

YOUNG ADULT CANCER SURVIVORS' EXPERIENCES OF
CONNECTEDNESS WITH THEIR HEALTHCARE PROVIDERS

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DEDICATION

This work is dedicated to adolescents diagnosed with cancer. May this work improve the way healthcare providers interact with you.

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ABSTRACT

Celeste Phillips-Salimi

YOUNG ADULT CANCER SURVIVORS' EXPERIENCES OF CONNECTEDNESS WITH THEIR HEALTHCARE PROVIDERS

Adolescents and young adults with cancer have poorer treatment and survivorship outcomes than either younger or older cancer patients. These individuals also have psychosocial late effects and engage in lifestyle behaviors that increase their risk of subsequent cancer and other chronic illnesses. Thus, there is a need to identify protective factors during the diagnosis and treatment period to foster healthy lifestyle behaviors. Connectedness with healthcare providers is a potential protective factor that may diminish risk-taking behaviors and foster healthcare self-management in adolescents with cancer. However, little is known about connectedness with healthcare providers from adolescents with cancer perspectives.

The purpose of this study was to describe young adult cancer survivors' experiences of connectedness with their healthcare providers as they negotiated the experience across the cancer continuum from diagnosis to survivorship during adolescence.

A qualitative, empirical phenomenological method guided this research. The sample consisted of 9 young adult cancer survivors who had cancer as adolescents. A broad, data generating question was constructed to elicit rich, narrative descriptions of participants' experiences of connectedness with healthcare providers, which were audio-taped and transcribed.

The narrative data were analyzed using Colaizzi's method, which involved a systematic process of extracting and analyzing significant statements for formulated

meanings and themes. Seven theme categories were identified and then used to develop a narrative of the essential structure of the experience of connectedness.

Connectedness with healthcare providers is a multi-faceted experience that encompasses instances of not only connectedness, but also unconnectedness and disconnectedness. Effective strategies that foster connectedness with adolescents were identified. Behaviors that foster disconnectedness relate to a lack of respect for the adolescent's personhood. Findings indicate that connectedness with healthcare providers may make adolescents more likely to engage in care partnerships and effective self-management during treatment and into survivorship. When there is no connectedness or a disconnection with healthcare providers, a door shuts: there are feelings of helplessness and vulnerability, anger and resentment, and reluctance to connect with healthcare providers for cancer prevention. Clinical implications for healthcare providers are discussed. Future research should focus on connectedness theory development, measures, and interventions that foster adolescent-provider connectedness.

Joan E. Haase, PhD, RN, FAAN, Chair

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CHAPTER I

INTRODUCTION

Background and Purpose

Adolescents and young adults (ages 15 to 24 years) with cancer have shown strikingly less improvement in treatment outcomes than either younger or older cancer patients even though there has been progress in the treatment of childhood cancer over the past three decades (Bleyer, Budd, & Montello, 2006). Adolescents and young adults have higher mortality and lower 5-year survival rates than younger children (Bleyer, 2002). Importantly, young adult cancer survivors who were diagnosed and treated for cancer during adolescence have poorer psychosocial outcomes than other age groups and are considered to be a vulnerable population (Evan & Zeltzer, 2006; Zeltzer, 1993).

According to the Institute of Medicine report on Childhood and Adolescent Cancer Survivorship (2003), adolescents and young adults are at risk for developing adverse health problems secondary to their previous cancer therapy. Treatment-related complications, also known as “late effects”, include neurocognitive dysfunction (Ochs et al., 1991; Waber et al., 2000), cardiopulmonary toxicity (Grenier & Lipshultz, 1998; Lipshultz et al., 1991; Steinherz, Steinherz, Tan, Heller, & Murphy, 1991), endocrinopathy (Byrne et al., 1998; Green et al., 2002; Oberfield & Sklar, 2002), psychological difficulties (Rourke, Hobbie, Schwartz, & Kazak, 2007; Zebrack et al., 2002; Zeltzer et al., 1997), and secondary malignancies (Bhatia et al., 1996; Henderson et al., 2007; Mertens et al., 2001). Researchers estimate that as many as two-thirds of young adult cancer survivors have at least one late effect, with about one-third having serious or life-threatening complications (Oeffinger, Eshelman, Tomlinson, Buchanan, & Foster, 2000; Sklar, 1999; Stevens, Mahler, & Parkes, 1998). Many of these late effects remain dormant for decades and require careful screening and monitoring throughout life

(Mertens et al., 2001). However, recent studies have indicated that the cancer screening behaviors and medical follow-up practices of young adult cancer survivors are less than optimal (Hudson et al., 2002; Oeffinger et al., 2004; Yeazel et al., 2004).

In addition to late effects, there is evidence that young adult cancer survivors engage in lifestyle behaviors that are likely to further increase their risk of subsequent cancer and other chronic illnesses. Some of these risk behaviors include substance abuse (e.g., alcohol, cigarettes, drugs, tobacco, pain reliever) (Butterfield et al., 2004; Emmons et al., 2002; Hollen & Hobbie, 1993), insufficient physical activity (Mulhern et al., 1995; Tercyak, Donze, Prahlad, Mosher, & Shad, 2006), non-adherence to sun-protection recommendations (Tercyak et al., 2006) and suicide attempts (Recklitis, Lockwood, Rothwell, & Diller, 2006). Although there is mixed evidence regarding the prevalence of these risk-taking behaviors, (Emmons et al., 2002; Hollen & Hobbie, 1993, 1996; Verrill, Schafer, Vannatta, & Noll, 2000), even low rates are alarming due to the survivors' risk of developing late effects. Thus, there is a need to identify protective factors that will help young adult cancer survivors monitor potential late effects and adopt better health behaviors.

Connectedness with healthcare providers is a potential protective factor that may diminish risk-taking behaviors and promote resilience in adolescents. However, little is known about the experiences of connectedness with healthcare providers as perceived by young adult cancer survivors who were diagnosed and treated for cancer during adolescence. The purpose of this study was to describe young adult cancer survivors' (ages 18 - 24 years) experiences of connectedness with their healthcare providers as they negotiated the experience across the cancer continuum from diagnosis to survivorship during adolescence (ages 15 - 21 years). Empirical phenomenology (Colaizzi, 1978; Husserl, 1970) was used to examine connectedness in this study. The specific aim and research question are as follows.

Specific Aim: Describe young adult cancer survivors' experiences of connectedness with their healthcare providers during diagnosis and treatment for cancer during adolescence.

Research Question: What is the essential structure of the lived experience of connectedness with healthcare providers from the perspectives of young adult cancer survivors who were diagnosed and treated for cancer during adolescence?

This chapter includes a description of the problem, the underlying assumptions of the study, as well as a discussion of the philosophical perspective guiding the study. Lastly, the unique contribution this study will make to nursing knowledge is provided.

Description of the Problem

Good communication and rapport with healthcare providers has been identified as a research priority by experts in the field of pediatric oncology (Sobo, 2004) and may contribute to appropriate cancer screening, decision-making, and health care management related to the late effects of cancer treatment. Counseling about the increased risks associated with certain adolescent/young adult lifestyle behaviors is more likely to occur when there is a good relationship between the adolescent/young adult and his/her healthcare providers (Hudson & Findlay, 2006; Oeffinger et al., 2004). Adequate management and monitoring of late effects require willingness on the part of young adult cancer survivors to remain in a relationship with their healthcare providers or to transition to new providers. This willingness to receive care may be influenced by young adult cancer survivors' experiences of being connected to their healthcare providers across the cancer continuum from the time of diagnosis into survivorship (Hudson & Findlay, 2006; Institute of Medicine & National Research Council, 2003). However, little research has been devoted to understanding the experiences that

influence young adult cancer survivors' perceptions of being connected to their healthcare providers.

Although perceptions of being connected to healthcare providers have rarely been reported in the literature, research performed over the past three decades indicates a scientific interest in patient-provider relationships. Researchers' attempts to conceptualize patient-provider relationships, its intricacies, and its influence on patient outcomes have thus far been limited. Historically, theorists, researchers, and clinicians have characterized patient-provider relationships using concepts such as patient-centered care (Mallinger, Griggs, & Shields, 2005; Mead & Bower, 2000), relationship-centered care (M. Beach, Inui, & the Relationship-Centered Care Research Network, 2006; Suchman, 2006), perceived social support from healthcare providers (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Brucker & McKenry, 2004; Ohaeri, Oladele, & Ohaeri, 2001), and therapeutic alliance (Hilsenroth, Peters, & Ackerman, 2004; Summers & Barber, 2003). However, these concepts may not adequately capture the patients' experience or perceived meaning of having a relationship with a healthcare provider (Thorne et al., 2005). This experience may best be described by a concept labeled "connectedness". Although definitions of connectedness are inconsistent in the literature, for this study connectedness with healthcare providers was defined as *the degree to which patients perceive that they have a meaningful, shared, and significant relationship with their healthcare provider(s) which is maintained over time to influence health outcomes.*

Interest in connectedness as a phenomenon in health care is increasing. It is believed that connectedness with healthcare providers will improve patient health outcomes (McManus, 2002; Suchman & Matthews, 1988; Thorne et al., 2005). Researchers have found that patients' perceptions of the extent of their connectedness or the quality of the relationship with their healthcare providers is associated with

increased participation in decision-making (Cooper-Patrick et al., 1997; Leidy & Haase, 1999; Marelich & Murphy, 2003), adherence to treatment (M. Beach, Keruly, & Moore, 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; van Servellen & Lombardi, 2005), and decreased risk-taking behaviors (M. Beach, Keruly et al., 2006; Ettner, 1999). Additionally, experts in the field of adolescent medicine have identified that connectedness with healthcare providers is a protective factor that may diminish risk-taking behaviors and promote health care self-management and resilience in adolescents (Ginsburg, Forke, Cnaan, & Slap, 2002; Woods, 2006). In the case of adolescents, whose risk-taking behaviors and difficulty in navigating disease and treatment issues are high, connectedness may be a way to influence survivorship outcomes of adolescents with cancer. However, little is known about the experiences of connectedness with healthcare providers as perceived by young adult cancer survivors who were diagnosed and treated for cancer during adolescence. Ultimately, gaining an understanding of how connectedness with healthcare providers is fostered and its potential influences will provide guidance to develop interventions that may diminish risk-taking behaviors, foster health care self-management, resilience, and improve survivorship outcomes of adolescent cancer patients.

Study Assumptions

Four assumptions were identified for this study:

1. Connectedness with healthcare providers is a subjective experience.
2. Connectedness can be investigated systematically.
3. Narratives of individuals' experiences of connectedness are sufficient sources of data to describe the components and processes of connectedness.

4. The perceived meaning of the experiences of connectedness with healthcare providers is likely to influence subsequent interactions of young adult cancer survivors. Thus, this information will be important for planning interventions.

Philosophical Perspective

Based on the implicit nature of connectedness, a qualitative approach has been selected for this dissertation research. In nursing, a variety of qualitative methods have been used to gain knowledge of phenomena important to clinical practice.

According to Morse and Field (1995), the selection of which qualitative method to use should be based on the nature of phenomenon, maturity of the concept, and the researcher's goals. Since little is known about the phenomenon of connectedness with healthcare providers and the primary objective was to describe these experiences from the perspective of young adult cancer survivors, empirical phenomenology was chosen as the most appropriate method for this study. The following is an overview of phenomenology and the philosophical assumptions that underlie the empirical phenomenological approach.

Overview of Phenomenology

Phenomenology has been recognized as a scientific approach used to study commonalities in human phenomena. Historically, experts in the field of psychology have taken a lead in understanding the philosophical underpinnings of phenomenological research and have developed ways to refine its methods (Colaizzi, 1978; Giorgi, 1970; van Kaam, 1959). However, the philosophical and historical background of phenomenology is very complex and can often be difficult to understand. Nevertheless, the majority of the phenomenological methods can be classified into two broad categories: empirical and interpretative. Empirical phenomenology arose from the philosophical ideas of Edmund Husserl who is known as the founder of phenomenology

and interpretive phenomenology emerged from the work of Heidegger, Sarte, and Merleau-Ponty. Both types differ in their philosophical assumptions, aims, and procedures for data analysis. The phenomenological approach chosen for this dissertation is empirical phenomenology using Colaizzi's method of analysis (Colaizzi, 1978; Husserl, 1970). The following is a description of the philosophical assumptions that underlie empirical phenomenology.

Philosophical Assumptions of Empirical Phenomenology

Phenomenology is known as a radical philosophical movement initiated by a German philosopher named Edmund Husserl. Husserl's work challenged the purely positivist orientation of science and philosophy in the early 20th century (Giorgi, 2005). Unlike other empiricists, who were wrapped up in studying the nature and processes of objective phenomenon, Husserl took a step back and set out to understand consciousness and all of its manifestations. He believed that "anything that had to be dealt with in the world had to come through consciousness" (Giorgi, 2005, p 76). In other words, before one can accurately determine the existence of an object, one must understand how the object presents itself in consciousness ("objects" refers not only to objects in the physical world but also objects that occur in our mind such as thoughts and dreams). Husserl's rationale for this notion was that objects appear in consciousness in their purest form. That is, objects are considered to be in pure form when they first enter consciousness because the "natural attitude" (characteristic of everyday understanding and reasoning) has not yet posited its existence (Giorgi, 2005). Husserl proclaimed that one must understand the subjectivity of an object in consciousness before its pure objectivity can be made. Thus, Husserl pronounced that phenomenology, the "science of consciousness", was a foundational science underlying all sciences (Hein & Austin, 2001).

One of the difficulties in defending Husserl's claim was that consciousness could not be examined through the traditional approaches of science. He described consciousness to be non-physical in nature and argued that it could not be explained by cause-effect interactions (Giorgi, 2005). Thus, Husserl developed a method to capture consciousness in its purest form (i.e., before our minds begins to make assumptions about the object's existence). He called this method "phenomenological reduction" which means setting aside previous knowledge of the phenomenon to gain an understanding of how the phenomenon presents itself to consciousness (i.e., to the experiencer) (Giorgi, 2005).

Researchers who claim to use an empirical phenomenological approach adhere to certain philosophical beliefs proposed by Husserl. These include specific notions regarding intentionality, the structure of a phenomenon, and phenomenological reduction. Husserl's meaning of each of these principles will be described in the subsequent paragraphs.

Intentionality. Husserl believed that one of the essential features of consciousness was intentionality. Intentionality refers to the notion that "every act of consciousness is directed towards an object of some kind (Sokolowski, 2000, p 9). This object may be concrete in nature such as a tree or another person or it could be abstract such as a thought or dream. Thus, "we are never merely conscious but are always conscious of something" (Valle & King, 1978, p 13).

Intentionality also implies that there is an unbreakable unity between humans and the world. In other words, humans and the world cannot exist without one another (Valle & King, 1978). This notion challenges the Cartesian belief that people and their environment are two separate entities. Instead, intentionality suggests that people and their environment (i.e., subjects and objects) are interrelated and the intentional nature

of consciousness allows us to present ourselves to the world and the world to present itself to us (Giorgi, 1997). Thus, consciousness creates the meaning of our experiences.

The Structure of a Phenomenon. Another important notion proposed by Husserl is that a phenomenon possesses a constant structure that is common to all people who experience it (Valle & King, 1978). This idea of commonalities of experiences is best described by Hein and Austin's (2001) example,

“Although we may have experiences of a variety of apples, which vary in color, size, and texture, these are all instances of ‘appleness’, which is also experientially real. The meaning of ‘appleness’ therefore remains the same despite variations in how it is manifested concretely” (p 4).

The goal of phenomenology, then, is to thoroughly describe the essential structure of a phenomenon as it first presents itself to consciousness, before the human mind begins to reflect on its existence (Valle & King, 1978). This structure (or generalized description) can be derived from evaluating the commonalities in the experience across participants (Colaizzi, 1978). Drawing from Colaizzi's methods of empirical phenomenology, open-ended questions are used to elicit rich narratives of a particular experience. The narratives are then used to identify meanings of the experience. Once the meanings are identified, commonalities of meaning across participants are identified and exhaustively described. Finally, a description of the essential structure of the experience is developed and then validated by participants (Colaizzi, 1978). When this is done carefully, a clearer understanding of the phenomenon is obtained.

In order to grasp the structure of a phenomenon, a researcher must assume a disciplined attitude that Husserl referred as the “transcendental attitude” (Valle & King, 1978). This means that the researcher must suspend his/her natural attitude where one thinks that objects in the world exist independently from us and can be explained through causal relations (Giorgi, 1997; Valle & King, 1978). Additionally, all previous

knowledge regarding the phenomenon must be bracketed. The process used to assume such an attitude is known as phenomenological reduction.

Phenomenological Reduction. Phenomenological reduction is a philosophical device developed by Husserl that must be acquired before one seeks to describe and examine the structure of a phenomenon. According to Giorgi (1997), this technique requires two things. First, the researcher must withhold his/her natural tendency to reason the existence of objects and events and link them to causes and/or conditions. Instead, the goal is to “understand why there are events and things at all” (p 240). Suspending the natural attitude helps the researcher refrain from making judgments about the existence of a phenomenon until all evidence is clear (Sokolowski, 2000). Husserl called this process *epoche* (Sokolowski, 2000).

The second requirement of phenomenological reduction is bracketing (Giorgi, 1997). Bracketing means sitting aside past knowledge of the phenomenon. Hein and Austin (2001) describe bracketing as the researcher’s attempt “to suspend or set aside his/her presuppositions, biases, and other knowledge of the phenomenon obtained from personal or scholarly sources” (p 5). Setting aside all past knowledge then allows researcher to consider the phenomenon precisely as it was intended to present itself (Sokolowski, 2000). In other words, without bracketing, the phenomenon will not appear as experienced by the participants, but only through the preconceived ideas of the researcher (Hein & Austin, 2001; Lopez & Willis, 2004). Thus, bracketing “involves a process of rigorous self-reflection” and helps the researcher to be “open and receptive as possible to the participant’s descriptions of their experience of the phenomenon” Hein & Austin, 2001, pp 5-6).

In sum, empirical phenomenology is a qualitative approach that arose from the philosophical ideas of Edmund Husserl. This method of inquiry seeks to describe the essential structure of a phenomenon common to all people who have experienced it. A

description of this structure can only be obtained when the researcher (1) withholds his/her natural attitude and (2) brackets all preconceived assumptions and ideas regarding the phenomenon.

Significance to Nursing

The importance of connectedness within the patient-provider relationship has long been recognized and explored by several nursing theorists (King, 1981, Peplau, 1952; Travelbee, 1971; Watson, 1988). Although these theories specifically stress the importance of nurses connecting with patient in order to achieve positive health outcomes, there is a limited understanding of how a sense of connectedness emerges between patients and nurses. One of the current priorities of the nursing discipline is to identify and clarify concepts that will ultimately guide and improve clinical practice (Meleis, 2007). Therefore, the results of this study will make a unique contribution to nursing knowledge in two ways. First, a much clearer understanding of connectedness with healthcare providers will be obtained. The results will help identify key components and processes related to connectedness that will be useful for future concept and theory development. Additionally, gaining an understanding of how connectedness with healthcare providers is fostered and its potential influences will provide guidance to develop interventions that may diminish risk-taking behaviors, foster health care self-management, resilience, and improve survivorship outcomes of adolescent cancer patients.

Chapter Summary

This chapter has identified the need to further investigate connectedness with healthcare providers from the perspective of young adult cancer survivors' who were diagnosis and treated for cancer during adolescence. Connectedness with healthcare

providers has been identified as a potential protective factor that may influence survivorship outcomes of adolescent cancer patients. However, little is known about how connectedness with healthcare providers is fostered, how connectedness influences subsequent healthcare self-management behaviors; and what it means to be connected to a healthcare provider. The purpose of this study was to describe young adult cancer survivors' (ages 18 - 24 years) experiences of connectedness with their healthcare providers as they negotiated the experience across the cancer continuum from diagnosis to survivorship during adolescence (ages 15 - 21 years). Empirical phenomenology was chosen to be the most appropriate method for this study. The results of this study will make a contribution to nursing knowledge by gaining information to: (1) help clarify the concept of connectedness and (2) provide guidance in developing future interventions to enhance adolescent patient-provider connectedness that may ultimately improve health outcomes of adolescents with cancer.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter includes (1) a review of the conceptual, theoretical, and methodological issues associated with studying connectedness between adolescents with cancer and their healthcare providers and (2) a discussion of preliminary studies. The chapter is divided into five sections: (1) conceptual and theoretical perspectives of patient-provider relationships; (2) overview of patient-provider communication and its potential influence on connectedness; (3) preliminary study I: concept analysis of connectedness; (4) review of the methodological issues of connectedness; and (5) preliminary study II: a pilot study to evaluate the acceptability and feasibility of conducting the study with young adult cancer survivors.

Conceptual and Theoretical Perspectives of Patient-Provider Relationships

Thirty years ago, Dr. George Engel (1977) criticized the biomedical model for its narrow, dehumanizing focus and inability to further guide the scientific inquiry of medical care (Borrell-Carrio, Suchman, & Epstein, 2004). Engel believed that the medical profession was in need of a more inclusive model that would take into account the biological, psychological, and social dimensions of illness. Rather than simply focusing on the objective nature of a patient's illness, Engel insisted that clinicians also seek the patient's subjective experience. This type of query would not only help clinicians better understand the determinants of the patient's disease and respond more appropriately, but it would also empower the patient. As a result, Engel introduced a new model that he called the biopsychosocial model.

Over the past three decades, Engel's biopsychosocial model has prompted the medical community to take a closer look at the impact of the patient-provider

relationship. It is assumed that the quality of the patient-provider relationship can influence patient's health outcomes, their functional status, and overall well-being (G. Williams, Frankel, Campbell, & Deci, 2003). However, research efforts have been hampered by the lack of agreement in the way patient-provider relationships have been conceptualized and researched.

The literature on patient-provider relationships reveals two problems. First, researchers sometimes use the term "patient-provider relationship" and "patient-provider communication" interchangeably. Thus, the conceptualization of patient-provider relationships is unclear and often difficult to separate from the communication literature. The second problem relates to the multiplicity of terms that have been used to conceptualize the patient-provider relationship. Such terms have included patient-centered care (Mallinger et al., 2005; Mead & Bower, 2000), relationship-centered care (M. Beach, Inui et al., 2006; Suchman, 2006), perceived social support from healthcare providers (Arora et al., 2007; Brucker & McKenry, 2004; Ohaeri et al., 2001), and therapeutic alliance (Hilsenroth et al., 2004; Summers & Barber, 2003). Unfortunately, none of these terms adequately describes the patients' perception of being connected to a healthcare provider (Thorne et al., 2005). To explicate this point, this section briefly summarizes and critiques the literature in four major areas of research regarding patient-provider relationships: patient-centered care, relationship-centered care, perceived social support from healthcare providers, and therapeutic alliance.

Patient-Centered Care

Patient-centered care or patient-centeredness is a concept derived from the general medical practice literature that refers to the style of the physician-patient interaction (Mead & Bower, 2000). Although this concept has also been explored by other disciplines including nursing (Lauver, Gross, Ruff, & Wells, 2004; Lauver et al., 2002; Radwin, 2003), the majority of the research on patient-centeredness has been

conducted in general medicine (Anderson et al., 2003; Buchner et al., 1998; Dijkstra, Niessen, Braspenning, Adang, & Grol, 2006; Mead & Bower, 2000). Patient-centered care is characterized by the physician's responsiveness to the patient's wants, needs, and preferences (Laine & Davidoff, 1996). The physician then uses this information to guide the interaction. According to Mead and Power (2000), patient-centeredness consists of five dimensions: (1) biopsychosocial perspective – willingness to become involved in the full range of difficulties brought by the patient, not just his/her biomedical problems; (2) patient as a person – understanding the individual's illness experience; (3) sharing power and responsibility – encouraging greater patient involvement; (4) therapeutic alliance – enhancing the physician-patient relationship by coming to an agreement on treatment goals and displaying a positive affective regard towards one another; and (5) doctor as a person – being cognizant of the influence that one (i.e., the doctor) may have on the emotional response of the patient.

Although the patient-centered approach has been recognized as a crucial component of delivering high-quality health care, this concept has been criticized for its lack of theoretical and conceptual clarity (Epstein et al., 2005; Howie, Heaney, & Maxwell, 2004; Mead & Bower, 2000, 2002). Epstein et al. (2005) have argued that patient-centered care is a multifaceted construct that encompasses several complex components that make it difficult to identify the underlying mechanisms that influence patient health outcomes. Furthermore, this concept focuses mainly on the physician's role in developing and achieving the relationship with the patient. Hence, patient-centeredness highlights some of the strategies that physicians can use to better address patients' needs but it provides little evidence in regard to the perceived meaning or influence that this style of interaction has on patients. In other words, whether or not patient-centered care increases patients' perceptions of being connected to their healthcare provider is unknown.

Relationship-Centered Care

In 1994, the Pew-Fetzer Task Force on Advancing Psychosocial Health Education introduced the concept of relationship-centered care (Tresolini & the Pew-Fetzer Task Force, 1994). Building upon the principles of the biopsychosocial model and patient-centered care, the concept of relationship-centered care calls attention to partnership, shared decision making, self-awareness, and considers relationships as a fundamental component of health care (M. Beach, Inui et al., 2006). According to Beach, Inui, et al. (2006), relationship-centered care is founded upon four principles: “(1) that relationships in health care ought to include dimensions of personhood as well as roles; (2) that affect and emotion are important components of relationship in health care; (3) that all health care relationships occur in the context of reciprocal influence; and (4) that the formation and maintenance of genuine relationships in health care is morally valuable” (p S4). Although the primary focus of relationship-centered care is on relationships between patients and healthcare providers, this concept also emphasizes the importance of the relationships of healthcare providers with themselves, with one another, and with the community.

Although the concept of relationship-centered care has attracted the attention of many researchers, its development is still in its infancy. In fact, Suchman (2006) asserts that relationship-centered care is more of a clinical philosophy than a theory. “Although its central theme – that relationships are essential to good care – is supported by a growing body of research, it does not elucidate the nature of relationships or explain how they work” (Suchman, 2006, p S40). Thus, the concept of relationship-centered care provides little evidence in regard to the nature of connectedness between patients and their providers.

Perceived Social Support from Healthcare Providers

Another concept that has been used to describe the relationship between patients and healthcare providers is perceived social support (Arora et al., 2007; Brucker & McKenry, 2004; Ohaeri et al., 2001). Social support has been primarily studied from the perspective of quantity and quality of support and the perception of the availability of support. Additionally, social support is conceptualized as being composed of emotional, informational, and instrumental support. However, not all social support is viewed as positive. Too much social support has been found to be burdensome or even harmful to one's sense of personal value, leading to feelings of alienation and uselessness (Charmaz, 1983; Tilden & Galyen, 1987). Furthermore, the perception of availability of social support may be influenced by one's perceived ability to reciprocate or exchange services and actively participate in social activity (Leidy & Haase, 1999). Additionally, patients primarily consider family and friends to be part of their social support network rather than healthcare providers (Finfgeld-Connett, 2005). Thus, social support may not be an adequate concept to describe the nature of the patient-provider relationship.

Therapeutic Alliance

Therapeutic alliance is a concept commonly used in the psychology literature to describe the patient-therapist relationship (Ackerman & Hilsenroth, 2003; Horvath & Luborsky, 1993; D. Martin, Garske, & Davis, 2000; Summers & Barber, 2003). Therapeutic alliance involves the formation of two general types of relationship bonding: rapport and the working alliance. Rapport is formed as individuals grow to like one another and experience the other as genuinely warm, respectable, and understanding (C. Rogers, 1975). The working alliance is formed as individuals collaborate with one another to develop common therapy goals and, as a result, develop a sense of shared responsibility for working on tasks involved in achieving those goals (Bordin, 1979). Hence, the therapeutic alliance is a relationship that develops over time and makes it

possible for the therapist and client to negotiate a contract appropriate to reach therapy goals (Horvath & Luborsky, 1993).

Therapeutic alliance describes the interaction and responsibilities of both parties to achieve therapy goals, but does *not* explain the perceived meaning or impact that this relationship has on the patient other than the degree of compliance. Nor is it known whether it is appropriate to apply therapeutic alliance principles to cancer patients, since the relationships are not meant to provide psychotherapy. Furthermore, there is little evidence about what motivates patients to become part of the alliance or to begin to seek and share information with their healthcare providers.

Summary

Although previous research into concepts examining patient-provider relationships provides some insight to the factors associated with these relationships, the research is not specific as to the depth or specific perspectives involved between patients and their healthcare providers. Research on connectedness should provide insight into both the depth and specific perspectives of patients regarding their relationships with their healthcare providers.

While there is little evidence in the literature regarding connectedness with healthcare providers, other concepts related to connectedness between patients and healthcare providers are found under the body of research on patient-provider communication. The next section will provide an overview the patient-provider communication literature and describe its relationship to connectedness.

Patient-Provider Communication and Its Relation to Connectedness

Over the past three decades, the importance of patient-provider interactions (i.e., communication and the relationship) and their potential influence on patients' behavior and health outcomes has been widely recognized (Kaplan, Greenfield, & Ware, 1989; L.

Ong, de Haes, Hoos, & Lammes, 1995; Roter, Hall, & Katz, 1987; Stewart, 1995). The significance of this interaction has attracted the attention of a number of different disciplines such as communication, medicine, nursing, psychology, public health, and sociology (J. Brown, Stewart, & Ryan, 2003). The majority of the research in this area has focused predominately on communication between patients and healthcare providers (J. Brown et al., 2003). Thus, the purpose of this section is to provide an overview of the research on patient-provider communication and its potential influence on patients' perception of being connected to healthcare providers.

Overview of Patient-Provider Communication

Consistent across the literature is the finding that communication research has focused on the process of how physicians and adult patients exchange and receive health-related information (Baile & Aaron, 2005; J. Brown et al., 2003; L. Ong et al., 1995; Stewart, 1995). One emphasis in the study of patient-provider interaction has been to identify specific communication behaviors and actions associated with clinical outcomes, such as patient satisfaction (Di Palo, 1997; Greene, Adelman, Friedmann, & Charon, 1994), adherence to treatment (McLane, Zyzanski, & Flocke, 1995; Ogedegbe, Harrison, Robbins, Mancuso, & Allegrante, 2004), and other patient health outcomes such as symptom resolution and physiologic status (Greenfield, Kaplan, & Ware, 1985; Kaplan et al., 1989). It is assumed that once these behaviors and actions are identified, interventions can be developed to improve communication between patients and physicians, which in turn would enhance patient health outcomes (J. Brown et al., 2003). As the significance of patient-provider communication is revealed through research, it becomes clear that communication is a major contributor to patients' perception of being connected to a healthcare provider. However, the research is focused predominately on identifying effective communication techniques rather than on understanding patients' perception of what being connected means or how connectedness influences

subsequent behavior. The oncology literature contains some of the most convincing evidence about the importance of patients' perception of being connected to healthcare providers.

Patient-Provider Communication in Oncology

Communication between patients and healthcare providers is especially important in major chronic illnesses such as cancer. A common reaction experienced among patients who are diagnosed with cancer is uncertainty and loss of control (McWilliam, Brown, & Stewart, 2000), which, in turn, can have a negative influence on health outcomes. Over the past three decades, researchers have recognized that poor communication between cancer patients and their providers can lead to uncertainty and denial (Maguire & Faulkner, 1988), anxiety and depression (Fallowfield, Hall, Maguire, & Baum, 1990; Mager & Andrykowski, 2002), non-compliance (K. Phillips, Kerlikowske, Baker, Chang, & Brown, 1998), and problematic psychological adjustment to cancer (Han et al., 2005; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). The National Cancer Institute (NCI) has identified patient-provider communication as a research priority (National Cancer Institute, 2003). The emphasis in the NCI's research initiative is on understanding and identifying communication approaches that will maximize the exchange of health-related information between cancer patients and healthcare providers. Increasing information exchange between patients and providers is thought to enhance patient health outcomes.

Parallel to the broader patient-provider interaction research, most of the research on cancer-related patient-provider interaction has focused on identifying specific communication behaviors or actions of physicians that may influence the process of communication with cancer patients during times of vulnerability. A number of research approaches have been used to examine this communication process, including conversation analysis (W. Beach, 2003; W. Beach, Easter, Good, & Pigeron, 2005),

direct observation using video or audio-taping (T. Albrecht, Blanchard, Ruckdeschel, Coover, & Strongbow, 1999; Tattersall, 2002), interactional analysis (Ford, Hall, Ratcliffe, & Fallowfield, 2000; L. Ong et al., 1998), self-reported questionnaires (Kleeberg et al., 2005; Smith, Winkel, Egert, Diaz-Wionczek, & DuHamel, 2006), and qualitative interviews (Bakker, Fitch, Gray, Reed, & Bennett, 2001; McWilliam et al., 2000; Thorne et al., 2005). Hence, there has been a substantial amount of research focusing on the process of health care communication encounters within the cancer context. Results from these studies provide evidence of the effectiveness of various types of questioning (R. Brown, Butow, Dunn, & Tattersall, 2001; Butow, Brown, Cogar, Tattersall, & Dunn, 2002), proper approaches to delivering bad news (Fallowfield, Jenkins, & Beveridge, 2002; Gordon & Daugherty, 2003), and the usefulness of audio or interactive computer programs for information delivery (Bruera, Pituskin, Calder, Neumann, & Hanson, 1999; Molenaar et al., 2001). Although these findings further indicate that certain types of communication practices are related to patient satisfaction with information or care given by their healthcare provider, this evidence provides little insight into how these approaches influence patients' perceptions of being connected to a healthcare provider.

Significance of Connectedness in Adult Cancer Patients

Qualitative investigations have provided some evidence about the significance of cancer patients' perception of being connected to a healthcare provider. For example, several qualitative researchers have asked cancer patients about their experiences of interacting/communicating with providers, and often the patients' descriptions include their perceptions of the meaning of being connected to their provider. This point can be best illustrated by the following three studies.

Bakker et al. (2001) interviewed 40 women about their experiences of interacting with healthcare providers while undergoing chemotherapy treatment for breast cancer.

Prevalent themes identified in the analysis were classified into two categories: (1) the nature of the information exchange and (2) the level of connectedness experienced in the patient-provider relationship. In this study, “connectedness was present if the women perceived that their healthcare provider(s) made an effort to focus and respond to the woman as an individual” (p 67). Some of the identified indicators of connectedness included (1) establishing an atmosphere that made the patient feel comfortable when discussing physical and emotional concerns; (2) developing a sense of trust by staying on top of the patient’s condition and being committed to helping the patient; and (3) validating the patient’s feelings, emotions, and beliefs. Women who experienced a high degree of connectedness with their providers were more likely to perceive themselves as an active partner in their cancer care. Moreover, the degree of connectedness experienced among these women was related to the *quality rather than the quantity* of the interaction. The consequence of being unable to connect with a provider resulted in a more passive and submissive role in the relationship.

McWilliam, Brown, and Stewart (2000) interviewed 11 women with breast cancer about their experiences (both positive and negative) of communicating with their physician throughout their medical care. In this study, the relationship with individual physicians was *not* emphasized in the interview. However, the descriptions provided by the women revealed that a positive communication experience involved a feeling of being part of a working relationship with their physician. This positive working relationship was established by the physician’s sensitive responsiveness to the woman’s feelings of vulnerability at diagnosis. Additionally, the relationship was further enhanced by the physician conveying a caring attitude, being attentive to the patient’s concerns, and not appearing rushed. Once this relationship was established, this experience influenced the women’s perception of regaining control of their lives and health, mastering the illness experience, and ultimately learning to live with cancer.

Furthermore, this sense of connectedness motivated the women to pursue an active role in seeking and using health related information from their physician. In contrast, when the working relationship did not develop, the women resented their physician and felt vulnerable, out of control, and unable to cope with their illness.

Connectedness with healthcare providers was also found to be predominant theme among a largely diverse group of cancer patients. Thorne et al. (2005) interviewed 200 cancer patients about their experiences of helpful and unhelpful communication encounters with healthcare providers. In this study, patients characterized helpful communication encounters as “being known” by their healthcare providers that facilitated a sense of connectedness. “Being known by healthcare providers was defined as “acknowledging the elements of one’s personhood within the context of the inherently difficult nature of having cancer” (Thorne et al., 2005, p 891). Although there were variations in what providers did or said that made each patient feel known and valued by their healthcare provider, the patients in this study commonly reported specific cues that promoted connectedness. These cues included taking time to listen, acknowledge, and validate the patients’ preferences, emotional needs, and beliefs. The essential part of effective communication perceived to be most helpful to this group of the cancer patients was feeling connected to their healthcare providers.

These three qualitative studies illustrate the importance of adult patients’ perception of connectedness with their healthcare providers during cancer treatment. Although connectedness was *not* specifically investigated in any of the above studies, the theme emerged from the patients’ perception of the interaction/communication with their health care providers. Therefore, it would seem that the interaction and communication between patients and healthcare providers would strongly influence the experiences of connectedness in patient-provider relationships.

Adolescent Patient-Provider Communication

Despite the apparent importance of connectedness and the ways in which communication influences it, knowledge about such experiences between adolescents and healthcare providers is limited. In a review of the literature on adolescent patient-provider communication, the majority of the studies were found to be descriptive in nature and focused on well and ill adolescent perceptions of interacting and communicating with healthcare providers (C. Phillips, 2005). Only one of the 24 articles reviewed involved adolescents with cancer (Young, Dixon-Woods, Windridge, & Heney, 2003). Because adolescence is a developmental period when adolescents are striving to gain independence and because cancer throws them back into a stage in which they must rely on their parents, adolescents with cancer may have more specific and unique communication needs than adolescents with other acute or chronic illnesses. Further research is needed to examine connectedness between adolescents with cancer and their healthcare providers.

The importance of connectedness is alluded to by the description of problems in both communication and relationships found between chronically ill adolescents and their healthcare providers. Studies indicate that: (1) mediated communication occurs when healthcare providers direct the conversation toward the parent rather than toward the adolescent, which likely diminishes opportunities to connect (Beresford & Sloper, 2003; Young et al., 2003); (2) adolescents report that their needs and concerns are of little interest to their providers (Beresford & Sloper, 2003; Young et al., 2003); (3) adolescents perceive that some providers are more interested in treating the illness than spending time getting to know them (Beresford & Sloper, 2003; Woodgate, 1998); (4) adolescents see themselves as having a marginal position in the communication with doctors (Young et al., 2003); and (5) adolescents have a need for and want their healthcare providers to get to know them (Woodgate, 1998).

Given the lack of research on adolescent patient-provider interaction, it is not surprising that interventions to enhance communication and/or connectedness have not been widely developed or rigorously assessed. In a Cochrane Review, Scott et al. (2001) found only nine studies that evaluated the effectiveness of an intervention to improve communication in children and adolescents with cancer. Of these nine studies, *none* focused on improving communication or connectedness between adolescents and their healthcare providers. This lack of research evidence attests to the need for further study in communication and connectedness and has been identified as a pediatric oncology research priority (Sobo, 2004).

Summary

The importance of effective communication between patients and healthcare providers is evident in the growing body of research on this topic. Although communication is likely to be a contributor to connectedness, little research has been devoted to understanding the patient's perception of this phenomenon. Furthermore, little is known about the experiences of communication and connectedness between adolescents with cancer and their healthcare providers. Thus, research on connectedness will fill an important gap in the literature. The next section will provide a synthesis of the conceptual issues of connectedness that were theoretically explored using an integrated concept analysis approach and that was preliminary to the empirical, phenomenological approach used for this dissertation study.

Preliminary Study I: Concept Analysis of Connectedness

Human relationships and the manner in which social interactions impact the health and well-being of individuals has been a growing multidisciplinary interest for the past three decades. Historically, researchers have examined the concepts of social support and social networks in an attempt to identify factors that are most likely to

benefit individuals throughout their lives. Some have argued that these theories have not captured the fullness of the human experience of relationships with others (Coyne & DeLongis, 1986; Haase, Britt, Coward, Leidy, & Penn, 1992; Ryff & Singer, 2000). An important component missing in the literature is an understanding of the perceived meaning of having a positive and significant relationship with another human being (Ryff & Singer, 2000). Connectedness is a concept that may fill this gap. As a broad concept, connectedness has been defined as “the extent to which an individual perceives that he/she has meaningful, shared, and significant relationship with another person, community, a spiritual being, nature or an inner aspect of one’s self” (Haase et al., 1992, p 146).

Although a large number of studies have used the term “connectedness” to describe and/or measure an individual’s perception of having a significant relationship with others, there is little consistency in the definition of connectedness. Thus, many studies have used various definitions and measurements that make it difficult to integrate findings. Additionally, there appears to be much confusion regarding the attributes, boundaries, antecedents, and consequences of connectedness.

One way to begin to clarify a concept is to investigate the ways in which it has been conceptualized in the literature. Concept clarification is an approach commonly used in nursing to refine concepts that have been used without a clear and shared agreement on the essential properties or meanings related to the concept (Meleis, 2007). Concepts can be clarified by: (1) examining commonalities across different perspectives of the concept; (2) identifying attributes of the concept and what conditions under which the concept appears; and (3) distinguishing the antecedents and consequences of the concept (Morse, Hupcey, Mitcham, & Lenz, 1996). The end result of such an approach is a description of the “current consensus regarding the concept which provides a foundation for further concept development” (B. Rogers, 2000, p 83).

The purpose of this preliminary study was to clarify the concept of connectedness through a critical appraisal of the literature. The following research questions guided this analysis:

RQ 1: How is connectedness described across the literature?

RQ 2: What are the characteristics/attributes of connectedness?

RQ 3: Do existing definitions of connectedness meet adequacy requirements?

RQ 3: What are the boundaries of connectedness?

RQ 4: What are the antecedents and consequences of connectedness?

Method of Analysis

According to Morse, Mitcham, Hupcey, and Tanson (1996), the first step in evaluating a concept is to determine its level of maturity. This step is crucial because “a concept must be considered mature (i.e., it is well-defined, attributes are clearly described, boundaries well-delineated, and antecedents and consequences are documented) before it can be operationalized and definable in measurable units” (Morse, Mitcham et al., 1996, p 387). To help evaluate the maturity of a concept, Morse, Hupcey, et al. (1996) proposed five indicators. Based on these indicators, the concept of connectedness can be evaluated as a *partially developed* concept because: “(1) the nature of the phenomenon appears to be somewhat described; however, much conceptual confusion exists; (2) competing explanatory concepts can be identified; (3) boundaries are blurred but comparative questions can be developed; (4) related concepts may be systematically compared and differentiated; and (5) the evaluation analysis selected for this concept is considered to be comprehensive” (Morse, Hupcey et al., 1996, p 269).

After evaluating the maturity level of the concept, Morse, Hupcey, et al. (1996) suggest that the next step is to select a method that best represents the purpose of the concept analysis inquiry. The question to consider is “is it for purposes of concept

development, identification, delineation, comparison, clarification, correction, or refinement and measurement” (Morse, Hupcey et al., 1996, p 271)? Based on the indicators for each concept analysis approach, described by Morse, Hupcey, et al. (1996), concept clarification is the most appropriate method for connectedness because “the concept appears somewhat mature, there is a large body of literature that includes definitions and rich descriptions but the concept is measured using various variables and is applied in different ways in research” (p 270). Thus, after considering the maturity of the concept of connectedness (partially developed) and type of concept analysis inquiry (concept clarification) needed, the methodological approach chosen for this analysis was a critical appraisal of the literature.

Due to the lack of clear methodological guidelines for conducting a critical appraisal of the literature, Morse (2000) proposed four guiding principles: “(1) be clear about the purpose of the inquiry; (2) ensure the validity of the data; (3) identify significant analytical questions; and (4) synthesize the results” (pp 337-343). Each of these guidelines was considered and incorporated throughout this analysis.

An integrated approach, that incorporates concept analysis strategies proposed by Wilson (1963) and then adapted by Chinn and Kramer (1991), Walker and Avant (1995), and Schwartz-Barcott and Kim (1993), was chosen to guide this analysis. The rationale for using an integrated approach, instead of one specific concept analysis strategy, was to not limit the conscious awareness of the concept. According to Meleis (2007), the inherent “recipe” related to existing concept analysis strategies restrict essential components of knowledge development such as critical thinking, consciousness raising, and value clarification. Additionally, existing strategies limit the investigator’s ability to acknowledge and affirm different perspectives based on their own clinical and personal experiences.

