting "My dad and I don't talk to each other. My mom doesn't know how to be affectionate towards me and my sisters have their own life". The same camper noted that fellow participants were better able to understand. In post-test data one camper reported feeling that it was easier to share thoughts, feelings and concerns with friends made at camp noting "people at home do not know exactly what cancer had done and been for me". In light of these testimonials from campers and the increase in pre-test and post-test means it is likely that statistically significant results could be realized with a larger sample size.

The emotional/informational support subscale measures the presence of a person who is available to listen, give information, give advice, confide in, and help the person through difficult situations. Family can be a strong source of this type of support as noted by this camper, "My family is always there to listen. They each fulfill a special need for me." Peers can also fulfill this need, especially peers who have undergone similar situations. In response to a question asking why the participant thinks they will stay in touch with other participants, this camper answered, "Because everyone is so very supportive. They listen with a caring ear." Another camper noted "I got to meet

someone who understands exactly what I went through and am still going through as well as someone who shared similar views on our future."

The tangible support subscale measures the physical presence of person or persons available for a ride to the doctor, activities of daily living assistance, and help with chores. Many campers reported that their favorite part of camp was the ropes course. The ropes course is a obstacle course suspended high above the ground. The campers reported that the physical and emotional support provided by campers and staff while they were doing the ropes course was like none they had ever experienced. Another participant reported that their favorite part of camp was sitting down and talking to everyone and hearing their stories. The reason that this was a favorite activity for this participant was because it "let's my feelings out – gives me perspective and motivation to keep on fighting." Attending camp provided the participants with an opportunity to meet others in similar situations and form tangible connections, "We were challenged together and accomplished it together which bonded us."

The subscale of affectionate support measures the presence of person or persons who show love and affection including physical contact in the form of hugs. Camp offers the participants an opportunity to form connections with others going through a similar experience. One camper reported "We create connections here that isn't available anywhere else". Another camper noted that camp provided connections not easily found in the "outside" world, "I come to camp to meet other young adults who understand my situation and help me grow and heal".

The sub scale of positive social interaction looked at having someone to have a good time with, to get together with and relax, and someone to do something enjoyable

with. As previously reported there was no observed increase in the mean for this subscale in either population. It is unclear why this has occurred, especially when the qualitative data is taken into consideration. One camper reported "I enjoyed spending time with the other campers as well as the outside activities planned like rafting, the play etc." In response to a question asking the campers what their favorite activity was, one camper replied "Getting to hang out with other people."

A popular and common theme that stands out in the testimonials of campers is the idea of making connections with someone who understands the unique position and experiences a person with cancer has. The following are just a few of the quotes shared by campers that demonstrate the aforementioned phenomenon. As related by one camper, "for a few people here I feel that I can share more than I've shared with anyone ever. Not so say my friends at home aren't amazing – but EMPATHY is a very powerful connecting force!" The same camper responded to the question in regards to maintaining contact with friends from camp "I have from the past 2 camps and I know these friendships can withstand distance and whatever else may come in the way. Again, the understanding and connections it is unique and you can't get this from non-survivors." The next quote is from a camper that left the hospital against medical advice to attend camp. This camper passed away shortly after returning from camp however her family has expressed that attending camp one last time was the best thing for her. The camper wrote on her survey the following, "A life shared is a life that is incredibly joyful to live." The testimonials provided by the campers overwhelmingly supported the benefits of attending camp.

Study Limitations

It is important to note that a potential bias of this study is that individuals who participated in the camp and in the study may be different from the general young adult cancer population. A recommendation for further study would be the utilization of a control group of young adults with cancer not attending camp.

Of concern in this study is the sample size. The results of this study did not show statistical significance despite an increase in observed means was demonstrated on comparison of pre-test and post-test scores. As previously mentioned these results are likely attributed to the size of the sample population and lack of power. Repeating this study with a larger sample size would be beneficial.

Finally it is difficult to determine the long terms effects of a camp experience on social support after only two measurements. Follow-up at regular intervals after attendance at camp would be beneficial in examination of the long-term effects of attending camp on the participant's perceptions of social support.

Future Research

As has been demonstrated in current and past literature, social support is a powerful force influencing multiple facets of an individual's life. Results from this study are encouraging and suggest further study is warranted. Repeating this study with an increase in sample size and utilization of a control group of young adults with cancer not attending camp would be suggested.

