

## ABSTRACT

### ADOLESCENT AND YOUNG ADULT ONCOLOGY: AN EVALUATION OF PATIENT-CENTERED CARE

While there is a large population of children and adults diagnosed with cancer, there is a significantly smaller number of individuals who have been diagnosed during their adolescent and young adult years. Due to their life course and developmental stages, this population presents with a unique set of needs while undergoing cancer treatment. This exploratory quantitative study evaluated the level of patient-centered care practiced with adolescent and young adult patients in the oncology unit at Valley Children's Hospital. The valid and reliable pre-established 20-item survey inquired about the adolescent and young adult patients' experiences with healthcare staff during their cancer treatments. This study found that high levels of patient-centered care was experienced among three of the four areas examined: (a) *supportive and respectful relationships*, (b) *information sharing/communication* and (c) *supporting independence*. The fourth area, *teen centered services*, however, demonstrated low levels of practice as reported by the subjects. The information gathered from this study may be utilized to inform training of healthcare staff, including medical social workers, to effectively meet the holistic needs of adolescent and young adult patients.

Savannah Rose Lyn Gomes  
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ADOLESCENT AND YOUNG ADULT ONCOLOGY: AN  
EVALUATION OF PATIENT-CENTERED CARE

by  
Savannah Rose Lyn Gomes

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APPROVED

For the Department of Social Work Education:

We, the undersigned, certify that the thesis of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the master's degree.

---

Savannah Rose Lyn Gomes  
Thesis Author

---

Nancy A. Delich (Chair) Social Work Education

---

Anne Petrovich Social Work Education

---

J. Daniel Ozeran Valley Children's Hospital

---

Lakeshia Miranda Valley Children's Hospital

For the University Graduate Committee:

---

Dean, Division of Graduate Studies

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And to myself: “You had the power all along my dear. You just had to learn it for yourself.”

Always,

Savannah R. Gomes

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## CHAPTER 1: INTRODUCTION

In 2016, there were over 1.6 million people diagnosed with cancer in the United States alone (American Cancer Society, 2016a). Included in the count and comprising approximately 6% of this population are adolescents and young adults, ages roughly 15-39 (Albritton, Caligiuri, Anderson, Nichols, & Ulman, 2006). Despite the advancements in health care and cancer treatments, this age group continues to have lower survival rates compared to their child and adult counterparts, whose survival rates have increased in the past two decades (Albritton et al., 2006; American Cancer Society, 2016b; Farjou et al., 2014; Fernandez & Barr, 2006; Teen Cancer America, n.d.). As such, the scope and intensity of adolescents and young adults' needs may be greater than any other age group due to their numerous developmental, social, and emotional developments (Albritton et al., 2006).

The population of adolescents and young adults (AYA) present a unique healthcare situation because they are no longer identified as children, but not yet classified as adults (Albritton et al., 2006; Bielack, 2011). AYA fall into an age category whose needs have yet to be specifically described and addressed. However, these patients are old enough to have opinions and verbal skills to express their emotional and physical needs. Cancer patients in this stage of life desire to be part of the process and want medical providers to not only listen but also be sensitive to their needs (A. Robertson, personal communication, October 8, 2016). For the purposes of this study, these needs were measured across four dimensions: (a) *supportive and respectful relationships*, (b) *information sharing/communication*, (c) *supporting independence*, (d) *and teen-centered services* (Gan, Campbell, Snider, Cohen, & Hubbard, 2008).

The four dimensions listed above have been identified as appropriately addressing the needs of AYA receiving ongoing medical care, such as those in a rehabilitation facility or those undergoing cancer treatments (Gan et al., 2008). They have also been identified as the four primary pillars in providing patient-centered care to AYA patients with ongoing healthcare needs. Patient-centered care is defined by the Institute of Medicine (2001) as providers' delivery of care being empathic and responsive to the patient's needs, values, and preferences, which are all used as a guide for the patient's medical care. As developing independence is key in the AYA developmental stages, patient-centered care also allows for patients to incorporate their own needs, values, and preferences to further advocate for medical processes.