Literature Search Strategy

Literature selected for this analysis was located through database search engines (CINAHL, ERIC, MEDLINE, PsychINFO, and Sociological Abstracts) using the keyword connectedness. The rationale for only using the term “connectedness” instead of related terms such as social support, social cohesion, attachment, and relatedness is because these concepts are more well-defined; however, they will be useful to further refine connectedness once a clearer understanding of connectedness has been obtained.

Database searches were limited to peer-reviewed research articles written in English. No limit was placed on the publication date. Since a very large number of articles (over 800) were retrieved, the search was limited to articles with the term “connectedness” in the title. After deleting duplicates, the abstracts of the 225 selected articles were read and 107 studies with a primary focus on connectedness were selected. Since the abstracts provided little information about definitions or assumptions used, the 107 selected articles were read in closer detail, focusing on definitions, assumptions, attributes, antecedents, and consequences of connectedness. Articles with no definitions or no assumptions were excluded. Reference lists from the selected articles were also examined for other relevant articles or book chapters. A total of 45 research articles, three review articles, and one book chapter were identified. These key articles/book chapters were then reread, and essential information related to the concept of connectedness was documented.

Results

Based on articles reviewed in this analysis, the concept of connectedness has been examined by a number of researchers from a variety of academic disciplines including child and adolescent development, education, marketing, medicine, nursing, psychology, and public health. Additionally, connectedness has been studied across the

life span from early childhood (Clark & Ladd, 2000) to older adults (Leidy & Haase, 1999; A. Ong & Allaire, 2005). The most common population where connectedness has been studied is with adolescents. Erickson's psychosocial perspective on adolescence seems to provide insight to this finding. According to Erickson (1954), adolescence is time period when adolescents are trying to form close, intimate relationships with individuals outside their family. Adolescents who are successful in this endeavor gain a strong sense of who they are as individuals and are committed to and secure within these relationships. In contrast, adolescents who have trouble forming close, intimate relationships with others are left with a sense of loneliness and despair that further complicate their psychosocial adjustment. Therefore, connectedness seems to be an important phenomenon to explore in the adolescent population.

Historical Perspectives on Connectedness

Connectedness has been conceptualized in numerous ways throughout the literature chosen for this analysis. The earliest conceptualization of connectedness appears to have emerged from the research on individuation. Cooper, Grotevant, and Condon (1983), for example, examined communication patterns among family members as a context for individual development, particularly for adolescents. In contrast to other theorists, who believed that individuation was a process of separating from parents and becoming independent, Cooper et al. (1983) believed that individuation was a property of family relationships. In particular, these authors viewed the expression of both individuality and connectedness in family relationships as an important indicator of individual and family functioning. Within their model of individuation, individuality and connectedness represent specific behaviors that occur within families that promote the psychosocial development of adolescents (Grotevant & Cooper, 1986, 1998). Specifically, "*individuality* refers to communication patterns that reflect self-assertion (i.e., displays awareness of own view point and responsibility for communicating it

clearly) and separateness (i.e., expresses distinctiveness of self from others), while *connectedness* refers to processes that link the self to others through permeability (i.e., expresses openness or responsiveness to the views of others) and mutuality (i.e., expresses sensitivity to or respect for the ideas of others)” (Cooper, Grotevant, & Condon, 1983, pp 45-46).

Similarly, Gavazzi and Sabatelli (1990) also believed that connectedness was part of the individuation process. However, their perspective of connectedness was quite different. They characterized connectedness as the extent to which an adolescent is emotionally, financially, and functionally dependent on his/her parents (Gavazzi & Sabatelli, 1990; Gavazzi, Sabatelli, & Reese-Weber, 1999). In other words, a well-individuated adolescent is less dependent on his/her parents. This perspective views connectedness in terms of the amount of dependency reflected in the family relationship with lower levels of connectedness being socially desirable.

Connectedness has also been commonly characterized as a social orientation. For example, many researchers view connectedness as an aspect of collectivism (Beyers, Goossens, Vansant, & Moors, 2003; Bush, 2000; Huiberts, Oosterwegel, VanderValk, Vollebergh, & Meeus, 2006; Lang-Takac & Osterweil, 1992; Liu et al., 2005; Wang, Bristol, Mowen, & Chakraborty, 2000). The assumption is that people who are socialized within collectivistic societies or families will have a greater tendency to develop a connectedness social orientation. In this perspective, connectedness is described as a sense of interdependence (Beyers et al., 2003; Wang et al., 2000), emotional closeness (Huiberts et al., 2006; Lang-Takac & Osterweil, 1992), and conformity to parents’ expectations (Bush, 2000).

Another perspective of connectedness emerges from the counseling psychology literature. Within this perspective, connectedness is thought to be a personality trait. For example, Lee and Robbins (1998) characterize social connectedness as “an internal

sense of belonging and is defined as the subjective awareness of being in close relationship with the social world” (p 338). In this perspective, it is assumed that the cumulative effects of all past and present relationship experiences, ranging from early attachment experiences to peer relationships and other social relationships, provide a relatively stable psychological sense of how an individual views him/herself in relation to others (R. Lee & Robbins, 1995, 1998, 2000). Once this global sense of connectedness is formulated, it is believed not to be susceptible to social disruptions such as loss of a friend or exclusion from a group (R. Lee, Draper, & Lee, 2001; R. Lee & Robbins, 1998). Connectedness within this perspective is believed to be a personality characteristic that remains stable over time.

Rude and Burnham (1995) also views connectedness as a personality characteristic. However, they describe connectedness as a dimension of dependency. In this context, connectedness is referred to as a more adaptive form of dependency (versus neediness that is a maladaptive form of dependency) and represents “a valuing of relationships and sensitivity to the effects of one’s actions on others” (Rude & Burnham, 1995, p 337).

The next perspective of connectedness emerges from the work of Karcher and colleagues (Karcher, 2005; Karcher, Davis, & Powell, 2002; Karcher & Finn, 2005; Karcher & Lee, 2002; Karcher & Lindwall, 2003). Karcher developed an ecological theory of adolescent connectedness. According to Karcher and Lee (2002), connectedness is described as “a movement towards others through affection and activity” (p 93). Within this perspective, connectedness is considered to be a consequence of relatedness and belonging. For example, “when individuals feel a sense of relatedness to others and belonging in general they, in turn, value those relationships and social institutions in which they experience belongingness and relatedness. They pursue activities and relationships which further cement their affective commitment.

Connectedness then, reflects one's perception of his or her own involvement in and affection for others, activities, and organizations" (Karcher & Lee, 2002, p 93). Other scholars also perceived connectedness as a movement towards others through affection and involvement (Aronowitz & Morrison-Beedy, 2004; Heifner, 1993; Schubert & Lionberger, 1995).

The most recent and common perspective on connectedness characterizes it as a perception or belief that an individual possesses when he/she feels cared for, respected, valued, and understood by significant others (Cunningham, Werner, & Firth, 2004; Grossman & Bulle, 2006; Shochet, Dadds, Ham, & Montague, 2006; Thomas & Smith, 2004; Whitlock, 2006). This perception or belief is thought to be fostered through experiencing positive social interactions with others and associated with enhanced psychosocial outcomes.

In summary, connectedness has been conceptualized in a variety of different ways throughout the past three decades. For example, connectedness has been viewed as a (1) component of the individuation process, (2) social orientation, (3) personality trait, (4) movement toward others through affection and activity, and (5) belief that one is cared for, respected, valued, and understood by others. Although each of these perspectives shed light on the nature and development of connectedness, the literature seems to be quite segregated and informs each other minimally. Nevertheless, there appears to be a considerable amount of overlap among these perspectives. This overlap can be exemplified by identifying the essential attributes of connectedness.

Attributes of Connectedness

Determining critical or defining attributes of a concept is an essential first step in clarifying the meaning of a concept (B. Rogers, 2000; Walker & Avant, 1995). Attributes are characteristics that define the concept and must be present in all instances in which the concept appears; however, attributes may present in various strengths and forms (J.

M. Morse, Mitcham et al., 1996). The attributes of connectedness identified in the literature set are listed in the third column of Table 2.1. These attributes were identified through the definitions used, descriptions of the characteristics of connectedness, and measurement indicators used by the investigators.

In this analysis, the essential attributes of connectedness were *not* easily identified or consistent across the literature set. However, upon closer examination, several similar attributes were noted across the various contexts. A description of each of these attributes follows.

Intimacy. Intimacy was the most common attribute identified within the literature set. This attribute was defined as a feeling of closeness (Beyers et al., 2003; Huiberts et al., 2006; Liu et al., 2005), having a unique bond with another person or group of others (Heifner, 1993; A. Ong & Allaire, 2005; Schubert & Lionberger, 1995; Wang et al., 2000), or a feeling of familiarity (Leidy & Haase, 1999). This attribute was also described as being in close relationship with the social world (R. Lee et al., 2001; R. Lee & Robbins, 1995, 1998, 2000) or the ability to form close relationships with others (Dunkley, Blankstein, Zuroff, Lecce, & Hui, 2006; Rude & Burnham, 1995). Although the degree of intimacy varied across contexts, this attribute was identified or could be inferred in all instances where connectedness occurred.

Empathy. Another common attribute described in the literature was empathy. Empathy was described as a behavior exhibited by family members (Beyers et al., 2003; Clark & Ladd, 2000), an expression of responsiveness or sensitivity to view points of others (Cooper et al., 1983; Grotevant & Cooper, 1986, 1998; Lang-Takac & Osterweil, 1992), the ability to sympathize with others (R. Lee et al., 2001; Russell, Norman, & Heckler, 2004), or a sense of being understood by others (Grossman & Bulle, 2006; Leidy & Haase, 1999). This attribute varied across the perspectives; but overall it appeared to be an essential attribute of connectedness.

Table 2.1 Antecedents, Attributes, and Consequences of Connectedness

Source	Antecedents	Attributes	Consequences
Component of the Individuation Process			
Bengtson & Grotevant, 1999; Copper et al., 1983; Grotevant & Cooper 1986; Grotevant & Copper, 1998	None identified	Sensitivity to and respect for the beliefs, values, feelings, and ideas of others Responsiveness or openness to the ideas of others Opinions of one another are valued and respected Considerate Intimacy (inferred) Reciprocity (inferred)	Adaptive identity development (identity exploration and role-taking skill) Enhanced self esteem Enhanced relational competence
Clark & Ladd, 2000	None identified	Reciprocity Empathy Caring Warmth Intimacy	Stronger pro social orientation (able to empathize with others) More friendships Higher levels of peer acceptance
Dwairy et al., 2006; Gavazzi & Sabatelli, 1990; Gavazzi et al., 1999	None identified	Emotional dependence Need for approval Monetary dependence Sharing of daily routines Interdependence	Adaptive psychosocial adjustment
Social Orientation			
Beyers et al., 2003	Social norms of family	Reciprocity Emotional closeness (intimacy) Interdependence Availability of parents Empathy Caring Communication	Adaptive psychosocial adjustment

Source	Antecedents	Attributes	Consequences
Bush, 2002	Parent behaviors that reflect collectivism	Conformity to parents, values, beliefs, and expectations Respect	Predicted self-esteem (Chinese girls only)
Huiberts et al., 2006	Parental behaviors that reflect collectivism	Emotional closeness (Intimacy) Positive affection: love, tenderness, and warmth Respect Parents are reliable Can talk to parents	None identified
Lang-Takac & Osterweil, 1992	None identified	Enmeshment or bond Expression of empathy Feeling closeness (intimacy) Share personal feelings with another	None identified
Liu et al., 2005	Cultural specific goals and values Parental behaviors that promote a connectedness social orientation include: Engaging in common activities Seeking emotional closeness Maintaining physical proximity	Compliance Cooperation Interdependence Reciprocity Awareness of responsibilities to the group and others Respect for authority Emotional closeness (intimacy) Physical proximity Displays concern for others	None identified
Wang et al., 2000	Eastern Culture Gender - women	Perception of oneself as the continuation of others or an extension of the self Interdependence Togetherness (unity) Closeness	More attracted to advertising messages that match the participants self-schema

Source	Antecedents	Attributes	Consequences
Stable Personality Characteristic			
R. Lee & Robbins, 1995; R. Lee & Robbins, 1998; R. Lee & Robbins, 2000; R. Lee et al., 2002; K. Williams & Galliher, 2006; Yeh & Inose, 2003	Past and present relationship experiences	Sense of belonging Subjective awareness of being in a close relationship with social world Trust Able to empathize with others Interdependence	Diminished trait & state anxiety Greater social identity in high cohesion conditions Higher social self-esteem Adaptive interpersonal behaviors
Dunkley et al., 2006; Rush & Burnham, 1995	None identified	Sensitivity to the effects of one's action on others Agreeable Affectionate (caring) Reciprocity Can easily form close relationships with others Receptive to their own inner feelings and emotions Concerned for others' welfare Moved by others' needs	None identified
Movement toward others through affection and activity			
Aronowitz & Morrision-Beedy, 2004	None identified	Feeling cared for Interaction with & presence of mother	More likely to have both an extended time perspective & fewer risk behaviors
Karcher & Lee, 2002; Karcher et al., 2002; Karcher & Lindwall, 2003; Karcher & Finn, 2005; Karcher, 2005	Relatedness Belonging Interpersonal support Affective arousal Active engagement Consistent presence of a significant other Growth in self-esteem, social	<u>Behavioral Involvement:</u> Cooperative Displays interest in getting to know others Displays concern Spending time together <u>Affective:</u> Affection for people or places (cares	Enhanced academic achievement Connectedness to parents and school: Decreased likelihood of youths' starting to smoke However, higher connectedness

Source	Antecedents	Attributes	Consequences
	skills, and self-management	for, values) Sense of being cared for, valued, enjoyment, comfort) Reciprocity Sense of closeness Perception of self being liked by others	to friends was associated with greatly increased risk for experimental smoking
Heifner, 1993	Display of vulnerability Shared commonalities	Sense of comfort Reciprocity Trust Bond Caring and concern Feeling valued by the patient	None identified
Schubert & Lionberger, 1995	Presence of a health problem that requires help from a nurse	Caring Respect Acknowledging the patient as a unique individual (valuing) Intimacy Trust	Improved health outcomes (inferred)
Belief that one is cared for, valued, respected and understood by others			
S. Albrecht et al., 2002	None identified	Sense of belonging Feels students are treated fairly Feels close to parents and people at school (intimacy)	Connectedness was NOT found to be a protective factor against risk-taking behaviors
Cunningham et al., 2004	None identified	Sense of belonging Feels cared for Feels supported	Enhanced coping

Source	Antecedents	Attributes	Consequences
Edwards et al., 2006	Shared experiences with teammates	Feels valued Part of the team (belongs)	None identified
Grossman & Bulle, 2006	Informal social interactions (hanging out, engaging in academic activities) Incorporating the youth's needs & desires into deciding what they do Helps with accomplishing tasks (tangible support) Expression of caring Shared interest or characteristics Displays respect	Feels cared for Feels respected Feels listened to Feels valued Feels understood Consideration of one's needs Sense of being known (inferred)	Reduction in school absences Higher colleague participation Less risky behaviors Positive school attitudes and behaviors Improved parental relationship
Jacobson & Rowe, 1999	Genetic and environmental factors between sibling pairs	<u>Parent/Family Connectedness:</u> Closeness to mother and/or father Perceived caring by mother and/or father Satisfaction with relationship to mother and/or father Feeling love and wanted by family members <u>School Connectedness:</u> Feel that teachers treat students fairly Close to people at school Feel part of school (belongs)	None identified
Leidy & Haase, 1999	None identified	Sense of gratitude Familiarity Shared experience Comfort Sense of being understood Trustworthiness	Preserved personal integrity Enhanced well-being

Source	Antecedents	Attributes	Consequences
King et al., 2002	None identified	Feeling of fitting in (belongs)	Enhanced mood (less depression and anger)
Markham et al., 2003	None identified	Closeness (intimacy) Warmth Consideration of needs Valued Respected	Less sexual risky-taking behaviors
A. Ong & Allaire, 2005	None identified	Warmth Satisfaction Trust Empathy Intimacy Reciprocity Bond Caring (concern for others)	Extended positive emotion Diminished systolic & diastolic blood pressure
Resnick et al., 1993 Resnick et al., 1997	Desire to connect with others Interactions with individuals who display caring and nurturing behaviors	<u>Parent/Family Connectedness:</u> Closeness to mother &/or father Perceived caring by mother &/or father Satisfaction with relationship to mother and/or father Feeling love and wanted by family members <u>School Connectedness:</u> Feel that teachers treat students fairly Close to people at school Feel part of school	Diminished risk health behaviors Lower rates of emotional distress
Rew, 2001	None identified	Belief that he/she is cared for by others Sense of closeness	Less loneliness Enhanced well-being Enhanced health status

Source	Antecedents	Attributes	Consequences
Shochet et al., 2006	Interaction with school and teachers at school	Sense of belonging Sense of encouragement Sense of acceptance Sense of inclusion Sense of support Sense of respect	Improved mental health outcomes (less depression and anxiety)
Thomas & Smith, 2004	Interaction among students and school personnel	Feels cared for or liked Enjoys school Sense of closeness (intimacy) to school personnel Bond	Less likely to be violent Less anger towards school
Whitlock, 2006	Opportunities for meaningful roles at school Sense of Safety Opportunities for creative engagement Feeling academically engaged at school	Caring Respect Trust Value Teacher attentiveness Reciprocity	None Identified
Miscellaneous			
Mashek et al., 2006	None identified	Interpersonal closeness (intimacy)	Psychological distress when simultaneously connected to communities with opposing values and beliefs
J. Owusu-Bempah & Howitt, 1997; K.. Owusu-Bempah & Howitt, 2000	Child must possess information about their natural parent's biological and social background	Shared similarities/experiences with parent Sense of belonging Self-awareness (or Self-identity) See her/himself as an offshoot of his/her parents' background	Enhanced well-being Enhanced emotional adjustment

Source	Antecedents	Attributes	Consequences
Russell et al., 2004	Emotional arousal Attentional intensity Shared similarities	Intimacy Commitment Respect Affective attachment to characters Empathy	Inspiration to achieve goals Enhances memory & retention Influences social judgment

Reciprocity. The next attribute was reciprocity. This attribute was most commonly portrayed in the articles that described connectedness in the context of family relationships. For example, Clark and Ladd (2000) observed the interaction behaviors among mother-child dyads. Several of the behavioral indicators of connectedness were the expression of reciprocity (i.e., mutual exchange of affection for one another, mutual involvement and interest in one another, etc). Similarly, this expression of reciprocity was found in Karcher and colleagues' work on adolescent connectedness and among the articles that described connectedness as a sense of interdependence with family members or others. Reciprocity was also identified among the articles that described connectedness to school. For instance, Whitlock (2006) described school connectedness as something that is *not* only received but also reciprocated (i.e., the extent to which one feels cared for and the extent to which one cares about school). Although reciprocity was not explicitly described in some of the articles, it could; however, be inferred in all instances where connectedness occurred.

Belonging. Belonging was identified as an essential attribute of connectedness. This attribute was described as a feeling that one belongs or a belief that one has a significant relationship with another person or group of others (S. Albrecht, Reynolds, Cornelius, Heidinger, & Armfield, 2002; Edwards, Wetzell, & Wyner, 2006; King, Vidourek, Davis, & McClellan, 2002). This attribute was particularly popular among the articles that described connectedness to school (Cunningham et al., 2004; King et al., 2002; Rasmussen, Damsgaard, Holstein, Poulsen, & Due, 2005; Resnick, Harris, & Blum, 1993; Shochet et al., 2006; Thomas & Smith, 2004; Whitlock, 2006). Although the intensity and description of this attribute varied across contexts; it could be found among all instances of connectedness.

Caring, Respect, and Trust. Other attributes of connectedness identified were caring, respect, and trust. Caring was illustrated by feeling cared for and/or cared about

(Aronowitz & Morrison-Beedy, 2004; Jacobson & Rowe, 1999; Resnick et al., 1997; Rew, 2002), being affectionate towards others (Clark & Ladd, 2000; Dunkley et al., 2006; Huiberts et al., 2006), caring for people or places (Karcher & Lee, 2002; Whitlock, 2006), experiencing warmth from others (Markham et al., 2003; A. Ong & Allaire, 2005), being considerate (Bengtson & Grotevant, 1999), or displaying concern for the well-being of others (Dunkley et al., 2006; Liu et al., 2005). Respect was described as feeling respected, displaying respect for others, or a sense of being valued (Grossman & Bulle, 2006; Heifner, 1993; Schubert & Lionberger, 1995). Respect was a particularly common attribute among the articles that described connectedness to family members (Bush, 2000; Huiberts et al., 2006; Liu et al., 2005) and school (Shochet et al., 2006; Whitlock, 2006). Additionally, respect was inferred in studies that examined the communication patterns of adolescent-parent dyads (Cooper et al., 1983; Grotevant & Cooper, 1986, 1998). Lastly, trust was described as being able to trust or depend on others; a sense of trustworthiness (Cooper et al., 1983; Gavazzi & Sabatelli, 1990; Leidy & Haase, 1999), or confidence in the availability of others for support (Grossman & Bulle, 2006; Huiberts et al., 2006; Leidy & Haase, 1999). Again, the strength and form of each of these attributes varied across the perspectives of connectedness, but overall they were all identified or could be inferred.

In sum, the identified attributes of connectedness revealed through this analysis were as follows: intimacy, empathy, reciprocity, belonging or feeling part of a significant relationship, caring, respect, and trust. Although these attributes were discussed separately, it should be pointed out that they are *not* mutually exclusive categories (i.e., there is a great deal of overlap among the attributes identified).

Adequacy of the Definitions of Connectedness

Once the essential attributes of connectedness were identified, the next step was to determine the adequacy of the previously used definitions of connectedness.

According to Hinds (1984), precise conceptual definitions are imperative for understanding the nature of the concept, choosing or developing appropriate methods for measurement, and analyzing theoretical relationships. Therefore, evaluating previously used definitions of connectedness will provide further insight to help clarify this concept.

To determine the definition adequacy of connectedness, each definition reported in the literature set was divided into the perspective categories described above. Sources were grouped together if the authors used the same definition. A total of 35 definitions were extracted (see Table 2.2).

Definitions were evaluated based on the rules for definitions proposed by Cohen and Nagel (1934) and Hamblin (1964), and first described for nursing by Hinds (1984). According to Hinds (1984), the use of definition rules helps to guide the formulation of construct definitions and also maximize the functionality of such definitions. These rules include: “(1) must give the essential, not accidental attributes; (2) must not be circular (i.e., must not directly or indirectly, contain the subject to be defined); (3) should be stated in positive terms; (4) should not be expressed in obscure or figurative language; (5) should reflect a continuum (i.e., uses the words ‘the degree to which’ or ‘the extent to which’); and (6) indicates the context of the construct” (Cohen & Nagel, 1934; Hamblin, 1964 as cited by Hinds, 1984, pp 360-361). The criteria as they were applied to each definition will be briefly discussed in the subsequent paragraphs.

Based on the six criteria, none of the reviewed definitions were adequate. Shochet et al.’s (2006) definition was the closest to meeting adequacy. The only criterion this definition did not meet was describing the essential attributes of connectedness (only three of the seven attributes were identified). The second closest definitions to meeting adequacy were Grossman & Bulle’s definitions of non-parental connectedness and Owusu-Bempah and Howitt’s (1997) definition of socio-genealogical connectedness;

Table 2.2 Definitions of Connectedness

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Component of the Individuation Process							
Grotevant & Copper, 1998; (Bengtson & Grotevant, 1999; Copper et al., 1983; Grotevant & Cooper 1986)	“Connectedness involves processes that link the self to others and has two dimensions: (1) <i>Permeability</i> - expressing responsiveness to the views of others & (2) <i>Mutuality</i> - expressing sensitivity and respect for others” (Grotevant & Copper, 1998, p 4).	4 out 7	+	+	+	-	-
Clark & Ladd, 2000	“Connectedness is a feature of the emotional bond formed between the parent and child.....we defined connectedness as a dyadic property of the parent-child relationship – as reflected in the mutuality of parent-child emotional expressions” (p 485).	1 out 7	+	+	-	-	+
Gavazzi et al., 1999 (Dwairy et al., 2006; Gavazzi & Sabatelli, 1990)	Multigenerational interconnectedness refers to the financial, functional, & psychological connections btw adolescents/young adults & their families. “Financial interconnections refer to the specific monetary ties between family members that reflect the extent to which a person is financially <i>dependent</i> on other family members” (Gavazzi, Sabatelli & Reese-Weber, 1999, p 1361).	1 out 7	+	-	+	+	+

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
	“ <u>Functional interconnections</u> refer to those activities in which family members share time with each other and reflect the extent to which a person is <i>reliant</i> on the family for daily care, companionship, and recreation” (Gavazzi, Sabatelli & Reese-Weber, 1999, p 1361).	1 out 7	+	–	+	+	+
	“ <u>Psychological (emotional) interconnections</u> refer to the approval, loyalty, obligation, and guilt that family members experience with one another and reflect the extent to which a person is emotionally <i>dependent</i> on other family members” (Gavazzi, Sabatelli & Reese-Weber, 1999, p 1361).	1 out 7	+	–	+	+	+
Social Orientation							
Beyers et al., 2003	Connectedness “refers to high levels of concern about parents’ well-being, high levels of empathy, strong and pervasive emotional ties with parents, openness and reciprocity in the communication with parents, and low levels of separateness from parents” (Borrowed from Frank et al. 1988, as cited on p 352).	4 out 7	+	+	+	–	–
Bush, 2002	A characteristic of the relationship between adolescents and their families represented by “conformity to parents’, values, beliefs, and expectations” (p 163).	–	+	–	+	–	+

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Huiberts et al., 2006	Provides a positive and negative definition. "In a positive way, connectedness is defined as emotional closeness: the presence of positive affection and confidence in the availability of parents as a source of help. In a negative way, connectedness is defined as the absence of emotional distance and conflicts" (p 316).	3 out 7	+	½ +	+	–	½ +
Lang-Takac & Osterweil, 1992	"Connectedness is characterized terms of empathy and desire for intimacy: (1) empathy was defined as the extent to which the person recognizes another's feelings and also shares those feelings at least at the gross affect level, such as pleasant/unpleasant and (2) desire for intimacy was defined as the extent to which the person desires a feeling of closeness or sharing with another" (p 280).	2 out 7	+	+	+	+	–
Liu et al., 2005	"Connectedness was defined as child's effort to affiliate/connect with his/her mother. Mother encouragement of connectedness included maternal behaviors that promoted the child's connectedness and affiliation" (p 491).	–	–	+	+	–	+
Wang et al., 2000	A connected self-schema or connectedness is "the degree to which an individual perceives others as an extension of self" (p 107).	1 out 7	+	+	–	+	+

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Stable Personality Characteristic							
R. Lee & Robbins, 1998 (<i>R. Lee & Robbins, 1995, 2000; R. Lee et al., 2002; K. Williams & Galliher, 2006; Yeh & Inose, 2003</i>)	“Social connectedness is defined as the subjective awareness of being in close relationship with the social world. The experience of interpersonal closeness in the social world includes proximal & distal relationships with family, peers, acquaintances, strangers, community, and society. It is the aggregate of all these social experiences that is gradually internalized by the individual & serves as a foundation for a sense of connectedness” (R. Lee & Robbins, 1998, p 338).	2 out 7	+	+	–	–	+
Rush & Burnham, 1995 (<i>Dunkley et al., 2006</i>)	Connectedness is a personality characteristic that is a relatively more adaptive form of dependency and represents “a valuing of relationships and sensitivity to the effects of one’s actions on others” (Rush & Burnham, 1995, p 337).	2 out 7	+	+	+	–	+
Movement Toward Others Through Affection and Activity							
Aronowitz & Morrison-Beedy, 2004	“Connectedness represents a daughter’s perception about being cared for by her mother and the mother’s involvement in the girl’s life” (p 33).	1 out 7	+	+	+	–	+
Karcher, 2005 (<i>Karcher & Lee, 2002; Karcher et al.,</i>	“Connectedness reflects youth’s activity with and affection for the people, places and activities within their life” (Karcher, 2005, p 66).	2 out 7	+	+	+	–	+

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
2002; Karcher & Finn, 2005; Karcher & Lindwall, 2003)							
Heifner, 1993	"A positive connectedness in the psychiatric nurse-pt relationship is a therapeutic state of interaction that enhances the effectiveness of the relationship and benefits the nurse and the patient" (p 14).	-	+	+	+	-	+
Schubert & Lionberger, 1995	"Mutual connectedness is the joining of the nurse and client in a relationship committed to the health and healing of the client. The nurse remains constant in caring, listening to, and focusing on the client. Client's trust may fluctuate until a feeling joining or bonding occurs in the relationship" (p 109).	2 out 7	+	+	+	-	+
Belief that one is cared for, valued, respected and understood by others							
S. Albrecht et al., 2002	"School connectedness defined in terms of the student reporting she or he feels the teachers treat students fairly, feels close to people at school, or feels part of the school" (p 17).	3 out 7	+	+	+	-	+
Cunningham et al., 2004	"School connectedness refers to a sense of belonging to one's school and experiencing care and support from individuals within that environment, such as teachers and peers" (p 140).	2 out 7	+	+	+	-	+

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Edwards et al., 2006	"A sense of connectedness with one's teammates is a common consequence of the shared experiences of the team membership" (p 136).	-	+	+	+	-	+
Grossman & Bulle, 2006	Non-parental connectedness is defined as "the degree to which youth feel they have a caring and supportive relationship with a non-parental adult" (p 788).	1 out 7	+	+	+	+	+
Jacobson & Rowe, 1999	Family connectedness was defined as "the degree to which adolescents were close to at least one of their parents" (p 930).	1 out 7	-	+	+	+	+
Leidy & Haase, 1999	"Connectedness is a sense of a significant, shared, and meaningful relationship with other people, a spiritual being, nature, or aspects of one's inner self" (p72).	1 out 7	+	+	+	-	-
King et al., 2002	"Connectedness [is a] feeling that one 'fits' in and 'belongs" (p 294).	1 out 7	+	+	+	-	-
Markham et al., 2003	Family connectedness defined as "family or parental closeness, warmth, support or responsiveness" (p 174).	3 out 7	+	+	+	-	-
A. Ong & Allaire, 2005	Social connectedness defined as "having quality ties with others" (p 476).	-	+	+	-	-	-

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Resnick, et al., 1993 (<i>Resnick et al., 1997</i>)	<u>Family connectedness</u> referred to as “adolescents who indicated that they enjoyed, felt close to and cared for by family members” (Resnick, Harris, & Blum, 1993, p S5). Also “referred to a sense of belonging and closeness to family, in whatever way family was comprised or defined by the adolescents” (Resnick, Harris, & Blum, 1993, p S6).	3 out 7	+	+	+	–	+
	<u>School connectedness</u> referred to as “students who enjoyed school, experiencing a sense of belonging and connectedness to it” (Resnick, Harris, & Blum, 1993, p S5).	1 out 7	–	+	+	–	+
Rew, 2001	“Connectedness refers to the individual’s perception that important others such as parents, teachers, church leaders, and peers care about the individual” (Borrowed from Blum & et al, 1989 as cited by Rew, 2001, p 55).	1 out 7	+	+	+	–	–
Shochet et al., 2006	“School connectedness is defined as “the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment” (Goodenow, 1993 as cited by Shochet et al., p 170).	3 out 7	+	+	+	+	+
Thomas & Smith, 2004	School connectedness defined as “caring at school and a sense of closeness to school personnel and environment” (p 136).	2 out 7	+	+	+	–	–

Primary Source (& Others)	Definition	Essence is provided	NOT circular	Stated in positive terms	No obscure or figurative language	Reflects a continuum	Indicates the context
Whitlock, 2006	School connectedness was defined as “a psychological state of belonging in which individual youth perceive that they and other youth are cared for, trusted, and respected by collections of adults that they believe hold the power to make institutional and policy decisions” (p 15).	4 out 7	+	+	+	–	+
Miscellaneous							
Mashek, et al., 2006	Community connectedness is defined as “the inclusion of community in self” (p 406).	1 out 7	+	+	+	–	–
J. Owusu-Bempah & Howitt, 1997 (K. Owusu-Bempah & Howitt, 2000)	“Socio-genealogical connectedness is defined as the degree to which children identify with their natural parents’ backgrounds is dependent upon the amount and quality of information they possess about their parents” (J. Owusu-Bempah & Howitt, 1997, p 207).	1 out 7	+	+	+	+	+
Russell et al., 2004	“Connectedness is the level of intensity of the relationship(s) that a viewer develops with the characters and contextual settings of a program in the para-social television environment” (p 152).	–	+	+	–	+	+

however, both of these definitions only described one of the essential attributes. The most common missed criterion for all of the definitions was providing the essential attributes of connectedness. The greatest number of attributes identified among the definitions was four. However, only three of the 35 definitions reported this many attributes indicating that the majority of the definitions failed to provide the essence of connectedness.

All but three definitions were found to be non-circular. In other words, only three definitions directly or indirectly contained the subject to be defined. For example, Jacobson and Rowe (1999) used the phrase “were close to” that indirectly referred to connectedness. In addition, both Resnick et al. (1997) and Liu et al. (2005) directly used the word “connectedness” in their definitions.

The majority of definitions were stated in positive terms. Definitions that were not stated positively were Gavazzi et al.’s (1999) definitions of financial, functional, and psychological interconnectedness and Bush’s (2002) definition. Gavazzi et al.’s definitions implied that too much connectedness resulted in a negative consequence. Bush used the word “conformity” in his definition which does not necessarily imply a positive or negative experience.

Only five definitions used obscure or figurative language that made the definition difficult to understand. For example, Clark and Ladd’s (2000) definition included the phrase “dyadic property” that seemed to confuse the meaning of the definition. Similarly, other authors used vague terms or phrases such as ‘para-social’ (Russell et al., 2004), ‘quality ties’ (A. Ong & Allaire, 2005), ‘extension of oneself’ (Wang et al., 2000), or ‘social world’ (R. Lee & Robbins, 1998). Despite these few definitions, the majority of the definitions used words that were easy to understand.

There appeared to be confusion whether connectedness reflects a continuum or whether it remains stable over time. For instance, nine definitions used phrases such as

'the degree to which', 'the extent to which', or 'the level of' that indicates connectedness may occur on a continuum. In contrast, seven definitions used terms such as "property of" or 'state of' that implies connectedness could remain constant. The remaining definitions (19 of 35) did *not* clearly specify whether connectedness was continuous or stable in nature.

The majority of the reviewed definitions indicated the context in which connectedness occurred. Connectedness was most commonly described as a social phenomenon that occurred among children/adolescents and their parents. Other social contexts where connectedness was believed to exist were at school (between students and teachers), within health care settings (between patients and nurses), and among a group of others (between peers, romantic partners, teammates, and colleagues). In addition, connectedness was also described as a phenomenon that exists within oneself. Ten of the definitions did not indicate a context.

In summary, none of the definitions of connectedness met all of the criteria for adequacy. The most common problem identified among the definitions was the failure to provide the essential attributes of connectedness. Additionally, this analysis revealed that there is much confusion regarding whether connectedness exists on a continuum or remains stable over time.

An Adequate Definition of Connectedness. Based on the identified attributes of connectedness and the analysis of definitions, a *broad* definition of connectedness was derived that met the criteria for definitions outlined above. Connectedness is the degree to which an individual perceives that he/she has a close, meaningful, and significant relationship with another person or group of others. This perception is characterized by positive expressions (i.e., empathy, belonging, caring, respect, and trust) that are both received and reciprocated through social interactions.

Boundaries of Connectedness

Boundaries of connectedness were also explored. Specific questions were asked about contextual influences (i.e., conditions under which connectedness exists, varies, or disappears), dimensions (i.e., subjective/objective and psychological/physiological), and underlying assumptions (i.e., growth vs. stability, state vs. trait) of connectedness. A description of the boundaries of connectedness follows.

Contextual Influences. Based on the articles reviewed in this analysis, connectedness most commonly occurs in the context of social relationships. However, connectedness was also described as taking place outside the context of social relationships. For example, socio-genealogical connectedness in lone-parent families is based on the amount and quality of information the child possesses about the absent parent rather than the presence or availability of the parent (J. Owusu-Bempah & Howitt, 1997; K. Owusu-Bempah & Howitt, 2000). In fact, a child can feel connected to their biological parent without ever having the opportunity to meet the absent parent. Additionally, Russell, Norman, and Heckler (2004), found that people can feel connected to TV program characters without ever having physical interaction with the character or actor. These studies suggest that connectedness can occur in the physical absence of others. Thus, connectedness may not be confined to objective social interactions.

Connectedness appears not to occur when an individual feels uncomfortable (Leidy & Haase, 1999), experiences mistrust (R. Lee & Robbins, 1998), or is violated by others (Rew, 2002). Leidy and Haase (1999) reported that patients with chronic obstructive pulmonary disease felt uncomfortable or embarrassed in public places because of their treatments and symptoms. These feelings lead to an increased sense of social disconnectedness because of their reluctance to venture out. Rew (2002) reported that homeless youths with histories of sexual abuse perceive themselves to be less socially connected, lonelier, and less healthy than other youths who were not

homeless. Furthermore, the homeless youths reported that the sexual abuse and feelings of being disconnected from others were the circumstances that originally led them to live on the streets.

Subjective/Objective Dimensions. There appears to be both subjective and objective dimensions of connectedness. Over two-thirds of the articles examined connectedness through self-reported measures asking individuals about their relationship with family members, peers, or members within a community. Most of these instruments asked questions about feeling cared for, valued, respected, and understood by others (Jacobson & Rowe, 1999; Resnick et al., 1997; Resnick et al., 1993; Whitlock, 2006) or about the ability to establish and maintain close relationships with others (Dunkley et al., 2006; R. Lee et al., 2001; R. Lee & Robbins, 2000). Other studies also included questions about particular activities with others rather than only focusing on the affective response of feeling connected (S. Albrecht et al., 2002; Karcher, 2005; Karcher et al., 2002; Karcher & Finn, 2005; Karcher & Lindwall, 2003; Rew, 2002). For example, Karcher and Lee (2002) developed an instrument that assessed both the degree of involvement and affection in close relationships.

A few of the studies examined objective dimensions of connectedness. For example, Clark and Ladd (2000) proposed that connectedness in young children is manifested directly in the personal narrative conversations they have with their mother. In this investigation, connectedness between mothers and their 5-year child was assessed by having observers view each narrative conversation and rate the dyad on the following six constructs: "(1) appeared to be mutually involved with and interested in each other (mutually positive engagement); (2) reciprocated positive affection and caring (mutual warmth); (3) evidenced synchrony in contingent responsiveness (mutual reciprocity); (4) displayed reciprocity in positive affect (mutual happy tone); (5) discussed each other's feelings (mutual intimacy); and (6) strongly expressed emotions verbally

and non verbally (mutual intensity)” (Clark & Ladd, 2000, p 486). Similarly, Bengston and Grotevant (1999) developed a Q-sort that could be used by observers to assess individuality and connectedness qualities in dyadic relationships. Thus, connectedness appears to have attributes that can be objectively observed.

In summary, there appear to be both subjective and objective dimensions of connectedness. However, there is little consistency in measuring these aspects among the investigators. This point will be further illustrated in next section (Methodological Issues of Connectedness).

Psychological/Physiological Dimensions. Psychological concepts associated with connectedness have been more widely examined than physiological concepts. Some of the psychological concepts that have been associated with connectedness include self-esteem, mood, coping, and well-being. What is not clear is whether the identified psychological variables influence the antecedents or consequences associated with connectedness, or whether they are components of connectedness.

Two studies examined physiological dimensions of connectedness. Ong and Allaire (2005) found that individuals who were perceived to be more socially connected had diminished diastolic and systolic blood pressure reactivity when encountering daily negative emotional states. Edwards, Wetzel, and Wyner (2006) found a positive association between salivary testosterone levels and connectedness among male and female college soccer players. Further work is needed to replicate these findings and to determine if these physiological variables were consequences or components of connectedness.

Growth vs. Stability Assumptions. Based on the literature set, it is not clear if connectedness is a phenomenon that exhibits growth (change) or stability. One might think that such a phenomenon would change over time; however, this assumption was not studied in the selected literature set. Understanding how connectedness either

changes or remains stable over time is important to measurement; the stability or tendency to change over time has implications for how and when a concept should be measured.

State vs. Trait Assumptions. The majority of the investigators implied that connectedness is situational or state-like. Based on the literature set, connectedness seems to occur in the context of social relationships, especially when an individual feels cared for, respected, and understood. Conversely, Lee and colleagues refer to connectedness as a cognitive representation of the self-in-relation-to-others which indicates that connectedness is trait-like (R. Lee et al., 2001; R. Lee & Robbins, 1995, 1998, 2000). These two conflicting assumptions require further investigation.

Antecedents

The antecedents of connectedness were infrequently described in the literature set (see Table 2.1 - second column). However, at least three factors were identified. The most common antecedent described among the articles that perceived connectedness as a social orientation was parental behaviors exhibited within families. For example, four articles assumed that connectedness was promoted through parental behaviors which exhibited emotional closeness and interdependence among family members (Beyers et al., 2003; Bush, 2000; Huiberts et al., 2006; Liu et al., 2005).

Similarly, Lee and colleagues conceptualized social connectedness as developing from the cumulative impact of past and present relational experiences. For example, individuals who grow up in a nurturing environment characterized by love, trust, and respect, are more likely to become social competent individuals. In contrast, people who have experienced repeated relationship failures throughout their life (i.e., abandonment, abuse, rejection, isolation) suffer from narcissistic wounds to the self and are more likely to feel less socially connected (R. Lee et al., 2001; R. Lee & Robbins, 1995).

Another antecedent described was shared experiences or characteristics. For example, Edwards, Wetzel, and Wyner (2006) believed that a sense of connectedness to one's teammates was the result of the shared experiences of team membership. Similarly, Grossman and Bulle (2006) reviewed adult-youth programs and reported that the most common determinant for youth feeling connected to non-parental adults was shared interests or personality characteristics. This idea of shared experiences, interest, or characteristics with others was also reported as an antecedent in connectedness with patients (Heifner, 1993) and TV characters (Russell et al., 2004).

Three potential antecedents were identified among the literature set: (1) parental behaviors exhibited within families; (2) cumulative impact of past and present relational experiences; and (3) shared experiences, interests, or characteristics with others. Although these antecedents were only identified in a few of the articles, the potential influence that each of these antecedents may have on connectedness needs further exploration.

Consequences

Consequences of connectedness were also identified (see Table 2.1 - fourth column). Although connectedness has been conceptualized from a variety of perspectives, similar consequences were noted. For example, articles that conceptualized connectedness as a component of the individuation process, a social orientation, or a personality characteristic most commonly found connectedness to predict variables related to enhanced psychosocial competence. These outcome variables included higher self-esteem (Grotevant & Cooper, 1998; R. Lee & Robbins, 1998), greater identity exploration and role-taking skill (Cooper et al., 1983), enhanced psychosocial adjustment (Beyers et al., 2003; Gavazzi & Sabatelli, 1990), greater social identity (R. Lee & Robbins, 1998), and adaptive interpersonal behaviors (Clark & Ladd, 2000; R. Lee & Robbins, 1998). Similarly, articles within the other perspectives identified

consequences that reflected enhanced psychosocial well-being. The consequences of connectedness identified among these studies included enhanced emotional adjustment (i.e., less anxiety, depression, and loneliness), health status and well-being (Leidy & Haase, 1999; J. Owusu-Bempah & Howitt, 1997; Rew, 2002; Shochet et al., 2006). Additionally, others identified diminished risk-taking behaviors as a consequence of connectedness (Aronowitz & Morrison-Beedy, 2004; Grossman & Bulle, 2006; Karcher & Finn, 2005; Resnick et al., 1997; Resnick et al., 1993). Thus, connectedness is believed to be an important concept that has a positive influence on a variety of psychosocial variables. However, further empirical work is needed to be examined the consequences of connectedness across other social relational contexts.

Summary

Connectedness has attracted the attention of many researchers from a variety of academic disciplines. However, this diversity of interest in connectedness has resulted in a number of differing perspectives that has made it difficult to understand its meaning. Furthermore, the inadequacies found among the definitions of connectedness attests to the need further clarify this concept.