There remain a great deal of unknown information on the exact mechanism of action on how social support affects the physical and psychological well being of the individual and the group. Also of interest are more studies on development of social

support networks and the effects associated with the absence of such a network. There is

a great deal of opportunity for further investigation in the realm of social support. The

possibilities are significant to understanding the human response and ability to cope.

Study Results and Previous Studies

As previously mentioned there are very few studies that have looked at the effects

of social support on young adults with cancer and the camp experience. A similar study

looked at social support, cancer, and camp in adults and found results consistent with the

results of this study. Yancey, Greger, & Coburn (1994) did not find significant increase

in reports of perceived social support in comparison of pre-camp and post-camp data,

they did find increases in mean scores for social support. The lack of significance was

attributed to not having a large enough sample size. Bluebond-Langner et al (1991)

reported that attendance at a pediatric oncology camp provided children and adolescents

with peer interactions with other with similar experience however these relationships

could not and did not replace interactions with healthy peers. These findings were based

on results from interviews with the children and adolescents and questionnaires mailed to

the their parents before and after camp.

Implications for Practice

The results of this study suggest that attendance at an oncology camp can provide

young adults with cancer a positive experience. Past and current literature has

demonstrated the benefits associated with the formation of a social support network for

both physical and mental health.

As a health care provider the nurse and the nurse practitioner are in a position to facilitate and coordinate a camp experience for a young adult diagnosed with cancer. A fundamental component of being a nurse is assessing, diagnosing, planning, and implementing care that address the needs of the entire individual, not just medical needs. The nurse and nurse practitioner can collaborate with other care providers and the patient to encourage and implement attendance at an oncology camp. Through participation in a camp experience the patient can establish social connections and networks with others in similar experiences and with an understanding of cancer that only a survivor knows. This notion of connection is a popular theme related by many campers, "The understanding and connections it is unique and you can't get this from non-survivors". Facilitating this opportunity provides an opportunity like none other to connect, relate, and possibly grow.

Conclusion

Current and past literature has repeatedly noted the benefits associated with social support. These benefits extend the realms of well-being and health. It is difficult to deny the formation of a social support network as being a positive and beneficial experience. A need for further investigation of the effects of social interaction with others experiencing the same or similar experiences is greatly needed. As previously mentioned further studies would benefit from the use of a control group for comparison purposes.

The results from this study suggest that cancer camp may be an effective intervention for establishing a social support network and possibly having a benefit on overall health and well-being. The stress associated with the cancer experience cannot be denied. Continuing to develop and test the effectiveness of the establishment of social

networks especially with person undergoing similar experiences is crucial to assist

individuals in coping with cancer.

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APPENDICES

<u>APPENDIX A</u>

RESEARCH TOOL

PRE-TEST RESEARCH TOOL

Young Adults with Cancer and the Camp Experience
Camp Mak-A-Dream
Young Adult Conference – Summer 2003

Place an "X" next to the answer that best answers each question or statement.

1. **How old were you on your last birthday?** (Mark only one response.)
   ____18 years old
   ____19 years old
   ____20 years old
   ____21 years old
   ____22 years old
   ____23 years old
   ____24 years old
   ____25 years old

2. **Sex**: (Mark only one response.)
   ____Male
   ____Female

3. **Which one of these groups would you say best represents your race?** (Mark only one response.)
   ____White
   ____Black or African American
   ____Hispanic
   ____Asian
   ____Native Hawaiian or Other Pacific Islander
   ____American Indian, Alaska Native
   Other: (specify)_____

4. **What is the highest grade or year of school you completed?** (Mark only one response.)
   ____Never attended school or only attended kindergarten
   ____Grades 1 through 8 (Elementary)
   ____Grades 9 through 11 (Some high school)
   ____Grade 12 or GED (High school graduate)
   ____College 1 year to 3 years (Some college or technical school)
   ____College 4 years or more (College graduate)

5. Are you currently: (Mark only one response.)
____Employed for wages
____Self-employed
____Out of work for more than 1 year
____Out of work for less than 1 year
____Homemaker
____Student
____Retired
____Unable to work