Patient-centered care is critical in providing quality care, which can be effectively measured through patient self-report (Zucca, Sanson-Fisher, Waller, & Carey, 2014). Despite the numerous research studies to assess patient-centered care, few studies have specifically surveyed AYA patients to gain their perspective regarding the patient-centered care they experience (Klassen et al., 2013). While this is a relatively new area to be explored, it is hoped that this research study will provide a foundation to better understand the needs of the AYA population.

### Problem Statement

Per the American Cancer Society (2016b), an average of 5,000 adolescents ages 15 to 19 years of age, are diagnosed with cancer each year. However, absent from research literature, AYA undergoing cancer treatment have yet to have their needs investigated nor addressed in regard to the patient-centered care they experience. While Canada and Holland have examined the needs of this population, the United States of America has not yet published studies with these

considerations for AYA (Gan et al., 2008; Klassen et al., 2013; Siebes et al., 2007). At Valley Children's Hospital (VCH) in Madera, California, staff members report that patient-centered care is the current conceptual framework utilized in the oncology unit for delivery of services. While parents are often surveyed as to the care their child receives, one physician noted that patients in this age group have yet to be surveyed on their perspectives about the care they receive (J. Gates, personal communication, August 19, 2016). As such, this study sought to evaluate the current level of patient-centered care practiced within the VCH oncology unit with AYA patients.

#### Purpose of the Study

The purpose of this quantitative research study was to compile de-identified information from oncology patients who underwent cancer treatment as adolescents and young adults in the VCH oncology unit. The collected information was used to assess the current level of patient-centered care being practiced in the unit. To understand the perspectives of the subjects regarding their experience of patient-centered care, a pre-established reliable and valid quantitative scale was utilized to survey subjects. The goal of this study was to provide an opportunity for adolescent and young adult patients to express their perspectives and needs while gathering information about current practice. It is hoped that by learning about the current level of practice, delivery of care for future patients identified as adolescent and young adult will be improved and that further studies will be conducted to educate and empower patients in becoming actively involved in their health care.

For patients in this age group who are on the verge of adulthood, involving them in the discussion and delivery of their care and allowing them to have their



voice heard and their needs understood, is critical (Gan et al., 2008). Without their input, the quality of care cannot be appropriately evaluated (Gan et al., 2008). It is believed that in gathering pertinent information regarding the AYA experience of patient-centered care, an evaluation of current practice can be concluded and staff can appropriately adjust their practice to better suit the needs of AYA patients.

### Research Question

The research question of this study was: What is the current level of patient-centered care being practiced in the oncology unit at Valley Children's Hospital? To answer this, the perspectives of adolescent and young adult oncology patients were examined in regard to the perceptions of their interactions with staff members and how their needs were addressed.

### Conceptual/Theoretical Frameworks

Due to the study's focus on this population, one important discussion centered around the various and contradictory descriptions of the AYA age range and how such discrepancies can both positively and negatively affect findings of research and practice behaviors. This report will begin by reviewing various definitions of the population and discuss how researchers have found the discrepancies to affect the population being served. Conceptual and theoretical frameworks that have been established and utilized in understanding patient-centered care and the AYA population will follow.

For the purpose of this research, three theoretical frameworks were utilized: Erickson's theory of psychosocial development, patient-centered care and empowerment theory. Due to the specific considerations of this population, Erikson's theory of development is critical as a founding theoretical framework. With this theoretical foundation, researchers were able to establish knowledge of

the developmental considerations and needs of AYA. Erikson theorized that each developmental stage in human development is characterized by a crisis (Berger, 2009). While progressing through a stage of transitional development and moving from childhood to adulthood, a typical adolescent can struggle. When coupled with the challenges of intensive treatments for cancer, this can become a confusing and overwhelming time for young people who are attempting to understand and identify who they are and their place in the world.

Additionally, as the primary focus of this research study, patient-centered care was included for further elucidation of the AYA's social needs. As both a theory and a practice, patient-centered care, has been shown to have a positive correlation with quality of life as reported by patients (Balogh et al., 2011). Utilizing empowerment theory to encourage patient participation and communication, patient-centered care can be implemented and improved upon to enhance patient experiences in the medical realm.