In addition to the vague meaning of connectedness and inadequate definitions, four other major conceptual issues were identified. First, little consideration has been devoted to examining the essential attributes of connectedness. Although seven attributes were found in this review, further research is needed to determine if these attributes are present in other instances where connectedness appears. Second, the boundaries of connectedness seemed to be blurred by the various conceptualizations and need further exploration. In particular, contextual influences, dimensions, and assumptions need to be examined. Third, there has been a lack of research on identifying the antecedents of connectedness. The antecedents extracted through this analysis could be a good place to begin. Lastly, although the consequences of

connectedness include a variety of positive psychosocial outcomes, these outcomes need to be replicated in other social relationship contexts.

Before recommendations for further concept development can be made, the methodological approaches used to measure connectedness must be reviewed. Thus, the next section will review and critique these methods and then provide recommendations for further concept and instrument development.

Methodological Issues of Connectedness

Conceptual confusion related to connectedness has also caused a great deal of perplexity in measuring connectedness. To illustrate this point, in this section the methodological approaches used to measure connectedness are reviewed and critiqued. This analysis used the same literature set described in the above section (Concept Analysis of Connectedness). Table 2.3 presents a brief summary of these measures. A total of 34 measures were identified. Although the articles were grouped together by their corresponding perspective, the discussion will be based on the type of method used: self-report or observation.

Self-Report

The most common method used to study connectedness was self-report. Among the 34 measures identified in this review, 30 collected data by directly questioning participants. This data was primarily gathered using self-report questionnaires or surveys. Four studies conducted semi-structured interviews. The most common population these instruments were delivered to was adolescents.

Questionnaires. An assortment of self-report questionnaires was identified among the literature set. In fact, very few studies used the same instrument. Nine studies were found to have developed their own questionnaire or survey. Eight studies used existing questionnaires. The remaining studies selected particular items from a

Table 2.3 Measures of Connectedness

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Component of the Individuation Process					
Copper et al., 1983	Two-parent families (including one adolescent & one to two siblings) (N = 84)	Authors developed <i>Family Discourse Code</i> - observation - coded scheme used to assess verbal utterances that demonstrate individuality and connectedness among family members.	Model of individuation (developed by the authors)	14 coded comm. behavior categories	Reliability evidence (% agreement between judges > .75) was demonstrated. Construct validity (isolation of four factors representing proposed conceptual dimensions) was demonstrated.
Bengtson & Grotevant, 1999	Two-parent families (including one adolescent & one to two siblings) (N = 46)	Authors developed <i>The Individuality & Connectedness Q-sort (ICQ)</i> – observation – coded scheme used to assess individuality and connectedness behaviors in dyadic relationships.	Model of individuation (Copper et al, 1983)	35	Inter-rater reliability ranged from .73 to .93 for individuality and from .83 to .93 for connectedness. Content validity (panel of 8 experts) was established. Construct validity demonstrated by using ICQ to assess similar constructs identified in previous studies using the <i>Family Discourse Code</i> (significant correlations found).
Clark & Ladd, 2000	Kindergarten children & their mothers (N=192)	Authors developed Coding scheme adapted from other instruments of family relationship quality - assessment of dyadic processes that corresponded to aspects of parent-child connectedness.	None identified – items based on other rating systems of relationship quality and literature on attachment	6 coded categories	Reliability evidence (Inter-rater agreement = 73%; Within-one-point agreement = 91%) reported. Convergent and Divergent validity (correlated with autonomy and family SES and did not correlated with child gender and family structure) was demonstrated.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Gavazzi et al., 1999 (<i>Dwairy et al., 2006; Gavazzi & Sabatelli, 1990</i>)	Late adolescents & early young adults (N = 337)	Authors developed <i>Multigenerational Interconnectedness Scale</i> – self-report instrument of the individual's degree of interconnectedness with his/her parents	Model of individuation (Allison & Sabatelli, 1988)	31	Internal Consistency ($\alpha = .87$) was reported. Construct validity (correlated with sex and age) was demonstrated. Some evidence of convergent and divergent validity (<i>emotional interconnectedness subscale</i> correlated with psychosocial maturity and family over involvement) was demonstrated.
Social Orientation					
Beyers et al., 2003	High school students (N = 601) First year college students (N = 374)	Used existing self-report instruments to assess the adolescent's perception of reciprocity; emotional closeness, mutuality, availability, quality of the emotional bond, cohesion, trust, and communication within the family.	NA	5 - 23	Authors noted that they only selected measures that were standardized and validated to some extent. However, only reliability estimates were reported. No evidence of validity reported.
Bush, 2002	Adolescents from China (N = 497) Adolescents from the US (N = 556)	Used an existing self-report instrument to measure the degree to which the adolescent conformed to the parents' values, beliefs, and expectations about leisure time activities, friends, dating, education, and careers.	NA	9	Internal consistency ($\alpha = .77$ for Chinese sample & $.85$ for US sample) was documented. No evidence of validity reported.
Huiberts et al., 2006	Adolescents living in the Netherlands (N = 102)	Used existing self-report instruments to assess (1) affective expression felt (love, respect, tenderness, and warmth) from mother/father and (2) attachment aspects (reliability,	NA	Not reported	Internal consistency (emotion scale $\alpha = .84$ for mother, $.85$ for father; attachment scale $\alpha = .75$) reported. No evidence to validity was reported.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
		communication, and alienation within relationships with parents).			
Lang-Takac & Osterweil, 1992	Men ($N = 30$) & Women ($N = 30$) (Israelis of western origin)	Used existing self-reported instruments to assess empathy and desire for intimacy.	NA	Empathy - 33 Intimacy - not reported	Existing reliability evidence reported. However, internal consistency for the sample was not reported. Evidence of validity (previous construct validity evidence for empathy and previous criterion validity for intimacy) was documented.
Liu et al., 2005	Toddlers and mothers from China ($N = 110$) Toddlers and mothers from Canada ($N = 102$)	Authors developed Developed a coding scheme to assess the frequency of the child's behavior to initiate connectedness & the mother's behavior that promoted the child's initiation.	None identified	Not reported	Child's initiation of connectedness: Inter-rater reliability = .86 in Chinese sample and .88 in Canadian sample Mother's encouragement of connectedness: Inter-rater reliability = .85 in Chinese sample and .81 in Canadian Sample No evidence of validity reported.
Wang et al., 2000	College students from China ($N = 105$) & from the US ($N = 96$)	Authors developed Self-report instrument to assess the three proposed dimensions of connectedness-separateness. High score reflects a connected self-scheme and low score indicates a separated self-scheme.	Items based on three dimensions of connectedness-separateness self-schema proposed by the authors	17	Internal consistency (α s = btw .65 and .75) was demonstrated. Construct validity (isolation of three factors) was demonstrated.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Stable Personality Characteristic					
R. Lee & Robbins, 1995 (R. Lee & Robbins, 1998, 2000; Yeh & Inose, 2003)	Colleague students (N = 626)	Authors developed <i>Social Connectedness Scale (SCS)</i> – self-report instrument to assess the individual's experiences of closeness in interpersonal contexts	Self-psychology theory (Kohut, 1984)	8	Internal consistency ($\alpha = .91$) was demonstrated. Test-retest stability ($r_s = .96$ and $.84$) was demonstrated. Content (expert judges) and Construct validity (confirmatory FA) evidence was demonstrated.
R. Lee et al., 2001 (K. Williams & Galliher, 2006)	College students (N = 218)	Authors revised <i>Social Connectedness Scale – Revised (SCS-R)</i> – self-report instrument to assess the individual's experiences of closeness in interpersonal contexts.	Self-psychology theory (Kohut, 1984)	20	Internal consistency ($\alpha = .92$) was demonstrated. Content (experts judges), convergent (correlated with collective self-esteem and independent self-construal), and discriminate validity (correlated with loneliness and distress) evidence was demonstrated.
Rush & Burnham, 1995 (Dunkley et al., 2006)	College students (N = 431)	Used criteria to select particular items from a self-reported dependency and items from another instrument. All items combined. Factor analysis revealed two factors: connectedness and neediness.	NA	34	Existing evidence of reliability (test-retest correlations) reported. However, the reliability for sample was not reported. Evidence of validity (factor analysis, construct validity) was demonstrated.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Movement Toward Others Through Affection and Activity					
Aronowitz & Morrision-Beedy, 2004	African American female adolescents (N = 443)	Used items from a large health survey that represented mother-daughter connectedness (Add Health): (1) <i>Maternal caring</i> – perception of the relationship with mother (caring, understanding, and attention); (2) <i>Mother-adolescent activities</i> - number of shared activities; (3) <i>Maternal presence</i> – frequency of maternal presence before school, after school, and at bedtime.	NA	19	Internal consistency (for maternal caring $\alpha = .86$) for sample was reported. No evidence of validity reported.
Karcher & Lee, 2002 (Karcher, 2005; Karcher et al., 2002; Karcher & Lindwall, 2003; Karcher & Finn, 2005)	High school students	Primary author developed <i>Hemingway Measure of Adolescent Connectedness</i> (originally developed and tested with US adolescents) – self-reported instrument to assess the adolescent's perception of caring and involvement in close relationships and important contexts.	Based aspects of attachment processes (Ainsworth, 1989) and belonging (Baumeister & Leary, 1995)	Varies depending on version	Initial internal consistency evidence reported. Initial evidence of validity (convergent and discriminant correlations) reported.
Heifner, 1993	Psychiatric nurses (N = 8)	Semi-structured interviews; analyzed using grounded theory.	NA	NA	Some evidence of credibility (peer debriefing) was reported.
Schubert & Lionberger, 1995	Nurses (N = 12) and their clients (N = 18)	Semi-structured interviews; analyzed using grounded theory.	NA	NA	Some evidence of credibility (peer debriefing) was reported.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Belief that one is cared for, valued, respected and understood by others					
S. Albrecht et al., 2002	Inner city adolescents (N = 53)	Selected items from a large scale survey believed to measure parent and school connectedness. However, these constructs were not part of the original scale.	NA	8/9	No evidence of reliability of selected items was reported. No evidence of validity was reported.
Cunningham et al., 2004	High school students (N = 300)	Selected items from an existing self-report instrument used to assess student's perception of their school environment (i.e., examined students' perception of their connectedness to peers, teachers, and school).	NA	4/5/4	Internal consistency (α s = .74, .83, and .84) for sample was reported. No evidence of validity was reported.
Edwards et al., 2006	Intercollegiate varsity soccer teams (N = 30)	Used an existing self-reported instrument (individual attraction to the group) - to assess the extent to which a respondent felt socially connected with their teammates.	NA	Not reported	Internal consistency (α = .85 for men sample; α = .93 for women sample) reported. No evidence of validity was reported.
Jacobson & Rowe, 1999	Adolescent-sibling dyads (N = 2302)	Selected items from a large scale survey (Add Health) – to assess the adolescent's perception of connectedness to family and school.	NA	7/8	Internal consistency (family α = .83, school α = .77) for sample was reported. No evidence of validity was reported.
Leidy & Haase, 1999	Men and women with COPD (N= 12)	Unstructured interviews; analyzed using Colaizzi's method of empirical phenomenology	NA	NA	Evidence of trustworthiness and credibility (audit trail reviewed by an external reviewer, themes validated by a person who had a COPD but was not a participant) was reported.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
King et al., 2002	Fourth grade students (N = 283)	Authors developed survey – derived from literature review Measured school, peer, and family connectedness	Items based on literature review	Unclear	Internal consistency of connectedness subscales ($\alpha = .80, .72, .76$) was reported. Test-retest reliability ($r_s = .81, .73, \text{ and } .73$) reported. No evidence of validity was reported.
Markham et al., 2003	High school students (N = 976)	Authors selected items from three large scale survey – assessed family connectedness	NA	14	Internal consistency ($\alpha = .87$) for sample reported. No evidence of validity was reported.
A, Ong & Allaire, 2005	Men and women with normal blood pressures (N = 33)	Used an existing self-reported instrument of positive relations with others – assessed social connectedness	NA	14	Internal consistency ($\alpha = .92$) for sample reported. No evidence of validity was reported.
Resnick, et al., 1993	Adolescents (N = 36,254)	Items from a large scale survey (Minn. Adolescent Health Survey) - assessed perceived connectedness with family and school	NA	Not reported	No evidence of reliability was reported. No evidence of validity was reported.
Resnick, et al., 1997	Adolescents (N = 12,118)	Items from a large scale survey (Add Health) – assessed adolescent's perception of connectedness to family and school.	NA	13/6	Internal consistency (family $\alpha = .83$, school $\alpha = .75$) for sample reported. No evidence of validity was reported.
Rew, 2001	Homeless adolescents (N = 96)	Items from a large scale survey (Minn. Adolescent Health Survey) - assessed perceived connectedness with family and others.	NA	10	Internal consistency ($\alpha = .81$) for sample reported. No evidence of validity was reported.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
Shochet et al., 2006	Middle school students (N = 2,022)	Used an existing self-report instrument of perceived school membership – assessed sense of belonging, respect, encouragement, and acceptance at school.	NA	18	Internal consistency ($\alpha = .89$) for sample reported. Some validity evidence reported.
Thomas & Smith, 2004	High school students (N = 282)	Authors developed Developed a large scale survey of health factors that included open-ended questions about school connectedness (i.e., feelings about school, classmates, and fairness at school).	Items based on literature review and clinical experience	3	No evidence of reliability was reported. No evidence of validity was reported.
Whitlock, 2006	Middle and high school students (N = 305)	Authors developed Developed a large survey that included questions to assess (1) the student's perception of their relationship with teachers; (2) extent to which they felt respected, trusted, and cared for by the adults at school; and (3) the extent to which they cared about and trusted the adults in their school.	Items based on commonalities presented in youth development theories	7	Internal consistency ($\alpha = .81$) for sample reported. No evidence of validity was reported.
Miscellaneous					
Mashek, et al., 2006	Jail Inmates (N = 256)	Used an existing measure (single-item pictorial measure with 6 pairs of overlapping circles) - asking participants to indicate which circle diagram best describes their relationships with others.	NA	1	Existing evidence of validity (test-retest reliability) reported. Existing evidence of validity (construct, convergent, and predictive validity) was reported.

Source(s)	Population (N)	Description of Measurement	Theoretical Underpinning(s)	No. of Items	Reliability & Validity Evidence
K. Owusu-Bempah & Howitt, 2000	Children (N = 50)	Semi-structured interviews with children and their parents regarding: (1) the quality of information the about absent parent; (2) nature of the information; and (3) amount of regular contact with parent.	NA	3	No evidence of reliability was reported. No evidence of validity was reported.
Russell et al., 2004	Initial testing: College students (N =175) Further testing: Website respondents (N = 12,263) & College students (Ns = 104 & 99)	Authors developed Self-report instrument to measure of TV connectedness.	Items based on review of literature	16	Initial reliability evidence ($\alpha = .84$) reported. Evidence of validity (confirmatory factor analysis; discriminant & predictive validity) was reported.

large scale survey or an existing questionnaire.

Among the nine studies that reported developing a self-report questionnaire, only four provided a theoretical foundation (Gavazzi et al., 1999; Karcher & Lee, 2002; R. Lee et al., 2001; R. Lee & Robbins, 1995). The theoretical perspectives used to develop these instruments were *not* focused on connectedness. Instead the authors used models of individuation (Allison & Sabatelli, 1988), self-psychology (Kohut, 1984), attachment (Ainsworth, 1989), and belonging (Baumeister & Leary, 1995). Whitlock (2006) did not specifically use a theory to guide the development of her questionnaire; however, she did indicate that the items represented commonalities found among the theories on youth development. The other three studies that developed an instrument were based on a review of the literature. Thus, there seems to be little consistency in the conceptual and theoretical foundations used to develop instruments to measure connectedness.

Inconsistency was also found among the studies that used existing self-report questionnaires to measure connectedness or some aspect of it. For example, five studies each selected a different self-report questionnaire (Bush, 2000; Edwards et al., 2006; Mashek, Stuewig, Furukawa, & Tangney, 2006; A. Ong & Allaire, 2005; Shochet et al., 2006). These instruments were originally designed to measure conformity to parents, group attraction, positive relations with others, school membership, and the inclusion of others in self. Similarly, three studies used more than one existing instrument that was believed to capture particular characteristics of connectedness. For instance, Lang-Takac and Osterweil (1992) measured connectedness using instruments to assess empathy and desire for intimacy. Huiberts et al. (2006) used instruments that assessed both affection and attachment. Probably one of the best measurements of connectedness was found in Beyer et al.'s (2003) study. These authors identified instruments that assessed the adolescent's perception of reciprocity, emotional

closeness, mutuality, quality of the emotional bond, cohesion, trust, and communication within the family; however, the validity of these instruments were not reported.

There was also a lot of discrepancy among the articles that selected items from existing surveys and questionnaires. For example, five studies elected to use items from the National Longitudinal Study on Adolescent Health (Sieving et al., 2001); however, the number of items reported in these studies varied. Resnick et al. (1997), the original developers of the survey, indicated that the instrument consisted of 13 items to assess connectedness to parents and 6 items to measure school connectedness. Nevertheless, the other studies that reported using items from this survey to measure parent and/or school connectedness did *not* report the same number of items. Although there may have been a reason for this discrepancy, none of the authors provided an explanation for it.

In addition, Aronowitz and Morrison-Beedy (2004), who conducted a secondary analysis using the Adolescent Health data, claimed that three other instruments within this large survey represented connectedness. Instead of using items that were originally designed to measure parent connectedness, these authors used items that assessed maternal caring, mother-daughter activities, and mother presence. An explanation for choosing these items over the other items labeled “parent connectedness” was not provided.

Two studies randomly selected items from other adolescent related health surveys. Albrecht et al. (2002) chose items from the Health Behavior Questionnaire-High School Form (Jessor, Donovan, & Costa, 1992) in which they believed represented parent and school connectedness. These constructs were *not* part of the original survey. Instead, the items were originally designed to measure parental support, parental support of school, attitude toward education, and feelings toward school. Similarly, Markham et al. (2003) also haphazardly took items from three surveys to measure family

connectedness. However, the authors did not describe which items were specifically taken or why.

One study, however, did select items to measure connectedness using a specified criterion. Rush and Burnham (1995) chose items from the Depressive Experiences Questionnaire based on scoring weights derived from the original factor analysis conducted by the instrument's developers (Blatt, D'Afflitti, & Quinlan, 1976). To identify specific items that represented dependency, Rude and Burnham selected items with a scoring weight of at least .04. These items were then submitted to principal component factor analysis and resulted into two factors that the authors believed best represented dependency: neediness and connectedness.

Besides the various measurements and discrepancies noted in the self-report measures of connectedness, the validity of these instruments was also found to be questionable. Less than half of the articles (10 out of 26) reported evidence of validity. Furthermore, very few of the studies reported or demonstrated the validity of these instruments across different populations.

Interviews. Four studies gathered self-reported data through interviews. Although these studies revealed some interesting evidence, several methodological issues noted among these studies. Prior to discussing these concerns, a brief summary of these studies will be provided.

Two studies did *not* specifically ask questions regarding connectedness; however, the essence of connectedness was revealed through the participants' descriptions. For example, Schubert and Lionberger (1995) interviewed 12 nurses and 18 adult patients about their interaction with one another. The authors then used grounded theory to describe the process of events that the authors believed symbolized mutual connectedness between the patient and their nurse. In addition, Leidy and Haase (1999) conducted unstructured interviews with 12 elderly patients with chronic

obstructive pulmonary disorder regarding their experiences of finding purpose and meaning through activity. Using phenomenology, the authors identified connectedness as an important aspect of preserving personal integrity. In this study, the authors identified five characteristics of connectedness: familiarity, comfort, shared experience, understanding, and trustworthiness.

The other two studies directly asked questions about connectedness based on the authors' conceptualization of connectedness. For instance, Owusu-Bempah and Howitt (2000) characterize connectedness as the amount and quality of information a child possess about an absent parent. Therefore, these authors used open-ended questions to determine the quality and nature of the information that the child had about their absent parent. In contrast, Heifner (1999) who defined connectedness as "a therapeutic state of interaction that enhances the effectiveness of the nurse-patient relationship" (p 14), used structured interviews to elicit nurses' descriptions of connectedness in the nurse-patient relationship.

Although most of these qualitative studies provided rich descriptions of connectedness, two problems were noted. The first problem was related to methodological differences found. These differences included the (1) research question; (2) type of qualitative analysis; and (3) sample. The second problem was the questionable validity of the findings. Among these four studies, only one study provided efficient information about the trustworthiness and credibility of their findings (Leidy & Haase, 1999).

Observation

Four articles used observation techniques to measure connectedness. Copper, Grotevant, and colleagues (Bengtson & Grotevant, 1999; Cooper et al., 1983) analyzed the verbal communication patterns that represented individuality and connectedness between adolescents and their family members. Originally, Cooper et al. (1986)

developed a coding system that focused on capturing the interpersonal function of verbal utterances and on the way the participants in the conversation collaborated to sustain the interaction. The coding system was based on their model of individuation.

Connectedness was displayed when participants expressed (1) responsiveness and openness to the views of others and (2) sensitivity and respect for the other's views. The authors later recognized the limitations of their coding scheme and decided to develop a new instrument, in which they called the Individuality and Connectedness Q-sort (ICQ) (Bengtson & Grotevant, 1999). The ICQ addressed the limitations noted in the previous coding system and demonstrated evidence of adequate inter-rater reliability and construct validity.

Similarly, Clark and Ladd (2000) developed their own coding system to measure dyadic processes that represented connectedness between toddlers and their mothers. The authors' coding system was derived from other instruments used to assess relationship quality and constructs identified in the literature on attachment. In this study, connectedness was assessed by observers rating the parent-child dyad on six constructs: positive engagement, warmth, reciprocity, happy tone, intimacy, and strongly expressed affectionate emotions. The authors reported evidence of good inter-rater reliability and construct validity for their coding system.

Liu et al. (2005) also observed and coded behaviors that represented connectedness between toddlers and their mothers. They developed a coding system that rated separate child and parent behaviors. For example, the child's effort to connect with her mother was based on the (1) frequency of the child's effort to initiate connectedness represented by cooperation, expression of emotional closeness, physical proximity to the mother and (2) amount of time the child engaged in common activities with the mother. Maternal engagement of connectedness was assessed by the frequency of maternal behaviors that supported the child's cooperation, emotional

closeness, and physical proximity. However, the authors did not provide a theoretical or conceptual basis for their coding system. Furthermore, no evidence of validity was reported.

The observation measures described in these studies indicate that connectedness has some characteristics that can be objectively accounted for. Although these coding systems categorize some of the behaviors that may signify connectedness, three problems were identified. First, the coded behaviors described in these measures were not similar. Other than the two studies that developed a coding scheme using the same theoretical model, different behaviors were coded in the other studies. Second, only two measures were based on a theoretical model; however, this model described the process of individuation rather than connectedness. Third, although three of these measures had evidence of construct validity, little is known about appropriateness of using these instruments in other social contexts. Further research is needed to understand whether these behaviors are indeed indicators or perhaps consequences of connectedness.

Summary

This review indicates that there has been a lack of consistency in the methodological approaches used to examine connectedness. Although a variety of approaches were identified, little similarity was found among these measures. Very few instruments had a theoretical foundation specific to connectedness or evidence of validity. In addition, none of the questionnaires, interviews, or observational approaches specifically sought descriptions of adolescents' experiences of connectedness. These problems were not surprising given the lack of conceptual clarity regarding connectedness identified in the concept analysis. Thus, recommendations for further concept and instrument development are needed.

Recommendations for Further Concept and Instrument Development

The analysis of the conceptual and methodological issues of connectedness provides a foundation for further concept and instrument development. Based on the findings, three broad recommendations can be made. First, additional research is needed to provide a clearer description of the characteristics, antecedents, and consequences of connectedness as well as the conditions in which connectedness manifest itself. Second, a preliminary model that begins to illustrate the proposed relationships between the characteristics of connectedness and related concepts needs to be developed. Third, a psychometrically sound instrument needs to be developed and evaluated. Fourth, other instruments will need to be identified or developed to examine the relationships between connectedness, its antecedents and consequences. A brief discussion of how these recommendations can be carried out follows.

Qualitative methods are generally believed to be well-suited for further conceptual clarity (Morse, Hupcey et al., 1996). By conducting inductive analyses of textual and observational data gathered from participants, the researcher can begin organize this data into respective categories (i.e., antecedents, attributes, and consequences). These categories can then be used to make comparisons with one another and to identify boundaries. Ultimately, this type of analysis would lead to the development of a clearer conceptual definition of connectedness. Some of the qualitative methods that could be used include phenomenology, grounded theory, and ethnography (Morse, Hupcey et al., 1996).

After the initial descriptive work has been completed, the researcher can then begin to diagram the proposed relationships among the characteristics of connectedness, its antecedents and consequences. This diagram will essentially become a preliminary theoretical model that will later be subjected to further examination and refinement using quantitative techniques.

Once a clear picture of connectedness has been developed, the researcher will then need to develop and test an instrument that measures its characteristics. The results uncovered through the first two recommendations will provide a foundation for the development and testing of this instrument. Quantitative methods will then need to be used to evaluate the instrument's psychometric properties. Additionally, statistical analyses, such as factor analysis, will help provide valuable information regarding the dimensionality and structure of connectedness.

Conclusions from the Literature

After reviewing and analyzing the literature, six major conclusions can be drawn: (1) connectedness with healthcare providers is a protective factor that may be associated with enhanced health outcomes in adolescents; (2) current conceptual and theoretical perspectives of patient-provider relationships do not consistently incorporate the patients' perceived meaning of being connected to a healthcare provider; (3) although connectedness with healthcare providers has seldom been directly studied, it has emerged as a theme of importance in the health care context; (4) most patient-provider interaction studies have focused on communication behaviors and actions rather than on patients' perceptions of being connected to their provider(s); (5) little is known about the communication and connectedness between adolescents and their healthcare providers; and (6) while there is lack of conceptual clarity regarding connectedness, some essential characteristics have been identified and provide a foundation for further concept and instrument development. There is a gap in the literature in regard to what connectedness actually is, what behaviors are associated with connectedness, what factors influence connectedness, and what connectedness with a healthcare provider means to adolescents who have cancer.

A necessary first step in building a program of research on adolescent patient-provider connectedness, and *the focus of this dissertation*, is to focus on the conceptual issues by evaluating the commonalities in the experience, so that the essential structure (a generalized description) can be revealed. In the case of adolescents with cancer, I have chosen to interview young adult cancer survivors (ages 18 – 24 years) who were diagnosed and treated for cancer during adolescence (ages 15 – 21 years) because these individuals have had time away from the traumatic event of being diagnosed with a life-threatening disease. In addition, young adult cancer survivors will be able to reflect on their experiences of connectedness across the cancer continuum including diagnosis, treatment, and survivorship. These findings will provide important information that can be used to develop future interventions to enhance adolescent patient-provider connectedness that *may* ultimately diminish risk-taking behaviors, foster health care self-management, resilience, and improve survivorship outcomes of adolescents with cancer. The next section presents the feasibility evidence of conducting an empirical phenomenology study on connectedness with young adult cancer survivors.

Preliminary Study II: Feasibility and Acceptability Pilot Study

In the spring of 2007, a pilot study was conducted to determine the feasibility of the proposed dissertation research. Colaizzi's (1978) method of empirical phenomenology was used for data collection and analysis. The purposes of the pilot study were to examine practical issues related to recruitment, data collection procedures (including participants' abilities to understand the data-generating question and provide meaningful data), and to gain a preliminary sense of performing data analysis.

Recruitment Procedures

Recruitment for the pilot study was initiated after obtaining approval from both the Scientific Review Committee (SRC) and Institutional Review Board (IRB) at Indiana

University-Purdue University, Indianapolis. Participants were recruited from the Cancer Survivor Clinic at Riley Hospital for Children. The pediatric nurse practitioner of the clinic initially approached potential participants to discuss the study and ascertain interest in participation. For those interested in participating, permission was sought before the nurse practitioner released his/her name and contact information to me. The nurse practitioner then provided me with the patient's preferred means of initial contact, which either was by telephone or via email. After the participant had given his/her verbal consent to participate in the study, a time and place for the interview that was convenient for the participant was arranged. In addition, a packet of information was mailed to each participant ahead of time that included (1) a letter containing study information; (2) the informed consent form; and (3) a copy of the data-generation question so they had time to reflect on their experiences of connectedness with healthcare providers.

Problem Identified. Recruitment of participants worked well; however, one problem was identified. Although all of the approached participants were successfully enrolled, very few survivors who met the eligibility criteria could be easily identified based solely on those who were coming into the cancer survivor clinic for their follow-up visit. Therefore, an amendment to the recruitment procedure was submitted and approved by the IRB. This additional recruitment mechanism involved having the physician director of the Cancer Survivor Clinic at Riley Hospital for Children mail a letter to study eligible participants describing the purpose of the study and providing an "opt out" option if participants did not want to receive a phone call access their interest in participating.

Data Collection Procedures

The second purpose of the pilot study was to examine whether or not the data collection procedures elicited rich descriptions of connectedness with healthcare providers. When using an empirical phenomenology approach, detailed descriptions of

an experience are gathered through a minimum number of broad data-generating questions (Cresswell, 1998). The goal of each interview is to obtain as clear and rich a description of the experience as possible and to insure that the participant, not the interviewer, determines the specific details of the experience that are discussed (Giorgi, 2005). Based on the pilot interviews conducted, the procedures for data collection were found to be effective. Lengths of interviews have ranged from around 20 minutes to over one hour. The data-generating question elicited a broad range of experiences and rich data. Participants understood the term connectedness and could fully describe their experiences. Thus, the data collection procedures seemed appropriate.

Data Analysis

Data were analyzed using Colaizzi's method. A detailed description of this method is presented in Chapter III. Briefly, the method involves a systematic, step-by-step process of extracting and analyzing statements for meaning and themes and then comparing themes across participants to arrive at a description of the essential structure of a phenomenon. The procedures for analysis were found to be effective to identify emerging themes and, thus, were not changed for the dissertation study. Additionally, data obtained and analyzed for the pilot study were combined into the larger dissertation study.

Preliminary Results

Sample. Three young adult cancer survivors were interviewed for the pilot study. Two participants were female and one was male. The pilot sample was incorporated into the sample for the larger dissertation study and is fully described in Chapter IV.

Preliminary Themes. Three preliminary themes emerged from the pilot data; *Genuine Connectedness – Displaying a Unique Appreciation for ME; In a League of Their Own – Not Just Your Ordinary Healthcare Provider; and Beware: Violators Will Be Prosecuted.* These preliminary themes were bracketed when analyzing data as a whole

for the larger dissertation study. Pilot data were combined with data, themes, and outlines derived from the dissertation study.

Summary

The pilot study provides support for the feasibility of the dissertation research, including (1) efficacy of the recruitment strategy; however, an additional recruitment strategy was needed; (2) appropriateness of the question for obtaining a full description of connectedness with healthcare providers; (3) ability of young adult cancer survivors' to recall the cancer continuum (3 to 5 years post-diagnosis); and (4) the importance of understanding the underlying perspectives that influence connectedness with healthcare providers. Additionally, the preliminary themes help illustrate the richness of the findings. Because the pilot study indicated the procedures were all feasible and acceptable, no changes, except the addition of another recruitment strategy, were made for the dissertation and pilot data were combined with the data collected for the dissertation study.

Chapter Summary

This chapter presented a review of the conceptual, theoretical, and methodological issues of examining connectedness with healthcare providers and a discussion of preliminary studies. Historical attempts to conceptualize patient-provider relationships have not been sufficient and there is a limited understanding of how patients' perceive their relationship with healthcare providers. Research on patient-provider communication indicates that communication is likely to be a contributor to connectedness; however, little research has been devoted to understanding patients' perception of this phenomenon. Additionally, little is known about the experiences of

communication and connectedness between adolescents with cancer and their healthcare providers.

Results of the concept analysis of connectedness revealed that further work is needed to clarify this concept. Research that provides a clearer description of the characteristics, antecedents, and consequences of connectedness with healthcare providers could provide a foundation for further concept and instrument development. Pilot study results indicated that the proposed procedures for studying connectedness with healthcare providers are adequate.

CHAPTER III

METHODOLOGY

This chapter describes the research approach and methods used to examine young adult cancer survivors' experiences of connectedness with healthcare providers. The chapter begins with a description of and rationale for the research approach, followed by the ethical considerations related to this study. Sampling procedures and methods for data collection and analysis are then delineated. Lastly, a potential methodological limitation of this study is acknowledged and addressed.

Research Approach

The qualitative approach chosen for this study was empirical phenomenology (Husserl, 1970) using Colaizzi's methods (Colaizzi, 1978). The goal of phenomenology is to provide a rich description of the commonalities of meanings of experiences across participants. In this approach, unstructured, one-on-one interviews are conducted separately with each participant, using open-ended questions to elicit rich narratives of a particular experience. The narratives are then used to identify meanings of the experience. Once the meanings are identified, commonalities of meaning across participants are identified and exhaustively described. Finally, a description of the essential structure of the experience is developed and then validated by participants (Colaizzi, 1978). The specific steps that were used to describe the experiences of connectedness as perceived by young adult cancer survivors' are outlined in the *Data Analysis and Interpretation* section of this chapter. But first, let's briefly review the concept of phenomenological reduction.

As described in Chapter I, phenomenological reduction is a philosophical stance that a researcher must acquire prior to describing and examining the structure of a

phenomenon (Giorgi, 1997). This perspective can be achieved in two ways. First, the researcher must suspend his/her natural attitude in which one thinks that objects in the world exist independently from us and can be explained through causal relations. The second requirement is bracketing which involves setting aside any preconceived notions or ideas when listening to and reflecting on the participants' lived experience of the phenomenon. Strategies to ensure that I suspended the natural attitude and bracketed my own preconceived thoughts regarding the research topic are described in the section on trustworthiness and credibility.

Rationale for Approach

Empirical phenomenology was chosen as a first step in my program of research on adolescent patient-provider connectedness for the following reasons:

1. Little is known about the antecedents and attributes of connectedness with healthcare providers, and thus a qualitative approach was chosen as a first step in developing knowledge of connectedness.
2. Young adult cancer survivors who were diagnosed and treated for cancer during adolescence are likely to have experiences of connectedness with healthcare providers that are rich in meaning that have not previously been explicated.
3. The perceived meaning of the experiences of connectedness is likely to influence subsequent interactions (Thorne et al., 2005; Woods, 2006). Thus, personal experiences seem to be a logical first data source.
4. Empirical phenomenology has been a useful first step in other programs of research that ultimately are focused on developing and testing interventions to improve patient quality of life outcomes, including my mentor's research on resilience (Haase, Heiney, Ruccione, & Stutzer, 1999).

5. Empirical phenomenology is accomplished primarily from a systematic analysis of the actual words used by participants to describe an experience, which is important for identifying or developing reliable and valid measures to evaluate interventions.
6. The products of empirical phenomenology - both the exhaustive description and the essential structure of the experience - will be rich sources of information for developing future interventions, since they reveal the young adult cancer survivor's perspective of the ways connectedness occurs - or doesn't occur.
7. Colaizzi's (1978) method involves a systematic, step-by-step process that provides a beginning empirical phenomenologist with enough structure to reduce the likelihood of premature closure to analysis and can be used to apply criteria for evaluation of trustworthiness and credibility to the findings.

Ethical Considerations

Ethical considerations related to this study included upholding the ethical principles of human subjects research, balancing the benefits and risks, obtaining informed consent, and submitting the proposal for institutional review. Human subjects approval for this study was obtained by both the Institutional Review Board (IRB) and Scientific Review Committee at Indiana University-Purdue University Indianapolis/Clarian. The letter of approval from the IRB can be found in Appendix A.

Upholding the Ethical Principles of Human Subjects Research

In 1979, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research published the Belmont Report that summarizes the three basic ethical principles that must be upheld when conducting research with human subjects. These principles include respect for persons, beneficence, and justice. Respect for persons requires that all subjects to be treated as autonomous agents and

that special protection should be provided to those who may be incapable of self-determination. For this study, respect was demonstrated by providing participants with adequate information about study procedures and allowing them to voluntarily choose to participate. Beneficence involves maximizing the potential benefits of the research, while minimizing subjects' risk for harm. This principle was maintained by implementing procedures to minimize risks described in the next section. Justice in human subjects research relates to the equal distribution of burdens and benefits associated with research, so that particular individuals or groups do not bear the risks while others reap the benefits. Fairness was sustained by providing all potentially eligible participants the opportunity to participate. Additionally, procedures were the same for all.

Balancing the Benefits and Risks of the Study

Benefits and risks associated with this study were minimal. One benefit identified by participants was a sense of gratitude for having the opportunity to share their experiences with me. Additionally, the knowledge gained from this research may benefit future patients through deepening an understanding of the experiences of connectedness with healthcare providers. Risks associated with this study were believed to be uncommon or relatively minor in severity. Risks of completing the interview for participants could have included feeling uncomfortable answering the questions or feeling too tired to complete the interview. Another risk was the possibility of the loss of confidentiality. The following is a description of the procedures that were carried out to ensure that these risks were minimized.

Procedures to Minimize Risks. I personally conducted all interviews. Precautions such as privacy and creating a relaxed atmosphere were paramount in reducing any associated anxiety. This type of environment was created by allowing participants to choose a location that was quiet and free from distraction. During the interview, participants were reminded that their participation was voluntary and that they may

refuse to answer any question and end the interview at any point in time. None of the participants expressed any discomfort while completing the interview. Additionally, no participants ended the interview prematurely or refused to answer any questions. In fact, participants were fully engaged in responding to questions and provided rich descriptions of their experiences of connectedness with healthcare providers.

A follow-up phone call was made to each participant within 48 hours after the interview to assess how the participant was doing post-interview and to ask if he/she had any questions or concerns. If there was any indication of distress noted during the follow-up call that required professional healthcare attention, the following steps would have been taken. These steps were not enacted because none of the participants indicated any distress.

1. The participant would have been asked if he/she had a primary care provider that he/she could talk to about any concerns. If yes, the individual would have then been encouraged to contact the primary care provider. If no, the contact information of local mental health resources, as well as information of the Riley Hospital for Children Cancer Survivor Clinic, would have been provided. The participant would have then been encouraged to identify and contact one of those resources to obtain follow-up care.
2. In either case, the investigator would have made arrangements to call the participant within 48 hours to see if he/she was able to make arrangements for follow-up care. If the participant had any difficulty obtaining mental health care he/she desired to have, the investigator would have assisted the participant to contact the Riley Hospital for Children Cancer Survivor Clinic to assist with appropriate referrals.

3. A report of adverse events would have been completed according to IRB guidelines to include the nature of the concern and actions taken for follow-up.

Efforts were also made to keep participants' information confidential. The risks to breach of confidentiality were minimal as names and identifying information were removed from the transcribed data. Code numbers were assigned to a participant's name and identifying information was kept separate from data in a locked file cabinet. Analysis of transcripts did not have any names (i.e., names of people, facilities, or places) associated with them.

Obtaining Informed Consent

Informed consent involves providing adequate information to ensure that potential participants understand and comprehend the nature and scope of the research. All participants who participated in this study were provided detailed information about the study purpose and procedures, associated risks and benefits, assurance of confidentiality, and provided the option to withdraw at any time. A copy of the approved informed consent form is in Appendix B. All signed consent forms were stored in a locked cabinet in the Center for Research and Scholarship in the School of Nursing and kept separate from interview information.

Sample

Sampling Method, Size, and Sample Inclusion/Exclusion Criteria

A purposive sample of nine young adult cancer survivors, who were diagnosed and treated for cancer during adolescence, was recruited. Purposive sampling is often used in phenomenological inquiry by selecting participants who have had experience with the phenomenon of interest and can give rich descriptions (Speziale & Carpenter, 2003). This type of sampling also helps ensure that multiple realities will be uncovered. It

was anticipated that a sample of 10 to 15 participants would be needed for this study. In qualitative research, the sample size is not determined a priori, but is related to the expectation that redundancy of themes drawn from the data will be achieved with a relatively small number of participants (Lincoln & Guba, 1985). In phenomenological research, the sample generally ranges from 5 - 25 (Cresswell, 1998). In this study, redundancy of themes was reached with a sample of 9 participants.

Because empirical phenomenology is used to describe the commonalities across experiences among diverse samples, no effort was made to control for the following demographic and clinical variables: age, gender, race, ethnicity, education, religious preference, socioeconomic status, marital status, cultural background, type of childhood/adolescent cancer, type of treatment, or length of time since diagnosis. However, demographic and clinical data were collected to provide a full and rich description of the sample. In order to achieve as diverse a sample as possible for gender and ethnicity, sample characteristics were evaluated after the fourth participant was enrolled. At that time, a list of under-represented minority young adult cancer survivors was obtained from the Cancer Survivor Clinic at Riley Hospital for Children in order to increase the diversity of the sample. Only five individuals were identified and numerous phone call efforts were made to contact these individuals.

Table 3.1 lists the inclusion and exclusion criteria that were used in the proposed study. The rationale for choosing to interview young adult cancer survivors who were diagnosed and treated for cancer during adolescence was that they have experienced the cancer continuum from diagnosis through treatment and survivorship. Thus, they have had time to reflect on their experiences with healthcare providers across the cancer continuum and, based on preliminary feasibility information, are able to fully describe their experience as a transitioning young adult. The rationale for interviewing survivors who have completed treatment for at least one year was because these individuals have

had time away from the traumatic event of being diagnosed and treated for a life-threatening illness. The rationale for interviewing survivors up to 9 years post-diagnosis was because the literature, as well as the preliminary interviews, indicates that individuals of a traumatic event can vividly remember the experience for many years (Jost & Haase, 1989; Morse, 1991).

Table 3.1 Inclusion and Exclusion Criteria

Inclusion Criteria:

1. Survivor of a childhood/adolescent cancer (i.e., not a cancer typically diagnosed in adults such as breast cancer).
2. Diagnosed and treated for cancer as an adolescent (ages 15 to 21 years).
3. Current age is between 18 and 24 years.
4. Treatment completed at least one year ago and no longer than 9 years previously.
5. Able to speak and understand English.
6. Able and willing to fully describe their experience of connectedness with healthcare providers.

Exclusion Criterion: Diagnosis of a major mood disorder, such as bipolar disorder or schizophrenia, which would preclude providing a full and accurate description of their experience.

Recruitment Procedure

Participants for this study were recruited from the Cancer Survivor Clinic at Riley Hospital for Children, adhering to IRB and HIPAA guidelines. The physician director of the survivor clinic or pediatric nurse practitioners initially approached potential participants to discuss the study and ascertain interest in participation. For those interested in participating, a letter containing the study information was provided. If a patient expressed an interest and gave permission for his/her name and contact information to be released, the referring provider then provided me with the patient's preferred means of initial contact, which was either done in the clinic, via the telephone or by email. After the participant gave his/her verbal consent to participate in

the study, a time and place for the interview was convenient for the participant was arranged.

Because recruitment using the above procedure was slow, a second strategy was implemented. The Cancer Center staff at Riley Hospital for Children generated a list of eligible young adult cancer survivors and the physician director of the survivor clinic sent letters to eligible participants describing the study. The letter contained a toll-free number for the young adult cancer survivor to opt out if he/she was not interested in receiving a phone call about the study. If the young adult cancer survivor did not opt out, then he/she was considered willing to participate (See Appendix D for a copy of the letter). From the list of potential participants willing to participate 8 were randomly selected and telephoned to further assess interest and eligibility. Of those selected for a phone call, 4 were not actually reachable (i.e., they did not answer the phone and/or did not return messages left on answering machines or with others in the household). All participants who were actually reached by phone agreed to participate.

Data Collection and Analysis

Data Collection Procedure

Prior to data collection, I thoroughly explained the study and obtained informed consent by reviewing the necessary information with the participant. Participants were then asked to complete the demographic and clinical questionnaire by self-report. I conducted all of the interviews, which were audio-digital recorded. Data were collected during face-to-face interviews at a time and location convenient to the participant, which was either in the participant's home or a private area in the Outpatient Clinic. Strategies such as asking that televisions to be turned off and putting "do not disturb" signs on the door were used to assure the setting was quiet and there are no or minimal interruptions.