6. Which of the following categories best describes your annual household income from all sources? (Mark only one response.)
____Less than $10,000
____$10,000 to less than $15,000
____$15,000 to less than $20,000
____$20,000 to less than $25,000
____$25,000 to less than $35,000
____$35,000 to less than $50,000
____$50,000 to $75,000
____Over $75,000

7. Are you: (marital status) (Mark only one response.)
____Married
____Divorced
____Widowed
____Separated
____Never married
____A member of an unmarried couple

8. Which best describes your living arrangement: (Mark only one response.)
____Live alone
____Live with spouse or significant other
____Have a roommate
____Live with parents or other family member

9. Which best describes the size of the city/town you are currently living in: (Mark only one response.)
____Less than 5,000 people
____5,001-10,000 people
____10,001-30,000 people
____30,001-50,000 people
____50,001 – 100,000 people
____More than 100,000 people

10. Have you ever attended Camp Mak-A-Dream or any other camp for children or young adults with cancer? (Mark only one response.)
____Yes – Go to question a.
____No – Skip question a.

    a. How many times have you attended this or the other camp? (Mark only one response.)
    ____Only once
    ____More than once

11. What kind of cancer do you have? (Mark all that apply.)
____Leukemia
____Lymphoma
____Brain Tumor
____Osteosarcoma
____Kidney Tumor
Other (please specify):_____

12. How old were you when you were diagnosed with cancer?_____

13. Are you currently in treatment for your cancer? (Mark only one response.)
____ Yes – Go to question a. and skip question b.
____ No – Skip question a. and go to question b.

    a. What kind of treatment are you currently receiving? (Mark all that apply.)
    ____Chemotherapy
    ____Radiation Therapy

    b. If not, how long ago was your last treatment and what kind of treatment was it? (Mark all that apply.)
    ____Months _____Years
    ____Chemotherapy
    ____Radiation Therapy

14. Are you currently in a support group? (Mark only one response.)
____Yes – Go to question a.
____No – Skip question a. and go to question #15.

    a. What kind of support group to you participate in?
    ____ Cancer support group.
    ____ Other support group not dealing with cancer.

Please read each statement and mark the response that is appropriate for you. Mark only one response. There are no right or wrong answers.

15. In general, would you say your health is:

____Excellent

____Very Good

____Good

____Fair

____Poor

16. Compared to one year ago, how would you rate your health in general **now**?

____Much better now than one year ago

____Somewhat better now than one year ago

____About the same

____Somewhat worse now than one year ago

____Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
17. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports.	[1]	[2]	[3]
18. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
19. Lifting or carrying groceries	[1]	[2]	[3]
20. Climbing **several** flights of stairs	[1]	[2]	[3]
21. Climbing **one** flight of stairs	[1]	[2]	[3]
22. Bending, kneeling, or stooping	[1]	[2]	[3]
23. Walking **more than a mile**	[1]	[2]	[3]
24. Walking **one block**	[1]	[2]	[3]
25. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? (Circle One Number on Each Line)

	Yes	No
26. Cut down the amount of time you spent on work or other activities	1	2
27. **Accomplished less** than you would like	1	2
28. Were limited in the **kind** of work or other activities	1	2
29. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (Circle One Number on Each Line)

	Yes	No
30. Cut down the **amount of time** you spent on work or other activities	1	2
31. **Accomplished less** than you would like	1	2
32. Didn't do work or other activities as **carefully** as usual	1	2

33. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (Mark only one response.)

____All of the Time
____Most of the Time
____Some of Time
____A Little of the Time
____None of the Time

34. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)? (Mark only one response.)
____Not at all
____A little bit
____Moderately
____Quite a bit
____Extremely

35. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Mark only one response.)
____Not at all
____Slightly
____Moderately
____Quite a bit
____Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks . . . (Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
36. Did you feel full of pep?	1	2	3	4	5	6
37. Have you been a very nervous person?	1	2	3	4	5	6
38. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
39. Did you have a lot of energy?	1	2	3	4	5	6
40. Have you felt downhearted and blue?	1	2	3	4	5	6
41. Did you feel worn out?	1	2	3	4	5	6
42. Have you been a happy person?	1	2	3	4	5	6
43. Did you feel tired?	1	2	3	4	5	6