### Methodology

Adolescents and young adults hold a unique set of needs related to their life course development. Allowing these patients the opportunity to express their opinions and needs is critical in providing quality patient-centered care. Through inquiries about the current experiences of AYA patients in the Childhood Cancer Survivorship Program at VCH, further information can be gathered to improve and expand upon the care which staff deliver to adolescents and young adults undergoing cancer treatment.

This study utilized a pre-established quantitative survey instrument to compile information regarding patient-centered care. The tool has been previously investigated to ensure its validity and reliability with subjects' ages 13-21 years of

age (Gan et al., 2008). Patients meeting the study criteria were sent information sheets introducing the research and inviting them to participate in the study. The survey was accessible through an online link that was provided in the information sheet. Survey questions were completed online via desktop computers, laptops, tablets, or cell phones. Following the collection of data, de-identified data points were exported into Microsoft Excel Spreadsheet Software to be appropriately scored.

### Implications for Social Work Practice

Researchers recognize social workers as the primary link for families in connecting with the resources they need as they have an extended history of providing responsive care to patients. Following psychologists and general practitioners, the field of social work handles more mental health cases than any other profession (Craig, Betancourt, & Muskat, 2015). As such, social workers have the unique ability to highlight the patient's experience through building rapport, practicing empathy, and advocating for their patient; allowing them to comprehensively address the needs of the person (Craig et al., 2015). These practices align with the basic aspects of patient-centered care. While medical doctors and care providers often focus on a specific aspect of a patient, such as their medical diagnosis, social workers present a broad perspective in working with an individual, allowing for more holistic care. For example, participants in one study reported that they experienced deficit focused care with their physicians, but when meeting with a medical social worker, they felt that they were addressed based on their strengths (Craig et al., 2015). Concentrating on strengths is a critical component of providing intensive medical care to youth.

The social work implications for this study are critical for the field of AYA health care. Due to their current life course development, the needs of AYA cancer patients differ vastly from those of their child or adult counterparts (Albritton et al., 2006). AYA facing a cancer diagnosis are thrust into a perplexing phase of life. While healthy adolescents and young adults are often entering a stage of autonomy and freedom from their parents, AYA diagnosed with cancer are often forced to mentally age rapidly in an effort to understand their complicated disease while also enduring a phase of vulnerability and dependency (Albritton et al., 2006).

### Chapter Summary

Cancer is a disease that does not discriminate. While some genetic traits and environmental exposure may increase an individual's risk, there is currently no known etiology for cancer. Any individual is at risk for receiving a cancer diagnosis, regardless of age, gender, lifestyle or ethnicity (Albritton et al., 2006). Though professionals continue to research causes of cancer and appropriate treatments, addressing the level or type of care provided to those diagnosed with cancer is within reach of healthcare providers. As stated earlier, patient-centered care is the newest standard of practice in the medical world (Epstein & Street, 2011) and is one of the conceptual frameworks, in addition to Erikson's theory of psychosocial development and empowerment theory, utilized in this study.

Chapter 2 reviews existing research and literature in the areas of patient-centered care as well as AYA oncological progress. Empirical research, theoretical frameworks, concepts, and definitions are presented as pertinent to this research study.

## CHAPTER 2: REVIEW OF LITERATURE

A cancer diagnosis, at any age, is daunting and potentially tragic. For those under the age of 20 who receive this diagnosis, a host of developmental factors come to play. Adolescents and young adults encounter age-specific experiences that converge with their cancer epidemiology, stage of development, place in education, and their entrance into the work force, to name a few issues for consideration (Fernandez & Barr, 2006). Each of these aspects has the potential to influence an adolescent's cancer diagnosis. Fifty years ago, childhood cancer had a low survival rate (Leukemia & Lymphoma Society, 2016). Today, there are an estimated 375,000 adult survivors of childhood cancer living in the United States (Valley Children's Hospital, 2016a). Due to the fact that more and more children are surviving these deadly diagnoses, it is even more critical to further understand how the experiences of those diagnosed with cancer at a younger age may affect the holistic well-being of the adults they will become.