To facilitate a rich description of the experience of connectedness, a mailed, written copy of the data-generating question were provided to the participants at least three days ahead of time and participants were encouraged to think about their experiences prior to the day of the interview. Such a strategy has been effective in obtaining full descriptions of an experience in previous studies (Haase, 1987; Haase & Rostad, 1994; Leidy & Haase, 1999) and was found to be helpful to survivors who participated in the pilot study. Participants were told that their confidentiality would be maintained by keeping identifying information separate from data and pseudonyms were used in place of names during the recorded interviews, analysis, and presentations of the findings. Participants were also told their participation was voluntary and that they may stop at any time.

Instruments (Method of Questioning)

To address the aim of this study, an unstructured, audio-digital recorded interview was conducted with each participant. In empirical phenomenology, detailed descriptions of an experience are elicited through a minimum number of broad data-generating questions (Cresswell, 1998). Data to describe young adult cancer survivors' experiences of connectedness with their healthcare providers during diagnosis and treatment for cancer during adolescence was obtained using the following data-generating question:

Please tell me about your experiences of connectedness with healthcare providers. Perhaps you experienced a strong connection with a healthcare provider. Perhaps you perceived yourself as never being connected with a healthcare provider. Or you might have experienced a connection but then became disconnected from your healthcare provider for some reason. Whatever your experiences were, I would like to hear about them. It is sometimes most useful to tell your experiences as a story, starting at the beginning of your contact

with healthcare providers. Please describe your experience as fully as you can, including all the circumstances, thoughts, and feelings you can remember.

The goal of each interview was to obtain as clear and rich a description of the experience as possible and to insure that the participant, not the interviewer, determined the specific details of the experience that were discussed (Giorgi, 2005). Full descriptions (i.e., participant-provided narratives) of experiences are quite different from participant analyses of experience and *not* the goal of empirical phenomenological interviews. The data-generating question was given to participants at least three days prior to the interview so that they could thoughtfully reflect on their experiences to provide rich descriptions based on thoughtful reflection.

Because empirical phenomenologists are interested in narratives of experiences, “interview-by-comment” strategies were used on topics raised by the participant, rather than a set agenda of items to cover (Snow, Zurcher, & Sjoberg, 1982). Examples of interview-by-comment strategies are open-ended probes such as, “Please tell me more about that” and “What did that mean to you?” and reflections of the informants’ statements, for instance, “So you feel.....?”. The interviewer literally interviews based on participant comments. These strategies have been used successfully in several studies (Haase, 1987; Haase & Rostad, 1994; Leidy & Haase, 1999) and were found to be helpful in this dissertation study.

Participants did not have difficulty beginning the interview and understood the term connectedness. Occasionally, participants asked for more questions in order to recall more experiences. Participants were encouraged to continue talking until he/she felt the experience was fully described. The interviews lasted between 15 and 99 (M = 43.2) minutes, which is consistent with reports from other phenomenological studies with adolescents/young adults (Dickinson & O'Reilly, 2004; Haase, 1987; Langeveld, Ubbink, & Smets, 2000; Turner et al., 2005).

A demographic and clinical data form was developed for this study. This form was based on literature indicating key factors that may be important for a full description of the sample. Variables included age, gender, race, ethnicity, age at diagnosis, time since diagnosis, type of cancer, date treatment (i.e., chemotherapy and/or radiation) was completed, education level and current school status, current living situation, and access to healthcare including frequency of visits to cancer-related healthcare provider and health care insurance status. A copy of this form is in Appendix C.

Data Analysis and Interpretation

All audio-digital recorded data from participants were downloaded into a secure server and then transcribed verbatim by professional transcriptionist. I checked each transcription for accuracy. Demographic and clinical data was used to describe the sample. The transcribed qualitative data was managed using features of Microsoft Word, including tables for steps of transforming raw data to formulated meanings within each interview (protocol) and using MSWord Outline for organizing themes across protocols.

Narrative data was analyzed using an seven-step procedure adapted from Colaizzi (1978) that has been used by my mentor in several studies (Haase, 1987; Haase & Rostad, 1994; Leidy & Haase, 1999). Analysis steps included (1) reading the interviews several times to get a sense of the meanings being conveyed; (2) identifying substantive phrases in the data; (3) restating the phrases in general terms; (4) identifying formulated meanings of the phrases; (5) validating the meanings with other experts; (6) identifying and organizing common themes across all the participants' data into theme categories and clusters; and (7) developing a full description of the common themes of the experience. An example of steps 2 through 4 is illustrated in Table 3.2. Analysis was done both individually and collaboratively with my mentor, Dr. Haase, a second PhD prepared nurse with expertise in phenomenology, and to varying degrees, other members of my committee. I independently performed steps 1 through 4 of analysis.

Then Step 5, validation of themes, was done collaboratively. Step 6 and 7 were initially completed independently and then validated with collaborators until a consensus was reached.

Table 3.2 Examples of Significant Statements, Re-Statements, and Formulated Meanings

Significant Statements	Re-Statements	Formulated Meanings
1.131 I don't like going up there for my checkups, even though I still need to continue doing it,	1.131 Dislikes going to follow-up visits even though it's necessary	1.131 Despite the fear related to follow-up, musters courage to continue going, knowing it is important and there are no sane alternatives.
1.132 but when Dr. ___ is there, he just makes me feel secure.	1.132 Despite the fear related to follow-up, Dr. ___ instills security	1.132 Connectedness with special MD contributes to a sense of security, even in the midst of facing the frightening possibilities inherent in the clinic visit.
1.133 He really makes me really feel like he knows what he's doing,	1.133 Feels secure because doctor demonstrates competence	1.133 Sense of comfort and relief in knowing that the physician is capable of tackling any problems that may be detected.

Data Safety

All audio-digital recorded, transcribed interviews, and subsequent, tracked analyses were stored on the School of Nursing server that is password-protected. Only I and my mentor had access to the data and analysis. Confidentiality of the participants were protected by providing pseudonyms and changing any identifying information revealed in the transcription (i.e., names of people, facilities, and places).

Trustworthiness and Credibility Strategies

In qualitative research, it is important to have criteria for evaluation of trustworthiness and credibility of the research findings, as noted by several authors (Appleton, 1995; Guba & Lincoln, 1981; Morrow, 2005; Sandelowski, 1986; Tobin & Begley, 2004). Trustworthiness refers to the study finding's applicability, truth value,

consistency, and neutrality and these are established by creating adequate procedures for an audit trail and an adherence to the methodology used to examine the data (Guba & Lincoln, 1981; Sandelowski, 1986). Trustworthiness and credibility was established in several ways. (1) A rigorous self-examination of biases and presuppositions was written, discussed with my mentor, and then bracketed during the conduct of the interviews and analysis of the data. (2) Colaizzi's method (1978) of data analysis was systematically applied. (3) The transcribed interviews and analysis steps 2 through 5 were reviewed with my mentor in bi-weekly meetings to assure that I am bracketing my own ideas and the formulated meanings reflect the participants' interview data. (4) An audit trail was maintained to assure each step of analysis can be traced back to the original protocol. (6) A full and rich description of the sample will be included in dissemination of findings.

Potential Methodological Limitation

There was one potential concern related to the research method. This concern was related to the rigor of the interview and data analysis process. During the interview process, two potential problems could have arisen: (1) the interviewer rather than the participant could have led the discussion; (2) the participant may have felt the need to analyze rather than to tell the story. Solutions that were implemented to minimize these problems included (1) acknowledging a personal awareness of the issues; (2) conducting a pilot study to further refine empirical phenomenological interviewing and analysis skills; and (3) having my mentor assist with quality assurance by listening to the first several audio-recorded interviews and providing feedback on how to obtain richer data. These solutions were successful in preventing these potential problems from occurring. During the analysis process, the problems that could have potentially arisen were premature closure and findings that do not accurately reflect the data. Solutions that were used to minimize these problems are described in the trustworthiness and

credibility strategies above. These solutions were effective and did not arise during the data analysis process.

Chapter Summary

This chapter provided an overview the research approach and methods used to examine young adult cancer survivors' experiences of connectedness with healthcare providers. Procedures for minimizing the risks related to participating in this study were found to be effective. Sampling procedures were efficient in enrolling 9 young adult cancer survivors. Data collection procedures were implemented as planned and participants fully engaged themselves in the interview and provided rich data. Data analysis strategies and collaboration efforts were found to be most useful. Rigor of the study was not jeopardized as potential problems were addressed ahead of time.

CHAPTER IV

RESULTS

This chapter presents the findings of this study. First, a description of the sample is provided. Second, narrative descriptions of the experiences of connectedness with healthcare providers are described from theme outlines. Third, the essential structure of connectedness is provided. Lastly, this chapter concludes with a summary of the findings.

Description of Sample

A detailed description of the sample is usually presented in most qualitative research reports. However, participants who participated in this study have had a long-term relationship with healthcare providers at the facility where they received cancer treatment. Therefore, it is possible that participants could easily be identified through a detailed description of sample demographics. Thus, in order to protect participants' confidentiality, the sample is described with summary data only.

Nine young adult cancer survivors participated in this dissertation research. Five were female and four were males. Eight participants were Caucasian, and one was African American. All participants declared a Non-Hispanic or Latino ethnicity. All participants were college students and had health insurance. The current age of the participants ranged from 20 to 23 ($M = 21.0$, $SD = 1.1$).

Each participant was diagnosed with cancer during adolescence. Age at diagnosis ranged from 15 to 18 ($M = 16.1$, $SD = 1.2$). Three participants had been diagnosed with Osteosarcoma, two with Hodgkin's Lymphoma, two with Ovarian Germ Cell, one with Leukemia, and one with Non-Hodgkin's Lymphoma. Only one participant had encountered a relapse; however, this participant's initial treatment was surgery only.

When the cancer returned, adjuvant therapies (i.e., chemotherapy and/or radiation), similar to what the other participants had received, were administered; thus, this participants' cancer experience was similar to the other participants. Length of treatment ranged from 3 months to 38 months ($M = 11.1$, $SD = 10.6$). Years post-treatment at the time of the interview ranged from 1.5 to 5 years ($M = 3.7$, $SD = 1.0$).

While undergoing cancer treatment, all participants had at least one parent who was actively involved in their care. Three participants had a parent who was either a healthcare provider or who held an executive position within the hospital.

Seven participants were attending follow-up visits at the Cancer Survivor Clinic once a year, one participant was returning every four months, and one participant was no longer attending follow-up appointments. Eight participants visited a primary care provider at least once a year and one visited a primary care provider once a month. Three participants were living with their parents full-time, two were living away from their parents full-time, and four were living at college part-time and living with their parents part-time.

Narrative of Findings

A total of 2988 significant statements were extracted from participant interviews. Formulated meanings of each significant statement were then used to identify theme categories relevant to participants' experiences of connectedness with their healthcare providers. Seven theme categories were identified. A representation of the commonality of themes across participants is in Appendix E. In order to illustrate the representativeness of each theme, the numbers beside each theme in Appendix E represents the participants' assigned numbers, and they reflect that at least one significant statement was stated by that particular participant (i.e., Participants 1, 2, 3, 4, 5, 6, 7, 8, and 9 had significant statements related to Theme Category 1).

The presentation of the results is organized by theme categories. Each theme category is thoroughly explained by describing its subsequent theme clusters and themes that provide detailed descriptions of the participants' narrative. Theme categories and theme clusters are described using metaphors. Such metaphorical descriptions are occasionally used to enhance the vivid description of participants' experiences when appropriate. Using metaphors to describe experiences has been employed before in relaying other research findings (Beck, 2004). Additionally, exemplary quotes were used to support narratives of theme categories and clusters. An effort was made to include quotes from all of the participants and no repetitive quotes were used to support the narratives. Names of people, facilities, and places were replaced with pseudonyms in order to protect the confidentiality of participants.

In phenomenology, it is not necessary for all participants to have statements representative of themes; decisions are made about the possible universality of the experience (Colaizzi, 1978). Under the assumption that it is probable that not all participants will touch on all themes, the researcher makes decisions regarding whether it is conceivable that all participants could have experienced the theme. Summary statements are used to describe themes; these summary statements are derived from the patterns discerned from multiple formulated meanings.

Seven theme categories were identified related to participants' experiences of connectedness. Table 4.1 is an overview of the theme categories and clusters derived from participant data. Each theme category is then described separately, along with a detailed description of theme clusters. The order of theme categories reflects sequences of events as they were described over time.

Table 4.1 Overview of Theme Categories and Theme Clusters

Theme Categories	Theme Clusters
The Context for Connectedness - A Cancer Diagnosis is Like a Terrorist Attack; It is a Time of Traumatic Confusion, Frustration, Fear, and Vulnerability	<ul style="list-style-type: none"> • What's Going On? Events Surrounding the Diagnosis Are Like a Terrorist Attack • Memories of Traumatic Events Takes Some Prompting • Describing Experiences Connectedness are Very Difficult to Tease Out Because of the Uniqueness of the Connections • Life Before and After the Terrorist Attack - Diagnosis as a Life Changing Experience that Makes Oneself and All Things Different
Collisions and Detours to Connectedness - Untenable Circumstances that Hinder the Ability to Connect	<ul style="list-style-type: none"> • The Sudden Collision - Cancer Diagnosis • Looking for Guidance through the Collision • Stuck in the Collision Zone - Feeling Trapped in an Environment • Wanting to Detour and Go Back Home - Emotional Things that Hinder the Desire to Connect • Dealing with the Aftermath of the Sudden Collision - Physical and Illness-Related Impediments to Connectedness • The Collision Aftermath - Consequences of Unconnectedness
"If I Fall Back, Will You Catch Me?" - How Connectedness Begins	<ul style="list-style-type: none"> • "If I Let Go then I Can Connect" - Coming to an Acceptance Fosters the Ability and Desire to Connect with Healthcare Providers • Sometimes it is a Two-Way Street - Strategies the Adolescent Uses to Connect with Healthcare Providers
A Connectedness Primer for Healthcare Providers	<ul style="list-style-type: none"> • Strategies Healthcare Providers Use to Facilitate Connectedness • When There is a Connection • On the Perfect Date - Blown Away Good Happens When Healthcare Providers and Adolescents Connect So Well • A Dream-Come-True - Sense of Gratitude
Tortured in a Prison Camp - Healthcare Providers Who Violate and Destroy Connections	<ul style="list-style-type: none"> • Introduction to the Prison Culture - Guards that Foster Disconnectedness from the Beginning • Cruel Prison Guards - Healthcare Providers who Violate Ethical Principles of Respect for Personhood • A POW Experience - Reactions when Ethical Principles of Respect for Personhood are Violated • The Aftermath of Being a POW -

Theme Categories

Theme Clusters

Parental Lenses - Parents Role in the Adolescents' Connectedness with Healthcare Providers

Now What? Life after High School Graduation - Connectedness in Survivorship

Consequences of Disconnectedness

- Looking through My Parent's Glasses - When Parents Make the Initial Connection
- Bifocals - Looking at Connectedness in Two Ways
- Majoring in Adulthood with a Minor in Adolescence - The Downside of Letting Go and Transitioning to New Healthcare Providers
- Reconnecting is Like a High School Reunion - Getting a Connectedness Recharge

Theme Category 1. The Context for Connectedness - A Cancer Diagnosis is Like a Terrorist Attack; It is a Time of Traumatic Confusion, Frustration, Fear, and Vulnerability

Before participants could fully describe their experiences of connectedness with healthcare providers, they talked about the context of the cancer diagnosis. Receiving the diagnosis of cancer is an unexpected time of traumatic confusion, frustration, fear, and vulnerability - much like a terrorist attack. The context of the diagnosis sets the stage for connectedness. Theme category one has four theme clusters (see Table 4.2).

Table 4.2 Theme Category 1

Theme Category	Theme Clusters	Themes
The Context for Connectedness - A Cancer Diagnosis is Like a Terrorist Attack; It is a Time of Traumatic Confusion, Frustration, Fear, and Vulnerability	What's Going On? Events Surrounding the Diagnosis Are Like a Terrorist Attack	<ul style="list-style-type: none"> • The timeframe • A completely unexpected awareness that something might be wrong • Obtaining a diagnosis was a struggle
	Memories of Traumatic Events Takes Some Prompting	<ul style="list-style-type: none"> • Difficulty in remembering subsequent details and needing questions to spark more memories
	Describing Experiences of Connectedness are Very Difficult to Tease Out Because of the Uniqueness of the Connections	<ul style="list-style-type: none"> • Elusive sense of what interactions/behaviors foster connectedness
	Life Before and After the Terrorist Attack - Diagnosis as a Life Changing Experience that Makes Oneself and All Things Different	<ul style="list-style-type: none"> • Diagnosed at a crucial time in social life - Set apart for the "in-crowd" • Lost time and opportunities that cannot be retrieved

Theme Cluster 1.1 What's Going On? Events Surrounding the Diagnosis Are Like a Terrorist Attack

The timeframe. Like many people who have survived a terrorist attack, participants in this dissertation study vividly remember the timeframe and setting during which they received their diagnosis. The moment of the diagnosis seems frozen in time with clear recollections of time-related events surrounding it. Participants precisely recall the date of diagnosis or age at diagnosis. For example, one participant began the interview by saying: "I'll start from the beginning then. [December 30th, 2005], I was diagnosed with leukemia. It was just after my Christmas vacation. I went back and noticed I was having a lot of trouble walking around" [8.001-8.003].

A completely unexpected awareness that something might be wrong. Part of the trauma surrounding the participants' initial diagnosis comes from feeling blindsided by

the cancer. Participants consistently described being in situations they thought were safe and comfortable (e.g., in church, at work, at school) when they first recognized something was wrong: “It was [at] a school play...and I felt a lump” [7.060]. Initially, participants described brushing off the severity of threat as if it was nothing to be concerned about. Yet, as the threatening symptoms lingered, participants described becoming concerned enough to seek medical attention: “I had problems with my face, and so it would go numb and it would hurt really bad...So, I had to leave school early one day to go to the Emergency Room...” [8.005-8.007].

Obtaining a diagnosis was a struggle. One particularly frustrating aspect of the participants’ diagnosis experience is the difficulty of finding out what is going on. The difficulty of obtaining a diagnosis of cancer is a difficult experience that is further compounded by experiences of being misdiagnosed or misinformed during the initial consultation. “I had gone to every major hospital in the city and they kept telling me I had strep throat. I mean it was so bad they kept giving me antibiotics but the antibiotics were making it worse because my immune system was so low. Then I went to [City’s Health Center]... and they drew blood and sent me to get a chest x-ray and they saw a mass in the chest x-ray” [3.002-3.004]. The situation becomes even more frustrating when there is an extensive period of time of waiting and worrying before the diagnosis is confirmed.

Theme Cluster 1.2 Memories of Traumatic Events Take Some Prompting

Difficulty in remembering subsequent details and needing questions to spark more memories. While some aspects of traumatic events stand out clearly, others are fuzzy or difficult to remember. In some ways, recalling the diagnosis enhances certain memories, but in other ways, such as initially recalling experiences of connectedness, participants have difficulty remembering details of their experiences: “I don’t honestly remember all that much from my first round [of chemotherapy], because of everything I

went through. I don't know if I blocked it out or just kind of don't remember" [8.50-8.051]. To help spark memories of more connectedness experiences, participants recognize the need to ask the researcher for additional questions: "Do you have any more questions that might prompt me to think of things?" [4.102]. Additionally, untapped experiences of connectedness reveal themselves through talking. For example, one participant recalled a meaningful interaction she had with the nurse and said: "I had forgotten all about that one actually. I don't know where it [the memory] came from" [4.180].

Theme Cluster 1.3 Describing Experiences of Connectedness are Very Difficult to Tease Out because of the Uniqueness of the Connections

For participants, connectedness is an elusive experience that is difficult to describe outside of providing examples, because each experience of connectedness is unique and special in its own way. In addition, participants have a sense that not everyone connects in the same way, and describing behaviors and interactions that foster their connectedness is necessarily abstract and hard to pin down. One participant commented: "I don't know, I can't really explain what she [nurse] does or what she ever did. It's just that she was always really friendly. She's like 'hey, how are you doing today?' She always called me honey. I always remember that. I don't know, I can't really explain that part" [4.033-4.038]. Although this participant sounds as if she could not identify the actions that foster connectedness, she later described specific examples of how the nurse was considerate of her feelings and displayed a personal interest in her well-being.

Theme Cluster 1.4 Life Before and After the Terrorist Attack - Diagnosis as a Life Changing Experience that Makes Oneself and All Things Different

Diagnosed at a crucial time in social life - Set apart from the "in-crowd".

Participants describe their life before and after the diagnosis, particularly how it makes life more challenging and interferes with normal connections adolescents wish to make, such as being with peers. One of the most troubling matters is being set apart from the much desired in-crowd: "It was about two months into my first high school year at [West High]. That was hard because socially, you want to get into the in-crowd as quickly as possible" [5.002-5.004].

Lost time and opportunities that cannot be retrieved. Participants experience lost time and opportunities when undergoing cancer treatment. One participant commented on how originally he thought the cancer treatment would not last long: "I was like yeah, I'll be out of here in like 6 months, I'll be fine, don't worry about it. Then two years later I'm like 'I'm done. I'm sickly but I'm done'...I ended up missing a whole lot of school that I had to make up" [6.096-6.099].

Theme Category 2. Collisions and Detours to Connectedness -

Untenable Circumstances that Hinder the Ability to Connect

Participants recognize that there are difficult circumstances that hinder both their ability and their willingness to connect with healthcare providers. The barriers to connectedness are most difficult to overcome at the time of diagnosis; some are dispelled once participants make sense of their diagnosis, what is happening to them, and come to know the strangers who are trying to help them. However, other challenges remain and continue to prevent participants from connecting with their healthcare providers. When participants are unable to connect with their healthcare providers - they

are left with a sense of unconnectedness. This theme category has six theme clusters (see Table 4.3).

Table 4.3 Theme Category 2

Theme Category	Theme Clusters	Themes
Collisions and Detours to Connectedness - Untenable Circumstances that Hinder the Ability to Connect	The Sudden Collision - Cancer Diagnosis	<ul style="list-style-type: none"> • Sense of one's world being turned upside down in a matter of minutes • At a complete loss - Sense of being numb or paralyzed • Sense of loneliness and despair - Unable to take in healthcare providers' efforts to connect • Sense of being surrounded by strangers who don't know me
	Looking for Guidance through the Collision	<ul style="list-style-type: none"> • Adolescents' assessment of healthcare provider characteristics • Limited knowledge of adolescent lingo • To connect or to not connect, that is the question - Certain healthcare providers trigger an unwillingness to connect
	Stuck in the Collision Zone - Feeling Trapped in an Intolerable Environment	<ul style="list-style-type: none"> • Circumstances that make the environment feel intolerable
	Wanting to Detour and Go Back Home - Emotional Things that Hinder the Desire to Connect	<ul style="list-style-type: none"> • Wanting to be anywhere but the hospital • In a bad mood
	Dealing with the Aftermath of the Sudden Collision - Physical and Illness-Related Impediments to Connectedness	<ul style="list-style-type: none"> • Side effects/symptom distress • The "not so nice" medications
	The Collision Aftermath - Consequences of Unconnectedness	

Theme Cluster 2.1 The Sudden Collision - Cancer Diagnosis

Sense of one's world being turned upside down in a matter of minutes. Much like being involved in a sudden collision and trying to make sense of what has happened, the cancer diagnosis is a time when participants try to grasp what is going on. Participants experience this moment as a time when, in the midst of coasting along in life, their world turns upside down in a matter of minutes. The life-threatening diagnosis of cancer is a sudden, devastating event that interrupts the life route participants were once traveling. Participants are so taken aback by the news that it's difficult to comprehend the reality of the situation. Additionally, when the diagnosis is presented in a matter of fact, everyday manner, as if cancer is normal, it immediately creates diversions from connectedness. "They [the doctors] took me into a little office and came in and just said 'I am sorry but you have Hodgkin's disease'...and [then] asked me where I wanted to be treated...I was in shock. I didn't know where I wanted to go. I didn't want to go anywhere...I thought they were lying...I don't have that" [3.010-3.015].

At a complete loss - Sense of being numb or paralyzed. Like being involved in a sudden collision that shocks the system, participants experience a sense of being at a complete loss; a sense of being numb or paralyzed by the intense flood of frightening emotions. For example, one participant explained: "That was the hardest part because I knew if I woke up and had a port, that meant I had cancer...that was the first thing that I checked...so that was difficult, really difficult..." [5.104-5.020]. Confirming one's own diagnosis, while alone post-surgery, interferes with the ability to connect with healthcare providers.

Sense of loneliness and despair - Unable to take in healthcare providers' efforts to connect. As the diagnosis sets in, participants experience a powerful sense of loneliness and despair. Participants are overwhelmed to the point that they are unable to take in healthcare providers' efforts to connect. One participant described this

experience as being stuck in the 'feeling sorry for myself phase' and said: "I thought...I am going to have this thing hanging on my chest and I am going to be a freak and nobody is going to want to talk to me. I just wanted to sleep all of the time. I didn't want to wake up...I felt sorry for myself" [3.209-3.214].

Sense of being surrounded by strangers who don't know me. Often at the scene of a major accident, many strangers gather around trying to help, which can add to the chaos and confusion of the wreck. Similarly, at the beginning of the cancer illness and treatments, participants experience a sense of being surrounded by strangers. Waking up in an unfamiliar and frightening environment, there is a sense of being beset by a myriad of unfamiliar healthcare providers coming in and out of the hospital room. Often, this is the participant's first time being in the hospital. One participant commented: "I was a little scared at first. They put me in isolation, in a room separate by myself for the first time, and I had a lot of people in and out, which was a little awkward for me because I was 16, [a] teenager" [7.012-7.014]. Being surrounded by unfamiliar people, in an unfamiliar environment, contributes to the difficulties in making connections with healthcare providers.

Theme Cluster 2.2 Looking for Guidance through the Collision

Adolescents' assessment of healthcare provider characteristics. Participants carefully assess healthcare provider characteristics before attempting to connect with them. Part of the assessment of whether connecting is worth it, is determining if the healthcare providers, themselves, can understand what life is like for an adolescent, who has just encountered a life-altering collision. If participants sense that healthcare providers do not understand or are unsympathetic about the stress their situation produces, then connectedness is less likely to occur. Participants described many healthcare provider characteristics that do not foster connectedness, such as being

awkwardly intrusive, unfriendly, hyper-vigilant, pushy, and unwilling to do more than the minimum. For example, one participant talked about having to interact with an unfriendly oncologist when her primary oncologist was absent and said: "...you could tell he [the oncologist] wasn't personable...I don't even know if I ever saw him smile. He was just always real serious" [4.272-4.274]. This type of unfriendliness closes the door to connectedness.

Limited knowledge of adolescent lingo. Another crucial part of participants' assessments of healthcare providers is the way in which healthcare providers communicate. Connectedness is improbable if healthcare providers display a limited knowledge of how to take care of and talk to an adolescent. For example, one participant described: "The nurses at [Hospital A], you could tell they were more adult nurses, or nurses for adults, than kids...they would come into my room and not know how to handle the situation when something would happen with me. They were great nurses, but...it was just that they lacked being able to interact with kids" [8.540-8.542].

To connect or to not connect, that is the question - Certain healthcare providers trigger an unwillingness to connect. According to participants, certain healthcare providers trigger an unwillingness to connect. There seems to be an instant judgment of liking or not liking, that is somewhat difficult for participants to explain and that is related to a non-explicit list of behaviors. For example, one participant described: "I guess there are some people you don't even have to know. You don't know anything about them...they [healthcare providers] would just walk in the room and I instantly [thought], I like you, [or] I don't like you, and that's kind of how it was" [2.102-2.108].

Theme Cluster 2.3 Stuck in the Collision Zone - Feeling Trapped in an Intolerable Environment

Circumstances that make the environment feel intolerable. Certain circumstances make participants feel as if they are trapped in an intolerable environment that they did not choose for themselves. Like being stuck in the collision zone, there are circumstances that make participants feel trapped in place they do not want to be, and such circumstances interfere with participants' ability to connect with healthcare providers. One of the most troubling circumstances for participants is the age-inappropriateness of the surroundings and activities. One participant described this as being stuck in a baby hospital: "I was 18 and...in a baby hospital...So I am like bored and I want to go home. I missed my friends. There is nothing but babies everywhere, crying" [3.134a-3.134d]. Other disturbing circumstances include smells within the hospital that provoke nausea and vomiting and having to experience one cascade of frightening, unfamiliar events after another.

Theme Cluster 2.4 Wanting to Detour and Go Back Home - Emotional Things that Hinder the Desire to Connect

Wanting to be anywhere but the hospital. Participants experience emotional circumstances within themselves that forces them to want to take a detour and metaphorically go back home. Having a strong desire to escape or withdraw, and needing to get in and out the hospital as quickly as possible, hinders one's desire to connect with healthcare providers. For example, one participant described having an overpowering desire to be anywhere but the hospital: "...I hated the hospital. It made me sick just to go in the hospital...I would have the nurses just keep me knocked out. They were waking me up, and they were getting on my nerves, so I really didn't give them the chance..." [1.026-1.030].

In a bad mood. Participants also recognize that their mood serves a role in connecting or not connecting with healthcare providers. Participants describe being in a bad mood, such as being grumpy and irritable, as hindering their desire to connect, as well as interfering with healthcare providers' willingness to even try to connect. One participant reported that she had a reputation with healthcare providers of being mean: "When they [healthcare providers] would all meet for rounds, everybody would talk about how they didn't want to go into my room because I was mean to them" [3.265].

Theme Cluster 2.5 Dealing with the Aftermath of the Collision - Physical and Illness-Related Impediments to Connectedness

Side effects/symptom distress. Because of the intense cancer treatment regimens, participants often feel too sick to talk which ultimately hinders their desire and willingness to connect. The side effects and symptom distress related to chemotherapy cause the most suffering. "I mean it was just horrible. A lot of throwing up. A lot, for hours. Just dry-heaving. Horrible, horrible pain" [6.227-6.230]. Although side effects are a hindrance to connectedness, they can also provide an opportunity for connectedness if healthcare providers' respond appropriately. Some of the actions that healthcare providers take that foster a sense of connectedness in the midst of suffering are described later under Theme Category 4.

The "not so nice" medications. Another impediment to connectedness is receiving the 'not so nice' medications. Participants feel overly drowsy and withdrawn when receiving certain types of medications. Additionally, some medications hinder the ability to be in control of one's attitude towards others because the medication interferes with mood regulation. For example, one participant described an experience where she verbally expressed her dislike of a healthcare provider: "One time I was on some other

drug, and it was like... 'I don't like you'. It was terrible. I didn't know that I was doing it" [2.024-2.025].

Theme Cluster 2.6 The Collision Aftermath - Consequences of Unconnectedness

Until participants are able overcome the circumstances of colliding with the diagnosis described above that hinder their ability and desire to connect, they experience negative emotional responses, such as anger and resentment, whenever they are compelled to interact with healthcare providers with whom they do not feel connected. One participant described: "...anytime the nurses would come in, at the end of their shift, and say; 'You have so and so [name of a certain nurse who would be working]'. I'm like, 'That sucks'... so when I would get this guy [the nurse the participant was unable to connect with], I was pretty irritated about it" [8.128-8.131]. When having no choice but to interact with healthcare providers with whom they feel unconnected, participants are unable to control sending out negative cues that they dislike the healthcare provider. They also find it difficult to relate to the healthcare provider. Other responses of unconnectedness include shutting down all avenues of communication, becoming a passive recipient of care, and being left with a sense that unconnected healthcare providers are not memorable.

Theme Category 3. "If I Fall Back, Will You Catch Me? -

How Connectedness Begins

In team building, games such as "If I fall back, will you catch me?" are often played. There is an underlying assumption that others who are playing the game can be trusted enough that one can blindly fall backwards and be caught. Likewise, there is a commitment on behalf of those behind the falling person that they will certainly not let them fall and hit the ground. Similar to this team building game, connectedness seems

to be reciprocal. Participants described certain circumstances that initially foster the desire to connect with healthcare providers. This theme category has two theme clusters (see Table 4.4).

Table 4.4 Theme Category 3

Theme Category	Theme Clusters	Themes
“If I Fall Back, Will You Catch Me?” - How Connectedness Begins	“If I Let Go then I Can Connect” – Coming to an Acceptance Fosters the Ability and Desire to Connect with Healthcare Providers and Others	<ul style="list-style-type: none"> • Acceptance of the illness, the need for help, and willingness to relinquish control • Acceptance is fostered by having the opportunity to gain a sense of comfort and familiarity with hospital, healthcare providers, and treatment routine
	Sometimes it is a Two-Way Street - Strategies the Adolescent Uses to Connect with Healthcare Providers	<ul style="list-style-type: none"> • Recognition of shared commonalities, experiences, or interest - Connecting thru common bonds • Other strategies

Theme Cluster 3.1 “If I Let Go then I Can Connect” - Coming to an Acceptance Fosters the Ability and Desire to Connect with Healthcare Providers and Others

Acceptance of the illness, the need for help, and willingness to relinquish control.

As participants begin to accept that they have cancer, they recognize that letting go fosters the ability and desire to connect with healthcare providers. Participants describe coming to an acceptance of the illness, understanding the need for help, and being willing to relinquish control as an early and crucial step in allowing oneself to connect. Letting go occurs by gaining an awareness of one’s existential plight, accepting the help being offered, and reconnecting with oneself. One participant described this awareness and said: “...I just decided I am sick whether I like it or not. I can either take the help they want to give me and fight this and hopefully be okay, or I can waste the help that they

are going to give me and feel sorry for myself and die...I didn't want to die so I had to stop feeling sorry for myself" [3.215-3.218].

Coming to an acceptance of their situation also allows participants to accept their new life circumstances and establish meaningful experiences with other cancer patients. For example, one participant described being terrified about losing her hair and looking dead, like the other cancer patients. But when her hair fell out, she surprisingly discovered the positive aspects of entering a new, more genuine, meaningful world and said: "...once I did [lose hair], it wasn't so bad...being on the cancer ward is different than being out in the world. Out here it's like if your hair isn't blond you're not cool and if you don't have big boobs and you don't have the right clothes and this and that. On the cancer ward everybody looks the same and everybody is wearing night clothes and house shoes...They don't look at you for what color your hair is or what clothes you are wearing...because you all look the same...They look at you for who you are" [3.230b-3.237].

Acceptance is fostered by having the opportunity to gain a sense of comfort and familiarity with hospital, healthcare providers, and treatment routine. Acceptance of participants' illnesses seems to occur when there are opportunities to gain a sense of comfort and familiarity with the hospital, healthcare providers, and treatment routine. Participants do not necessarily recognize familiarity as being part of 'coming to' acceptance; rather, they describe that gaining a sense of familiarity makes them begin to feel more comfortable. For example, one participant described being very intimidated and shy around healthcare providers during her initial diagnosis when she was only in the hospital for a few days; however, when she relapsed and returned to the hospital for an longer period of time, she talked about gaining a sense of familiarity and said: "It might have been me being there for a while and me realizing...it's not such a scary place. These people are actually [nice]... [4.103].

Theme Cluster 3.2 Sometimes it is a Two-Way Street - Strategies the Adolescent Uses to Connect with Healthcare Providers

Participants experience connectedness as reciprocal; in addition to healthcare providers' responsibilities to connect, participants also feel personally responsible for making efforts to connect. There are certain strategies that both adolescents and healthcare providers use to connect with one another. One particular strategy participants described is recognizing common bonds (i.e., experiences or personal interests) they share with healthcare providers.

Recognition of shared commonalities, experiences, or interest - Connecting through common bonds. Participants feel more inclined to connect when they discover common ground with healthcare providers. For example, one participant talked about connecting with a nurse who shared the same love and passion for music: "One of them [the nurses] was an organist, she played piano too, so when I was in the hospital, and she was in,...I'd get really excited because she would take me downstairs to this room that had a piano, and we could read duets and stuff together, and that was really fun" [9.020-9.021]. Interests that are actively shared between healthcare providers and adolescents seem to evoke and deepen the connectedness participants feel for the healthcare provider.

Other strategies. Participants indicated there are other strategies which encourage connectedness on their part. Other strategies include bringing items from home into the hospital, using humor when discussing procedures, initiating healthcare providers' sympathy when having to do silly school-related projects, and testing whether or not they can trust healthcare providers. For example, one participant described testing the extent of the oncologist's trust by covering her head: "...when I was feeling sorry for myself, I had my head under the blanket..., [Dr. Brown] comes in and he's like trying to tell us what is going on... My mom is like [Carrie] take that blanket off of your head and

listen...[Dr. Brown] said, 'she's listening'. I was listening. He knew. He knew that I had my mind set, I was feeling sorry for myself right then, but I was still listening" [3.269-3.274]. A sense of connectedness is fostered when healthcare providers recognize and respond positively to participants' efforts to connect.

Theme Category 4. A Connectedness Primer for Healthcare Providers

Historically, primers, or primary school books, were used by rulers, such as King Henry, to uniformly educate children living within the kingdom. Primers contained straightforward, yet essential information so children could learn to read, write, or spell. Primers therefore, contain basic, yet crucial information that allows the reader to develop a base of knowledge from which to be successful in their endeavors. Participants in this study vividly described basic, yet indispensable circumstances and strategies that advance connectedness with healthcare providers. Theme category four is conceptualized as a primer of simple, yet imperative actions and interactions that participants feel are basic for getting beyond the beginning stages of connectedness. Theme category four has four theme clusters (see Table 4.5).

Table 4.5 Theme Category 4

Theme Category	Theme Clusters	Themes
A Connectedness Primer for Healthcare Providers	Strategies Healthcare Providers Use to Facilitate Connectedness	<ul style="list-style-type: none"> • Connectedness worthy • Connectedness accessible • Being watchful - The best offense is a good defense • “Did you hear the one about...?” - Humor and other means to foster connectedness • Honoring the altar of “teenagedom” - The manner of healthcare provider communication that conveys respect, support, and caring
	When There is a Connection	<ul style="list-style-type: none"> • Sense of being cared about, known, respected, and valued • A comfortable haven in the midst of chaos • Limitations of connectedness
	On the Perfect Date - Blown Away Good Happens When Healthcare Providers and Adolescents Connect so Well	<ul style="list-style-type: none"> • A date that's too good to be true • Sense of disappointment when connectedness vanishes with or without closure
	A Dream-Come-True - Sense of Gratitude	<ul style="list-style-type: none"> • For being treated as a unique human being • For the existential knowledge about self • Thankful the long journey finally ended

Theme Cluster 4.1. Strategies Healthcare Providers Use to Facilitate Connectedness

Connectedness worthy. Just as information in primers is essential to success in basic education, strategies used by healthcare providers are described as essential to connectedness. Participants described certain healthcare providers who instinctively knew how to connect by being themselves. Such healthcare providers seem to naturally possess characteristics or qualities that foster a desire to connect with them. Healthcare

provider characteristics that facilitate a sense of connectedness include being caring, calm, honest, friendly, endearing, thoughtful, competent, understanding, and unexpectedly approachable (i.e., down to earth, unpretentious). Other valuable characteristics that are considered to make connecting worth the effort include physical attractiveness of the healthcare provider and being close in age.

Connectedness accessible. Participants described many strategies that healthcare providers use to promote a sense of connectedness. Some strategies are simple, such as the availability of healthcare providers (i.e., being able to see the same healthcare provider over and over and seeing a healthcare provider enough to establish a meaningful connection), while other strategies stand out as key exemplars that facilitate connectedness, such as being watchful, using humor to transcend the relationship, and honoring adolescence.

Being watchful - The best offense is a good defense. Primers are about basic information that is crucial for success. In football, one such basic, yet critical strategy is an understanding that a good offensive line protects the team, and ultimately provides the best defense. Like offensive football players, participants described healthcare providers implementing offensive strategies of recognizing and responding to their need for help in preventing or quickly managing the side effects/symptom distress related to treatment. For example, one participant described an experience of healthcare providers having difficulty controlling his pain until finally one doctor came in and presented a better solution: "...halfway through I had so many complaints about [the pain medications not working]...and eventually they were doing things like methadone and I mean [giving] hard core [pain medications]. And it was [Dr. Smith] that came in and he was like, 'You know, I'm going to try one more thing and I really think it's going to work'...he ended up writing a prescription for Marinol...and it worked" [6.237-6.244]. When healthcare providers use such offensive strategies, participants label them as

always being on top of it of the situation. According to participants, healthcare providers who are continuously watchful and attentive to both physical and personal needs and are prompt in alleviating symptom distress are people with who they want to connect.

“Did you hear the one about...?” - Humor and other means to foster connectedness. According to participants, a willingness to foster the adolescent-healthcare provider relationship is a valuable way to connect. Strategies healthcare providers use to show they are willing to extend the relationship include interacting with the adolescent more like a friend than a patient, spending quality time with the adolescent, and self-disclosing personal information, interest, and experiences, all with an underlying sense of humor.

Participants described humor as being a valuable means to connectedness. The use of humor seems to ease any awkwardness in relating to healthcare providers. Participants described the healthcare providers' ability to incorporate humor in the interaction as being both beneficial and enjoyable. Humor strategies that foster a sense of connectedness with healthcare providers include responding to silly requests such as singing, making the adolescent laugh, and using humor to promote positive health behaviors. Participants also recognize and accept humor as a way to cajole them to do self-care. For example, one participant described a story in which a patient care assistant used humor to encourage her to get out of bed and engage in normal daily activities: “She [the patient care assistant] would come in at 9:00 o'clock and say, 'It's 9:00 o'clock. I have made this many beds, and I've done this and this. What have you done today?' I would be lying there like 'ah, um', [and she would say] 'I want you to get up and walk around'. Or 'you need to eat something right now...' and that just worked so well for me” [2.029a-2.030]. Incorporating humor in the interaction demonstrates to the adolescent that healthcare providers are considerate and feel comfortable enough to

joke around at the adolescent's level, and this creates an environment within which adolescents can connect.

Participants indicate that when healthcare providers are perceptive in knowing the appropriate times to employ humor, it is done in a sophisticated way, not just with outright joking. Oftentimes, adolescents with cancer are not feeling well and want to be left alone. For example, one participant said: "They'd come in, and tease me ...when I'd be awake. They'd kind of know when to do it, too. They'd know when I'd be having a bad day and they'd just kind of leave me alone" [1.090-1.091]. When healthcare providers are perceptive about the timing of humor, and adolescents believe they are sensitive to their needs, this encourages adolescents to connect with them.

Honoring the altar of "teenagedom" - The manner of healthcare provider communication that conveys respect, support, and caring. Like simple information in primers, adolescents have a simple code that, when honored, allows healthcare providers to be part of their in-crowd. Healthcare providers who honor the altar of "teenagedom" (i.e., validating adolescence) are described by participants as more likely to be able to connect with them. Honoring the altar of "teenagedom" includes conveying respect for the adolescent's personhood. This manner of communication is viewed as crucial to connectedness. Conveying respect is described by participants as healthcare providers who display an appreciation for adolescents' personhood by treating them as more than just another cancer patient, acknowledging and respecting the adolescent's space, providing enough information so they know what to expect, handling embarrassing situations delicately, and taking the time to inquire about the adolescent's needs, opinions, and desires. Additionally, communicating in an age-appropriate manner that respects the adolescent's autonomy is important. For example, one participant described a situation where a surgeon communicated in such a manner: "...[Dr. Parker, the surgeon] would walk in and say 'well if it is okay with you we were thinking about

doing this and...we just wanted to make sure it was okay with you before we scheduled you for surgery'. That was cool because I am not the type of person that likes somebody to come in and say this is what we are doing...But the way [Dr. Parker] did it...he knew how I was, so he asked me that way knowing that I would be like 'oh, okay'" [3.287-3.291].

Participants feel that their personhood is recognized and honored when healthcare providers communicate in way that conveys support and caring. Communicative actions that convey support include being supportive of the adolescent's need to keep up with the outside world, being supportive of the adolescent's autonomy and independence, and helping the adolescent work through difficult situations. Healthcare providers also convey caring by going above and beyond participants' expectations. For example, one participant described a situation where the nurse went above the call of duty to make her birthday a special one: "I had my seventeenth birthday in the hospital and...my parents...forgot about [getting] a cake...so this one nurse...[had] a cake brought up to my room...[and] we had a mini little party...I just thought that was really cool because I know she was so busy and she thought about giving me a cake" [4.017-4.021].