44. How much **bodily** pain have you had during the **past 4 weeks**? (Mark only one response.)
____None
____Very mild
____Mild
____Moderate
____Severe
____Very severe

How TRUE or FALSE is each of the following statements for you. (Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
45. I seem to get sick a little easier than other people.	1	2	3	>4	5
46. I am as healthy as anybody I know.	1	2	3	4	5
47. I expect my health to get worse.	1	2	3	4	5

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Circle One Number on Each Line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
48. Someone to give you good advice about a crisis.	1	2	3	4	5
49. Someone to give you information to help you understand a situation.	1	2	3	4	5
50. Someone you can count on to listen to you when you need to talk.	1	2	3	4	5
51. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
52. Some whose advice you really want.	1	2	3	4	5
53. Someone who hugs you.	1	2	3	4	5
54. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
55. Someone to do things with to help you get your mind off things.	1	2	3	4	5
56. Someone to help you if you were confined to bed.	1	2	3	4	5
57. Someone to take you to the doctor if you needed it.	1	2	3	4	5
58. Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5
59. Someone to help with daily chores if you were sick.	1	2	3	4	5
60. Someone who shows you love and affection.	1	2	3	4	5
61. Someone to love you and make you feel wanted.	1	2	3	4	5
62. Someone to share your most private worries and fears with.	1	2	3	4	5
63. Someone to have a good time with.	1	2	3	4	5
64. Someone to get together with for relaxation.	1	2	3	4	5
65. Someone to do something enjoyable with.	1	2	3	4	5
66. Someone who understands your problems.	1	2	3	4	5

Pre-Test Qualitative Questions

    67. How would you rate your current relationship with your family?

        ____Excellent

        ____Very Good

        ____Good

        ____Fair

        ____Poor

        Briefly explain why you would rate your relationship with your family this way.

        _____

        _____

        _____

    68. How would you rate your current relationship with your friends?

        ____Excellent

        ____Very Good

        ____Good

        ____Fair

        ____Poor

        Briefly explain why you would rate your relationship with your friends this way.

        _____

        _____

        _____

    69. What factors influenced your decision to attend camp?

        _____

        _____

        _____

POST-TEST RESEARCH TOOL

Young Adults with Cancer and the Camp Experience
Camp Mak-A-Dream
Young Adult Conference – Summer 2003

Please read each statement and mark the response that is appropriate for you. Mark only one response. There are no right or wrong answers.

    15. In general, would you say your health is:

        ____Excellent

        ____Very Good

        ____Good

        ____Fair

        ____Poor

16. **Compared to one year ago**, how would you rate your health in general **now**?

____Much better now than one year ago
____Somewhat better now than one year ago
____About the same
____Somewhat worse now than one year ago
____Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
17. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports.	[1]	[2]	[3]
18. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
19. Lifting or carrying groceries	[1]	[2]	[3]
20. Climbing **several** flights of stairs	[1]	[2]	[3]
21. Climbing **one** flight of stairs	[1]	[2]	[3]
22. Bending, kneeling, or stooping	[1]	[2]	[3]
23. Walking **more than a mile**	[1]	[2]	[3]
24. Walking **one block**	[1]	[2]	[3]
25. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? (Circle One Number on Each Line)

	Yes	No
26. Cut down the amount of time you spent on work or other activities	1	2
27. **Accomplished less** than you would like	1	2
28. Were limited in the **kind** of work or other activities	1	2
29. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (Circle One Number on Each Line)

	Yes	No
30. Cut down the **amount of time** you spent on work or other activities	1	2
31. **Accomplished less** than you would like	1	2
32. Didn't do work or other activities as **carefully** as usual	1	2

32. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (Mark only one response.)
    ____All of the Time
    ____Most of the Time
    ____Some of Time
    ____A Little of the Time
    ____None of the Time

17. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)? (Mark only one response.)

____Not at all
____A little bit
____Moderately
____Quite a bit
____Extremely

18. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Mark only one response.)