This chapter first presents the purpose of the study and the research question. A discussion of definitions and categories of the AYA population then follow. Prior to proceeding into the theoretical frameworks, it is critical for the reader to understand the discrepancies occurring in definitions and viewpoints. The theoretical frameworks used to approach this study are then presented followed by empirical literature. Past and current research tools conclude this chapter before addressing the methodology in chapter 3.

### Purpose of the Study

The purpose of this research study was to compile and share de-identified information. De-identified information of the research's subjects means that the information cannot be traced to a specified individual, thus this process serves to

protect their confidentiality. The research question of this study was: What is the current level of patient-centered care being practiced in the oncology unit at Valley Children's Hospital? It was hypothesized that an examination of the current practice of patient-centered care, as self-reported by adolescent and young adult patients, would yield meaningful, statistically significant results by reporting high levels of patient-centered care experienced. In gathering this information, an evaluation of current practice can be concluded and therefore, used to inform staff of how they may appropriately adjust their practice to better suit the developmental needs of adolescent and young adult patients.

#### Defining Pediatric Patients

The age range for AYA diagnosed with cancer is variously defined. The American Cancer Society (2016b) refers to adolescents with cancer as between the ages of 15 and 19. In contrast, the World Health Organization (n.d.) defines adolescence as between the ages of 10 and 19, while the National Institutes of Health (2010) define the young adult age group as between the ages of 18 and 35 years. Some professionals assert that there is a transitional stage between adolescence and young adulthood called emerging adulthood (Ashford & LeCroy, 2010). Those in emerging adulthood are able to move into adult roles while simultaneously exploring areas of love, work, and worldviews. However, despite the various labels, age differences and discrepancies in definitions, the statistics often categorize both groups together as "childhood diagnoses" (Albritton et al., 2006).

St. Baldrick's, a fund-raising non-profit organization for pediatric cancer research, advocated for use of the slang term, *kid* ("About Childhood Cancer", n.d.). Their rationale for using this term instead of *child* is that the term, *kid*, may

be considered more inclusive. For instance, though not considered a child, an AYA may be in college as “a college kid” (“About Childhood Cancer”, n.d.). However, following the definitions outlined by the World Health Organization (n.d.) and the National Institutes of Health (2010), any person between the ages of 10 and 35 would be identified as “pediatric” and thus, these “pediatric patients” would fall into the category of AYA. The various definitions of the pediatric patient can lead to confusion and discrepancies among appropriate courses of treatment. Hence, the inconsistencies in operationalizing the term, pediatric, may cause failure in meeting the unique needs of AYA patients. To further confuse the issue, researchers have included individuals up to 40 years of age within the age group of AYA according to their developmental stage. The inclusion of patients up to the age of 40 was enacted as a result of 40-year-old individuals being perceived to have more in common with a younger population than that of individuals in middle age or older adults (Albritton et al., 2006).

This lack of a uniform definition for adolescents and young adults has been noted among various research studies and sources (Geiger & Castellino, 2011). Researchers have stated that multiple definitions can be of significant disadvantage in providing care for a population already identified as having poorer health outcomes when compared to their younger and older counterparts (Geiger & Castellino, 2011). Recognizing that although specific definitions yield more accurate data, the Adolescent and Young Adult Oncology Progress Review Group (Albritton et al., 2006) chose a broader age range to be more inclusive, thus potentially sacrificing a degree of accuracy. Because this specific population has experienced poorer survival rates and less success in having their needs met, researchers found it beneficial to keep the wider age range in an effort to gain

more knowledge about the AYA population and with the goal of better addressing their unique health care needs (Albritton et al., 2006).

In contrast, other researchers guard against creating a rigid and clear-cut definition as they believe this age range cannot be clearly defined (Bielack, 2011). As the current developmental traits of an individual may not always clearly align with the theoretically designated stage, it follows that the various categories of development may not be consistent with the age of the person under question (Bielack, 2011). Having a vague age description appropriately matches the ambiguity of the AYA's development (Bielack, 2011). Though efforts have been made to define the AYA population as well as their age range, it is also important to consider the developmental tasks and needs of this often-overlooked population in order to tailor and provide appropriate healthcare services.