Theme Cluster 4.2. When there is a Connection

Sense of being cared about, known, respected, and valued. Primers were used to produce outcomes, such as a literate and educated population. Like these outcomes, lessons learned in a connectedness primer lead to certain outcomes of connectedness as described by participants. When healthcare providers implement strategies that facilitate connectedness, participants experience a sense of being cared about and feel that they are known, understood, respected, and valued as unique individuals. "The way he [the surgeon] made sure every incision that I had...he made sure it was hidden. He

[the surgeon] was like 'I know you might want to wear a bikini or swimsuit, you might want to go swimming'. So he wasn't like 'I'm just going to cut you here and this is how it's going to be'. He was working with me because he knew that I was a kid and that I was concerned about that kind of stuff. So he was very cool...I was appreciative” [4.074-4.079].

A comfortable haven in the midst of chaos. Participants described experiences of connectedness with healthcare providers as having a comfortable haven in the midst of chaos. In other words, amongst all of the turmoil related to the diagnosis and treatment, connectedness is a pleasant surprise that facilitates a sense of comfort. Participants gain a sense of comfort in communicating within the adolescent-healthcare provider relationship when connected. For example, one participant described how connectedness makes it easier to talk about more uncomfortable subjects after having the opportunity to first sit down and talk to the healthcare provider like a friend: “We could just talk, sit and talk...then we would move on to the side conversation, ‘when was your last period’...[2.319].

Participants also experience a sense of comfort in expressing themselves, their concerns and frustrations, to healthcare providers with whom they feel connected. For example, one participant described having this comfort with one doctor and said: “I was able to talk with her [the doctor], which was something I found I couldn't do with some of the other doctors. Some of the others [doctors] just don't tend to have the greatest bedside manner, so they are kind of harder to talk to...especially for somebody my age and in that position, ...so when she would come in, I would tell her things I wouldn't tell the other doctors...[8.508-5.011]. This sense of comfort encourages participants to actively interact with healthcare providers and participate in the care plan.

According to participants, connectedness also fosters a sense of intimacy, security, and trust. One participant, who instantly connected with a nurse in the surgery

room, described this sense of intimacy with and security in the nurse while she was being put under general anesthesia prior to surgery: "...He [the nurse] held my hand while they...you know, when you counted back from 100...I was confident in him that he would do a good job, whether he did or not I have no idea. But for that split second...I felt confident that he would do a good job and take care of me...[5.232-5.234].

Participants also believe that a sense of connectedness with healthcare providers buffers some of the discomfort they endure while being in the hospital. Participants feel that a sense of connectedness with healthcare providers alleviates the tension of having to deal with healthcare providers they feel unconnected to and connectedness facilitates a tolerance for having to endure things that might otherwise be considered intolerable intrusions. For example, one participant described this tolerance when interacting with a physician who eased his discomfort by using humor and taking the time to provide a rationale for putting him "on display" for learning purposes: "He [the infectious disease doctor] would bring all the other doctors in with him, and put me on display basically, is what it felt like, and he would always kid me about it. He's like, 'I'm going to start charging admission for all these kids coming in here to take a look at you'...I had certain things he said he wanted them to see" [8.228a-8.230].

Limitations of connectedness. Although participants experience many positive outcomes related to feeling connected to healthcare providers, they also recognize that there are some limitations of connectedness. In other words, there are some things that connectedness, no matter how meaningful, can fix. For example, connectedness is unable to minimize the terrible situation the participant is stuck in, prevent anticipatory symptoms when returning to hospital for follow-up, and prevent other setbacks from occurring. For example, one participant described a circumstance where he was arguing with the nurses about how his pain medication was administered. When he sought the help of the oncologist, with whom he felt very connected, to resolve the argument, the

oncologist let him down by not taking a stronger stance: "...anytime there was a problem, she [the oncologist] would come and take care of it...she basically was the mediator through most of the arguments...[however] she didn't have much to say to the nurses at the time. It was basically, 'you have pain so I prescribed you this medication. You should get it, and I'm really not going to fuss about how you get it'. That is why I think it remained a problem throughout my treatment, is because she didn't really say one way or another..." [8.071-8.075].

Theme Cluster 4.3. On the Perfect Date - Blown Away Good Happens When Healthcare Providers and Adolescents Connect so Well

A date that's too good to be true. Once having completed the connectedness primer homework, people going on first dates are aware of the few simple rules that make the date go well. Like being on the perfect date, participants are blown away by healthcare providers who carefully uphold the primer for connectedness and connect well. When healthcare providers use the essential strategies to connect, participants describe the "date" (i.e., interaction with a healthcare provider) as being too good to be true. Participants experience an overwhelming persuasiveness to connect and anticipate opportunities to interact with the healthcare providers again. In addition, participants are "blown away" by healthcare providers who go the extra mile to connect. They hold a sense of admiration for who the healthcare providers are as people and are filled with a sense of joy and pleasure when interacting with healthcare providers who connect so well. Additionally, the 'good dates' with connected healthcare providers are described as increasing participants' sense of confidence in self, a sense of empowerment, and enhanced well-being. For example, one participant talked about the important role that connectedness serves in enhancing one's well-being: "They all really care...they all understand...[your] prognosis depends on that...it [also] depends on all of the medical

stuff [too] but like if you don't feel okay...you're not going to be okay...Like your emotions play on you mentally and all of that plays into your physical well-being. So, I think that helps a lot. When you know that other people are caring for you and care about you and really like are focusing on 'what can I do to help this person'. I just think it's really cool" [4.136-4.142].

Sense of disappointment when connectedness vanishes with or without closure.

Like a date that goes so well, but the other person never calls for another date, participants experience a sense of sadness and disappointment when connectedness vanishes with or without closure. In some situations, participants relayed never knowing what happened to the healthcare provider they connected with (i.e., the healthcare provider was suddenly gone), while in other situations they knew and dreaded the fact that the healthcare provider would no longer be available to care for them. For example, one participant described his sadness about saying farewell to one of his favorite nurses who was moving away: "He [the nurse] was a pretty good guy. I was sad to see him go. He came in, and it was kind of ceremonial, 'I'm passing it on to you [Sara]', that type of thing...It was a sad day when he left..." [8.754-8.761].

Theme Cluster 4.4 A Dream-Come-True - Sense of Gratitude

A dream-come-true sense of gratitude was an unexpected finding described by participants. It seems that when healthcare providers implement strategies to facilitate connectedness, participants are pleasantly surprised by this action and left with an overwhelming sense of gratitude. Although participants never directly used the word "gratitude", the tone and words spoken conveyed a strong sense of gratitude they felt for healthcare providers who establish a meaningful connection with them. Gratitude was described by participants in the following ways: for being treated as a unique human being, for the existential growth of self, and for the long journey finally coming to an end.

For being treated as a unique human being. Participants described a deep sense of gratitude for being treated as a unique human being. In other words, participants expressed being highly appreciative of healthcare providers who went out of their way to provide above and beyond care that was unexpected, knew how to cater to their emotional needs, took the time to get to know them, and acknowledged and respected their personhood. In one example described earlier, a participant talked about a surgeon who communicated in a way that conveyed respect. This same participant expressed her gratitude for this action by saying: "...it was cool that he [the surgeon] did that because he knew I'm 18 [and] I don't have to do what you are saying...I can sign myself out and leave...But it was cool that he worded it like that even though he was going to do it anyways...Most surgeons won't do that..." [3.292-3.296].

For the existential growth of self. Participants described a sense of gratitude for having the opportunity to grow in meaningful ways through their connectedness with healthcare providers. Participants seem to gain insight into who they are from being a cancer patient and they are enriched by the opportunities to be connected. The gratitude contributes to experiences of empathic understanding for healthcare providers with whom they feel connected. For example, participants are less angry and demanding of healthcare providers they feel connect to, even when legitimate needs are not addressed promptly. One participant described this empathic understanding when talking about a nurse practitioner she feels connected to: "...She [the nurse practitioner] runs around like a chicken with her head cut off because she has all of this stuff to do... if I call her and say '[Susan] I need you to call me in a prescription'...she's like 'okay, I'll get right on that'. Well, four hours later you call her back and say '[Susan] did you call in that prescription?' 'No, I forgot.' So, you might get your prescription in a week or you might not get it at all. That's annoying but you can't be mad at her...because she has all of this stuff she has to do, so you really can't be mad at her for forgetting" [3.078-3.084].

Participants also described that their sense of connectedness and gratitude overflows to others. In other words, when participants express a sense of gratitude for healthcare providers they feel connected to, this gratitude expands to all healthcare providers who were involved their care. Consequences of this overflowing sense of connectedness and gratitude includes realizing that the environment is not as bad as originally perceived, being reluctant to say that even healthcare providers who exhibit an unwillingness to connect as uncaring, and taking a active part in achieving desired health outcomes.

For the long cancer journey finally coming to an end. Part of the participants' sense of gratitude for healthcare providers seems to be linked to their partnership with connected healthcare providers through the cancer journey and into survivorship. The experience includes being grateful that the cancer journey finally comes to an end, for being cancer-free with little long-term side effects, and regaining a sense of normalcy. "It went by so fast, it's surprising. It seemed like there were times when the clock just stopped...but now, it's already 2008, and I was diagnosed in 2006. I'm doing pretty good...to be honest. The only problem I have is blurry eyesight and... numbness in my toes, and that's really it. So, considering most of the other kids have lots of problems, I feel pretty lucky that I've done so well" [8.583-8.589].

Theme Category 5. Tortured in a Prison Camp - Healthcare Providers Who Violate and Destroy Connections

Similar to prisoners of war being tortured in prison camps, participants feel tormented when some healthcare providers violate ethical principles of respect for personhood. When participants perceive healthcare providers as being insensitive and behaving in cruel and hurtful ways, the door is immediately closed to connectedness. Participants' suffering is intensified when they enter the hospital already feeling

disconnected and have to interact with healthcare providers who ignore basic rules of respect, which violates and destroys other potential opportunities for connectedness. When participants do not feel respected as individuals, they experience a sense of dehumanization, powerlessness, and a lack of freedom for self-determination. Insensitive and cruel behaviors exhibited by healthcare providers leave lingering feelings of anger and resentment, even after treatment ends. Theme category five has four theme clusters (see Table 4.6).

Table 4.6 Theme Category 5

Theme Category	Theme Clusters	Themes
Tortured in a Prison Camp - Healthcare Providers Who Violate and Destroy Connections	Introduction to the Prison Culture - Guards that Foster Disconnectedness from the Beginning	<ul style="list-style-type: none"> • Depersonalization • From bad to worse - Moving into a prison camp
	Cruel Prison Guards – Healthcare Providers who Violate Ethical Principles of Respect for Personhood	<ul style="list-style-type: none"> • Violating the rights of personhood • Violating autonomy • Intrusion on privacy • Violating trust • Lack of vigilance over basic needs
	A POW Experience - Reactions when Ethical Principles of Respect for Personhood	<ul style="list-style-type: none"> • Sense of dehumanization • Sense of powerlessness and lack of freedom for self-determination • Sense of torment • Appalled, shocked, fearful when ethical principles of respect for personhood are violated • Anger and resentment • Sense of disconnectedness
	The Aftermath of Being a POW - Consequences of Disconnectedness	<ul style="list-style-type: none"> • Examining one’s own role in becoming a POW • Unresolved feelings towards healthcare providers who were involved in negative experiences • All things can be forgiven, but not forgotten

Theme Cluster 5.1 Introduction to the Prison Culture - Guards that Foster

Disconnectedness from the Beginning

Depersonalization. During the time of diagnosis, participants may experience a sense of depersonalization because of the way some healthcare providers treat them. Healthcare providers who fail to take time and recognize unique, individual concerns leave participants with a sense of not being heard and a perception of harm being done. When healthcare providers lack sensitivity and therapeutic communications skills they destroy the potential to connect. Participants report that healthcare providers' behaviors are particularly troubling when providers betray them, are dishonest, or make false accusations about them. For example, one participant who consulted her pediatrician about constant stomach pain described her experience; "He [the pediatrician] said, 'Well, there's usually only one reason that you get a lump in your stomach', implying that...maybe I was pregnant. At that point, I was like, 'Okay mom. I'm done talking to him'" [2.182-2.183]. Such encounters at diagnosis produce major barriers to connectedness before participants even enter the hospital.

From bad to worse - Moving into a prison camp. Much like moving into a prison camp, participants experience an array of intense emotions when they enter the hospital for treatment. In addition to accepting the reality of a life-threatening diagnosis, participants are forced to enter an unfamiliar environment, given treatments that strip away their physical and emotional sense of self, and are at the mercy of strange healthcare providers. Participants experience feelings of being out of control, being angry, and feeling vulnerable. When participants have to interact with insensitive healthcare providers, these negative feelings are intensified. For example, one participant provided an example of a nurse who said something very insensitive during a vulnerable moment: "...It was when I started to lose my hair. I was feeling really angry. I was like, 'Ugh, I don't know why this is happening'. It was almost all gone [but] I was

preserving every little strand that I had left...and...she [the nurse] goes 'Well...if you just shave it all off it won't be a problem'...I was just kind of like whoa...you don't know what I'm going through. It was really inconsiderate" [4.040b - 4.047]. In light of all of the hardships participants are experiencing, such acts of perceived insensitivity displayed by some healthcare providers seem inappropriate and destroy the potential to connect.

Theme Cluster 5.2 Cruel Prison Guards - Healthcare Providers who Violate Ethical Principles of Respect for Personhood

The potential to connect with participants is destroyed when healthcare providers violate ethical principles of respect for personhood. Like there are guidelines that are supposed to be followed to protect the basic rights of prisoners of war, set by the Geneva Convention, healthcare providers are educated in basic ethical principles and medical ethics in order to uphold the basic rights of patients. However, participants' in this study described disturbing experiences where healthcare providers displayed a lack of respect for their personhood, autonomy, privacy, trust, and basic needs. According to participants, perceived violations of the ethical principles of respect for personhood are the experiences that stand out in their minds as most disturbing and immediately destroy the opportunity for participants and healthcare providers to connect.

Violating the rights of personhood. According to participants, healthcare providers violate the rights of personhood. Sometimes, participants feel that healthcare providers have a lack of appreciation for who they are as a person. Participants feel this way when some healthcare providers show no respect for their privacy, fail to take the time to get to know them personally, and are apathetic of their needs and preferences. Occasionally the experience of violation of personhood reaches the level of feeling physically abused. In this kind of environment, participants feel as if they have minimal rights and little power to stand up for themselves under the cruel acts of rude,

disrespectful, and even physically hurtful healthcare providers. For example, one participant described an experience where the medical residents would abruptly enter the room, without acknowledging him and physically abusing him, in order to go about their own business: “If you were sleeping...they’d come like three or four at a time, flip on the light, uncover you....Some of them...wouldn’t care [that] I was laying there asleep, they’d come in, pull my shirt up and [start] pushing on my stomach ...I just didn’t see any reason for it...it was just torture” [1.100-1.108]. When healthcare providers violate the rights of personhood by placing the participant in a position of extreme powerlessness, and with no ability for self-determination, the opportunity to connect is destroyed.

According to participants, some healthcare providers seem to inflict unnecessary physical harm or discomfort. If the healthcare provider’s behaviors are believed to be the result of careless actions or speculated to be purposefully harmful, it leads to an immediate disconnect. For example, one participant relayed a situation where a nurse seemed to purposely inflict harm because the participant refused to have a port placed: “...I didn’t want to get a port...I was like... ‘Let’s just try an IV the whole time’. They were like ‘Hey, you should get a port’. I’m like ‘Well, I don’t really want that’, so we kind of went back and forth...[later] she [the nurse] was starting the IV on my hand ... and I don’t know if this was on purpose or what or if she was just [not] being careful... but something happened when she started my IV. I don’t know if she hit something...but it did like this twitch thing in my hand...and then for like four months after that I would get...this numbing feeling in my hand, like a sensation and then it would go away. I was like it had to be from that [careless IV technique]...” [4.082-4.093].

Violating autonomy. As described by participants, some healthcare providers violate their rights of autonomy by undermining their self-determination. Participants recalled circumstances where healthcare providers categorized them as a child,

incapable of understanding the rationale for certain procedures. For example, one participant talked about how irritated she becomes when a nurse practitioner talks to her in such a manner: "...she talks to me like I'm younger, and I would much rather her talk to me like I knew everything rather than I knew nothing..." [2.424a-2.424b]. Patronizing communication angers participants and slams the door shut to communication.

In addition to being talked down to, participants experience being left out of important conversations about their care. One participant described a circumstance where she was never informed about a significant surgical procedure: "... I didn't find out until like last year when I was talking to my mom about somebody else who had the same treatment done that they got their appendix taken out...She [mother] was like, 'Well, you don't have an appendix either.' [Participant then said] 'I've been walking around for three years not knowing that I don't have an appendix?'...That's just one of the things I guess maybe they told my parents, and it didn't get relayed [to me]. But I'm 20 years old. I should probably know if I have an appendix" [2.060-2.065].

Intrusion on privacy. Participants experience an immediate disconnect when healthcare providers intrude on their privacy. The intrusiveness in privacy of healthcare providers is highly distressing to participants, as described in this example of a participant's sleep being interrupted: "He [the medical student] would always come in, and he was really rude about how he would wake me up...[because] most of the time when he would come in I was asleep, and that ended up being a problem after a while, because he would just come in and shake me, and he was really rude about waking me up" [8.183-8.186]. This intrusiveness angers participants and severs the opportunity to connect.

Violating trust. According to participants, some healthcare providers violate their trust. Participants feel that some healthcare providers betray them by being dishonest and/or failing to do their job, such as protecting them from harm. For example, one

participant recalled a resident who lied to her about being careful so harm would be minimized: "...I don't know where he [the resident] got off doing this but I [had] an incision [and a] big dressing over it. It was time to change it ... and I was like 'okay, I just have one request please do not just rip it off really fast'. I was like 'please do it slowly because it hurts'. He was like 'Okay, all right, I won't'. And then he gets down there and he just rips it off and I was like, 'Hello, you told me that you were going to do what I asked you'. I was just like why did he do that..." [4.184-4.190].

Lack of vigilance over basic needs. Participants described experiences where some healthcare providers failed to be vigilant, or watchful, for their basic needs. For example, one participant talked about the nurses who were not watchful for her need to rest: "...when it came to visitors, I had a lot of people come, especially after school. It was almost too open to visitors. At [the Children's Hospital], you can kind of go in and out. There's somewhere you can go and visit and you can come back to your room...throw up and do all that stuff. But in my room at this other place [which was not a children's hospital], they gave me a bigger room because they knew I was having people come in all the time...and they would just circulate in and out and in and out, and there wasn't really a time for me to rest, so a lot of times I would get worse...I didn't have that time [to rest]...I don't think they [the nurses] understood. I would be in my room but I wasn't feeling well, so maybe a visitor isn't the best idea right now" [2.066-2.080]. In this instance, the nurses failed to read the participants' cues for the need to rest.

Theme Cluster 5.3 A POW Experience - Reactions when Ethical Principles of Respect for Personhood are Violated

Much like prisoners of war who are often mistreated by prison guards, participants experience a sense of depersonalization, powerlessness, and torment when healthcare providers violate ethical principles of respect for personhood. Because these

violations place participants in a position of extreme powerlessness, they respond in a passive-aggressive manner since they did not feel they had the power to fight back or protect themselves. Ultimately, participants dissociate themselves from these healthcare providers and the chance to connect is destroyed.

Sense of dehumanization. When interacting with healthcare providers who violate their personhood by being disrespectful, participants experience a sense of dehumanization and a powerless to protect themselves against physical abuse. For example, one participant described feeling as though he had no role other than being a body for trainees to assess: “Some of the medical students I would like to forget. I hated that. It was just they [the medical students] would come in, look at your chart and then feel you up. It was just very impersonal” [6.144-6.148].

Sense of powerlessness and lack of freedom for self-determination. Participants experience a sense of powerlessness and lack of freedom for self-determination when healthcare providers behave in ways that violate their autonomy. Because participants are in a vulnerable position and lack the skills to stand up for their rights, particularly because they are adolescents, they often feel they have no control in preventing such violations. For example, one participant described this powerlessness: “...he [the urologist] had to take a look at things and he brought in more than six different people, not my age but they were young enough that I was uncomfortable with it and I didn’t say anything ...he was kind of showing everything [private parts] to them, and it was pretty uncomfortable, and the fact that he had to feel...and I don’t know why, but he asked me if one of the other doctors could feel, to understand what he was talking about, rather than him explain it, and I thought, ‘I don’t know how I feel about that’. He had this younger guy come over and have ‘a feel’, which I didn’t really get into that all too much...” [8.236-8.246]. In this instance, the participant experienced objectification and deep embarrassment as well as a sense of powerlessness in expressing his discomfort

with the urologist's invitation for a young, unfamiliar doctor to look and feel his private body area. The participant felt he had no right to override the doctor's authority and allowed the violation to occur; all the while wishing the doctor would not have put him in this position in the first place.

Sense of torment. Participants experience a sense of torment when healthcare providers behave in cruel ways, treat them as someone with minimal rights, and ignore their needs. For example, one participant talked about his ongoing battle with healthcare providers over the administration of medications to relieve his symptom distress: "...I would say I was in a great deal of pain, but my doctors always looked at me like, 'You don't look like it'...She [the nurse] ended up getting all skeptical...and said 'I don't think you really need what you say you need'. I'm just lying there, at the time with everything that was happening to me, I ended up getting pretty emotional about it, and I started crying..." [8.152-8.156]. Although the participant admits that he later recognized that the rationale for the healthcare providers' skepticism was because of other teenagers who took advantage of the situation in order to get high, the participant suffered from being stereotyped as one who would abuse medications.

When adolescents have opportunities to know other adolescent patients, a prison-of-war kind of camaraderie develops from common experiences of victimization and torment with other adolescent patients: "...there were a couple times where some of the other guys [adolescent patients] would come in and talk to me. 'Like, I know, they [healthcare providers] do that to me too'" [8.772].

Appalled, shocked, and fearful when ethical principles of respect for personhood are violated. Participants are appalled, shocked, and fearful when healthcare providers violate ethical principles of respect for personhood. For example, one participant described a situation where a nurse ignored his symptom distress and was exceedingly casual in responding to what he felt was a life-threatening situation: "Once my

chemotherapy started, I had really bad mucositis...it was pretty bad one night, and I remember I couldn't breathe at all, and the nurse came in...I was nearly incapacitated. I couldn't talk. I couldn't really function. I mean, I thought I was having a heart attack, it hurt so bad, and she just kind of looked around and she sat down on the floor, and said; 'Well, Mom and Dad, what do think we should do?'...That was the first time I was really, really scared, throughout the entire thing" [8.020-8.026b].

Anger and resentment. Participants experience anger and resentment when having to interact with rude, insensitive healthcare providers. Anger and resentment sets in when healthcare providers communicate in a patronizing manner and/or show little respect for their personhood. For example, one participant talked about how much he hated having to interact with psychologists: "Man, I hated them [the psychologists]. I really did. They just acted so uninterested" [6.387-6.388]. As participants are left with no choice but continue to interact with apathetic healthcare providers, they become more resentful and respond by not communicating: "...I never told them [the psychologists] what was going on. 'If I want to talk to somebody, I will talk to my friends. I don't need help from you. You're not helping anything'. So I would always kick them out" [6.391-6.393].

Sense of disconnectedness. Participants are greatly disturbed when healthcare providers violate ethical principles of respect for personhood. When these experiences occur, participants immediately dissociate themselves from these healthcare providers. For example, one participant mentioned that he did not give rude healthcare providers the opportunity to connect after they violated basic rules of respect: "They were waking me up, and they were getting on my nerves, so I really didn't give them the chance [to connect]" [1.030].

Theme Cluster 5.4 The Aftermath of Being a POW - Consequences of Disconnectedness

Examining one's own role in becoming a POW. Much like a prisoner of war who survives being tortured by prison guards, participants try to make sense of the violations made by healthcare providers and deeply examine their own roles in the experience. Participants struggle to pinpoint an acceptable explanation for why some healthcare providers were so cruel to them and this weighs heavily on their mind even after treatment ends. Because there seems to be no logical explanations for why healthcare providers would behave in such ways, participants often experience a sense of guilt associated with the violations, which prompts participants to search for their role in the violation. For example, one participant expressed a sense of responsibility and guilt for an intense argument that occurred between him and the nurses over being forced to move out of his private room in order to better accommodate another patient. Ultimately, the situation prompted the patient to leave the hospital: "I feel like it ended up being a whole stupid thing now, looking back on it. I could have just moved rooms and saved everybody a lot of trouble" [8.354-8.355].

Unresolved feelings towards healthcare providers who were involved in the negative experiences. Participants are left with unresolved feelings towards healthcare providers when they are unable to make sense of why some healthcare providers behaved unkindly. Participants expressed a need to hold onto the anger of being mistreated. Although participants were troubled by these experiences, they willingly shared details surrounding the interactions that fostered a sense of disconnectedness in hope that their experience would help make a change: "That was basically all my negative experiences. There were a lot of good ones [i.e., good examples of negative experiences with healthcare providers]...telling me about your ultimate goal, I felt like

maybe the bad ones were more important [to share] than the good ones...” [8.401-8.404].

All things can be forgiven, but not forgotten. Participants feel that they can forgive healthcare providers who are remorseful, honest, and apologetic for violations of personhood. For example, one participant said he was able to forgive his nurse when she apologized for being so skeptical about giving him his pain medicine: “...she [the nurse] apologized, which was nice because I liked her a lot...” [8.162]. Although this participant forgave the nurse after she apologized, the violation was vividly remembered.

Theme Category 6. Parental Lenses - Parents Role in the Adolescents'

Connectedness with Healthcare Providers

Participants indicated that as adolescent patients, connectedness with healthcare providers is influenced by the role parents play in their illness and treatment. Because participants are minors at the time of diagnosis, their parents legally must make decisions about treatment and medical care. For participants, when their parents are involved, connectedness experiences are like seeing the world through someone else's glasses. When healthcare providers speak directly to participants' parents and leave participants out of the initial opportunity to connect, participants' perception of their own connection with the healthcare provider is blurred. Initially, participants are too overwhelmed with their diagnosis to participate in much of their own decision-making or health care, so they readily allow or expect parents to deal with healthcare providers and critical decisions. Once participants finally begin to grasp what is happening to them and have the capability and desire to participate in their own health care decisions, their parents are already connected and have become the point persons with healthcare providers. Although parental connectedness with healthcare providers does not hinder participants' abilities to form their own connection with healthcare providers, it does

leave participants with an uncertainty about the possibility and legitimacy of their own connections with healthcare providers. Such concerns are compounded if participants do not eventually have their own opportunity to form connections.

Because participants' parents are involved in their connectedness with healthcare providers there are two sides to this aspect of the connectedness experience. Like wearing bifocals and being able to view something two ways, participants and parents are both aware of one another's cues of connectedness. Theme category six has two theme clusters (see Table 4.7).

Table 4.7 Theme Category 6

Theme Category	Theme Clusters	Themes
Parental Lenses - Parents Role in the Adolescents' Connectedness with Healthcare Providers	Looking through My Parent's Glasses - When Parents Make the Initial Connection	<ul style="list-style-type: none"> • Connectedness blurred - Missed opportunities for connectedness • Unsure of the reality of the connection or what the relationship should/could be
	Bifocals - Looking at Connectedness in Two Ways	<ul style="list-style-type: none"> • Connectedness by-proxy - Benefits of having a parent who is already connected with the hospital/health care system • Cues of connectedness used by both the adolescent and parent

Theme Cluster 6.1 Looking through My Parent's Glasses - When Parents Make the Initial Connection

Connectedness blurred - Missed opportunities for connectedness. Participants experience being left out of initial conversations regarding their diagnosis and/or having few opportunities to meet or connect with some healthcare providers. Participants who are physically or mentally absent (i.e., participants are in surgery, in a state of shock, or asleep) during the initial opportunity to connect with healthcare providers experience an

interference in their abilities to connect with healthcare providers. Instead of connecting with the participants, healthcare providers establish connections with participants' parents. For example, one participant remembered being introduced to his surgeons after surgery was completed and well after the initial connection was made with his mother: "I think I met...a couple of them [the surgeons], maybe even while I was in treatment, but later [my mother told me]; 'This is Dr. So and So. He did your central line, or your biopsy, or the tumor removal, or whatever'. But I don't think I actually talked to them before the surgery" [9.075]. Like wearing someone else's prescription glasses, connectedness is experienced as a blur or out of focus when participants miss out on the initial opportunity to connect with healthcare providers while their parents clearly see the benefits of connecting.

Unsure of the reality of the connection or what the relationship should/could be.

When participants miss out on early opportunities to connect, they are unsure of the reality of the connection. In other words, participants are uncertain about the authenticity of their connection to a particular healthcare provider who initially connects with their parent. For example, one participant described feeling connected to a nurse because of the relationship the nurse had with his mother: "Before I even...started the treatments, I woke up one time and mom was talking to this nurse and [my mother] become real good friends with this nurse, and I hadn't even met anybody on the floor yet...but they really connected, and throughout my whole stay, when she [the nurse] was on the floor, I was really happy [my] mom was happy because we had someone we would know, and she would come and talk to us and made things a lot better" [1.038a-1.043]. In this case, the participant's connection with the nurse occurred as a result of his appreciation for the nurse who connected with his mother.

Theme Cluster 6.2 Bifocals - Looking at Connectedness in Two Ways

Like wearing bifocals and being able to see things two ways, participants and parents have an awareness of one another's connectedness with healthcare providers. Through one part of the bifocal, parents who are already familiar with and have connections at the hospital are able to help facilitate their adolescents' connection. These same parents, along with parents who do not have pre-existing healthcare connections, are described as attentive to and aware of the participants' likes and dislikes as far as the care they receive and who is giving the care. Through the other part of the bifocal, participants take cues from their parents about which healthcare providers the parents are connecting.

Connectedness-by-proxy - Benefits of having a parent who is already connected with the hospital/health care system. In this study, three participants out of nine, have parents who were already connected to the hospital or health care system because their parents are either healthcare providers or in an executive position within the hospital. Although these participants' experiences of connectedness are similar to the other participants, there may be additional benefits and consequences of having parent who are already connected.

When participants have a parent who is already connected to the hospital or health care system, they feel as if this connectedness-by-proxy is like an insurance policy. In other words, participants have an idea of what to expect and are confident that healthcare providers can be trusted because of their parent's connection. "Well, one nice thing is my mom being a doctor. She knew the people [the healthcare providers], so she'd know if she heard of them or not...So, before I went in, I kind of already had a clear [idea that] this is how they're going to be. My mom had patients who've talked to them and they've been good to her, so luckily I had that leg up per se" [5.078-5.081]. Other benefits of connectedness-by-proxy include the ability to keep emotions of

devastation at bay and to maintain a positive outlook. “I more took having cancer as just like riding a bike and falling off of it as opposed to some great drastic event in my life. Because I really didn’t have a choice, it’s not like I could [say], ‘oh, I don’t want to do chemo now’. I didn’t have a choice so I had to do it and I had to get through it that was my only option...So that’s how I viewed it...” [5.044-5.048].

Cues of connectedness used by both the adolescent and parent. Participants rely on their parents to read their cues of connectedness. In other words, participants trust their parents to recognize when they connect with a particular healthcare provider and when they dislike a healthcare provider: “...my mom said she could tell instantly whether I liked somebody [a healthcare provider]...” [2.022]. Cue reading is especially meaningful when healthcare providers violate basic rules of respect because participants’ parents validate their feelings of healthcare provider wrong doing and fight back in their defense. For example, one participant described the action her mother took when a nurse insulted her: “...she was my nurse...and we would just tease and play around and call each other bad names, but we were just playing...Well one time she came and saw me and she pushed it a little too far and my mom heard her and she got fired...[the nurse said] ‘you are just a stupid bitch’ and was laughing. I knew that she was playing because we did that playing but that was a little far, especially when there was other nurses standing around that heard her say it and my mom heard her say it...she got fired, which I didn’t do that, my mom did” [3.309-3.316]. Although the participant was uncomfortable with the nurses’ comment, she felt that she had little power to stand up for herself in this situation. Thus, the participant appreciated that her mother took action but was also embarrassed and did not want to be held accountable to terminating the relationship.

Likewise, participants recognize their parents’ cues of connectedness. Participants know when their parents like or dislike a particular healthcare provider. One circumstance that can be somewhat troubling for participants is when tension surfaces

between healthcare providers and their parents. Participants quickly read their parents' frustration and feel caught in the middle. For example, one participant described such feelings when his mother became angry at the nurses for wanting to move him from a private room into a room with a contagiously ill patient: "They [the nurses] were going to put me in [another room] with somebody else...I really didn't care at the time...But my mom ended up having a few problems after she found out who I was going to be put with, because this kid was really, really sick. She couldn't see how it made any sense for me to not be allowed to have any visitors, yet be put in [a room] with this other kid who was really, really sick and actually contagious...[it was] none of my business, though, so I didn't say anything. But my mom was pretty irritated...and she refused to have me moved" [8.326-8.331]. In this instance, the participant supported his mother decision to terminate the relationship with healthcare providers but later said that he was regretful for having to do so.

Theme Category 7. Now What? Life after High School Graduation -

Connectedness in Survivorship

Much like graduating from high school, participants feel that completing treatment for cancer is a significant milestone. Although participants are joyful when treatment ends, they also experience a great deal of uncertainty as they try to navigate life after cancer. New responsibilities accompany the transition to survivorship, such as attending follow-up appointments and monitoring health behaviors, which require participants to take on a more active role in their health care.

Assuming new adult responsibilities for one's health care and transitioning from an adolescent cancer patient to an adult cancer survivor are complicated by specific concerns expressed by participants. The transition to survivorship is marked by feelings of fear about the cancer coming back, as well as the complexities of transitioning to new

healthcare providers because of their age (i.e., pediatric healthcare providers will no longer be able to address their emerging adult health needs). Participants are concerned about how and when the transition to adult cancer care should occur; however, no clear answers are provided. Additionally, the connectedness participants feel with their pediatric healthcare providers compounds the difficulty in transitioning to new adult cancer providers because there is a sense of guilt that they will be abandoning the healthcare providers to whom they feel most connected.

Immediately after treatment ends, participants have a period of time during which they can remain with their pediatric healthcare providers. Participants enjoy the opportunity to reconnect with their known and trusted healthcare providers during follow-up appointments. According to participants, reconnecting is a cherished, joyful experience that feels like a reunion. It is a time to show off their new status (as a survivor) to those with whom they connected during treatment. Theme category seven has two theme clusters (see Table 4.8).

Table 4.8 Theme Category 7

Theme Category	Theme Clusters	Themes
Now What? Life after High School Graduation - Connectedness in Survivorship	Majoring in Adulthood with a Minor in Adolescence - The Downside of Letting Go and Transitioning to New Healthcare Providers	<ul style="list-style-type: none"> • Uncertainty and reluctance in moving on • Other troubling matters that hinder transitioning
	Reconnecting is Like a High School Reunion - Getting a Connectedness Recharge	<ul style="list-style-type: none"> • Sense of joy of reconnecting with old friends • Reconnecting strategies • Benefits and losses of reconnecting

Theme Cluster 7.1 Majoring in Adulthood with a Minor in Adolescence - The Downside of Letting Go and Transitioning to New Healthcare Providers

Similar to high school graduates who are not fully prepared to assume adult responsibilities, participants feel inadequate in assuming their new role as a young adult cancer survivor. The dual transition to survivorship and adulthood prompts many questions and concerns for participants. Now that participants are cancer survivors, they feel uncertain of what it means to assume responsibility for their own healthcare because their experience as an 'adolescent' patient does not prepare them for such a transition. During diagnosis and treatment, participants have parents who are involved in their care. Although parental support creates an additional sense of security when interacting with healthcare providers, it also seems to hinder participants' ability to learn how to deal with healthcare providers on their own.

Uncertainty and reluctance in moving on. Post-treatment, participants begin to think about how their health care will be attended to in the future. Although participants say they are comfortable with returning to the children's hospital for follow-up, they recognize that eventually they will have to transition to new, adult healthcare providers. However, participants are uncertain how this transition will occur and where they will go for health care: "As far as going to a different hospital later, I don't know what I'll do later...I guess I would go to...I don't know. I guess I'd have to go to a regular one, but I don't know. So far I'm happy [going] there [the Children's Hospital]" [2.402-2.409]. The uncertainty about the whole transition process prompts participants to express their concern to healthcare providers; however, no clear answers are provided: "They [healthcare providers] have told me that I can keep going [to my pediatric oncology healthcare providers] as long as I feel comfortable, and I was kind of like; 'What happens if [the cancer comes back when I am older]...', but they didn't really elaborate what steps I would take if I need to go to a different hospital. But I can always cross that road when I

come to it” [2.411-2.414]. Since there seems to be no clear plans or criteria for participants to transition from pediatric to adult healthcare providers, participants ignore transitioning until it becomes a necessity.

An additional barrier to transitioning to adult healthcare providers is that participants are reluctant about changing to new, unfamiliar healthcare providers. Reasons for this reluctance include a belief that the experience in an adult health care setting will be different (i.e., not as positive) and an uncertainty of finding new healthcare providers who instill the same sense of security as current healthcare providers. For example, one participant said: “[How] I am going to find a doctor like Dr. [Smith] that makes me feel...like they know what they’re doing. I’m not going to just go pay someone just to check me over. He [a new, adult doctor] is going to get tired of it [checking to see if cancer returns] over time” [1.157-1.160].

A final barrier to participants transitioning to adult healthcare providers is that participants feel as if they are betraying their old providers with whom they are connected. Participants need an impetus and clear reasons for making a change in healthcare providers, not just because they are supposed to because they are getting older: “I really like the doctor that I have now, so I couldn’t leave him, just because [I am getting older]...” [2.417].

Other troubling matters that hinder transitioning. Despite the uncertainty and reluctance of transitioning, participants express a desire to find new, adult healthcare providers to whom they can go when health issues arise. Participants want healthcare providers who understand the fears and concerns of a person who had cancer as an adolescent, are available to answer questions, and are able to provide knowledgeable reassurance. Participants sometimes convey a reluctance or lack of ability to take the lead in their own healthcare advocacy. Participants need healthcare providers who can provide an assertive lead in investigating concerns, such as fear of recurrence. One

participant conveyed what happens when neither the participant nor the healthcare provider is connected, assertive, or aware of the specific transition barriers for an adolescent cancer patient transitioning to survivorship: “One time I was bruising a lot...and I was really concerned about it...I went to the Health Center [and said]; ‘Can I get a blood test to see if my iron is okay?’...they did [the test and] told me that my iron was fine. I was like, ‘There’s so much else that is in my blood. What else is there?’ [meaning she wanted to know if there were any other changes in her blood that would indicate that the cancer may have returned]. They had just left a voice mail on my phone, telling me that my iron was low. I was like; ‘There’s so much more in there, I have all of my charts, maybe if there’s anything there, I would be able to just look at it and see if there is any changes. I didn’t call them back” [2.165-2.172]. When efforts to find a new healthcare provider with whom participants can trust and connect are unsuccessful, they become discouraged and are willing to forgo information about present health concerns.

One particularly overwhelming part of transitioning to the adult health care setting is that participants feel overwhelmed with large amounts of health-related information about which they have to keep track. For example, one participant talked about the difficulty of keeping track of the information, specifically related to their cancer: “I have so many stupid pieces of paper...there are just so many brochures [and] packets. I even have a binder that they [my pediatric oncology healthcare providers] said I’m supposed to carry around. Not carry around but like have [with me]...but even that, it seems like there is so much stuff...if I just had the quick kit, maybe on a magnet. I don’t know I’m so disorganized about everything” [2.204-2.209]. With no sense how to organize and prioritize health-related documents, participants find the process of gaining knowledge and skills to assume responsibility for their own adult healthcare overwhelming and not user-friendly.

Theme Cluster 7.2 Reconnecting is Like a High School Reunion - Getting a Connectedness Recharge

Sense of joy in reconnecting with old friends. Follow-up health care, post-cancer treatment, presents an opportunity for participants to reconnect with healthcare providers. Much like a high school reunion, participants anticipate a sense of joy when returning for follow-up because they enjoy reconnecting with their beloved healthcare providers; "...whenever I have [follow-up] appointments I get excited. I'm like; 'Hey! [How are you?]', I mean I don't like being there all day or anything but when you get to see people you haven't seen in forever, like the people that you feel pretty close too, I think it's kind of cool" [4.243-4.245]. According to participants, reconnecting is a pleasurable experience because participants and healthcare providers have the chance to converse like old friends who have not seen one another in awhile, without having to focus on illness related topics: "It's pretty cool because you get to talk like your friends...like friends would talk, 'How are you doing, how's this and how's that" [4.250-4.251]. The opportunity to reconnect makes the follow-up visit feel non-threatening: "I don't even feel like I'm going to the doctor anymore. It's just like a second home going back to visit, that's what it feels like" [7.048-7.049].

Reconnecting strategies. When returning for follow-up, participants make an effort to reconnect with as many healthcare providers as possible. Participants do this by taking the time to talk to the healthcare providers they know, who are present in the out-patient clinic that day, and by returning to the in-patient cancer unit within the hospital: "It's kind of like whenever I go in there [the out-patient clinic for follow-up appointments], it's kind of like a big reunion going on. And then, I don't have to go upstairs [to the cancer in-patient unit]... but I always kind of peek around in there and look for a nurse or two" [2.386-2.387]. Other strategies participants use to reconnect with their beloved healthcare providers include asking about how the healthcare provider is doing, talking

about memorable experiences that occurred while the participant was in the hospital, and writing letters to healthcare providers who are absent the day the participant is visiting.

Participants acknowledge that healthcare providers also make an effort to reconnect with them. Strategies participants say that healthcare providers use to reconnect include taking the time to say hello while he/she is in the out-patient clinic, displaying a continual interest in the participant's personal life, talking about the past, and sending cards to the participant's home address. According to participants, healthcare providers' personal efforts to reconnect can be as simple as just saying hello and knowing that one is remembered: "...Even if he [the oncologist] can't come in, if he's so covered up [with work], he always seems to stick his head in and says 'Hi, and how have you been?'" [1.145].

Benefits and losses of reconnecting. Participants relayed that there are benefits and losses related to reconnecting with healthcare providers. One of the most powerful benefits of reconnecting is the sense of security that is instilled in participants, even in the midst of facing the frightening possibilities inherent in the clinic visit: "I don't like going up there for my checkups, even though I still need to continue doing it, but when Dr. [Smith] is there, he just makes me feel secure. He really makes me really feel like he knows what he's doing...and he just gives you a little reassurance that someone is there who cares...he recognizes me over and over. Not all doctors do that. When I come in he remembers things from the past, and he talks about that, and it makes you feel reassured, like you've got someone who cares" [1.131-1.142]. Other benefits of reconnecting include a sense of being known/remembered, a sense of comfort in returning to hospital for follow-up, and a sense of gratitude that threads of connectedness with healthcare providers are maintained.

Despite the benefits, participants also experience a sense of disappointment and regret. For example, participants experience a sense of disappointment if they are unable to see healthcare providers they feel connected to: “I haven’t seen Dr. [Brown] in awhile because the last three checkups he wasn’t there. He wasn’t working. So, I really haven’t seen him in almost a year I bet” [6.314-6.315]. Participants also experience a sense of guilt for losing the opportunity to reconnect with healthcare providers because of schedule conflicts: “I feel bad because I had an appointment yesterday but I had to cancel because I had to work” [6.305].

Essential Structure of Connectedness with Healthcare Providers

Based on the participants’ descriptions, the essential structure of connectedness with healthcare providers was derived. According to Husserl, the essential structure of a phenomenon can be determined through phenomenological reduction in which researchers must set aside presuppositions, biases, and other knowledge of the phenomenon and allow the common features of the phenomenon to present itself (Giorgi, 1997). When this setting aside, or bracketing, is done appropriately, commonalities of experience are identified and used to exhaustively describe the experience (Hein & Austin, 2001; Sokolowski, 2000). The essential structure is believed to represent the way the phenomenon presents itself to all people who experience it (Giorgi, 1997; Hein & Austin, 2001).

As described by participants, the experience of connectedness with healthcare providers is multi-faceted and encompasses instances of connectedness, unconnectedness, and disconnectedness. A description of how these different instances present themselves to adolescents follows.