____Not at all
____Slightly
____Moderately
____Quite a bit
____Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks . . . (Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
36. Did you feel full of pep?	1	2	3	4	5	6
37. Have you been a very nervous person?	1	2	3	4	5	6
38. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
39. Did you have a lot of energy?	1	2	3	4	5	6
40. Have you felt downhearted and blue?	1	2	3	4	5	6
41. Did you feel worn out?	1	2	3	4	5	6
42. Have you been a happy person?	1	2	3	4	5	6
43. Did you feel tired?	1	2	3	4	5	6

45. How much **bodily** pain have you had during the **past 4 weeks**? (Mark only one response.)

____None
____Very mild
____Mild
____Moderate
____Severe
____Very severe

How TRUE or FALSE is each of the following statements for you. (Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
45. I seem to get sick a little easier than other people.	1	2	3	>4	5
46. I am as healthy as anybody I know.	1	2	3	4	5
47. I expect my health to get worse.	1	2	3	4	5

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Circle One Number on Each Line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
48. Someone to give you good advice about a crisis.	1	2	3	4	5
49. Someone to give you information to help you understand a situation.	1	2	3	4	5
50. Someone you can count on to listen to you when you need to talk.	1	2	3	4	5
51. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
52. Some whose advice you really want.	1	2	3	4	5
53. Someone who hugs you.	1	2	3	4	5
54. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
55. Someone to do things with to help you get your mind off things.	1	2	3	4	5
56. Someone to help you if you were confined to bed.	1	2	3	4	5
57. Someone to take you to the doctor if you needed it.	1	2	3	4	5
58. Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5
59. Someone to help with daily chores if you were sick.	1	2	3	4	5
60. Someone who shows you love and affection.	1	2	3	4	5
61. Someone to love you and make you feel wanted.	1	2	3	4	5
62. Someone to share your most private worries and fears with.	1	2	3	4	5
63. Someone to have a good time with.	1	2	3	4	5
64. Someone to get together with for relaxation.	1	2	3	4	5
65. Someone to do something enjoyable with.	1	2	3	4	5
66. Someone who understands your problems.	1	2	3	4	5

Post-Test Qualitative Questions

    67. How would you rate your overall camp experience?

        ____Excellent

        ____Very Good

        ____Good

        ____Fair

        ____Poor

        Briefly explain why you would rate your camp experience this way.

        _____

        _____

        _____

    68. What did you enjoy the most while at camp?

        _____

        _____

        _____

        Briefly explain why you enjoyed this particular aspect of camp.

        _____

        _____

        _____

    69. Do you think you will in the future attend camp again?

        ___Yes

        ___No

        ___Maybe

        ___Not sure

        Briefly explain why you have chosen the above answer.

        _____

        _____

        _____

    70. Do you think you will maintain contact with people you have met at camp?

        ___Yes

        ___No

        ___Maybe

        ___Not sure

        Briefly explain why you have chosen the above answer.

        _____

        _____

        _____

71. Do you feel that you can openly share thoughts, feelings, and concerns with the friend(s) you have met at camp?
   ___Yes
   ___No
   ___Maybe
   ___Not sure
   Briefly explain why you have chosen the above answer.
   _____
   _____
   _____

72. Do you feel more or less able to share your thoughts, feelings, and concerns with the friend(s) you have made at camp versus the friends you have at home?
   ____More Able to Share
   ____Less Able to Share
   ____About the Same
   ____Not Sure
   Briefly explain why you have chosen the above answer.
   _____
   _____
   _____

APPENDIX B

INFORMED CONSENT

INFORMED CONSENT

SUBJECT CONSENT FORM FOR PARTICIPATION IN HUMAN RESEARCH AT
MONTANA STATE UNIVERSITY

Project Title: Young Adults with Cancer and a Camp Experience

Purpose
You are being asked to participate in a study examining some of your experiences as they
relate to a camp experience. This may help us better understand how a camp experience
may impact a person.

Procedure
You have been chosen to participate in this study because you are attending camp. If you
agree to participate you will be given a questionnaire related to health and the camp
experience. In addition to the questionnaire you will be asked to answer some questions
about your personal background. This process will take approximately 20 minutes to
complete. You will be asked to fill out the same questionnaire at the end of your camp
experience.

Risks
Answering the questions may cause you to think about your feelings and could make you
feel sad or upset. If you start to feel sad or upset please stop answering the questions and
immediately contact the person from which you received the questionnaire. They will
refer you to either Stuart J. Kaplan, M.D., the medical director at Camp Mak-A-Dream,
or Kristie Scheel, the Camp Mak-A-Dream camp director.