For the purpose of this research study, the AYA population will be defined as anyone between the ages of 12 and 21. The next section will discuss the AYA's developmental characteristics and the needs they may experience as a result of this development.

### Theoretical Frameworks of the Research Study

Theoretical frameworks provide the foundations for a more comprehensive view of the AYA case scenario. As previously stated, there are many developmental changes at this stage of life, thus special consideration to appropriately care for this group in a medical setting is warranted. Erikson's theory of psychosocial development provides the rationale, in coordination with the theoretical philosophy of patient-centered care, for supporting the holistic needs of AYA oncology patients.



### Erikson's Stages of Development

According to Erikson's theory of psychosocial development, humans are categorized by the crises they experience throughout a lifespan (Berger, 2009). Similar to all life stages, it is important for AYA to resolve the developmental crises occurring in their particular stage. The adolescent crisis is defined by Erikson as identity versus role confusion. During this period in life, individuals often struggle to discover their own self in a secular context (Dunkel, & Harbke, 2016). Without addressing the particular developmental crisis of their stage, they may remain confused about their roles in life and not successfully navigate into the next stage of their psychosocial development.

At this stage, adolescents begin to create distance between themselves and their parents while drawing closer to their peer groups in an effort to establish their identities (Berger, 2009). Egocentrism, defined as a characteristic of adolescent thinking that lead adolescents to increase focus on themselves and exclude others (Berger, 2009) is a significant aspect of this stage. Not only are self-image and perception intensely challenged, but young adolescents are also concerned with what others may think of them (Berger, 2009). As the brain continues to develop, age specific characteristics may evolve. It is important for healthcare staff who work with AYA to continually consider the plasticity of a youth's development in providing appropriate care.

Due to the continual development of the pre-frontal cortex and accompanying cognitive changes, a cancer diagnosis can become particularly devastating for AYA (Albritton et al., 2006). The prefrontal cortex coordinates planning, impulse control, and self-regulation (Berger, 2009). The immaturity of the brain can lead adolescents to overrate pleasure and minimize danger when confronted with the opportunity to engage in risky behaviors such as careless

driving (Berger, 2009). AYA often consider themselves invincible with limited awareness of their mortality (Albritton et al., 2006). The immaturity of the brain of this population has been associated with the highest number of injuries and violent deaths compared to other age group (Berger, 2009). For adolescents, this time of their life is self-focused, concerned with their selves and how they are perceived. As such, a cancer diagnosis presents a shock to their self-perception and vulnerability.

Comparatively, adolescents are more likely to remain preoccupied with themselves while those in the developmental stage of young adulthood shift their focus to social and intimate relationships (Ashford & LeCroy, 2010). The developmental stage of young adults is characterized by two significant tasks: economic independence and independent decision-making (Ashford & LeCroy, 2010). While Erikson's stage of identity versus role confusion may still be applicable to individuals in young adulthood, those higher in the developmental process may move into the phase of intimacy versus isolation, where romanticism, love and displays of vulnerability are the primary characteristics. Vulnerability is crucial to establishing relationships with another being; by being one's true self through displays of both strengths and weaknesses, a young adult is able to develop substantive connections to others (Ashford & LeCroy, 2010).

The two stages discussed above are the primary crises of this developmental age group (Berger, 2009). Together, AYA begin to experience new levels of autonomy, allowing them to test their freedom and responsibility (Berger, 2009). While developmental stages do not vary between sexes, it is worth noting that there are biological differences between females and males in terms of communication patterns. With a focus of expressing emotions and wanting others to listen, females are more likely to join social support groups than men (Ashford

& LeCroy, 2010). Conversely, males, in search of power, will listen and communicate with the intent of discussing their knowledge and displaying their skill sets. These differences are important to consider when interacting and caring for the AYA population, specifically in a medical setting. Though two patients, a male and a female, may be the same age with a similar diagnosis, a male may require a distinct set of needs and communication style than his female counterpart. Understanding these individual needs is important in providing appropriate care for each patient. The provision of individualized care cohesively supports the theory and practice of patient-centered care.