From participants’ descriptions, connectedness occurs when healthcare providers exhibit characteristics and behaviors that welcome a relationship such as

being approachable and accessible, being watchful for and attentive to the adolescent's needs, displaying a willingness to foster the relationship, using humor as appropriate, and communicating in a manner that conveys respect for the adolescent's personhood. When adolescents perceive that healthcare providers are going above and beyond what is expected in order to connect, the adolescents experience awe, amazement, and gratitude, and they feel compelled to connect.

The experience of connecting is reciprocal; that is, both adolescents and healthcare providers must make the effort to form connections. Strategies that adolescents use to connect with their healthcare provider include recognizing common bonds they share with healthcare providers, using humor, and eliciting healthcare providers' empathy.

Once connectedness occurs with healthcare providers, adolescents experience a sense of being cared about, understood, respected, comforted, and valued as unique individuals. Consequences of connectedness include a sense of confidence and comfort in expressing oneself to healthcare providers, anticipation of interacting with healthcare providers in the future, a sense of gratitude for healthcare providers, and enhanced well-being. Additionally, there are brief moments that foster a sense of connectedness that is short-lived versus repetitive moments that foster a sense of connectedness that is long lasting.

Based on participants' descriptions, unconnectedness occurs when an adolescent feels that there is little to no common ground on which to establish any relationship with a healthcare provider or group of healthcare providers; therefore, no relationship exists. Unconnectedness is sustained during the cancer experience when healthcare providers exhibit characteristics or behaviors adolescents perceive as not welcoming such as being unfriendly, unwilling to take the time to get to know the adolescent as an individual rather than just another patient, and displaying limited

knowledge of how to take care of and/or talk to an adolescent. Consequences of unconnectedness for the adolescent include (1) difficulty in relating to the unconnected healthcare provider; (2) a sense of annoyance when having to spend time and energy interacting with the unconnected healthcare provider; and (3) an unwillingness to make efforts to communicate with the healthcare provider.

Based on participants' descriptions, disconnectedness occurs when an adolescent's willingness to establish or maintain a relationship with a healthcare provider or group of healthcare providers is destroyed because of a violation of respect for personhood, perpetrated by the healthcare provider. Disconnectedness occurs when adolescents perceive healthcare providers' interactions or behaviors as cruel, hurtful, or disrespectful. When healthcare providers are perceived as having no respect for adolescents, adolescents feel dehumanized, powerless, and sense a lack of freedom for self-determination. Additionally, disconnected adolescents experience a sense of torment, anger, resentment, and shock. Consequences of disconnectedness include a sense of guilt, a continued struggle on the part of the adolescent to find acceptable reasons for the violation, and unresolved feelings of anger towards healthcare providers, even after treatment ends.

There are three critical time points and two contexts during the cancer journey, when connectedness can be fostered, hindered, and/or altered. Additionally, there are times and contexts in which unconnectedness and disconnectedness can be fostered or altered. One key time point is the time surrounding diagnosis. Diagnosis is a time of traumatic confusion, frustration, fear, and vulnerability for the adolescent. These traumatic experiences can heighten adolescents' awareness of healthcare provider efforts to connect or their absence of efforts to connect. The traumatic experiences

around the time of diagnosis can also interfere with adolescents' own receptiveness to connect with healthcare providers.

A second key time point is when adolescents begin to move away from avoidant ways of responding to their diagnosis. The movement occurs when that adolescent accepts the reality of their having cancer, understands the need for help, and are willing to accept the healthcare provider's expertise to guide the treatment, even when treatments cause symptom distress.

A third key time point occurs once cancer treatment is complete. Adolescents, who are now young adult cancer survivors, are torn between the need to transition to new adult healthcare providers and their desire to remain connected to their beloved pediatric healthcare providers, whom they trust. Since there seems to be no clear plans or criteria for young adult cancer survivors to transition from pediatric to adult healthcare providers, survivors ignore the transition process until it becomes a necessity.

There are also contextual influences that can foster, hinder, and/or alter connectedness. One context that influences connectedness is the involvement of parents in the interactions with healthcare providers. For adolescents with cancer, parents can serve as bridges for connectedness during the uncertainty of initial diagnosis and treatment; however, if the interactions of parents with healthcare providers replace interactions with the adolescent, adolescent unconnectedness may be prolonged. The initial opportunities to connect with the adolescent are done between parents and healthcare providers, instead of with the adolescent. Another contextual influence that fosters connectedness is opportunities to gain a sense of comfort and familiarity with healthcare providers, the hospital environment, and treatment routines.

Chapter Summary

In this chapter, nine young adult cancer survivors, who were diagnosed and treated for cancer during adolescence, provided a narrative of their experiences of connectedness with healthcare providers. A total of 2988 significant statements were extracted and restated. Meanings were then formulated for each significant statement. Seven theme categories and 25 theme clusters were identified. Based on the theme categories and clusters, an essential structure of connectedness with healthcare providers was identified. The essential structure of connectedness revealed that connectedness is a multi-faceted experience and encompasses instances of connectedness, unconnectedness, and disconnectedness. There are also key time points and contexts during the cancer trajectory that can foster, hinder, and/or alter the experiences of connectedness.

CHAPTER V

DISCUSSION

This chapter provides discussions of the methods, the findings, and the application of findings for further concept and theory development. Research and clinical implications are described throughout, as are study limitations and strengths. The chapter concludes with recommendations for future research.

Discussion of Methods

The discussion of methods is separated into four sections. First, lessons learned from the recruitment process are described. Second, a description of how the sample characteristics may have influenced the findings is presented. Third, key data collection strategies believed to help produce rich data are identified. Lastly, a personal reflection of the data management and analysis process is provided.

Recruitment Lessons

The literature indicates that recruiting young adult cancer survivors to studies is often difficult (Hudson et al., 2004). In this dissertation study, three important lessons were learned from the recruitment process. Lessons were related to: (1) difficulty in recruiting young adult cancer survivors diagnosed during adolescence from the survivor clinic; (2) participant initial contact preferences; and (3) helping participants accept their expertise status.

The first lesson learned was that recruitment from survivorship clinics may not be an effective or efficient site for recruiting a representative sample of young adult cancer survivors who were treated for cancer during adolescence. Recruiting eligible participants attending a follow-up appointment in the survivor clinic was very slow. Reasons that this initial strategy failed to recruit participants in a timely fashion included

(1) the survivor clinic only took place once a month and (2) very few survivors who attended the clinic on any given clinic day were diagnosed during adolescence. Additionally, many potentially eligible participants were not reachable, because they were not followed through the survivorship clinic for a variety of reasons (e.g. not wanting to return to survivorship clinic or having no health insurance).

One of the difficulties of conducting research with young adult cancer survivors is that many of them are lost after treatment ends (Hudson et al., 2004; Oeffinger et al., 2004). A number of these patients do not return for follow-up appointments or their contact information becomes outdated. Therefore, as described in Chapter III, an additional opt-out strategy was adopted following approval by the IRB. This strategy involved having the physician director of the survivor clinic send letters to eligible survivors describing the study and providing a toll-free number to opt out if they were not interested in receiving a phone call about the study. Contacting eligible participants using an opt-out option will not resolve the issue of outdated information; however, adding the opt-out strategy to this study worked very well in obtaining the remaining number of participants needed to reach redundancy and could be an effective way to contact young adult cancer survivors for future research studies.

The second lesson learned from the recruitment process was the preference of some participants to have initial contact by email; two of the five participants recruited from the survivor clinic preferred to be first contacted by email. When email was chosen as the preferred initial contact, I sent a message introducing myself, describing the study's purpose and asking if they would be interested in participating. Both participants who were contacted via email agreed to participate and gave me their telephone numbers in order to schedule an appointment for the interview. Therefore, presenting the option to be first contacted by email, rather than in-person or via the telephone, may be

an important means of contact to consider for the young adult cancer survivor population.

The third lesson learned was related to the high recruitment rates (100% of participants contacted) and the rich data obtained from participants. The success seems to be related to my effort to establish connectedness with each participant during the initial contact. I did this by assigning the participant the role of being the expert and explaining my role of being a learner based on their expertise. Specifically, I told them I was interested in improving the way healthcare providers interacted with adolescents diagnosed with cancer and because of their experiences they were really the expert on this topic. Additionally, I told them that I was interested in an array of connectedness experiences, both positive and negative. This seemed important for potential participants who may have felt that they did not have anything to share because of a lack of positive connectedness experiences, and it was important to convey that the sharing of negative experiences was appropriate. This strategy seemed to work well. One participant actually said that he felt that sharing more of his negative experiences would be more helpful in obtaining my ultimate goal.

Sample Characteristics

Several sample characteristics may have influenced the findings of this dissertation research. A description of these characteristics is separated into the following categories: individual characteristics, disease-related characteristics, and current health-related characteristics.

Individual characteristics believed to have influenced the findings included: age, gender, race, and ethnicity. Age among the participants in this study was narrow; however, it seems to offer a somewhat representative view of adolescent cancer survivors who are just entering young adulthood. The ratio of males to females was 4:5. This distribution appears to be reasonable; however, national statistics indicate that the

incidence of cancer among males aged 15 to 19 years is slightly higher than among females of the same age (Adolescent and Young Adult Oncology Progress Review Group [AYAO PRG], 2006). This dissertation study did not have a good minority representation. Only one African American participant was recruited and none of the participants declared a Hispanic or Latino ethnicity. Although efforts were made to increase minority representation (see pg 91 in Chapter III), these efforts were unsuccessful. Thus, the findings of the study may not represent the experience of minorities.

Disease-related characteristics that may have influenced the findings included: age at diagnosis, type of cancer, length of treatment, treatment location, and parental presence and availability during treatment. The age range at diagnosis for this sample (15 to 18 years) represents the age group that the National Cancer Institute labels as the adolescent risk group (15 to 19 years) (Soliman & Agresta, 2008). Types of cancer reported by participants were reflective of the common types of cancer that occur during adolescence (Bleyer, 2007) and included Osteosarcoma, Hodgkin's Lymphoma, Germ Cell, Leukemia, and Non-Hodgkin's Lymphoma. The average length of treatment ($M = 11$ months) across participants seemed to be enough time to have encountered several interactions with healthcare providers. All but one participant was hospitalized while receiving treatment (i.e., one participant received treatment on an out-patient basis). The connectedness experience of the participant who was not hospitalized for treatment was somewhat different than the other participants, in that this was the only participant who did not report experiences of disconnectedness. All participants had at least one parent who was present and actively involved in their care. It is important to note that the experiences of connectedness may be different for adolescents who do not have available parents.

Three participants had a parent who had a pre-existing connection with the hospital because they were either a healthcare provider themselves or a hospital administrator. This was an unexpected characteristic and it may have had an influence on these three participants' experiences. A potential influence could have been a diminished need to connect or reconnect with healthcare providers. The reason for considering such an influence is that even though these participants described experiences of connecting and reconnecting with healthcare providers, their expression of these experiences were slightly less enthusiastic than the other participants. It is possible that they may have had a diminished need to connect or reconnect because of the sense of safety and security they gained from having a parent with a pre-existing connection. Therefore, this may be a characteristic to consider for future sample inclusion criteria.

Current health-related characteristics believed to have the possibility to influence the findings included: frequency of cancer-related visits and insurance status. All but one of the participants was attending follow-up appointments at the hospital. This may be a limitation to the findings because participants who attend follow-up appointments may feel more connected to their healthcare providers and want to reconnect with them than those who do not return for follow-up. The rationale for the one participant's reason for not attending follow-up appointments is unknown. All of the participants also had insurance which allowed them the opportunity to return to the hospital for follow-up. Reconnecting experiences may be different for those without insurance.

Data Collection Strategies

Procedures for data collection were effective in obtaining rich data from participants. Key strategies believed to have helped produce such rich data included (1) mailing a written copy of the data-generating question at least three days ahead of time so participants had time to think about their experiences prior to the interview; (2) telling

the participants that their confidentiality would be protected by removing all identifying information and using pseudonyms in place of names discussed in the interview; and (3) assigning the participant the role of the expert and explaining my role as a learner from their expertise. This last strategy was not something that I had originally planned on doing but when I met the participants I felt that it was important to make them feel that we were on the same level. This strategy seemed to work because the participants appeared to be relaxed and were willing to even share embarrassing experiences with me.

Participants chose the time and location for the interview. All but one of the interviews took place in the participants' home. One participant preferred to drive down from Northern Indiana to meet me. This participant's interview took place in a private room within the hospital. As described in Chapter III, efforts to ensure that the setting was quiet were effective.

The interview protocol continued to be appropriate and produced rich data. Participants understood the term 'connectedness' and easily entered into the description of their experiences. However, there were times when the participants needed help in tapping into their experiences. When participants needed prompting, the interview-by-comment strategies were effective (Snow et al., 1982). For example, when a participant would have trouble thinking of other experiences to share and asked for more questions, I responded by asking them to tell me more about a particular situation they had discussed earlier. Or I would ask them to tell me more about how a particular occurrence came about or how they felt during the interaction. Participants were encouraged to talk until they felt their experiences were fully described. The average length of the interviews ($M = 43$ minutes) was consistent with reports from other phenomenological studies with adolescents/young adults (Dickinson & O'Reilly, 2004; Haase, 1987; Langeveld et al., 2000). Although three of the interviews were short (less than 20

minutes) and two of the interviews were over an hour long, the richness of the data did not seem differ between interviews. In other words, there was as much meaning from the short interviews as there was from the long interviews.

Untapped experiences of connectedness revealed themselves to participants as they continued talking. This finding supports the subconscious nature of experiences that are tapped into with phenomenology (Colaizzi, 1978; Giorgi, 1997).

Participants in this study expressed a perceived therapeutic benefit from participating; that is, participants expressed a sense of gratitude for having the opportunity to share their experiences. This finding has been reported in other phenomenological studies (Haase, 1987; Kooken, 2008).

Data Management and Analysis

The use of Microsoft Word Outline layout was helpful to manage the data. In this study, over 2900 formulated meanings needed to be organized into themes. Formulated meanings derived for each participant's interview were cut and pasted into the theme outline in order to create themes. The final data analysis document was 294 pages. When using the outline layout, themes could be viewed at different levels with level one being the theme category, level two theme clusters, level three themes, and level four subthemes. This analysis went out to the sixth level. Another helpful strategy in the beginning stages of this analysis was to color coordinate similar themes. For example, all emerging themes related to the experiences of disconnectedness were given the color brown.

The procedures for data analysis were effective. Breaking down the narrative into significant statements, then identifying each statement's formulated meaning was a long, but important process. The process was very instrumental in achieving a deeper understanding of what the participants experienced. The validation discussions with mentors and peers were also helpful in gaining a deeper understanding of the

participants' experiences and to develop the essential structure. The analysis process was emotionally difficult at times, particularly when analyzing the statements related to disconnectedness. At these times, the work with mentors and peers was helpful to validate and deal with strong emotional responses.

Interpretation of the Findings

Discussion of findings is separated into six sections based on the identified key findings (see Table 5.1). Each key finding is discussed separately, along with its research and/or clinical implications.

Table 5.1 Key Findings

Key Finding	Corresponding Theme Categories
1 Adolescents begin relationships with healthcare providers from a disconnected perspective.	1, 3, 5
2 Diagnosis is a pivotal moment when opportunities for healthcare providers to connect with adolescents can be missed, lost, or severed if not done delicately.	2, 5
3 System-wide health care efforts to connect with adolescents are not working; participants feel the environment is teen-unfriendly.	2, 5
4 A connectedness primer was developed based on the key strategies that participants identified as essential for healthcare providers to use to foster a sense of connectedness.	4
5 In survivorship, participants continue to struggle with disconnectedness experiences in which they were dehumanized and tortured by some healthcare providers.	5
6 Participants struggle with transitioning to new adult healthcare providers.	6, 7

Key Finding 1. Adolescents Begin Relationships with Healthcare Providers from a
Disconnected Perspective (From Theme Category 1, 3, and 5)

Summary

Based on participants' descriptions, the context of the diagnosis sets the stage for connectedness with healthcare providers. The context involves both the events prior to and after the diagnosis. This key finding focuses on the events prior to the diagnosis.

The circumstances leading up to the diagnosis are frustrating for adolescents when answers to their unusual symptoms are not provided in timely or sensitive manner. Participants in this study described being misdiagnosed or misinformed during initial consultations and/or having to interact with healthcare providers who displayed a lack of sensitivity or respect for their concerns. Therefore, adolescents begin their relationship with healthcare providers in a deficit, that is, from a disconnected perspective and healthcare providers need to work hard to overcome this barrier.

Discussion

Evidence supports the finding that adolescents enter cancer diagnoses from a disconnected perspective. Research suggests that adolescents with cancer experience a delay in their diagnosis and this may be one of the reasons for the decrease in survivorship outcomes in this population (Bleyer, 2007; AYAO PRG, 2006). American and Canadian studies of pediatric and adolescent cancer patients indicate that the number of days from the onset of symptoms to diagnosis increases with age, and that the lag time in diagnosis is twice as long for older adolescents as compared to younger children (Dang-Tan et al., 2008; Klein-Geltink, Shaw, Morrison, Barr, & Greenberg, 2005; Pollock, Krischer, & Vietti, 1991). Both provider and patient factors are believed to contribute to the delay in diagnosis (Bleyer, 2007; AYAO PRG, 2006). Healthcare provider factors contributing to delayed diagnoses include under-recognition of how the signs and symptoms of cancer present themselves in adolescents, a lack of skills in

caring for and communicating with adolescents, and an unwillingness to care for adolescents (Bleyer, 2007). Patient factors include (1) a sense of invincibility (AYAO PRG, 2006); (2) a lack of routine medical care (Ziv, Boulet, & Slap, 1999); and (3) having no health insurance (S. Martin et al., 2007). Because of these many factors, adolescents, as a group, seem to have a pre-existing cultural disconnect from the healthcare system. When adolescents with cancer encounter negative experiences with healthcare providers, such as being misdiagnosed, misinformed, or not taken seriously, this compounds the sense of disconnectedness that is already in place.

Research Implications

Results of this study suggest that connectedness may have implications for early cancer detection in adolescents. Further research is needed to explore the relationship of adolescent-healthcare provider connectedness to delayed diagnoses. The hypothesis would be that if adolescents have healthcare providers to whom they were connected, prior to the onset of cancer symptoms, the lag time for diagnosis would be shortened. Adolescents who are in a connected relationship with healthcare providers would be more likely to share unusual symptoms with healthcare providers, so appropriate cancer screening measures could be implemented early. Likewise, healthcare providers in such connected relationships would know adolescents well enough to detect cancer symptoms when first noticed. Policy implications would include ensuring that all adolescents had healthcare insurance coverage and accessibility to adolescent appropriate cancer screening services.

Clinical Implications

The primary clinical implication is to enhance the knowledge base of primary care providers, emergency room doctors, and other specialists, who are typically the first to evaluate adolescents' concerns, about how cancer symptoms present themselves in adolescents (Bleyer, 2007). Additionally, healthcare providers need to know specific

strategies to effectively connect with adolescents to efficiently obtain the necessary information to make a differential diagnosis of cancer. Case-study examples and role-playing exercises with adolescent actors would be valuable resources for establishing this basic, potentially life-saving knowledge.

Key Finding 2. Diagnosis is a Pivotal Moment when Opportunities for Healthcare Providers to Connect with Adolescents can be Missed, Lost, or Severed If Not Done Delicately (From Theme Category 2 and 5)

Summary

According to participants, the confirmation of the cancer diagnosis is a traumatic moment. The trauma of the diagnosis places adolescents in a state of shock and disbelief. As the diagnosis sinks in, and as initial treatment related symptom distress increases, a powerful sense of loneliness and despair emerges. Adolescents feel most vulnerable immediately after the diagnosis and begin to use avoidant or defensive coping strategies (i.e., become withdrawn or ill-tempered) in order to deal with their frustration about what is happening to them. As adolescents begin to make sense of the diagnosis, they carefully assess the characteristics of and interactions with healthcare providers. Although adolescents may appear to be withdrawn, uninterested, and unable to connect, they are still making assessments of whether or not healthcare providers can be trusted and making key judgments about how their experiences with healthcare providers might go. If efforts to connect with adolescents are not done in a delicate manner, the opportunity to connect may be missed and divert adolescents away from the optimal consequences of connectedness. Therefore, healthcare providers need to have an awareness of their role in both connectedness and the trauma experienced by the adolescents related to the initial diagnosis.

Discussion

This finding relates to two issues that need to be considered when interacting with newly diagnosed adolescents with cancer. First, interactions with adolescents are crucial and must be delicately handled, especially around the time of diagnosis. Although adolescents may be unable to take in healthcare providers' efforts to connect, they are carefully assessing the characteristics and behaviors of healthcare providers during this time. This finding makes a unique contribution to the literature because there is little evidence regarding how to establish a relationship with adolescents with cancer. Recent studies that have examined young adult cancer survivors' perception of communication during diagnosis and treatment support the finding that adolescents are assessing healthcare provider actions (Zebrack, Chesler, & Kaplan, 2009; Zwaanswijk et al., 2007). Thus, healthcare providers must pay close attention to how their behaviors and actions may be perceived by adolescents.

The second issue, relevant to connectedness, is healthcare providers' awareness of the trauma the adolescent feels with the cancer diagnosis. The adult oncology literature supports the finding that a cancer diagnosis is a traumatic event for patients, and serious psychological consequences can result, if healthcare providers do not appropriately handle interactions at this time (Mager & Andrykowski, 2002; Paul, Clinton-McHarg, Sanson-Fisher, Douglas, & Webb, 2009; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). Research reveals that healthcare providers can have a profound impact on how patients cope with their diagnosis (Bakker et al., 2001). A theoretical model that demonstrates the potential impact that healthcare providers have on adolescent cancer patients is the Adolescent Resilience Model (Haase, 2004). In this model, the nature of the adolescent-healthcare provider relationship is a protective factor and considered to have an influence on moving adolescents away from the use to defensive coping strategies and towards courageous coping strategies. Although

defensive ways of coping are initially used for protection in life-threatening situations, they become problematic when they are sustained and prevent the development of more positive ways of coping (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Parle, Jones, & Maguire, 1996; Phipps, Fairclough, & Mulhern, 1995). Therefore, if healthcare providers make early efforts to connect with adolescents and display an acceptance of the use of defensive coping strategies, then adolescents may be more likely to use courageous coping strategies, especially supportant coping, which is defined as the willingness to reach out and ask for help/support when needed (Haase, 2004).

Research Implications

Further research is needed on the communication styles that minimize the trauma of the diagnosis and foster connectedness. Although there is a growing research interest in how the diagnosis is communicated to cancer patients (Baer et al., 2008; Paul et al., 2009; S. Williams et al., 2008), the research is focused primarily on adult cancer patients. Little research has been devoted to examining communication styles that buffer the trauma of the diagnosis for adolescents. However, Zebrack et al. (2009) recently reported that young adult cancer survivors who were diagnosed during adolescence perceived the information provided by physicians in regards to diagnosis, prognosis, and potential long-term effects was cold, aloof, or presented in a patronizing manner. Exploring how healthcare providers present the diagnosis to adolescents will help shed light on ways to minimize the trauma. Ways of doing this may include video-taping physicians relaying the diagnosis to adolescents and then later having the adolescent, their parents, and the physician discuss their perceptions' of the interaction (Frankel, Sung, & Hsu, 2005).

Role-playing using cancer survivors is another potentially effective and innovative strategy that could be used to help healthcare providers learn behaviors that foster

connectedness. Baer et al. (2008) used this strategy to teach medical students how to better deliver the diagnosis of cancer to adult patients. Young adult cancer survivors could participate in role-playing exercises to help teach pediatric oncology trainees and medical students how to exhibit characteristics and interactions that help foster a sense of connectedness which begins at the diagnosis.

Clinical Implications

This finding has clinical implications for healthcare providers who should carefully make an effort to connect with adolescents at diagnosis. Strategies that would display a willingness connect at diagnosis include: (1) demonstrating confidence that answers will be provided; (2) including the adolescent in all conversations prior to and after the diagnosis; (3) displaying an acceptance of and understanding for adolescent avoidant behaviors; (4) providing information in an understandable and caring manner; and (5) being honest about what to expect during the diagnosis and treatment process.

Key Finding 3: System-Wide Health Care Efforts to Connect with Adolescents
Are Not Working; Participants Feel the Environment is Teen-Unfriendly

(From Theme Category 2 and 5)

Summary

Based on participants' descriptions, the healthcare system at large seems to be making little effort to connect with adolescents. Participants in this study described feeling that the environment was intolerable at times. Circumstances that contributed to the negative perceptions of the environment included the teen-inappropriateness of the surroundings and lack of age appropriate activities, as well as some healthcare providers who displayed a limited knowledge of how to take care of and talk to adolescents. Although participants in this study eventually learned to ignore or accept these annoyances, the teen-unfriendliness of the environment was perceived by

participants to be a factor that hindered the ability and willingness to connect with healthcare providers, especially at the beginning of hospitalization or treatment. Thus, the healthcare system needs to devote a stronger effort in supporting the age appropriate needs of adolescent cancer patients.

Discussion

The lack of adolescent-appropriate health services has been recognized as a major problem in the United States. To address the nation's deficit in providing adequate health services to adolescents, the National Research Council and the Institute of Medicine, along with the Board of Children, Youth, and Families, recently formed the Committee on Adolescent Health Services and Models of Care for Treatment, Prevention, and Healthy Development. According to the Committee on Adolescent Health Services (2009),

“the health system – health services, the settings where these services are delivered, how the services are delivered and by whom – has an important role to play in promoting healthful behavior, managing health conditions, and preventing disease during adolescence. Yet health services and settings in the United States today are not designed to help young people at this critical time in their lives, and providers often are not adequately trained in adolescent issues. As is the case in many other parts of the nation's health system, adolescents face gaps in care, fragmented services, and missed opportunities for health promotion and disease prevention” (p 1).

Similarly, in the field of adolescent oncology, there has been an increased focus on how to better meet the needs of adolescents with cancer (Bleyer, 2005; Haase & Phillips, 2004). Although researchers have acknowledged that adolescents with cancer have unique needs that differ from their younger or older counterparts, there is little empirical evidence on how to best support the needs of adolescents undergoing cancer treatment (Whelan, 2003; AYA0 PRG, 2006). One of the reasons that it may be difficult to examine standards of practice that best support the needs of adolescent cancer patient is that currently there is no consensus on where adolescents with cancer should

be treated. Depending on their diagnoses and means of referral, adolescents are either treated in a pediatric or adult oncology setting (Bleyer, 2007). In either setting, adolescents have expressed feeling misplaced (Enskar, Carlsson, Golsater, & Hamrin, 1997; Zebrack et al., 2009).

Researchers in the United Kingdom believe that a specific environment that provides specialized cancer care to adolescents may have a positive influence on the health outcomes of adolescents with cancer (Kelly, Pearce, & Mulhall, 2004; Mulhall, Kelly, & Pearce, 2004; Whelan, 2003). In the UK, Teenage Cancer Units are specialized units created for adolescents and their development is supported by a charitable organization called the Teenage Cancer Trust (www.teenagecancertrust.org). Teenage Cancer Units are equipped with computers with internet access, satellite televisions, web cams, PlayStations, musical instruments, DVDs, and IPODs. There are also lounges for adolescents to just relax or visit with family and friends. Healthcare providers who work on these units receive special training in how to communicate and care for adolescents. Currently, there are 8 teenage cancer units in the United Kingdom. Only two descriptive studies were found to have evaluated the activities on a specialized adolescent cancer unit (Kelly et al., 2004; Mulhall et al., 2004). Results of these studies have indicated that both patients and parents highly valued and appreciated the teen-friendliness of the environment as well as the staff's sensitivity towards teenagers. However, there seems to be some hesitancy of implementing teenage cancer units in other countries. Some of the reasons for this hesitancy include the cost-effectiveness of developing a specialized unit for such a small number of patients and difficulty of coordinating the care for adolescents in one specific area who are followed by pediatric oncologists versus adult oncologists (Whelan, 2003).

Research Implications

As reported by adolescent oncology experts, the current standards of care are clearly not meeting the needs of adolescents with cancer (Bleyer, 2007; Haase & Phillips, 2006). Based on the results of this dissertation study, the lack of an adolescent friendly environment seems to have an influence on adolescents' ability and willingness to connect with healthcare providers. Further study is recommended on the characteristics of the environment that foster and hinder connectedness. One way of examining these features might be to determine if the experiences of connectedness with healthcare providers in general treatment facilities are different than in settings that have a specialized teen unit. Comparison between the Teen Cancer Units in the United Kingdom with general pediatric oncology units in the United States may provide evidence for environmental impact on outcomes for adolescents with cancer.

Clinical Implications

An awareness of adolescents' perception of the environment needs to be brought to the attention of hospital administrators. A lack of teen-appropriate services for adolescent cancer patients seems to be unfair and possibly unethical. Many adolescents with cancer spend weeks, sometimes months, in the hospital when receiving treatment and need to have a variety of available teen-appropriate activities that help foster some sense of normalcy. Additionally, adolescents with cancer need to receive care from healthcare from providers who are trained in delivering adolescent-appropriate care that supports their normal development. A hospital setting viewed as teen-unfriendly may be perceived by adolescents as a place that does not care about the needs and preference of adolescents, and is most likely a barrier to fostering a connection between adolescents and healthcare providers.

Key Finding 4: A Connectedness Primer was Developed Based on the Key Strategies that Participants Identified as Essential for Healthcare Providers to Use to Foster a Sense of Connectedness (From Theme Category 4)

Participants in this dissertation study described key healthcare providers strategies which were essential for fostering a sense of connectedness. Some healthcare providers made connecting with adolescents seem effortless; they seem to instinctively know how to connect with adolescents. Also, healthcare providers who made themselves available were viewed as facilitating connectedness. Other strategies involved a little more work on the part of healthcare providers, such as actively being watchful for and attentive to the adolescent's needs; displaying a willingness to foster the relationship; using humor as a means of connecting; and communicating in a manner that conveys respect for the adolescent's personhood. These strategies provide a foundation for teaching healthcare providers how to connect with adolescent cancer patients.

The discussion of this key finding is separated into five sections, reflecting each key strategy. Each section will briefly summarize the elements of the key strategy, discuss whether or not the strategy is supported in the literature, and describe the research or clinical implications related to the strategy.

Characteristics that Express Knowledge of Knowing How to Connect and Being Available

Summary. Participants described connecting with healthcare providers who seemed to instinctively know how to connect with adolescents. Healthcare provider characteristics that exhibited this "know-how" included being caring, calm, honest, friendly, endearing, thoughtful, competent, understanding, and unexpectedly approachable (i.e., down to earth, unpretentious). Other characteristics such as physical

attractiveness of the healthcare provider and being close in age to the adolescent were considered as “bonus” characteristics that made participants want to connect with certain healthcare providers. These bonus characteristics were not described as being essential, but rather an additional perks.

Healthcare provider availability was described by participants as an influential factor for connecting. Being able to see the same healthcare providers over and over again fostered a sense of familiarity and comfort that facilitated a sense of connectedness. This is not to say that adolescents only connected with healthcare providers that they saw on a consistent basis. Adolescents could connect with providers that they saw briefly, but only if healthcare providers skillfully knew how to connect.

Discussion. This finding indicates that there are certain healthcare provider characteristics that affect adolescent cancer patients’ willingness to connect. Based on the participants’ descriptions, there seems to be distinct differences in the characteristics of healthcare providers who know how to connect versus those who do not know how to connect. For example, participants believe that healthcare provider characteristics which do not foster connectedness include, being awkwardly intrusive, unfriendly, hyper-vigilant, pushy, unwilling to do more than the minimum to foster the relationship, and displaying a limited knowledge of how to take care of or talk to an adolescent. Alternately, healthcare providers who exhibit a persona of kindness, are honest, and demonstrate a confidence in their competence in interacting with adolescents are likely to make a connection with adolescents. Therefore, adolescents’ assessment of healthcare provider characteristics seems to play an instrumental role in their discernment of whether or not they will connect with healthcare providers.

The identified healthcare provider characteristics believed to foster connectedness are supported in the literature. Several qualitative investigations have been conducted with healthy and chronically ill adolescents in an effort to identify their

healthcare preferences and expectations. Results from these studies indicate that adolescents want healthcare providers who are caring, friendly, honest, respectful, competent, trustworthy, and non-judgmental (Britto et al., 2004; Clowers, 2000, 2002; Ginsburg, Menapace, & Slap, 1997; Ginsburg et al., 1995; Rosenfeld et al., 1996). Additionally, adolescents have reported that having the ability to see the same healthcare provider for all health visits has an influence on their ability to trust healthcare providers (Ginsburg et al., 1997). Although these previous studies did not evaluate the influence of these characteristics on adolescents' perceptions of their relationship with healthcare providers, these same characteristics were of importance to participants in this dissertation study as related to connectedness.

The wider literature on patient-provider interaction also suggests that these healthcare provider characteristics are important (Bakker et al., 2001; McWilliam et al., 2000; Throne et al., 2005). However, there is a limited understanding of how the characteristics of healthcare providers influence patients' perception of feeling connected to their healthcare providers. Results from this study indicate that healthcare providers who exhibit these characteristics demonstrate a competence in connecting with adolescents and are interpreted by adolescents as the healthcare provider's way to expressing their desire to connect. Thus, when adolescents interact with healthcare providers who possess these characteristics they are likely to want to connect with them.

Research implications. Future research is needed to explore how healthcare providers who are specifically identified as experts at connecting with adolescents enact these characteristics. One way this could be done is to video-tape healthcare providers who exhibit such characteristics while they are interacting with adolescents. These video-taped interactions then could be used to as exemplars for trainees. Another research effort could be do a matrix analysis of the themes identified in this study and

compare the characteristics of healthcare providers who were identified as being good at connecting with those who were not (Averill, 2002).

Being Watchful for and Attentive to Adolescents' Needs

Summary. Participants in this study described a desire to connect with healthcare providers who demonstrated that they were watchful for and attentive to the participant's needs. Healthcare providers demonstrated this strategy by: (1) picking up on the adolescent's cues of symptom distress; (2) validating their need for symptom relief; and (3) working quickly to alleviate their distress. Additionally, participants described connecting with healthcare providers who were attentive to their personal needs as well. Therefore, the ways in which healthcare providers are watchful (or vigilant) for and attentive to adolescents' needs is likely to be an important factor in fostering connectedness.

Discussion. Little research has been devoted to examining adolescents' perception of healthcare providers' watchfulness for their needs and how this may influence their perception of their relationship with healthcare providers. However, there is some evidence that healthcare providers' lack of attentiveness for adolescents' needs may be a barrier to connectedness. For example, two qualitative studies reported that chronically ill adolescents felt that their needs and concerns were of little interest to their healthcare providers (Beresford & Sloper, 2003; Young et al., 2003). In Beresford and Sloper's (2003) study, adolescents expressed a desire to have information about how to manage and cope with the impact of their chronic condition on a daily basis; however, healthcare providers rarely helped them obtain such information. Therefore, adolescent patients' perception of healthcare providers' watchfulness for and attentiveness to their needs is likely to be an important contributor to connectedness with healthcare providers.

Some evidence for the importance of watchfulness was found in the adult oncology literature. One study, conducted in Japan, reported that cancer patients considered nurses who demonstrated an awareness of their needs, feelings, and subtle changes in their condition, as being 'good nurses' (Izumi, Konishi, Yahiro, & Kodama, 2006). McWilliam et al. (2000) also reported that breast cancer patients believed that their relationship with their physician was enhanced when the physician demonstrated attentiveness to their needs and concerns. Although the primary focus of both these studies were not patient-provider connectedness, it does suggest that healthcare providers' watchfulness/attentive to the needs of the patient is important to cancer patients and is likely to influence their sense of connectedness with healthcare providers.

In a recent dissertation study on perceptions of vigilance among adult cancer patients, their family members, and nurses, Kooken (2008) reported that one aspect of vigilance in cancer care relates to patient-provider connectedness. In Kooken's study, cancer patients believed that nurses, who knew them well and to whom they felt connected, were more vigilant than the nurses with whom there was no connection. Nurses' data confirmed and further explained patient perceptions. Nurses reported purposely connecting with patients to gain the knowledge necessary to more readily identify 'different than normal' aspects of the patient; thus, allowing the nurses to respond more quickly to things that could threaten the patient's health or well-being. Thus, there seems to be a relationship between patients' perceptions of healthcare provider vigilance and connectedness.

The concept of patient-centeredness also supports watchfulness/vigilance as being a means to connectedness. As described in Chapter II, patient-centered care is characterized by physicians' responsiveness to patients' wants, needs, and preferences and is believed have a positive influence on patient health outcomes (Laine & Davidoff,

1996; Mead & Bower, 2000). Although investigators are still defining the specific communication behaviors of healthcare providers that represent patient-centeredness (Epstein et al., 2005), it can be assumed that demonstrating attentiveness to patients' needs influences how patients' perceive their relationship/connectedness with healthcare providers.

Clinical implications. Healthcare providers who care for adolescents with cancer need to be aware that their responsiveness to adolescents' needs, particularly symptom distress, is interpreted as being watchful/vigilant and is an influencing factor in fostering a sense of connectedness. If healthcare providers are perceived by adolescents as recognizing and doing whatever it takes to alleviate their distress, even if attempts are unsuccessful, adolescents are likely to connect with these healthcare providers. In contrast, when healthcare providers are perceived by adolescents' as being hesitant in or skeptical about alleviating the adolescents' distress, healthcare providers are perceived as not being watchful/vigilant and, the opportunity of connect is destroyed. If, indeed, vigilance and connectedness are related, there are also clinical implications for patient safety when connectedness is fostered. Having a primary nurse, who has opportunities to connect over time, may foster patient safety by picking up on changes in patients status more quickly and preventing errors (Kooker, 2008).

Displaying a Willingness to Foster the Relationship

Summary. Based on participants' descriptions, displaying a willingness to foster the adolescent-provider relationship was an important strategy that encouraged a sense of connectedness with healthcare providers. Strategies healthcare providers used to show participants that they were willing to foster the relationship included interacting with the adolescent more like a friend than a patient, spending quality time with the adolescent, and self-disclosing personal information about themselves.

Discussion. Although the importance of healthcare providers' efforts and willingness to foster the patient-provider relationship has been recognized and described in the literature (Dowling, 2006; Mitchell, 2007), little evidence supports its influence on patients' perspectives of being connected with healthcare providers. One study obtained similar results to those found in this dissertation study. When interviewing adult cancer patients about their perceptions of effective and ineffective communication behaviors of healthcare providers, patients reported that healthcare providers, who disclosed personal information about themselves, were considered to be willing to extend the relationship and that this type of interaction facilitated a sense of connectedness (Thorne et al., 2005). Therefore, self-disclosure on part of the healthcare provider is likely be an indicator that informs patients that healthcare providers are willing to foster a connected relationship with them.

Research implications. Further work is needed to examine adolescents' and healthcare providers' perceptions' of self-disclosure within the patient-provider relationship. One aspect would be to explore the therapeutic benefit of healthcare provider self-disclosure.

Using Humor as Means of Connecting

Summary. Humor was described by participants as a valuable means to connectedness. Participants expressed that the use of humor eased any awkwardness they felt while interacting with healthcare providers. Humor strategies implemented by healthcare providers that fostered a sense of connectedness were perceived by participants as having an influence on both their mood and willingness to engage normal daily activities. Participants also reported that healthcare providers were perceptive in knowing the appropriate times to employ humor. When healthcare providers incorporated humor in the interaction and were perceptive about its timing, this action

demonstrated that they were considerate and felt comfortable enough to joke around at the adolescent's level. This type of interaction created an environment of equality in which the adolescent was able to connect.

Discussion. The importance of the use of appropriate humor in the patient-provider relationship and how humor may influence the well-being of adult cancer patients has been well documented (Astedt-Kurki, Isola, Tammentie, & Kervinen, 2001; Beck, 1997; Christie & Moore, 2005; Erdman, 1991; Johnson, 2002; McCabe, 2004). Similar evidence has been found in research studies involving adolescents with cancer. Recently, Fallon et al. (2008) interviewed adolescents and young adults with cancer to elicit topics that they felt were most important to incorporate in a training module for healthcare providers caring for adolescent cancer patients. In this study, the importance of healthcare providers having a sense of humor was identified as the topic of highest priority. Additionally, Hinds, Martin, and Vogel (1987) found that nurses' ability to incorporate humor in the care for adolescents with cancer seemed to have a direct influence on promoting hopefulness. Similarly, Dowling and colleagues (2003) found that children and adolescents with cancer who had a greater sense of humor were more psychosocially adjusted to having cancer. Thus, the incorporation of humor with adolescent cancer patients appears to be a strategy valued by adolescents and a means to moderating the stress related to having cancer.

Clinical implications. Findings related to humor suggest that the importance of using humor with adolescents with cancer should be brought to the attention of healthcare providers. Workshops focused on how to use humor appropriately in the healthcare setting may help reinforce the actions of humorous healthcare providers and may be helpful to healthcare providers who feel that do not have a sense of humor (Wood, 2009).

In addition to exploring ways to be more humorous, healthcare providers should make an individualized assessment of what the adolescent perceives as humorous (Astedt-Kurki et al., 2001). What may be humorous to one adolescent may not be humorous to another adolescent. Gathering information about humor preferences would help healthcare providers obtain and provide humorous materials that matches what the adolescent believes is funny such as comical teenage movies or books. Incorporating humor based adolescents' preferences is likely to demonstrate to adolescents that healthcare providers are willing to connect and able to create an environment that is relaxed and sociable where adolescents can relieve their frustrations related to the cancer experience (Astedt-Kurki, et al, 2001).

Communicating in a Manner that Conveys Respect for the Adolescent's Personhood

Summary. Communicating in a manner that conveys respect for the adolescent's personhood is another strategy that participants perceived as facilitative to connectedness with healthcare providers. Participants in this study, reported that healthcare providers conveyed respect for their personhood by: (1) treating them as a person of value; (2) acknowledging and respecting their need for space/privacy; (3) providing enough information so they knew what to expect; (4) handling embarrassing situations delicately; (5) inquiring about their needs, opinions, and desires; (6) communicating in an age-appropriate manner that demonstrates respect for their autonomy (e.g. talking to the adolescent as a competent individual who is capable of handling even the difficult facts related to treatment); (7) being supportive of the adolescent's need to keep up with the outside world (i.e., school and social-related activities); and (8) doing unexpectedly nice things for them such as, going out of their way to do make the adolescent feel special or bringing in age-appropriate distraction activities for the adolescent.

Discussion. Evidence related to the importance of healthcare providers' recognition and respect for the patient's personhood is quickly emerging in the literature, especially in adult oncology. Previous qualitative investigations have reported that adult cancer patients perceive that communication exchange between them and their healthcare providers is enhanced when healthcare providers take the time to get to know them as a unique individual (Bakker et al., 2001; Izumi et al., 2006; McWilliam et al., 2000; Thorne et al., 2005; S. Williams et al., 2008). Additionally, these studies indicated that when patients' feel known and respected by their healthcare providers, they are more likely to pursue an active role in obtaining and using health-related information from their healthcare providers. Thus, communication behaviors of healthcare providers that demonstrate respect for a patient's personhood is likely to have a significant influence on patients' sense of connectedness with healthcare providers and lead to positive health outcomes.

Participants in this dissertation study made it very clear that connectedness occurs when adolescents feel that healthcare providers understand and respect who they are as individuals. This finding supports the emerging concept of relationship-centered care in which patients' personhood is sought, acknowledged, and used to guide patient-provider interactions (M. Beach, Inui et al., 2006; Tresolini & the Pew-Fetzer Task Force, 1994). As described in Chapter II, the concept of relationship-centered care is still in early stages of research in regards to explaining what behaviors promote a sense of connectedness with healthcare providers. The results of the study indicated that when healthcare providers communicate in a manner that displays respect for the adolescents' personhood, a sense of connectedness is fostered. Findings from this study provide a foundation to further examine the specific communication behaviors and actions of healthcare providers that make adolescents feel that their personhood is respected.