Benefits
The potential benefit for you and/or others is a possible increase in the understanding of
how a camp experience impacts a person, especially persons dealing with a chronic
illness.

Participation
If you do not wish to participate in the study you can tell the person who gave you the
questionnaire that you do not wish to be involved. You may also continue to answer the
questionnaire, however DO NOT sign the consent form if you do not want your data to
be included in the study. There is no associated cost to you to participate. If you have
any questions at this time please notify the person who gave you the questionnaire.

Confidentiality
If you choose to participate in this study your identity will be kept confidential. The
investigator will treat your identity with professional standards of confidentiality. The
information obtained in this study may be published in a nursing journal, but your
identity will not be revealed.

Authorization to Share Personal Health Information in Research

We are asking you to take part in the research described. To do this research, we will be collecting health information that may identify you. For you to be in this research, we need your permission to collect and share this information.

Additional questions about the rights of human subjects can be answered by the Chairman of the Human Subjects Committee at Montana State University – Bozeman, Mark Quinn, (406) 994-5721.

_____

AUTHORIZATION: I have read the above and understand the purpose, procedure, risks, and benefits of this study. I, _____ *(please print your name),* agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time.

Signed: _____

Witness: _____

APPENDIX C

IRB AND CAMP MAK-A-DREAM APPROVAL

IRB AND CAMP MAK-A-DREAM APPROVAL

Children's Oncology Camp Foundation

P.O. Box 1450, Missoula, Montana 59806
Phone (406) 549-5987   Fax (406) 549-5933
E-mail: camp@montana.com
Web site: http://www.campdream.org

CAMP MĀK-A-DREAM

To: Montana State University Institutional Review Board
From: Camp Mak-A-Dream
RE: Letter of support for Stacy Handley

Dear MSU Institutional Review Board,

This letter is in response to the graduate work that Stacy Handley
will be conducting at the 2003 summer Young Adult Conference at
Camp Mak-A-Dream.

The Children's Oncology Camp Foundation (Camp Mak-A-Dream)
supports all aspects of the project and survey. The survey,
questioning how a week long camp experience for young adults with
cancer affect their perceived view of social support from their peers,
will be conducted in a way that no information will be accessed via
participant medical charts and that each participant must give
consent before any information is collected.

Please contact us if you should require any more information or have
further questions. Thank you for your time.

Sincerely,

Kristie Scheel
Kristie Scheel
Camp Director

WWAMI Medical Program
308 Leon Johnson Hall
P.O. Box 173080
Montana State University
Bozeman, MT 59717-3080
Telephone: 406-994-4411
FAX: 406-994-4398
E-mail: wwami@montana.edu

MEMORANDUM

....

TO: Stacy Handley

FROM: Mark Quinn, Ph.D. *Mark Quinn*
            Chair, Institutional Review Board

DATE: August 5, 2003

SUBJECT: *Perceived Social Support and the Camp Experience for Young Adults with Cancer*

The above research, described in your submission of July 29, 2003 is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 101. The specific paragraph which applies to your research is

___ (b)(1)   Research conducted in established or commonly accepted educational settings, involving normal educational practices.

_X_ (b)(2)   Research involving the use of educational tests, survey procedures, interview procedures or observation of public behavior.

___ (b)(4)   Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these specimens are publicly available, or if the information is recorded by the investigator in such a manner that the subjects cannot be identified.

___ Other

Although review by the Institutional Review Board is not required for the above research, the Committee will be glad to review it. If you wish a review and committee approval, please submit 3 copies of the usual application form and it will be processed by expedited review.