#### Patient-Centered Care

Patient-centered care is defined by the quality of relationships between persons, professionals, and organizations (Epstein & Street, 2011). The purpose of patient-centered care is to gather enough information to enable health care staff to more effectively engage patients and families in consistent and meaningful interactions. This may include gathering background information of the patient such as values, cultural considerations, and developmental needs. Contacts between patients, families, and their health care providers can ensure service delivery that is accurate, sensitive and important for that patient in the medical, social, and cultural realms (Balogh et al. 2011). Studies indicate that data regarding patient-centered care and level of patient inclusion are positively correlated with patient satisfaction and mental well-being (Gan et al., 2008; Law, Hanna, King, Hurley, King, Kertoy, & Rosenbaum, 2003; Rosenbaum, King, Law, King, & Evans, 1998). Furthermore, these findings show patient-centered care to be an adequate measure of quality of care (Mah, Tough, Fung, Douglas-England, & Verhoef, 2006).

Patient-centered care has been studied with a wide variety of populations, including but not limited to patients with cancer, disabilities, heart disease, and those in rehabilitation (Gan et al., 2008; Mah et al., 2006; Siebes, et al., 2007). Research has found that this model of care is highly applicable in a vast array of diseases and environments such as those listed above. A 2014 study by Zucca and colleagues assessed cancer patients' evaluation of patient-centered practices in the facility where they were being treated. Results indicated that those who actively participated in their own care and had open pathways of communication with medical staff self-reported feelings of positively influencing their own mental well-being and outlook on their diagnosis. Additionally, they found five salient features that patients reported as resulting from the establishment of the patient-centered model: (a) medical attendants being responsive to patients' needs, (b) values, (c) preferences, (d) being relieved of physical discomfort, and (e) having been provided with appropriate emotional support.

The patient-centered care model has received increasing attention in recent years, creating a wealth of knowledge available to health care providers (Epstein & Street, 2011). Once viewed as a competitor of evidence-based medicine, such as the medical model, patient-centered care is no longer facing that battle. While historically, physicians and healthcare professionals would dominate conversations with patients, current practice explicitly outlines engaging patients as active participants (Epstein & Street, 2011). This is accomplished through appropriate and thorough training and education of physicians to be mindful and empathetic (Epstein & Street, 2011). The medical model implies that "good" medical goals are defined by the doctors and medical staff. However, researchers state that a "good outcome" must be defined by the patients and their goals for medical intervention (Epstein, & Street, 2011). Patient-centered care has

premiered not only in the arena of healthcare institutions and medical care, but into congress and insurance agencies as well (Epstein, & Street, 2011). Currently, insurance companies are beginning to support the practice of patient-centered care, requesting that allied facilities operate on the theoretical foundations of patient-centered care as they have been shown to improve quality of life for patients (Epstein & Street, 2011).

In comparison to the medical model, where the focus is on pathology, the patient-centered model supports and encourages communication and education to enable patients to make informed decisions regarding their course of treatment (Zucca et al., 2014). Prominent levels of communication and education have been shown to improve quality of life in cancer patients, allowing them to be more content with their medical processes. Patients treated through the patient-centered model maintain a more active role in comparison to those treated through the medical model. Norms of patient-centered practice include consulting with patients regarding their cultural identifications and practices, their therapy goals, and their preferred extent of family involvement. However, the opposite is true for the medical model. While these norms are positive characteristics, the most salient feature of the patient-centered model is that this model does not focus on the disease as the core of the patient's life. Rather, it allows patients to live and focus on their family and life events instead of centering their lifestyle on their ailment (Stang & Mittelmark, 2008). Though cancer is a serious diagnosis, the patient-centered care model posits that the lives of patients should not revolve around their cancer diagnosis regardless of the expected outcome.