Research implications. A recommendation for future research is to obtain direct observational information regarding the communication behaviors that exhibit a respect for the adolescent's personhood. As suggested earlier, one way this could be explored is to video-tape healthcare providers who adolescents with cancer identify as being good at exhibiting respectfulness towards them. Taped interactions would help identify the specific healthcare provider communication behaviors that convey respect for adolescents. This information could then be used to develop or identify observational measures to help quantitatively explain the communication dynamics that influence adolescent-provider connectedness.

Key Finding 5. In Survivorship, Participants Continue to Struggle with Disconnectedness Experiences in Which They were Dehumanized and Tortured by Some Healthcare Providers (From Theme Category 5)

Summary

Participants in this study described disturbing experiences in which some healthcare providers displayed a lack of respect for their personhood and destroyed the opportunity to connect with them. A sense of disconnectedness occurs when adolescents perceive the interactions and behaviors of healthcare providers as being cruel, hurtful, and/or disrespectful. Specific healthcare provider behaviors that foster a sense of disconnectedness include: (1) exhibiting a lack of appreciation for who the adolescent is as a person; (2) inflicting unnecessary harm or discomfort; (3) being apathetic of the adolescents needs and preferences; (4) treating the adolescent like they have minimal rights; (5) speaking to the adolescent in a patronizing manner; (6) intruding on their privacy; (7) being dishonest; and (8) failing to be vigilant for their basic needs. When adolescents perceive that healthcare providers have no respect for adolescents, they feel dehumanized, powerless, and feel a lack of freedom for self-determination.

Adolescents also experience a sense of torment, anger, resentment, and shock when healthcare providers behave in such a manner. Experiences of disconnectedness leave lingering feelings of anger and resentment, even after treatment ends. This finding is particularly troubling because the participants in this study are now young adults, on average about three and half years out from treatment, and they are still struggling with the experiences of disconnectedness.

Discussion

Experiences of disconnectedness with healthcare providers and the impact that such experiences have, on adolescent cancer patients, has rarely been reported in the literature. However, two qualitative studies were found that reported similar findings. In both of these studies, survivors of adolescent cancer and chronically ill adolescent patients perceived particular aspects of healthcare providers' communication as hurtful or harmful, such as breaking bad news in a insensitive manner, withholding information about changes in treatment, speaking to the adolescent in a patronizing manner, and not taking the adolescent seriously (Hsiao, Evan, & Zeltzer, 2007; Zebrack et al., 2009). While these qualitative studies did not develop conclusions about connectedness or disconnectedness, the findings clearly point to behaviors that impede relationship development. Disconnectedness with healthcare providers may be experienced by adolescent patients more often than what is reported in the literature.

The findings from this dissertation study suggest participants perceived experiences with disconnectedness is traumatizing. This finding may add additional insight into the literature on post-traumatic stress disorder (PTSD) in young adult cancer survivors. PTSD and other post-traumatic stress symptoms have been reported in young adult cancer survivors (Hobbie et al., 2000; Langeveld, Grootenhuis, Voute, & de Haan, 2004; Y. Lee & Santacroce, 2007; Zebrack et al., 2002); however, little is known about the nature of the traumatic experiences during cancer treatment that lead to PTSD

(Rourke et al., 2007). Results from this dissertation suggest that adolescents' experiences of disconnectedness with healthcare providers may be a contributing factor contribute to PTSD. Although PTSD was not a focus of this study, it was obvious that, as participants recounted certain experiences of disconnectedness, they were still struggling to make sense of the cruel and disrespectful actions of some healthcare providers. While these unresolved feelings about experiences of disconnectedness did not seem to hinder the participants' willingness to return to follow-up, it is possible that other survivors who are reluctant in returning to the hospital may be unwilling to do so because of their experiences of disconnectedness with healthcare providers.

Research Implications

The research implications for disconnectedness with healthcare providers include (1) investigating the hospital culture that facilitates such behaviors and (2) identifying ways to help adolescents deal with the unaddressed and unforgotten trauma. First, future research is needed to understand the hospital culture and other environmental influences that make some healthcare providers behave in such a disrespectful manner towards adolescents. Based on participants' description, some of the behaviors of healthcare providers, such as being rudely awakened, seemed to be a norm for the environment because participants discovered that other adolescents shared similar feelings of being mistreated. One possible explanation for the poor behaviors of healthcare providers may be that some healthcare providers have a negative perception of adolescents, such as believing adolescents are like children and are incapable to understanding difficult subjects and that adolescents are disrespectful, moody, and drug-seeking. An ethnographic approach could be used to examine the characteristics of the environment to influence these behaviors.

Further research is needed to gain a better understanding of the unaddressed and unforgotten trauma caused by the experiences of disconnectedness with healthcare

providers. One research avenue that could help address this issue is to do an exit interview at the end of treatment asking patients to describe their experiences of connectedness with healthcare providers. As illustrated in this study, participants expressed an appreciation for being able to share their experiences. Thus, the opportunity to talk about experiences of disconnectedness, in hopes that things will be changed for other adolescent patients, could help survivors sort through some of their unresolved feelings about these experiences.

Interviewing survivors about their experiences of connectedness could also help identify patients who may be unlikely to return for follow-up health care. As described in the study, young adult cancer survivors who generally felt connected to their healthcare providers during treatment, despite some brief moments of disconnectedness, were likely to engage in long-term follow-up. However, this experience may not be the same for all young adult cancer survivors. There is a good chance that young adult cancer survivors who may have not established meaningful connections with healthcare providers and encountered more disconnectedness experiences beyond just brief moments, remained disconnected throughout treatment and follow-up. Thus, survivors who felt disconnected from healthcare providers during treatment may be unwilling to return to for follow-up because they are reluctant to encounter more disrespectful experiences.

Clinical Implications

The primary clinical implication of this finding is to bring an awareness of this issue to hospital administrators, medical and nursing educators, and healthcare providers who care for adolescents with cancer. It is possible that some healthcare providers may not be aware that their behaviors are perceived by adolescents as being cruel or disrespectful. For example, healthcare providers who speak to adolescents in a child-like or patronizing manner may be doing so because this is their everyday norm

when speaking to younger pediatric patients. Although this type of talk may be appropriate for younger children, it is clearly inappropriate and not appreciated by adolescents. One way to begin to eliminate these behaviors in healthcare setting is to share adolescents' stories of disconnectedness with healthcare providers. Such an approach may help healthcare providers gain a new perspective about how some of their behaviors are being interpreted. Additionally, this information could be used to help teach students what "not to do" when interacting with adolescents.

Because many of the experiences of disconnectedness were done by medical students or residents, the second clinical implication relates to the clinical ethics of using adolescents as teaching subjects. According to Jonsen, Siegler, and Winslade (1998), patients entering a teaching hospital sign a general consent form that includes their acceptance of being a teaching subject. Due to the circumstances surrounding the admission, many patients have probably not being given adequate information about what the experience of being a teaching subject entails. Jonsen, Siegler, and Winslade recommend that healthcare providers should seek permission from the patient before each teaching encounter begins and invite the patient to participate. Additionally, if a particular procedure is being done by a student for teaching purposes an explanation of this purpose should be made clear to the patient. Request to be involved in teaching encounters should be made politely and refusals accepted kindly.

Implementing the recommendations with adolescents as proposed by Jonsen, Siegler, and Winslade (1998) could help eliminate some the intrusiveness that the participants in this study described. If healthcare providers took the time to acknowledge and sought permission from the adolescent before going about their business, adolescents would probably be more inclined to participate and not feel disrespected. A respectful, adolescent-centered approach is likely to demonstrate to adolescents that healthcare providers are respect and care about them as individuals. Based on the

results of this dissertation study, it is apparent that such approaches encourage connectedness.

Key Finding 6: Participants Struggle with Transitioning to New Adult Healthcare Providers (From Theme Category 6 and 7)

Summary

Participants in this study expressed a great deal of concern and frustration regarding transitions to new adult healthcare providers. These concerns included (1) a sense of uncertainty about how and when the transition to new adult healthcare providers should occur; (2) a lack of support in finding new healthcare providers who demonstrate a confidence in handling the needs and concerns of a person who had cancer as an adolescent; (3) fear that the experience with new healthcare providers will not be as positive; (4) a sense that new healthcare providers cannot be trusted; and (5) a sense of inadequacy in assuming responsibility for their own health care independently from their parents. Although participants voiced their concerns about transitioning with their current healthcare providers, no clear answers were provided. The decision and plans to transition were perceived by participants as their responsibility and seemed to be a daunting task that is postponed as long as possible. The major issue with all of this uncertainty and reluctance is that it hampers young adult cancer survivors' efforts to build new relationships and connections with adult healthcare providers who can help provide anticipatory guidance regarding health promotion and disease prevention that will help minimize the risk of treatment-related morbidity and mortality.

Discussion

Possible reasons for participants' uncertainty and reluctance about transitioning to new, adult healthcare providers are discussed in the literature. Due to the recent advances in the treatment of childhood cancer, there is a growing number of childhood

cancer survivors (Freyer & Brugieres, 2008). Being diagnosed with cancer during childhood or adolescence encompasses the need for lifelong monitoring in order to detect potential treatment late-effects (Hudson & Findlay, 2006). Late-effects among pediatric/adolescent survivors include cardiac complications, pulmonary disease, renal compromise, infertility, growth impairment, secondary malignancies, and psychosocial dysfunction (Hudson et al., 2003; Rourke et al., 2007). There is a consensus that an orderly transition of medical care from the pediatric to adult health care setting is necessary for childhood cancer survivors to ensure longitudinal survivor care (Freyer & Brugieres, 2008; Ginsberg, Hobbie, Carlson, & Meadows, 2006); however, it is not clear how that process should be implemented or what level/kind of specialty care is necessary. Currently, there is no universal model of care for long-term follow-up of childhood cancer survivors. Additionally, little literature is available on how pediatric oncology healthcare providers can help support patients in the transition to new adult healthcare providers. As a result, the likelihood of survivors attending a cancer-related visit or having a general physical examination decreases over time and implies that survivors are not receiving the monitoring they should be (Oeffinger et al., 2004).

Based on the results of this study, another factor that adds to young adult cancer survivors' difficulty in transitioning to the adult health care setting is the degree to which their parents were involved in their connectedness with healthcare providers, while undergoing treatment. Although parents play an instrumental role in supporting their adolescent during diagnosis and treatment, their responsibility in making the legal decisions for the adolescent and their own need to connect with healthcare providers may interfere with the opportunities for adolescents' to gain the skills they need to assume responsibility for their own health care post-treatment. While this issue has been discussed in the literature on adolescents with other chronic illnesses (Tuchman, Slap, & Britto, 2008; Viner, 2008; Watson, 2005), there is little evidence to support this finding.

However, there is evidence that young adult cancer survivors are poor consumers of health care and engage in risky-behaviors that jeopardize their health (Institute of Medicine & National Research Council, 2003). Thus, future research is needed to examine the influence of parent-provider connectedness on adolescent health care self-management.

Research Implications

Difficulty in transitioning to adult providers warrants the need for future research to examine the factors related to connectedness with healthcare providers that may be hindering the young adult cancer survivors' transition to new adult healthcare providers for long-term follow-up care. Such factors include (1) parental involvement during diagnosis and treatment process and (2) healthcare provider communication interactions that exclude adolescents from the initial conversations regarding the diagnosis and treatment. Another factor to consider, that was discussed in Key finding 5, are adolescents' experiences of disconnectedness with healthcare providers prior to and during the diagnosis, as well as during treatment, and its influence on transitioning to adult providers and long term follow-up care.

Clinical Implications

This finding highlights the need for healthcare providers to have early conversations with adolescents and their parents about the transitioning process. Clearly, concerns about transitioning weighs heavily on the minds of young adult cancer survivors. These concerns and frustrations could be avoided if conversations about the importance of monitoring for potential treatment late-effects and the reasons for having to transition to new adult healthcare providers were discussed before treatment ends (Children's Oncology Group, 2007). If topics related to long-term follow-up were discussed before the completion of treatment, it may diminish the uncertainty and reluctance participants feel about the process transitioning process. It could also help

prevent participants from feeling that they are abandoning their beloved healthcare providers. Additionally, early discussions about transitioning would give participants time to identify and the opportunity to connect with a new primary care provider. This strategy would also be helpful to the primary care provider because it would give he/she the opportunity to gain a understanding of what the participant has been through, gather the necessary information needed to appropriately monitor potential treatment late-effects, and help establish a ongoing relationship with the pediatric oncology specialists so questions and concerns could be asked if needed. This type of connectedness partnership between the patient, primary care provider, and pediatric oncology specialists could ultimately optimize the follow-up care for young adult cancer survivors and lead to enhanced health outcomes.

The finding also highlights the need to increase healthcare providers' awareness of including adolescents in all conversations regarding their care and encouraging them to assume a more active role in their health care management during treatment.

Summary

The results of this dissertation research indicate that there are several research and clinical implications related to adolescents' experiences of connectedness with healthcare providers. Conducting further research on fostering adolescents' sense of connectedness with healthcare providers could improve the health outcomes of adolescents by (1) improving the early detection of cancer in adolescents; (2) minimizing the traumatic impact of the diagnosis; (3) enhancing healthcare providers' efforts to connect with the adolescent during the diagnosis and treatment; (4) increasing environmental characteristics in the hospital that better support the needs of adolescents undergoing cancer treatment; (5) eliminating experiences of disconnect; and (6) fostering the development of the skills adolescents will need to assume responsibility for

their health care post-treatment. Results of this study also provide a foundation for the development of interventions to enhance adolescent-provider connectedness.

Implications for Further Concept and Theory Development

This section discusses the findings in relation to the implications for further concept and theory development. The discussion is divided into four categories: (1) antecedents of connectedness; (2) attributes of connectedness; (3) boundaries of connectedness; and (4) consequences of connectedness. Each category describes how the findings of this dissertation research builds upon the findings identified in the concept of analysis of connectedness described in Chapter II.

Antecedents of Connectedness

The results of the concept analysis of connectedness, described in Chapter II, revealed that the antecedents of connectedness were infrequently described across the literature set. Nevertheless, three probable antecedents were identified. These antecedents included (1) parent behaviors that reflect emotional closeness and interdependence among family members (i.e., behaviors that demonstrate a sense of intimacy, openness of communication, and mutuality between parent and child) (Beyers, Goossens, Vansant, & Moors, 2003; Bush, 2000; Huiberts, Oosterwegel, VanderValk, Vollebergh, & Meeus, 2006; Liu et al., 2005); (2) cumulative impact of past and present relationship experiences (R. Lee, Draper, & Lee, 2001; R. Lee & Robbins, 1995); and (3) shared experiences, interests, or characteristics with others (Edwards, Wetzel, & Wyner, 2006; Heifner, 1993; Russell, Norman, & Heckler, 2004). The results of this dissertation study expand the antecedents identified in the concept analysis. The relationship between the identified antecedents and the dissertation findings follows.

The findings from this dissertation study indicate that adolescents' perceptions of healthcare providers' behaviors influence their sense of connectedness. This finding

provides information to help expand the antecedent about parental behavior. In the concept analysis, parental behavior was the most common antecedent described across the literature set. The majority of the articles reviewed for the concept analysis were focused on the parent-child relationship, as there is little literature focused on adolescent-healthcare provider relationships. Results of this dissertation study give a broader perspective of behaviors, beyond just parental behaviors, that precede the development of connectedness. The antecedent should not just be specific to parental behaviors, but to the behaviors of the individuals who have the potential to develop a sense of connectedness with one another, which includes both parents and healthcare providers.

The second antecedent identified in the concept analysis was the cumulative impact of past and present relational experiences. Researchers who described this antecedent proposed that individuals who grow up in a nurturing environment characterized by love, trust and respect, are more likely to be socially connected (R. Lee et al., 2000; R. Lee & Robbins, 1995). In contrast, individuals who have repeated experiences of relationship failures such as abandonment, abuse, or rejection, are more likely to feel less socially connected.

The results of this dissertation support the cumulative impact of past and present relational experiences as an antecedent because it appears that both positive and negative experiences of connectedness, across time, contribute to participants' present sense of connectedness with their healthcare providers. In other words, even though participants in this study had both positive and negative experiences of connectedness with healthcare providers, the overall sense of feeling connected outweighed the negative experiences and likely contributed to the decision to continue to return to the hospital for follow-up appointments. The results also indicate that adolescents who remain unconnected with healthcare providers during treatment, or encountered

experiences of disconnectedness, may continue to remain unconnected or disconnected from healthcare providers after treatment ends. Thus, the cumulative impact of positive or negative experiences of connectedness is likely to influence the long-term trajectory of connectedness or disconnectedness with healthcare providers, which influences the long-term health of adolescents with cancer.

Lastly, the results of this dissertation study provide support to the shared commonalities with others as an antecedent. Much like the participants in the studies examined in the concept analysis, participants in this dissertation described connecting with healthcare providers who shared something in common with them such as sharing similar interests, having similar personality characteristics, or knowing someone in common.

Additional antecedents, specific to adolescents' sense of connectedness with healthcare providers, were identified from the results of this study and grouped into four parts: (1) circumstances surrounding the diagnosis; (2) adolescents' factors; (3) treatment factors and (4) environmental factors. Table 5.2 is a list of identified antecedents.

Table 5.2 Antecedents of Adolescents' Connectedness with Healthcare Providers

Circumstances Surrounding the Diagnosis

Factors that *hinder* connectedness

- Being misdiagnosed or misinformed
- Left out of the initial conversations regarding the diagnosis
- Blunt delivery of the diagnosis

Adolescent Factors

Factors that *hinder* the ability to connect

- Stress related to diagnosis
 - state of shock and disbelief
 - sense of loneliness and despair
- Use of defensive or avoidant coping strategies
 - Withdrawing (i.e., refusing to interact with others)
 - being grumpy and irritable towards others

Factors that *foster* the ability to connect

- Move from avoidant toward supportant coping
 - acceptance of the illness
 - recognition of the need to connect
- Making an effort to connect

Treatment Factors

Factors that *hinder* connectedness

- Symptom distress
- Medications

Environment Factors

Factors that *hinder* connectedness

- Age-inappropriateness of the surroundings and activities
- Unfamiliar HCPs
- HCPs unskilled in caring for adolescents
- HCP characteristics that do not welcome connectedness
- HCP behaviors that display a lack of respect
 - exhibiting a lack of respect for the adolescents' personhood
 - inflicting unnecessary harm or discomfort
 - being apathetic of the adolescent's needs and preferences
 - treating the adolescent like they have minimal rights
 - talking to the adolescent in a patronizing manner
 - intrusion on the adolescent's privacy
 - being dishonest
 - failure to be vigilant for the adolescent's basic needs

Factors that *foster* connectedness

- Opportunities to gain a sense of familiarity and comfort with environment, HCPs, and treatment
- HCP strategies that facilitate connectedness
 - characteristics that exhibit a know-how to connect with adolescents
 - availability of HCPs
 - being watchful/vigilant for and attentive to adolescents' needs
 - displaying a willingness to transcend the relationship
 - using humor
 - communicating in a manner that conveys respect for the adolescent's personhood

Attributes of Connectedness

The concept analysis described in Chapter II revealed the attributes of connectedness to be vague, which contributes to a lack of consistency in the instruments used to examine connectedness. Through a careful examination of the literature set used for the concept analysis, seven attributes of connectedness were identified. These attributes included intimacy, empathy, reciprocity, belonging, caring, respect, and trust. Although the expression of each attribute varied across the different conceptualizations of connectedness, each attribute could be inferred in all instances where connectedness occurred.

The results of this dissertation research support and expand the attributes identified in the concept analysis and begin to clarify the essential attributes of adolescents' connectedness with healthcare providers. Based on the participants' descriptions, connectedness with healthcare providers is now identified as a process (i.e., adolescents must have time to adjust to the cancer diagnosis before they can connect and it takes time for the relationship to develop). In addition to being a process, the attributes identified in the concept analysis matched what was found in this study (see Table 5.3). Therefore, the results of this study provide support to the identified attributes of connectedness found in the concept analysis and provides a foundation for the development of instruments to measure adolescents' perceptions of their connectedness with healthcare providers.

Table 5.3 Comparison of Attributes of Connectedness

<u>Attributes in Concept Analysis</u>	<u>Attributes in Dissertation</u>
	Connectedness is a process
Intimacy – described as a feeling of closeness; a feeling of familiarity; or being able to form close relationships with others.	Sense of intimacy/closeness with HCPs
Empathy – described as an expression of responsiveness or sensitivity to the view points of others; the ability to sympathize with others; or a sense of being understood by others.	Sense of being known and understood
Reciprocity – described as mutual affection and interest in one another.	Reciprocal - both the adolescent and healthcare provider make an effort to connect
Belonging – described as feeling that one belongs or believing that one has a significant relationship with another person or group of others.	Sense of comfort in interacting with HCPs
Caring – described as feeling cared for and/or about, being affectionate towards others; experiencing warmth from others; or displaying concern for the well-being of others.	Sense of being cared about
Respect – described as feeling respected; displaying respect for others; or a sense of being valued.	Sense of being respected and valued as a unique individual- recognized personhood
Trust – described as being able to trust or depend on others; sense of trustworthiness; or confidence in the availability of others for support.	Sense of security and trust in HCPs

Boundaries of Connectedness

The boundaries of connectedness were examined in the concept analysis. Specific questions were asked about contextual influences (i.e., conditions under which connectedness exists, varies, or disappears), dimensions (i.e., subjective/objective and psychological/physiological), and underlying assumptions (i.e., growth vs. stability, state vs. trait) of connectedness. An explanation of how the dissertation findings build upon the concept analysis findings follows.

Contextual Influences. The results of the concept analysis, described in Chapter II, indicated that connectedness most commonly occurs in the context of social relationships; however, connectedness can exist in the physical absence of others (J. Owusu-Bempah & Howitt, 1997; K. Owusu-Bempah & Howitt, 2000; Russell et al., 2004). Connectedness was not found to occur when a person feels uncomfortable, experiences mistrust, or feels that they have been violated by others (R. Lee & Robbins, 1998; Leidy & Haase, 1999; Rew, 2002).

The findings in this dissertation research support the concept analysis findings. Participants in this study reported feeling connected to their healthcare providers when they perceived healthcare provider interactions as showing a genuine interest of wanting to develop a relationship with them. Participants indicated that connectedness remained even post-treatment, in the physical absence of healthcare providers. Connectedness with healthcare providers did not occur when healthcare providers were perceived as harming the adolescents' sense of personhood. Thus, the results of this study support the contextual influences identified in the concept analysis.

Subjective/Objective Dimensions. The concept analysis indicated that there was both an affective component of feeling connected and direct behaviors that exhibit connectedness. This finding was supported by the dissertation findings. Thus, both subjective and objective measures should be developed.

Psychological/Physiological Dimensions. The results of the concepts analysis revealed that there are both psychological and physiological dimensions of connectedness. Psychological concepts were more commonly described than physiological concepts. Psychological concepts associated with connectedness included self-esteem, mood, coping, and well-being. Although these concepts were described as being associated with connectedness, it was unclear whether these variables were antecedents, attributes, or consequences of connectedness.

The results of this dissertation study provide some insight into vagueness of the psychological dimensions of connectedness. As described earlier, the adolescents' coping and mood is an antecedent of connectedness. For example, immediately after being diagnosed, if adolescents are using defensive coping strategies and in a bad mood, then they are more likely to not connect with healthcare providers. As adolescents move away from the use of defensive coping mechanisms towards more positive ways of coping, such as supportant coping (i.e., accepting the help offered by healthcare providers), their mood improves and they begin to allow themselves to connect with others. Therefore, the results of this study support the notion that coping and mood are both a psychological dimension of connectedness and that these concepts influence connectedness.

The finding from this study also identified an association between connectedness and psychological well-being. Based on the participants' descriptions, enhanced well-being is believed to be a consequence of connectedness. In this study, it appeared that when adolescents felt connected to their healthcare providers, they felt more upbeat and optimistic about getting through their treatment. Future research using quantitative measurements would help provide support for this finding.

Physiological concepts related to connectedness which were identified in the concept analysis were diminished blood pressure reactivity when encountering negative emotional events (A. Ong & Allaire, 2005) and elevated saliva testosterone levels (Edwards et al., 2006). Based on the literature, these variables seemed to be either an attribute or consequence of connectedness; however, this was unclear.

Although this dissertation research did not examine the physiological concepts related to connectedness, they should not be dismissed. Further research should be done to see if the findings found in the concept analysis could be replicated. If so, then

work needs to be done to determine if these physiological variables are components or consequences of connectedness.

Growth vs. Stability Assumptions. The concept analysis revealed that it is not clear whether connectedness is a phenomenon that exhibits growth (i.e., change) or stability. The findings from this study suggest that connectedness is not experienced as a stable phenomenon; however, what is not clear is whether or not connectedness is on a continuum (i.e., ranging from somewhat connected to highly connected) or if the concepts of unconnectedness and connectedness are polar opposites (i.e., either you are not connected or connected). There seems to be some evidence that connectedness may be on growth continuum. For example, an adolescent can have brief encounter with a healthcare provider that fosters a sense of connectedness that is short-lived because there are no or few opportunities to see the healthcare provider again. In contrast, an adolescent can also experience repetitive moments that foster a sense of connectedness that is long-lasting because there are additional opportunities to interact with the healthcare provider.

Although the findings seem to suggest that connectedness is a dynamic phenomenon that changes over time, the disconnectedness portion of this experience appears to be stable. When adolescents experience disconnectedness from a particular healthcare provider, they are unlikely to make any effort to connect in the future. Disconnectedness does not seem to be on a continuum from unconnected to disconnected or connected to disconnected.

State vs. Trait Assumptions. The concept analysis found conflicting evidence regarding the assumptions whether or not connectedness has state-like or trait-like properties. The majority of the articles reviewed in the concept analysis implied that connectedness is situational or state-like because it occurs in the context of social relationships. Other authors referred to connectedness as a cognitive representation of

the self-in-relation-to-others which indicates that connectedness is trait-like (R. Lee et al., 2001; R. Lee & Robbins, 1995, 1998, 2000).

The findings from this dissertation supports the assumption that connectedness is state-like because participants' perception of being connected with healthcare providers was influenced by the actions and behaviors of healthcare providers. It is possible that there may be trait-like properties that influence an individual's ability to connect such as personality; however, this was not explored in this study.

Consequences of Connectedness

The results of the concept analysis described in Chapter II revealed that connectedness has a positive influence on a variety of psychosocial variables. These variables included self-esteem, identity exploration, role-taking skill, social identity, interpersonal skills and behaviors, emotional adjustment, sense of well-being, and health behaviors.

The results of this dissertation research support the identified consequences of connectedness and provide a clearer understanding the influence of adolescents' sense of being connected to their healthcare providers. Based on participants' descriptions, consequences of connectedness with healthcare providers matched all but two of the consequences identified in the concept analysis (See Table 5.4). More research is needed to examine how connectedness with healthcare providers may or may not influence the adolescents' self-esteem and involvement in risk-taking behaviors.

Table 5.4 Comparison of the Consequences of Connectedness

<u>Consequences in Concept Analysis</u>	<u>Consequences in Dissertation</u>
Higher self-esteem	
Greater identity exploration (i.e., seeking opportunities to help define one's identity)	Sense of gratitude for existential knowledge about self
Greater role-taking skill (i.e., the ability to consider the different experiences and perspectives of another person and to consider those perspectives in subsequent behaviors)	Empathic understanding of healthcare providers' workload (i.e., less angry and demanding of healthcare providers when legitimate needs are not addressed promptly)
Greater social identity (i.e., the extent to which a individual identify and seek relationships with others)	Sense of anticipation in interacting with healthcare providers in the future & Sense of gratitude for healthcare providers
Enhanced interpersonal skills and behaviors	Sense of confidence and comfort in expressing oneself to healthcare providers & Sense of empowerment
Enhanced emotional adjustment	<i>Attributes of connectedness seem to reflect this</i>
Enhanced sense of well-being	Enhanced sense of well-being
Diminished risk-taking behaviors	

Summary

This section discussed the study findings in relation to the concept analysis findings described in Chapter II. The antecedents of connectedness were supported by the findings described in this study. Additional antecedents specific to adolescent-provider connectedness were listed in Table 5.2. The attributes of connectedness found in the concept analysis matched the attributes found in the study with one additional attribute (i.e., connectedness is a process). Contextual influences of connectedness were supported as well as the assumption that there are both subjective and objective dimensions of connectedness. The psychological and physiological dimensions of connectedness still seem to be vague but both dimensions are believed to exist. Based on the findings from this study, connectedness seems to be a phenomenon that exhibits

growth but more work needed to examine how it changes. The findings added some clarity to the confusion of whether connectedness is state-like versus trait-like. The consequences of connectedness described in this study were found to be similar to those identified in the concept analysis. Thus, the comparison between the study findings and concept analysis findings adds strength to the results of this dissertation and illustrates that the concept of connectedness with healthcare providers is an important and developmental appropriate phenomenon for adolescents diagnosed with cancer.

Recommendations for Future Research

The results of this dissertation research have helped begin to clarify to the concept of connectedness and its potential impact on adolescents with cancer. Future steps to further refine the concept of adolescent-provider connectedness is as follows.

1. Gather direct observational data related to the interaction between adolescents, parents, and their healthcare providers so comparisons can be made between the narrative results with actual behavior.
2. Examine parents' and healthcare providers' perceptions of connectedness.
3. Begin to develop a preliminary theoretical model of adolescent-provider connectedness that illustrates the proposed relationships between characteristics of connectedness and related concepts.
4. Develop psychometrically sound instruments to measure connectedness.
5. Identify or develop other instruments to help examine the relationships between connectedness, its antecedents and consequences specified in the preliminary model.
6. Develop and evaluate interventions to enhance adolescent-provider connectedness that may ultimately diminish risk-taking behaviors, foster

health care self-management, and improve survivorship outcomes of adolescents with cancer.

Chapter Summary

This chapter presented a discussion of the methods, findings, and application of findings for further concept and theory development. Several research and clinical implications related to the findings were identified and recommendations for future research were made.

APPENDIX A
IRB APPROVAL

INTERDEPARTMENTAL COMMUNICATION
Research Compliance Administration
Indiana University - Purdue University Indianapolis

DATE: October 12, 2006
TO: Joan Haase
Nursing Research
NU 330
IUPUI
FROM: Tara Bateman
Research Compliance Administration
SUBJECT: Final Approval

Study Number: 0607-70
Study Title: Adolescent/Young Adult with Cancer: Provider Connectedness
Sponsor: NIH/HINR Individual NRSA

The study listed above has received final approval from the Institutional Review Board (IRB-02). **IMPORTANT NOTICE:** The Institutional Review Board (IRB) requires that the consent statement given to subjects have the IRB approval stamp on the last page – OR – include information regarding granting of waivers.

Please note that although this study has been granted final approval by the IRB, special requirements apply if the principal investigator becomes aware that an individual enrolled on the study either is a prisoner or has become a prisoner during the course of his/her study participation (and the study has not been previously granted approval for the enrollment of prisoners as a subject population). In such cases, all research interactions and interventions with the prisoner-participant must cease and if it is wished to have the prisoner-participant continue to participate in the research, Research Compliance Administration (RCA) must be notified immediately. In most cases, the IRB will be required to re-review the protocol at a convened meeting before any further research interaction or intervention may continue with the prisoner-participant. Refer to the IUPUI/Clarian Standard Operating Procedure (SOP) on *Involving Prisoners in Research* for further information.

As the principal investigator of this study, you assume the responsibilities as outlined in the SOP on *Responsibilities of Principal Investigators*, some of which include (but are not limited to):

1. **CONTINUING REVIEW** - A status report must be filed with the Board. The Research Compliance Administration (RCA) staff will generate these reports for your completion. This study is approved from **October 3, 2006 to October 3, 2007**.
2. **STUDY AMENDMENTS** - You are required to report on these forms ANY changes to the research study including changes to protocol design, diseases, timing or type of test performed, nomenclature of the study, and informed consent statement. An amendment form can be obtained on our website at: <http://www.iupui.edu/%7Eeresgrad/spon/download2.htm>.
3. **UNANTICIPATED PROBLEMS INVOLVING RISKS TO SUBJECTS OR OTHERS AND NONCOMPLIANCE** - You must report to the IRB any event that appears on the **List of Events that Require Prompt Reporting to the IRB**. Refer to the SOP on "Unanticipated Problems Involving Risks to Subjects or Others and Noncompliance" for more information and other reporting requirements. The SOP can be found at: [http://www.iupui.edu/%7Eeresgrad/spon/download2.htm](#). **NOTE:** If the study involves gene therapy and an adverse event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).
4. **UPDATED INVESTIGATIONAL BROCHURES, PROGRESS REPORTS and FINAL REPORTS** - If this is an investigational drug or device study, updated clinical investigational brochures must be submitted as they occur. Progress or final reports must be provided to the Board with your written assessment of the report, briefly summarizing any changes and their significance to the study.
5. **ADVERTISEMENTS** - If you will be advertising to recruit study participants and the advertisement was not submitted to the Board at the time your study was reviewed, a copy of the information contained in the advertisement and the mode of its communication must be submitted to the reviewing board as an amendment to the study. These advertisements must be reviewed and approved by the Board PRIOR to their use.
6. **STUDY COMPLETION** - You are responsible for promptly notifying the IRB when the study has been completed. This is done by contacting RCA staff to request that a continuing review report be generated for your completion within 90 days after termination or completion of the investigation or the investigator's part of the investigation.
7. **LEAVING THE INSTITUTION** - If the principal investigator leaves the Institution, the Board must be notified as to the disposition of EACH study.

PLEASE REFER TO THE ASSIGNED STUDY NUMBER AND THE EXACT TITLE IN ANY FUTURE CORRESPONDENCE WITH OUR OFFICE. In addition, SOPs exist which cover a variety of topics that may be relevant to the conduct of your research. See link [http://www.iupui.edu/%7Eeresgrad/spon/download2.htm](#)

All documentation related to this study must be neatly typed and must also be maintained in your files for audit purposes for at least three years after termination of the research; however, please note that research studies subject to HIPAA may have different requirements regarding file storage after termination. If you have any questions, please call Research Compliance Administration at 317/274-8289.

Enclosures: Documentation of Review and Approval Advertisement(s)
 Expedited Review Checklist Authorization form(s)
 Informed Consent Statement(s) Other:

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

CONTINUING REVIEW

STATUS: ONGOING – CLOSED TO ENROLLMENT

Reviewing IRB (please choose one):

IRB-01 IRB-02 IRB-03 (Methodist) IRB-04 IRB-05

IRB STUDY NUMBER: 0607-70

DOCUMENT DATE: 06/19/09

Please type only in the gray boxes. To mark a box as checked, double-click the box, select "checked", and click "OK".

SECTION I: INVESTIGATOR INFORMATION

Principal Investigator: Haase, Joan, E Department: Nursing

(Last, First, Middle Initial)

Building/Room No.: School of Nursing/ NU481 Phone: 317-274-2982 E-Mail: johaase@iupui.edu

Contact Information:

Name: Celeste Phillips-Salimi Address: NU338 Phone: 317 -442-2973

Fax: 317 -278-2021 E-Mail: cephilli@iupui.edu

Project Title: Adolescent/Young Adult with Cancer: Provider Connectedness

Sponsor/Funding Agency: NIH/NINR Individual NRSA Sponsor #: 1 F31 NR009733-01AI

SECTION II: CURRENT STUDY STATUS

ONGOING – CLOSED TO ENROLLMENT

Date study was initiated: 01/20/2007

Projected date of completion: 05/2010

Re-consenting/re-authorizing

NOT re-consenting/re-authorizing

(Select one)

Participants are still receiving research-related intervention or interaction

Participants have completed research-related intervention or interaction; however, long-term follow-up continues

Participants have completed all research-related intervention or interaction and long-term follow-up has been completed. The remaining research activities are limited only to data analysis that may require access to records and/or specimens.

Please check here if the study is currently suspended (temporarily) and indicate the reason(s) for the suspension:

SECTION III: SUBJECT SUMMARY

Check here if your study utilizes records or specimens only, i.e. there is no interaction with human subjects. When the form asks for the number of subjects, document the number of subjects for which data/specimens have been collected.

Check here if the IRB has approved a waiver of consent for your study. When the form asks for the number of subjects, document the number of records that have been reviewed.

1. SUBJECT SUMMARY TABLE

		On-Site
Since last IRB review	Total number of subjects CONSENTED	2
	Total number of subjects who FAILED SCREENING (e.g. found ineligible to participate)	0
	Total number of subjects who have WITHDRAWN from the study	0
Since beginning of study	Total number of subjects CONSENTED	9
	Total number of subjects who FAILED SCREENING (e.g. found ineligible to participate)	0
	Total number of subjects who have WITHDRAWN from the study	0

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

CONTINUING REVIEW

STATUS: ONGOING – CLOSED TO ENROLLMENT

Number of ACTIVE subjects	0
Number of subjects who have COMPLETED the study	9

If necessary, please provide further explanation regarding the subject summary: _____

2. **WITHDRAWAL.** Have any subjects withdrawn from the study since the last IRB review?

No

Yes, state the reasons for withdrawal: _____

3. **Vulnerable Populations.** Are any of the subjects who have consented or enrolled in the study members of a vulnerable population **which have not previously been approved for enrollment by the IRB?** This includes children, pregnant women and human fetuses, prisoners, cognitively impaired individuals, and students.

No

Yes. Please indicate which population(s) have consented or enrolled:

Children

Pregnant Women and Human Fetuses

Prisoners

Economically/Educationally Disadvantaged

Cognitively Impaired

Students

Please note that you must submit an amendment to the IRB to request the inclusion of these subjects.

4. **For studies employing waivers of assent:**

a. State the number of assent waivers that were employed since the last IRB review: _____

b. Explain the circumstances surrounding each assent waiver employed: _____

SECTION IV: ETHNIC/RACIAL REPORTING REQUIRED FOR FEDERALLY-SPONSORED AND VA STUDIES				
SUBJECT ACCRUAL				
Ethnic Category	Sex/Gender			Total
	Females	Males	Unknown or Not Reported	
Hispanic or Latino	0	0	0	0
Not Hispanic or Latino	5	4	0	9
Unknown (Individuals Not Reporting Ethnicity)	0	0	0	0
Ethnic Category Total of All Subjects*	5	4	0	9
Racial Categories				
American Indian/Alaska Native	0	0	0	0
Asian	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0	0
Black or African American	1	0	0	1
White	0	8	0	8
More Than One Race	0	0	0	0
Unknown or Not Reported	0	0	0	0
Racial Categories Total of All Subjects*	1	8	0	9

If ETHNIC and RACIAL category totals are not equal, please explain: This study was open to all racial and ethnic groups; however, there are limited number of racial or ethnic minorities available as potential participants through the clinic

Have there been any unexpected difficulties accruing subjects in a particular category (including children and women)?

No.

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

CONTINUING REVIEW

STATUS: ONGOING – CLOSED TO ENROLLMENT

Yes. Please explain: _____

FOR STUDIES CONDUCTED AT OR USING VA PATIENTS: Please indicate the total number of VA subjects enrolled in the study and indicate in which categories those subjects fall and how many represent each category indicated.

Total number of VA subjects: _____

<input type="checkbox"/>	Children:	_____
<input type="checkbox"/>	Cognitively Impaired:	_____
<input type="checkbox"/>	Economically/Educationally Disadvantaged:	_____
<input type="checkbox"/>	Pregnant Women and Fetuses:	_____
<input type="checkbox"/>	Prisoners:	_____
<input type="checkbox"/>	Students:	_____

SECTION V: SUMMARY OF EVENTS

V.A. Since the last IRB review, did any unanticipated problems, including adverse events, protocol deviations, or subject complaints, or noncompliance occur that required prompt reporting to the IRB?

- No.
 Yes. Were these events reported previously to the IRB and VA, if applicable?
 No. Please explain why these events were not previously reported: _____
 Yes. Provide a **summary** of these events: _____
 Check here if the **summary** is attached.

V.B. Since the last IRB review, did any related problems, including adverse events, protocol deviations, or subject complaints, or noncompliance occur on-site that did **not** require prompt reporting to the IRB?

- No.
 Yes. Provide a **summary** of these events: _____
 Check here if the **summary** is attached.

V.C. Is there a Data Safety Monitoring Board for this study?

- No.
 Yes. Provide the most recent monitoring report if it has not already been provided to the IRB or explain why one cannot be provided: _____

V.D. Based on the above information, do you feel the validity of the data is affected?

- No.
 Yes. Explain: _____

V.E. Based on the above information, do you feel there is an increase in risk to subjects or others or in the frequency or severity of adverse events, protocol deviations, problems, complaints, etc. since the last IRB review?

- No.
 Yes. Explain: _____

SECTION VI: SUMMARY

VI.A. Describe the progress of the research, including any preliminary observations and information about study results or trends: This study began in January 2007 and is Mrs. Phillips-Salimi's dissertation study. Nine young adult cancer survivors completed the interview. The narratives have been analyzed and the results are currently being written. Seven theme categories have been identified. Benefits of connectedness include a sense of trust, comfort, gratitude, appreciation, and security with healthcare providers that influence young adult cancer survivors' willingness to engage in care partnerships and effective self-management during treatment and into survivorship. When there is no connectedness or a disconnection with healthcare providers, a door

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

CONTINUING REVIEW

STATUS: ONGOING – CLOSED TO ENROLLMENT

shuts: there are feelings of helplessness and vulnerability, anger and resentment, and reluctance to connect with healthcare providers for cancer prevention.

VI.B. Have subjects experienced any **direct** benefit(s) from their participation in the study?

- No.
 Yes.

Please explain: _____

VI.C. If any recent literature has been published or presented by you or others since the last IRB review, has it demonstrated a significant impact on the conduct of the study or the wellbeing of subjects?

- N/A. There has not been any recent literature published or presented since the last IRB review.
 No.
 Yes. Attach a copy or explain: _____

VI.D. Have there been any audits from federal agencies conducted since the last IRB review that identified unanticipated problems involving risks to subjects or others or noncompliance?

- No.
 Yes. Attach the report(s).

VI.E. Do you believe the risk:benefit ratio has changed based on all of the information provided on this form and any attachments?

- No.
 Yes. Explain: _____

SECTION VII: REQUIRED ATTACHMENTS

All of the following documents must be included with your continuing review submission. Please check the appropriate boxes as they apply to your study.

- Continuing review form*
 Summary safeguard statement (SSS)
 Informed consent document(s), if there are active subjects who will require re-consenting
of consent documents: _____
 Check here if a waiver of informed consent was approved by the IRB
 Assent document(s), if there are active subjects who will require re-assenting
of assent documents: _____
 Check here if a waiver of assent was approved by the IRB
 Authorization(s), if there are active subjects who will require re-authorizing
of authorizations: _____
 Check here if a waiver of authorization was approved by the IRB
 Protocol, if there are active subjects who continue to receive research-related intervention or interaction or long-term follow-up
 Other, description:

Include the following documents, as applicable:

- Publications, if you answered YES to VI.C. above
 Audit reports, if you answered YES to VI.D above
 Summaries, if you indicated in Section V that summaries are attached
 DSMB report, if the study includes a DSMB and you are submitting the most recent DSMB report
 Interim findings, if there are any to report
 Multi-center trial reports, if there are any available

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

CONTINUING REVIEW

STATUS: ONGOING – CLOSED TO ENROLLMENT

NOTES:

- No changes to previously approved study documents are allowed at the time of continuing review unless requested by the IRB.
 - Incomplete submissions will result in a processing delay, which could result in study expiration.
- * **VA Requirements:** For studies conducted at the VA, utilizing VA funding or VA patients, you must provide a copy of the approved continuing review form to the VA Research Service office.

Your submission of this form certifies that this study has been and will continue to be conducted in full compliance with the IRB-approved protocol, HHS/FDA regulations and the IUPUI/Clarian policies governing human subject research. You also certify that the information contained on or with this form is accurate.

SECTION VII: IRB APPROVAL

*** For Office Use Only ***

Type of review:

Full Board

Expedited, Category: 8

IRB Reviewer:

Check here to confirm that the most recent informed consent statement has been reviewed and no additional information needs to be provided to subjects based on any new findings.

STATUS OF STUDY: **ONGOING, Closed to Enrollment**

This continuing review has been reviewed and approved as meeting the criteria for IRB approval as outlined in 45 CFR 46.111(a) by the IUPUI/Clarian Institutional Review Board (IRB). Based on the criteria for determining the frequency of continuing review and the level of risk, this study will expire on: AUG 18 2010. If the study is not re-approved prior to that date all research activities must cease on that date, including enrollment of new subjects, intervention/interaction with current participants, and analysis of identified data.