‹WWAMI›

Regional Medical School for Washington, Wyoming, Alaska, Montana & Idaho

APPENDIX D

PRESENT MODELS OF SOCIAL SUPPORT

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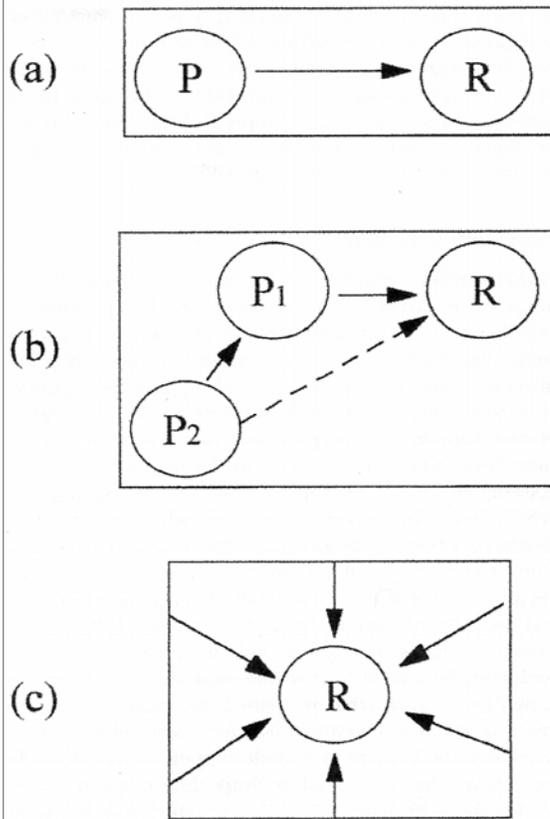
(a) Provider-recipient model: One provider meets all the needs of the recipient. (b) Primary-secondary provider model: secondary provider assists primary provider in meeting the needs of the recipient. (c) Multiple provider model: more than one provider involved in meeting the needs of the recipient.

Adapted from: Hupcey, J. E. (1998). Clarifying the social support theory-research linkage. *Journal of Advanced Nursing*, 27, 1231-1241.

<u>APPENDIX E</u>

PROPOSED MODELS OF SOCIAL INTERACTIONS

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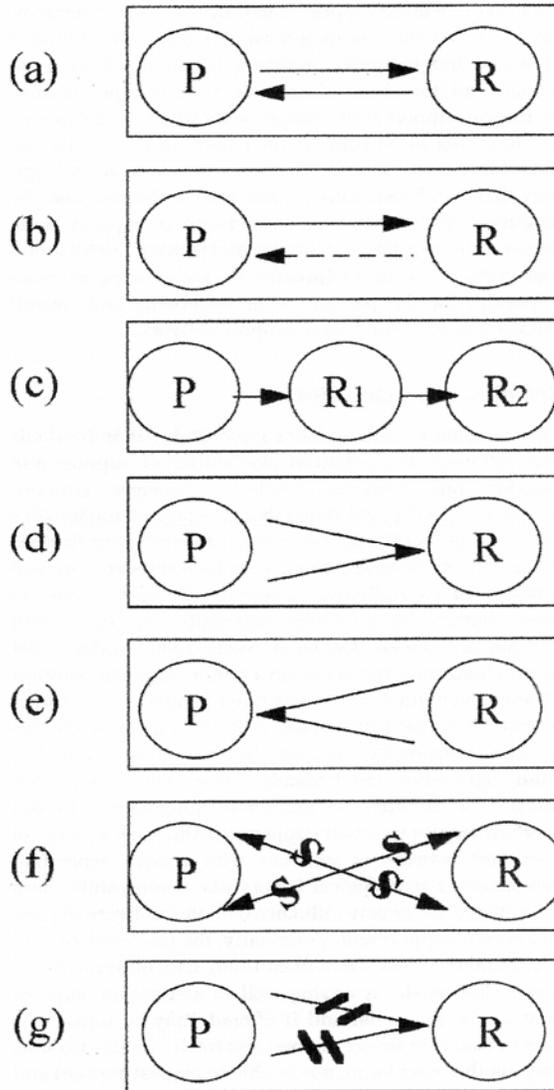
(a) Direct reciprocation model: recipient provides direct reciprocal acts towards the provider.
(b) Delayed reciprocation model: recipient reciprocates at a later time or because of pat
relationship with the provider does not need to reciprocate. (c) Secondary reciprocation model:
recipient reciprocates to a second person in need of support. (d) Non-reciprocal recipient model:
recipient receiving more support than is reciprocated. (e) Non-reciprocal provider model:
recipient providing more support than received. (f) Stressful interaction model: Interaction
between the provider and recipient is stressful, even though behaviors may be intended to be
supportive. (g) Negative provider support model: support provide is negative, perceived as
negative, or the outcome is negative.

Adapted from: Hupcey, J. E. (1998). Clarifying the social support theory-research linkage.
Journal of Advanced Nursing, 27, 1231-1241.