Historically, researchers investigating cancer have tailored their focus narrowly on the adult experience. Adolescents and young adults who undergo treatments for cancer, have yet to receive adequate attention to their

developmental needs due to lack of information in conjunction with the specific needs of this age group (Klassen et al., 2013). While adolescent and young adult patients are not discouraged from speaking up about their care, neither are they empowered to do so. In addition, as minors, medical providers rarely inquire about the young patient's needs and wants.

Goldfarb and Castillas (2014) found that when compared to adult cancer patients, the AYA population has been reported as not having their psychological and emotional needs fully addressed. Although most children's health care facilities set limits at serving children ages 16-18, significant gains have been made in delimiting age restrictions at pediatric hospitals across the United States (Fernandez, & Barr, 2006). This has resulted in AYA cancer patients benefitting from treatment by a multidisciplinary team addressing the holistic needs of the young patient and not strictly the medical aspect, as the latter is often found in adult facilities (Fernandez, & Barr, 2006). This emphasis echoes the underlying theme of patient-centered care, where cancer is not the focus of an individual's life. Building on the results of past research on patient-centered therapy in adult populations may allow current and future researchers to better understand how the patient-centered model may benefit AYA undergoing cancer treatments.

While patient-centered care has been extensively researched, and shown to be a successful model of care, Balogh et al. (2011) reported that implementing this model is not always simple. Health care providers and medical staff may face difficulties in relaying the importance of the patient-centered care model. Thus, it becomes challenging to motivate patients to actively participate in their care due to their emotional state, lack of confidence, and health knowledge regarding their illness. The Adolescent and Young Adult Oncology Progress Review Group stated that the AYA populations do not match the communication paradigms of either

children or adults (Albritton et al., 2006). Primarily serving a population of adults or young children, health care staff have not yet been appropriately educated and trained to communicate with and elicit responses from AYA patients (Albritton et al., 2006). Though the patient-centered care model includes cultural competency and sensitivity within the scope of medical care, staff may find that patients may be unaccustomed to actively participating in their treatment processes. Thus, it is important for medical staff to encourage and empower their patients to adopt a more active position in terms of their care and needs (Pulvirenti, McMillan, & Lawn, 2014).

In recognition that the two theories are mutually compatible, social work's empowerment theory and health care's patient-centered care approaches have begun to fuse together (Pulvirenti et al., 2014). Implementing empowerment strategies can promote patients' autonomy and provide a sense of control in their lives through taking an active role in their care (Pulvirenti, et al., 2014). Through the practice of patient-centered care, patients are empowered not only to become actively involved in their medical care, but to also involve family and friends in the treatment process as well (Pulvirenti et al., 2014; Zucca et al., 2014). Stang and Mittelmark (2008) focused on female patients with breast cancer and found that the empowerment process contained four components: (a) consciousness-raising, (b) acquisition of objective knowledge, (c) learning from others' experiences, and (d) discovery of new perspectives about both life and self. Through interventions in a self-help group, the female participants acquired new strategies for self-empowerment, which significantly contributed to their recovery. Further research follow-up discovered that the participants applied empowerment techniques not only for their medical care, but also to other areas of their lives (Stang & Mittelmark, 2008). Though this study was conducted in a support group

specific to adult women with breast cancer, the researchers proposed that information gathered from their study may be relevant for other populations with various types of cancers and recommended that groups remain time limited and comprised of no more than 5-6 members. Just as research findings with solely male participants, especially in the area of health, may not be applicable to female participants because of gender differences (Moynihan, 2002), it is important to recognize that the research results with adult participants may also not be generalizable to youth.

Utilizing patient-centered care in medical facilities not only benefits the patient in the medical realm, but may positively influence other areas of a patient's life (Stang & Mittelmark, 2008). As many health care providers enter the field of medicine to serve and help people, this model can ensure that they remain focused on what is best for the patient instead of exclusively on the disease.