Authorized IRB Signature: _____

IRB Approval Date: AUG 18 2009

APPENDIX B
INFORMED CONSENT FORM

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Adolescent/Young Adult with Cancer: Provider Connectedness

STUDY PURPOSE:

You are invited to participate in a research study that involves interviewing young adult cancer survivors about their experiences of connectedness with healthcare providers. Connectedness is the degree to which individuals perceive that they have a meaningful, shared, and significant relationship with other people. The purpose of this study is to gain an understanding of how patients are connected or disconnected with their healthcare providers and what that experience means for survivorship.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 15 individuals who will be participating in this research.

PROCEDURE FOR THE STUDY:

If you agree to be in the study, you will do the following things:

You will be asked to participate in an interview with the primary researcher about your experiences of connectedness with healthcare providers. The interview will take place at a time and location convenient to you. This may be in your home or a private area in the Outpatient Clinic. The interview will be audio-digital recorded to ensure the researcher does not miss what you are saying. Tapes are only heard by the research team. This recording will be typed word for word so it can be examined by the researchers, but no names or any other identifying information will be attached to those typed transcriptions of the interviews. They will only be identified by a code number that will be kept in a separate, locked file in the investigator's office. The interview will last approximately 30 to 60 minutes. The researcher will contact you within 48 hours after the interview to see if you have any questions or concerns related to what was discussed. Additionally, you may be contacted after the initial interview, to give further information, or to make clear what you have already told the researcher.

RISKS OF TAKING PART IN THE STUDY:

While participating in the study, the risks are minimal.

The risks of completing the interview could include feeling uncomfortable answering the questions or you may feel too tired to complete an interview. You may request that the interview be stopped at any time. You also may refuse to answer any questions that you feel too uncomfortable talking about.

Another risk is the possibility of the loss of confidentiality. However, your information will be kept confidential by not having your name associated with the interviews or their transcriptions (the written version of what was said). To reduce the risk of the loss of privacy, your signed consent form will be kept separate from the interview information. Your name or any other identifying information will not appear on the interview transcription. All information related to the study will be kept in locked file cabinets or in password protected computers, with only investigators having access. See below for further information on confidentiality.

REVISED

____ Participant's Initials
09/18/06

BENEFITS OF TAKING PART IN THE STUDY:

The benefits to participation are minimal for you. The research may benefit future patients through deepening an understanding of the experiences of connectedness with healthcare providers. This information will be used to develop and clarify the understanding of connectedness and to help healthcare providers more effectively connect with their adolescent/young adult patients.

ALTERNATIVES TO TAKING PART IN THE STUDY:

You are free to refuse to participate in the study. Your decision not to participate will not affect your care in any way.

CONFIDENTIALITY:

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the investigator and his/her research associates, the study sponsor, the Office for Human Research Protections (OHRP), and the IUPUI/Clarian Institutional Review Board or its designees.

COMPENSATION FOR INJURY:

In the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

COSTS/COMPENSATION:

You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS:

If you cannot reach the research during regular business hours (i.e. 8:00AM - 5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

For questions about the study, contact the researcher Celeste R. Phillips-Salimi at xxx-xxx-xxxx

In the event of an emergency, you may contact Celeste R. Phillips-Salimi at xxx-xxx-xxxx

For questions about your rights as a research participant or complaints about a research study, contact the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696.2949.

____ Participant's Initials
09/18/06

VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part or may discontinue participation in the study at any time which will not result in any penalty or loss of benefits to which you are entitled. This would not affect the quality of care you receive, either.

In consideration of all of the above, I give my consent to participate in this research study.

I acknowledge receipt of a copy of this informed consent statement.

SUBJECTS SIGNATURE: _____ Date: _____
(must be dated by the subject)

SIGNATURE OF PERSON OBTAINING CONSENT: _____ Date: _____

Study No. _____

IRB Approval Date:	OCT 19 2006
Continuing Review Due:	OCT 3 2007

____ Participant's Initials
09/18/06

APPENDIX C

DEMOGRAPHIC/CLINICAL FORM

Date of Interview: _____

Gender: ___ Male ___ Female

Date of Birth: _____

Age: ___

Race: ___ White

___ Black or African American

___ Asian

___ Native Hawaiian or Other Pacific Islander

___ American Indian/Alaska Islander Native

Ethnicity: ___ Hispanic or Latino ___ Not Hispanic or Latino

Education Level _____ Current School Status: _____

Type of Cancer: _____

Date of Diagnosis: _____

Age at Diagnosis: _____

Date Treatment Completed: _____

Current Living Situation:

___ Living with Parents Full-Time

___ Living Away From Parents Full-Time

___ Living At College Part-Time/ Living with Parents Part-Time

Frequency of visits to cancer-related healthcare provider: _____

Frequency of visits to primary care healthcare provider: _____

Do you have health insurance? _____

APPENDIX D
RECRUITMENT LETTER

March 18, 2008

Name
Address
City, State

Dear _____,

We are writing you to tell you about a research study that involves interviewing young adult cancer survivors about their experiences of connectedness with healthcare providers. The purpose of this study is to gain an understanding of what patients feel when they are connected or disconnected with their healthcare providers and what that experience means for survivorship. The outcome of this study is to gain information that will be helpful in teaching healthcare providers how to effectively connect with their adolescent and young adult patients.

In the next few days, someone may be calling you to discuss the details of this study and to invite you to participate. If you do not want to be called, please call this toll-free number 1-866-XXX-XXXX and leave a voice message stating your name and that you do not wish to be called.

Sincerely,

Terry A. Vik, MD
Director, Childhood Cancer Survivor Program
Riley Hospital for Children
Indiana University School of Medicine

APPENDIX E

COMMONALITIES OF THEMES

*Note: Numbers represent participants' assigned numbers and reflect that at least one significant statement was stated by that particular participant.

Theme Category 1: The Context for Connectedness - A Cancer Diagnosis is Like a Terrorist Attack; It is a Time of Confusion, Frustration, Fear, and Vulnerability (1, 2, 3, 4, 5, 6, 7, 8, 9)

What's Going On? Events Surrounding the Diagnosis Are Like a Terrorist Attack (2, 3, 4, 5, 6, 7, 8, 9)

The timeframe (3, 4, 5, 8)

Date of diagnosis (3, 5, 8)

Age at diagnosis (4)

Attacked on my home turf (2, 5, 6, 7, 8, 9)

Unexpected threats in usually safe, comfortable places (5, 6, 7)

First response was to brush off the severity of the threat (2, 6, 7, 8)

Looking for someone to make sense of the attack (2, 5, 6, 7, 8, 9)

Obtaining a diagnosis was a struggle (3, 6, 7, 8, 9)

Misdiagnosed/misinformed in the beginning (3, 6, 7, 8, 9)

Sense of abandonment from HCPs: Extended time of waiting and worrying (6, 7, 8)

Memories of Traumatic Events Takes Some Prompting (1, 3, 4, 5, 6, 7, 8, 9)

Difficulty in remembering subsequent details and needing questions to spark more memories (1, 3, 4, 5, 6, 7, 8, 9)

Describing experiences takes careful consideration (1, 4, 5, 8, 9)

Need for questions to spark more memories (1, 4, 6, 7, 9)

Untapped experiences of connectedness can be recovered through talking (4, 5, 8)

Describing Experiences of Connectedness are Very Difficult to Tease Out because of the Uniqueness of the Connections (1, 2, 3, 4, 5, 6, 7, 8, 9)

Elusive sense of what interactions/behaviors foster connectedness (1, 2, 3, 4, 5, 6, 7, 8, 9)

Not everyone connects with others in the same way (1, 2, 3, 4, 6, 7, 8, 9)

Life Before and After the Terrorist Attack - Diagnosis as a Life Changing Experience that Makes Oneself and All Things Different (1, 2, 5, 6)

Diagnosed at a crucial time in social life - set apart from the "in-crowd" (2, 5)

Lost time and opportunities that cannot be retrieved (1, 6)

Theme Category 2: Collisions and Detours to Connectedness - Untenable Circumstances that Hinder the Ability to Connect (1, 2, 3, 4, 5, 6, 7, 8, 9)

The Sudden Collision - Cancer Diagnosis (1, 2, 3, 4, 5, 6, 7, 8)

Sense of one's world being turned upside down in a matter of minutes (3, 4, 5, 6, 7, 8)

At a complete loss - Sense of being numb or paralyzed (3, 4, 5, 6, 7)

Shocked, at a complete loss (3, 4, 5, 6, 7)

Immobilizing fear (3, 4, 5)

Sense of loneliness and despair - Unable to take in healthcare providers' efforts to connect (3, 5, 7, 8)

Sense of being surrounded by strangers who don't know me (1, 2, 3, 4, 7)

Looking for Guidance Through the Collision (1, 2, 3, 4, 5, 6, 8, 9)

Adolescents' assessment of healthcare providers' characteristics (1, 2, 3, 4, 8, 9)

Awkwardly intrusive (4, 8)

Unfriendly, showed no effort to connect (4, 8, 9)

Very matter-of-fact (4)

Hyper-vigilant (4)

Bearer of bad news (4, 8)

Nagging (2)

Pushy (8)

Overly cautious, lack of confidence (8)

Only did the minimum (1, 2, 3, 4, 9)

Limited knowledge of adolescents lingo (2, 6, 8)

Limited knowledge in how to talk to and care for an adolescent (2, 6, 8)

To connect or to not connect, that is the question - Certain providers trigger an unwillingness to connect (2, 8)

Instant judgment of liking or not (2, 8)

Non-explicit list of behaviors that inhibit the desire to connect, it's unexplainable (2, 8)

Stuck in the Collision Zone - Trapped in an Intolerable Environment (1, 2, 3, 4, 5, 6, 7, 8)

Circumstances that make the environment feel intolerable (1, 2, 3, 4, 5, 6, 7, 8)

Age-inappropriate environment (2, 3, 5, 6, 8)

Unpleasant smells of the hospital that provoke nausea and vomiting (1, 2, 5, 6, 7)

One cascade of frightening, unfamiliar events after another (4, 5, 6, 7)

Wanting to Detour and Go Back Home - Emotional Things that Hinder the Desire to Connect (1, 2, 3, 4, 5, 6, 8)

Wanting to be anywhere but the hospital (1, 3, 4, 6, 8)

Hospital was detestable (1)

Strong desire to escape/withdraw (1, 4)

Need to get in and out as quickly as possible (5)
No desire to become engaged or to socialize with others (3, 6, 8)
In a bad mood (1, 2, 3, 4, 5, 8)
Grumpy/irritable attitude/mean (1, 2, 3, 8)
Unable to give more of self (3)
A need to be left alone (1, 3, 4, 8)
Inability to accept what was to come (3)
Sense of denial, disbelief, and anger (3)
Sense of vulnerability, loss of control (3, 5, 8)

Dealing with the Aftermath of the Collision - Physical and Illness-Related Impediments to Connectedness (1, 2, 3, 4, 5, 6, 7, 8, 9)

Side effects/symptom distress (1, 2, 3, 4, 5, 6, 7, 8)

Pain/agonies (2, 6, 8)

Hair loss (3, 6)

Mucositis (8)

Nausea/vomiting (1, 4, 6, 7)

Sense of anxiety/panic about the inevitable chemotherapy and potential side effects (5, 6)

Weight loss, went from looking normal to looking emaciated (6, 8)

Experienced a lot of yeast infections (3)

Other unexpected complications that prolonged treatment (broken leg) (7)

The "not so nice" medications (1, 2, 4, 6, 8, 9)

The Collision Aftermath - Consequences of Unconnectedness (1, 2, 3, 4, 6, 7, 8, 9)

Emotional Responses (2, 4, 6, 7, 8)

Annoyance and resentment (2, 4, 8)

Unable to control sending negative cues (2, 8)

Not the right kind of connections - Struggling how to relate to an unconnected HCP (tension) (2, 4)

Just because you're good at your job doesn't mean I feel connected to you (8, 9)

Sense of being known by HCPs, but not knowing (6, 7)

Other Responses (1, 2, 3, 4, 6, 8, 9)

Shutdown on communication/listening (1, 2, 3, 4, 8)

A passive recipient of care (1, 8)

Didn't leave a lasting positive impression (6, 9)

Theme Category 3: "If I Fall Back, Will You Catch Me?" - How Connectedness Begins (1, 2, 3, 4, 5, 6, 7, 8, 9)

"If I Let Go Then I Can Connect" – Coming to an Acceptance Fosters the Ability and Desire to Connect with Healthcare Providers and Others (1, 2, 3, 4, 5, 6, 7, 8)

Acceptance of the illness, the need for help, and willing to relinquish control (2, 3, 4, 5, 6, 7, 8)

By gaining insight into one's illness situation (3, 4, 5)

By gaining an awareness of one's existential plight (6, 8)
By accepting/trusting the help offered (6)
By letting go of anger (2, 3)
By moving beyond any awkwardness (2, 3, 4, 6, 8)
By looking beyond the childishness of activities in order to connect with others (2, 3)
By recognizing there are no other choices (3, 5, 6, 7, 8)
By doing up/down comparisons (2, 3, 8)
By knowing that there were others who were enduring the same ordeal (5, 8)
By reconnecting with self (3)
By allowing oneself to share meaningful experiences with other patients (3, 4, 6, 8)

Acceptance is fostered by having the opportunity to gain a sense of comfort and familiarity with hospital, healthcare providers, and treatment routine (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sometimes it is a Two-Way Street - Strategies the Adolescent Uses to Connect with Healthcare Providers (2, 3, 4, 5, 6, 8, 9)

Recognition of shared commonalities, experiences, or interest:

Connecting thru common bonds (2, 4, 5, 6, 8, 9)

Shares a unique common bond with the healthcare provider (2, 4, 5, 6, 8, 9)

Other strategies (2, 3, 8)

Brings in items from home into the hospital (2)

Using Humor (3, 8)

Initiating sympathy (2)

Testing trust (3)

Theme Category 4: A Connectedness Primer for Healthcare Providers (1, 2, 3, 4, 5, 6, 7, 8, 9)

Strategies Healthcare Providers Use to Facilitate Connectedness (1, 2, 3, 4, 5, 6, 7, 8, 9)

Connectedness worthy (1, 2, 3, 4, 5, 6, 7, 8, 9)

Characteristics of a provider than facilitates a sense of connectedness (1, 2, 3, 4, 5, 6, 7, 8, 9)

Such an contrast to insensitive providers (1, 3, 8)

Connectedness accessible (1, 4, 5, 6, 7, 8)

Availability of healthcare providers (1, 3, 5, 6, 7, 8)

Continuity of care that fosters familiarity and comfortableness (2, 4, 7, 9)

Brief encounters – saw just enough to establish a good rapport (2, 4, 5)

Being watchful - Best offense is a good defense (2, 3, 4, 5, 6, 7, 8, 9)

Responding to the adolescent's need for help in managing side effects/symptom distress (3, 4, 5, 6)

Always on top of it – vigilant healthcare providers (2, 3, 4, 5, 6, 7, 8, 9)

“Did you hear the one about...?” Humor and other means to transcendent relationships of connectedness (1, 2, 3, 4, 6, 7, 8, 9)

Willing to transcend the patient-provider relationship (2, 3, 4, 5, 7, 8, 9)

Incorporates humor in the interaction (1, 2, 3, 4, 8, 9)

Perceptive in knowing the appropriate time to use humor and the need to be left alone (1, 2)

Honoring the altar of “teenagedom”- Manners of healthcare provider communication that conveys respect, caring, and support (1, 2, 3, 4, 5, 6, 7, 8, 9)

Respectful of the adolescent’s personhood (1, 2, 3, 4, 5, 6, 7, 8, 9)

Conveys caring by doing unexpected good things (1, 3, 4, 5, 6, 7, 8)

Conveys support (2, 3, 4, 5, 7, 8)

When there is a Connection (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of being cared about, known, respected, and valued (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of being cared for (1, 3, 4, 6, 7, 8)

Sense of being known/understood/respected (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of being valued as a person (1, 3, 4, 5, 6, 7, 8, 9)

A comfortable haven in the midst of chaos (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of comfort (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of intimacy/closeness (2, 3, 5, 6, 8)

Sense of security (1, 2, 5)

Sense of trust/confidence in the healthcare provider (3, 4, 5, 6, 8, 9)

Sense of normalcy (5, 6, 8, 9)

Buffers discomfort (1, 2, 4, 8, 9)

Limitations of connectedness (1, 2, 8)

Doesn’t minimize the terrible situation one is stuck in (1)

Doesn’t prevent anticipatory symptoms when returning for follow-up (2)

Doesn’t mean that setbacks won’t happen (8)

On the Perfect Date - Blown Away Good Happens When Healthcare Providers and Adolescents Connect so Well (1, 2, 3, 4, 5, 6, 7, 8, 9)

A date that’s too good to be true (1, 2, 3, 4, 5, 6, 7, 8, 9)

Compelled to connect (3)

Sense of anticipation (1, 4, 5, 8, 9)

Blown away by above and beyond behaviors of healthcare providers (1, 3, 4, 5, 6)

Sense of admiration for who the healthcare provider is as a person (2, 8)

Sense of joy/pleasure (2, 3, 4, 5, 7, 8, 9)

Sense of confidence in oneself (2, 3, 8)

Sense of empowerment (2, 4, 5, 7, 8)

Enhanced well-being (4, 6)

Am I worthy of dating this person? (3)

A relationship that can't be broken by intruders (3)
Sense of feeling like an Insider with healthcare team (1, 3, 6, 8)
A Lasting Impression: Capturing the Essence of Connectedness in a Unique Moment (2, 4)
Leaves a lasting positive impression (2, 4, 5, 8, 9)
Sense of disappointment when connectedness vanishes with or without closure (7, 8, 9)

A Dream-Come-True - Sense of Gratitude (1, 2, 3, 4, 5, 6, 7, 8, 9)

For being treated as a unique human being (1, 2, 3, 4, 5, 6, 7, 8, 9)
For healthcare providers who went out of their way to provide above and beyond care that was unexpected (1, 2, 3, 4, 5, 6, 7, 8)
For healthcare providers who had emotional expertise: Knew how to cater to my emotional needs (2, 3, 4, 5, 6, 7, 8)
For healthcare providers who took the time to get to know the AYA and formed a meaningful relationship with them (1, 2, 5, 4, 6, 7, 8, 9)
For healthcare providers who acknowledged and respected the adolescent's personhood (2, 3, 4, 5, 6, 7, 8, 9)
For being known, understood and accepted (1, 3, 5, 6, 8)
For the existential knowledge about self (1, 2, 3, 4, 5, 6, 8)
For the valuable knowledge gained that enriches who one is and helps shape future career (4)
Empathic understanding for healthcare providers—not demanding or angry, even when legitimate needs are not addressed (3, 6, 8)
Sense of connectedness and gratitude overflows to others (1, 2, 3, 4, 5, 6, 8)
For the long cancer journey finally coming to an ended (2, 5, 6, 8)
Grateful that the cancer journey came to an end (5)
Grateful for being cancer free with little side effects (5, 6, 8)
Grateful for regaining a sense of normalcy (2, 5, 6)

Theme Category 5: Tortured in a Prison Camp - When Healthcare Providers Violate and Destroy Connections (1, 2, 3, 4, 6, 7, 8, 9)

Introduction to the Prison Culture - Guards that Foster Disconnectedness from the Beginning (2, 3, 6, 7, 8)

Depersonalization (2, 3, 6, 7, 8)
Sense of not being heard (3)
Perception of harm being done by the actions taken (3, 8)
Sense of betrayal and dishonesty (3, 6)
Wrongly accused (2)
Insensitive in the delivery of bad news (3, 8)
From bad to worse: Moving into a prison camp (3, 4, 8)
Anger (3, 8)
Irritability (8)
Emotional turmoil/vulnerability (4)
A need to maintain some control (4)

Uncertainty/anxiety/fear of pain (4, 8)

Cruel Prison Guards - Healthcare Providers Who Violate Ethical Principles of Respect for Personhood (1, 2, 3, 4, 6, 7, 8, 9)

Violated the rights of personhood (1, 2, 3, 4, 6, 7, 8, 9)

Lack of appreciation for one's personhood -

Insensitive/dismissive/apathetic of concerns (2, 3, 4, 6, 7, 8)

Treated as a person with minimal rights (1, 4, 6, 8)

Uncaring and disrespectful of one's personhood (1, 2, 3, 4, 6, 7, 8, 9)

Whatever happened to the "to do no harm" oath? – Feeling physical abused (1, 2, 3, 4, 6, 8)

Violated autonomy (2, 4, 6, 7, 8, 9)

Undermining the adolescent's freedom for self-determination (2, 4, 6, 7)

Patronizing - talking down to the adolescent and undermining the adolescent's ability to understand things (2, 8)

Left out of conversation about self (2, 4, 6, 7, 8, 9)

Intrusion on privacy (1, 2, 6, 8)

Intrusiveness (1, 2, 6, 8)

Violated trust (1, 2, 3, 4, 6, 8)

Believed to not be doing their job (2, 8)

Betrayal (1, 3, 4, 6, 8)

Dishonesty (3)

Coercion, systems needs taking precedence over individual care needs (8)

Intentions to help were selfish rather than caring (8)

Lack of vigilance over basic needs (1, 2, 8)

Rest (1, 2, 8)

Withheld their assistance in minimizing one's suffering (8)

Not being watchful of their own or other healthcare providers' reckless actions (8)

A POW Experience - Reactions when Ethical Principles of Respect for Personhood are violated (1, 2, 3, 4, 6, 7, 8)

Sense of dehumanization (1, 3, 4, 6, 8)

Sense of powerlessness and lack of freedom for self-determination (1, 4, 8)

Sense of torment (1, 4, 8)

Sense of helplessness (8)

Sense of humiliation (8)

One last beating (8)

A need to fight back (8)

Fearful of one's safety (1, 8)

Appalled, shocked, fearful when ethical principles of respect for personhood are violated (1, 2, 4, 6, 8)

Anger and resentment (1, 2, 4, 6, 8)

Towards rude, insensitive, hurtful healthcare providers (1, 2, 4, 6, 8)

Towards healthcare providers' need for control and inconsistency in fulfilling requests (8)

For being forced to deal with rude, insensitive, unskilled healthcare providers (1, 6, 8)
When treated like a child who was incapable of understanding (patronizing) (2, 8)
Being good at your job doesn't dismiss what you did (8)
Dismissive: Immediate shut down on communication (2, 3, 4, 6, 8)
Sense of disconnectedness (1, 2, 3, 4, 6, 7, 8, 9)

The Aftermath of being a POW - Consequences of Disconnectedness (1, 2, 3, 4, 6, 7, 8)

Examining one's own role in becoming a POW (1, 2, 3, 4, 6, 7, 8)
Need to make sense of the violations of ethical principles (1, 2, 3, 4, 8)
Awareness that healthcare providers could have used an alternative approach (3, 4)
Unresolved feelings towards healthcare providers who were involved in negative experiences (3, 4, 6, 7, 8)
Leaves a lasting impression that will always be remembered as a bad/negative or as mixed experience (3, 4, 6, 7, 8)
A desire to erase some healthcare providers from memory (6, 8)
Had an overflowing opportunity to discuss and deal with emotions through interview (8)
All things can be forgiven, but not forgotten (6, 8)

Theme Category 6: Parental Lenses - Parents Role in Connectedness with Healthcare Providers (1, 2, 3, 4, 5, 6, 7, 8, 9)

Looking Through My Parents Glasses - When Parents Makes the Initial Connection (1, 4, 6, 7, 8, 9)

Blurred Connectedness: Missed the opportunities to connect (1, 4, 6, 7, 8, 9)
Left out – started too late (1, 6, 7, 9)
Lack of opportunities to connect (4, 7, 8, 9)
Unsure of the reality of the connectedness or what the relationship should/could be (1)
Not optimal connectedness but appreciative of proxy HCPs who offered material support and extended their care to parents (1)
Proxy connected nurse alleviated worry about parents (1)

Bifocals - Looking at Connectedness in Two Ways (2, 3, 4, 5, 6, 8, 9)

Connectedness by-proxy - Benefits of having a parent who is already connected with the Hospital/Health Care System (5, 6, 9)
Benefits of Connectedness by-proxy (5, 6, 9)
Cues that are used by both the adolescent and parents (2, 3, 4, 6, 8, 9)
Sense of trust that parents read the cues of connectedness and disconnectedness (2, 3, 8)
Sense of being caught in the middle (3, 8, 9)

Theme Category 7: Now What? Life after High School Graduation - Connectedness in Survivorship (1, 2, 3, 4, 5, 6, 7, 8, 9)

Majoring in Adulthood with a Minor in Adolescence - The Downside to Letting Go and Transitioning to New Healthcare Providers (1, 2, 6, 8, 9)

Uncertainty and reluctance in moving on (1, 2, 6, 8)

Sense of anxiety and concern about the transition process (1, 2)

Sense of reservation about the transition (1, 2, 6, 8)

Other troubling matters that hinder transitioning (1, 2, 6, 8, 9)

Developmental Crises - Having to act like an adult (2, 6)

Cancer-related fears (1, 2)

Consequences of not transitioning (2)

Reconnecting is Like a High School Reunion - Getting a Connectedness Recharge (1, 2, 3, 4, 5, 6, 7, 8, 9)

Sense of joy in reconnecting with old friends (1, 2, 4, 6, 7, 8, 9)

Sense of joy and excitement (1, 2, 4, 6, 7, 8)

It's like a reunion (2, 4, 7)

Reconnection occurs instantaneously (1)

Timelessness -Time nor distance impedes connectedness (3, 4, 6, 8)

Reconnect strategies (1, 2, 5, 6, 7, 8, 9)

Strategies the adolescent uses to reconnect (2, 6, 8)

Strategies healthcare providers use to reconnect (1, 2, 5, 6, 7, 9)

Benefits and losses of reconnecting (1, 2, 3, 4, 5, 6, 7, 8, 9)

Benefits of reconnecting (1, 2, 5, 6, 7, 8, 9)

Losses of reconnecting - When reconnecting is unsuccessful (1, 2, 3, 4, 6, 7, 8)

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CURRICULUM VITAE

Celeste Phillips-Salimi

EDUCATION:

<u>Institution</u>	<u>Dates</u>	<u>Degree</u>	<u>Field of Study</u>
Indiana University; Indianapolis, IN	2004-2009	PhD	Nursing Science Minor: Communication
Indiana University; Indianapolis, IN	2000-2004	MSN	Nursing; Pediatric Clinical Nurse Specialist
Indiana University; Indianapolis, IN	1995-1999	BSN	Nursing

LICENSURE:

Registered Nurse License Number - Indiana

CERTIFICATION:

2004-present Certified Pediatric Oncology Nurse (CPON), Oncology Nursing
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CLINICAL APPOINTMENTS:

2004-2009 Staff Nurse (PRN), Stem Cell Transplant Unit, Riley Hospital for
Children, Indianapolis, IN

2002-2004 Staff/Charge Nurse, Stem Cell Transplant Unit, Riley Hospital for
Children, Indianapolis, IN

2000-2002 Staff Nurse, Adult Intensive Care Unit, St. Vincent Hospital,
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RESEARCH EXPERIENCE:

<u>Dates</u>	<u>Study Title/Funding/PI</u>	<u>Role and Responsibilities</u>
2006-present	Music & Stories for Adolescents & Young Adults Resilience during Transplant (NIH/NINR R01 R008583/ Children's Oncology Group ANUR0631), PI: Joan E. Haase, PhD, RN, FAAN	Evaluator and Quality Assurance Monitor — Responsibilities include administering questionnaires to adolescents and young adults in the clinic/hospital setting and participating in the quality assurance of data collection.

<u>Dates</u>	<u>Study Title/Funding/PI</u>	<u>Role and Responsibilities</u>
2006-2009	(DISSERTATION) Adolescent/Young Adult with Cancer: Provider Connectedness (NIH/NINR F31 NR009733-01A1), PI: Joan E. Haase, PhD, RN, FAAN	Co-Investigator — Responsibilities include implementing study design, data collection, data analysis, and grant writing.
2004-2008	Palliative Care and End-of-Life Communication Experiences of Pediatric Oncology Nurses (Oncology Nursing Society Foundation), PI: Verna Ferguson, PhD, RN.	Co-Investigator — Responsibilities included collaborating with advanced practice nurses and other nursing staff, coordinating focus groups, and data analysis.
2002-2004	Therapeutic Music Video Production for Adolescents and Young Adults Undergoing Stem Cell Transplantation (American Cancer Society Institutional funded pilot study), PI: Debra Burns, PhD, MT-BC	Project Coordinator — Responsibilities included coordinating the delivery of the intervention and data collection. Also lead the analysis of phenomenological interview data, assisted in the preparation of the report of preliminary findings as part of an R01 grant submission, and presented poster and podium presentations.
2002-2004	Resilience and Quality Life in Adolescents with Cancer (NIH/NINR R29 NR03882-01A1), PI: Joan E. Haase, PhD, RN, FAAN	Research Assistant — Responsibilities included data entry, data analysis, preparing manuscripts, and presenting results at national research conferences. Also completed three secondary analysis studies using data from this parent study.
2002-2004	Enhancing Connections: Helping the Mother with Breast Cancer Support Her Child (NIH/NCI R01 CA 78424-01A1), PI: Frances Lewis, Ph.D., RN; FAAN	Evaluator — Responsible for the evaluation of the intervention through the administration of outcome measures in home settings to parents and one child.

RESEARCH TRAINING GRANTS AND FELLOWSHIPS:

2008-2009	Indiana University School of Nursing Research Incentive Fellowship (\$15,000)
2007-2009	F31 Individual National Research Service Award, NINR (NR009733-01A1), Adolescent/Young adult with cancer: Provider connectedness (\$57,586)
2006-2007	Mary Margaret Walther Cancer Institute/Behavioral Oncology Cooperative Group Pre-Doctoral Fellow (\$20,772)
2005-2009	American Cancer Society Doctoral Degree Scholarship Recipient (DSCN-05-181-01) (\$60,000)
2005	Oncology Nursing Society Foundation Doctoral Scholarship Recipient (\$3,000)
2003-2007	T32 Institutional National Research Service Award, NINR (NR 07066), Pre Doctoral Fellow (\$44,547)
2004-2005	Indiana University School of Nursing Research Incentive Fellowship (\$10,000)
2003-2004	Indiana University School of Nursing Research Incentive Fellowship (\$10,000)
2003-2004	American Cancer Society Master's Degree Scholarship Recipient (MSCN-03-210-01-SCN) (\$10,000)

TEACHING EXPERIENCE:

2007	Guest Lecture, Indiana University School of Nursing: Research Ethics (Instructor: Joan E. Haase, PhD, RN, FAAN)
2006-2007	Mentor, BSN Honors Program, Indiana University School of Nursing
2005	Teaching Assistant, Indiana University School of Nursing: Middle-Range Theory Development for Nursing (Instructor: Joan E. Haase, PhD, RN, FAAN)

PROFESSIONAL SOCIETIES:

2004- present	Midwest Nursing Research Society
2002-present	American Nurses Association
2002- present	Association of Pediatric Hematology/Oncology Nurses
2002-present	Indiana Chapter of the Association of Pediatric Hematology/Oncology Nurses
2005-2009	President
2004-2005	Vice President
2002-present	Indiana State Nurses Association
2002-present	Oncology Nursing Society
1999-present	Sigma Theta Tau International Honor Society of Nursing, Alpha Chapter

HONORS & AWARDS:

- 2008-2009 Research Incentive Fellowship Award, Indiana University School of Nursing (\$15,000)
- 2007-2009 F31 Individual National Research Service Award, NINR (NR009733) (\$57,586)
- 2007 Travel Fellowship to attend the Midwest Nursing Research Society 31st Annual Research Conference; Indiana University School of Nursing (\$600)
- 2007 Indiana University School of Nursing Graduate Fellowship for Research (\$930)
- 2006-2007 Pre-doctoral Fellowship, Behavioral Oncology Cooperative Group, Mary Margaret Walther Cancer Institute (\$20,772)
- 2005-2009 Doctoral Degree Scholarship in Cancer Nursing (DSCN-05-181-01), American Cancer Society (\$60,000)
- 2005 Thomas Jordan Doctoral Scholarship, Oncology Nursing Society Foundation (\$3,000)
- 2004 Travel Fellowship to attend the Midwest Nursing Research Society 29th Annual Research Conference; Indiana University School of Nursing (\$440)
- 2004 Certification in Pediatric Oncology Nursing (CPON)
- 2004 First Place Research Poster Award, Association of Pediatric Oncology Nurses' 28th Annual Conference & Exhibits (\$100)
- 2003-2006 National Research Service Award, Pre Doctoral Fellowship (NR 07066), T32 Training Grant, NINR (\$44,547)
- 2004-2005 Research Incentive Fellowship Award, Indiana University School of Nursing (\$10,000)
- 2003-2004 Research Incentive Fellowship Award, Indiana University School of Nursing (\$10,000)
- 2003-2004 Master's Degree Scholarship in Cancer Nursing (MSCN-03-210-01-SCN), American Cancer Society (\$10,000)
- 2003 Scholarship to attend the NIH/NINR Workshop entitled "Moving the Research Agenda Forward for Children with Cancer", NINR (\$1,600)
- 2003 Travel Fellowship to attend the Oncology Nursing Society 28th Annual Congress; Indiana University School of Nursing (\$800)
- 2002 Travel Fellowship to attend the Association of Pediatric Oncology Nurses' 26th Annual Conference & Exhibits; Indiana University School of Nursing (\$800)
- 2002 Travel Fellowship to attend the Oncology Nursing Society 27th Annual Congress; Indiana University School of Nursing (\$800)
- 2002-2003 Advanced Education Nursing Traineeship, Department of Health & Human Services, Grant #2 A10 HP0033 (\$6597 + tuition)
- 1999 Inducted, Sigma Theta Tau International Honor Society of Nursing, Alpha Chapter

SERVICE:

University Committee Service

2003-2005 Nursing Representative, IUPUI Graduate Student Organization

Community Service

2006 Volunteer, Cancer Survivor Day, Riley Hospital for Children
2006 Team Participant, Susan Komen Foundations' Race for the Cure
2005 Volunteer, Relay for Life, American Cancer Society
2004 Volunteer, Stem Cell Transplant Reunion, Riley Hospital for Children
2004 Volunteer, Daffodil Days in Marion County, American Cancer Society
2003 Volunteer, Cancer Survivor Day at the Zoo, Riley Hospital for Children
2003 Volunteer, Relay for Life, American Cancer Society
2003 Volunteer, Riley Telethon, Riley Hospital for Children
2003 Volunteer, Daffodil Days in Marion County, American Cancer Society
2002-2007 Member, Cancer Control Action Team, American Cancer Society

Professional Service

2007 Mentor, BSN Honors Program, Indiana University School of Nursing
2005-present President of the Indiana Chapter of the Association of Pediatric Hematology/Oncology Nurses
2004-2007 Peer Reviewer for the *Oncology Nursing Forum* continuing education questions
2004-2005 Vice President of the Indiana Chapter of the Association of Pediatric Hematology/Oncology Nurses
2003-2007 Peer Reviewer for the *Clinical Journal of Oncology Nursing* continuing education questions

PUBLICATIONS:

Manuscripts Published (Peer Reviewed)

1. Haase, J. & Phillips, C.R. (2004). The adolescent/young adult cancer experience. *Journal of Pediatric Oncology Nursing*, 21(3), 145-149.
2. Decker, C., & Phillips, C.R., Haase, J.E. (2004). Information needs of adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 21(6), 327-334.
3. Hinds, P, Burghen, L, Haase, J.E., & Phillips, C.R. (2006). Advances in defining, conceptualizing, and measuring quality of life in pediatric oncology patients. *Oncology Nursing Forum*, 33(1), 23-29.

4. Phillips-Salimi, C.R., Haase, J.E., Kintner, E.K., Monahan, P. & Azzouz, F. (2007). Psychometric properties of the Herth Hope Index in adolescents and young adults with cancer. *Journal of Nursing Measurement*, 15(1), 3-23.

Manuscripts Published (Invited)

1. Phillips, C.R. (2005). Chiron mentoring program: Leadership opportunity in nursing. *Nursing Outlook*, 53(3), 160-162.

Manuscripts Submitted for Publication

1. Burns, D., Robb, S., Haase, J., & Phillips-Salimi, C.R. (Submitted). Parent perspectives of an adolescent/young adult stem cell transplant and a music video intervention.

Manuscripts In Preparation

1. Phillips-Salimi, C.R., Dossey, A., Haase, J.E. & Monahan, P.O (In preparation). Examination of family protective factors in adolescents diagnosed with cancer.

Book Chapters (Peer Reviewed)

1. Haase, J.E., Chen, C., Phillips-Salimi, C.R., & Bell, C.J. (2009). Chapter 16: Resilience. In S. Peterson & T. Bredow (Eds.), *Middle-Range Theories: Application to Nursing Research* (Rev. ed.). Philadelphia, Lippincott, Williams & Wilkins.

PRESENTATIONS:

Podium Presentations (Peer Reviewed)

1. Phillips-Salimi, C.R., Kookan, W.C, & Haase, J.E. (2009, February). The connectedness-vigilance advantage: Untapped resources for cancer care. Podium presentation at the 10th National Conference on Cancer Nursing Research; Orlando, FL.
2. Stegenga, K., Phillips-Salimi, C.R., Docherty, S., Hendricks-Ferguson, V., Barnes, Y., Donovan, M. & Haase, J.E. (2009, February). The SMART approach: An innovative method for multi-site qualitative data collection analysis. Podium presentation at the 10th National Conference on Cancer Nursing Research; Orlando, FL.
3. Phillips-Salimi, C.R., Bell, C.J. & Haase, J.E. (2008, February). Strategies and issues of monitoring quality assurance in a multi-site behavioral intervention for adolescents and young adults. Podium presentation for an accepted Symposium at the American Psychosocial Oncology Society (APOS) 5th Annual Conference; Irvine, CA.

4. Phillips-Salimi, C.R., Bell, C.J. Haase, J.E, Monahan, P.O (2007, March). Examination of family protective factors in adolescent diagnosed with cancer. Podium presentation for the adolescent health research section's guaranteed symposium at the *2007 Midwest Nursing Research Society 31st Annual Conference*; Omaha, NE.
5. Phillips-Salimi, C.R., Bell, CJ, Haase, J.E. & Decker, C.L (2007, March). Strategies to monitor quality assurance of data in a multi-site behavioral intervention. Podium presentation for the pediatric research section's guaranteed symposium at the *2007 Midwest Nursing Research Society 31st Annual Research Conference*; Omaha, NE.
6. Burns, D, Haase, J.E., Robb, S., Phillips, C.R., & Bell, C.J. (2006, October). Messages in the music: AYA and parent perspectives of the TMV intervention. Podium presentation for an accepted Symposium at the *8th World Congress of International Psycho-Oncology Society (IPOS)*; Venice, Italy.
7. Haase, J.E, Phillips, C.R., Bell, C., Burns, D., & Robb, S. (2005, August). Evaluation of a therapeutic music video intervention to enhance resilience in adolescents and young adults undergoing stem cell transplant. Podium presentation at the *International Pediatric Transplant Association 3rd World Congress*; Innsbruck, Austria
8. Harley, J., Haase, J.E., Swart, J., Phillips, C.R., Bell, C., Hartman, D., Kight, K., Wichman, L., & Vonbergen, J. (2005, September). Hands across the gap: Establishing clinical practice and research partnerships to create a palliative care/end-of-life initiative. Podium presentation at the *Association of Pediatric Oncology Nurses' 29th Annual Conference & Exhibits*; Portland, OR.
9. Phillips, C.R., Haase, J.E., Kintner, E.K., Monahan, P. & Azzouz, F. (2005, February). Measurement of hope in adolescents and young adults with cancer. Podium presentation at the *8th National Conference on Cancer Nursing Research*; Ft. Lauderdale, FL.
10. Haase, J.E., Swart, J., Phillips, C.R., Bell, C., Harley, J., Hartman, D., Kight, K., Wichman, L., & Vonbergen, J. (2004, December). Strategies to establish collaborative research in the clinical setting: A palliative care/end-of-life communication research initiative. Podium presentation at the *30th Annual Patient Care Research Conference*; Indianapolis, IN.
11. Phillips, C.R., Haase, J.E. & Monahan, P. (2003, December). Measurement of hope in adolescents with cancer. Podium presentation at *29th Annual Patient Care Research Conference*; Indianapolis, IN.
12. Burns, D., Robb, S., Haase, J., Hannan, A., Maddux, R., & Phillips, C.R. (2003, November). Therapeutic music video intervention for adolescents & young adults undergoing stem cell transplantation - Phase 2. Podium presentation at the *American Music Therapy Association Annual Conference*; Minneapolis, MN.

13. Haase, J.E & Phillips, C.R. (2002, October). Resilience and quality of life in adolescents with cancer: Preliminary results. Podium presentation as the *Association of Pediatric Oncology Nurses' 26th Annual Conference & Exhibits*; Salt Lake City, UT.

Poster Presentations (Peer Reviewed)

1. Lee, M., Spiegel, C., Phillips-Salimi, C.R., Donovan, M., Garrison, L., Ryan, R., Haase, J.E. (2008, October). The processes, advantages, and challenges of serving as an evaluator on ANUR063 COG's first behavioral intervention study. Poster presentation for the *Children's Oncology Group Conference*; Denver, CO.
2. Phillips-Salimi, C.R. (2008, March). Young adult cancer survivors' experiences of connectedness with their healthcare providers - Preliminary findings. Poster presentation for the graduate poster session at the *2008 Midwest Nursing Research Society 32nd Annual Conference*; Indianapolis, IN.
3. Bell, C.J., Phillips-Salimi, C.R., Haase, J.E. & Monahan, P.O. (2007, March). Relationship of communication to family adaptability and cohesion in adolescents diagnosed with cancer. Poster presentation at the *2007 Annual Meeting of the Society of Adolescent Medicine*; Denver, CO.
4. Phillips, C.R. & Haase, J.E. (2007, February). A pilot study of young adult cancer survivors' experiences of connectedness with their healthcare providers. Poster presentation at the *9th National Conference on Cancer Nursing Research*; Hollywood, CA.
5. Phillips, C.R., Haase, J.E., Kintner, E.K., Monahan, P. & Azzouz, F. (2005, April). Hope in adolescents with cancer. Poster presentation for the graduate poster session at the *Midwest Nursing Research Society 29th Annual Conference*; Cincinnati, OH.
6. Phillips, C.R., Decker, C, & Haase, J.E. (2005, February). Information needs of adolescents with cancer. Poster presentation at the *8th National Conference on Cancer Nursing Research*; Ft. Lauderdale, FL.
7. Decker, C., Phillips, C.R., & Haase, J.E. (2005, January). Information needs of adolescents with cancer. Poster presentation at the *2005 Society for Social Work Annual Research Conference*; Miami, FL.
8. Phillips, C.R., Haase, J.E. & Monahan, P. (2004, October). Hope in adolescents with cancer. Poster presentation at the *Association of Pediatric Oncology Nurses' 28th Annual Conference & Exhibits*; Kansas City, MO
9. Phillips, C.R., Haase, J.E. & Monahan, P. (2004, November). Hope in adolescents with cancer. Poster presentation at the *Indiana University Cancer Center Second Annual Cancer Research Day*; Indianapolis, IN.

10. Burns, D., Robb, S., Haase, J., Hannan, A., Maddux, R. & Phillips, C.R. (2003, October). Therapeutic music video intervention for adolescents & young adults undergoing stem cell transplantation. Poster presentation at the *Association of Pediatric Oncology Nurses' 27th Annual Conference & Exhibits*; Philadelphia, PA.

Educational Presentations (Not Peer Reviewed)

1. Phillips, C.R. (2003, October). ABCs of stem cell transplant. Roundtable luncheon presentation at *Riley Hospital's Progressive Pediatrics Conference*; Indianapolis, IN.
2. Phillips, C.R & Stancombe, K. (2003, December). Spirituality & hope in adolescents with cancer. Presentation at the *Indiana Chapter of the Association of Pediatric Oncology Nurses' Meeting*; Indianapolis, IN.