#### Empirical Literature

A review of the literature showed that adolescent and young adult oncology patients have yet to receive appropriate attention that considers their developmental needs and stage of life regarding patient-centered care (Albritton et al., 2006). Within the population of people diagnosed with cancer, AYA make up less than 1% of all cancer patients (American Cancer Society, 2016b). Multiple studies have found that this age group has lower survival rates than younger children (American Cancer Society, 2016b; Farjou, et al., 2014; Fernandez & Barr, 2006). While the adult and childhood cancer populations have improved their survival rates over the recent decades, the AYA cancer survivorship has remained relatively stagnant (American Cancer Society, 2016b). Adolescent and young adult cancer survivors are 67% more likely than their cancer-free peers to forego



routine medical care due to healthcare costs (Mitka, 2012). This factor may be contributing to the plateau of cancer survival in the AYA population. Another factor was the lack of awareness and knowledge about their medical circumstances and the importance of long-term follow up care (Mitka, 2012).

### Developmental Tasks and Needs of the AYA Population

When diagnosed with cancer, young people may go through distinctive age-appropriate psychological and emotional experiences as related to the life stage they are in during the treatment process, which is different from their adult and child counterparts (Fernandez & Barr, 2006). During the stage of adolescence, humans have three primary domains which significantly affect their development and self-identification. These three domains are: family, school, and peers. Researchers believe that vicarious experiences with peers strongly influence an adolescent's self-efficacy, or in other words, their own perceived abilities to accomplish a task as they observe others' successes and mistakes (Schunk & Meece, 2006). Because youth identify friendships based on perceived similarities to themselves, they are more likely to be influenced by a friend's modeling behaviors.

It is through the three environmental domains of family, school, and peers, that growing individuals develop an awareness of their intellectual abilities, interpersonal relationships, emotional being, practicality, existential/spiritual roles, and cultural considerations (Albritton et al, 2006). Through positive experiences in the three domains of family, school and peer relationships, a resilient and confident persona can be formed, contributing to the process of healthy human development. For the AYA, peers are crucial in their identity formation as they become emotionally and psychological independent from their families. Age

specific socialization may be further supported through the developmental concept that human functioning results from interactions between persons, their behaviors, and their environment (Schunk & Meece, 2006). As a primary cognitive factor in their development, individuals seek to establish their own self-identity as a result of their interactions with the three aforementioned domains.

Youth diagnosed with cancer are often removed from social environments where they typically interact with peers such as schools and clubs or even with their families. Instead, they find themselves in medical settings, such as hospitals, which by the very nature of their purpose, do not provide conventional peer exposure for the discovery process of their identities. For this population of AYA oncology patients, a fourth environmental factor, in addition to family, school, and peers, is proposed: the hospital setting. It is within this medical domain that AYA continue their development with an atypical set of friends found among fellow patients and medical staff. Such friendships influence and support the AYA patients' identity formation and development that considers their exceptional life situation. Though the medical staff remain important in this domain, the critical factor of identity development rests with other AYA oncology patients/peers and the interactions between members of this cohort. However, these interactions are not always easily sustained due to medical policies, health status, or access to peer-based social environments.

Through continued research, one significant area impacting AYA cancer patients was found to be the availability of age-specific events where patients were given opportunities to meet and form support from their peers (Gan et al., 2008; Goldfarb & Castillas, 2014). This request to meet and socialize with peers was frequently posted during an evaluation. Thus, the researchers found that socialization with peers can be an important aspect in normalizing the cancer

experience of the teens (Farjou et al., 2014). Attending to the social components of AYA oncology populations has led to increased awareness of the need for age-specific socialization events and support groups (Farjou et al., 2014).

Though there are differences between AYA and children in terms of developmental traits, many AYA are considered minors. Therefore, they are treated primarily at pediatric hospitals. There are numerous hospitals across the nation, both pediatric specific hospitals and general hospitals; however, very few facilities have adolescent/young adult specified units (Teen Cancer America, n.d.). At this time of writing, there are 14 hospitals in the United States with units specifically designed to address the needs of teens and young adults with cancer. Of the 14 hospitals, two of these specialized units are located in the State of California (Teen Cancer America, n.d.). The scarcity of developmental stage specific care for this group confirms that the age-related needs of this population are not being addressed. Because adolescents and young adults are a minority population in the health care environment, it is important to focus on their lived experience as they transition into adulthood. In congruence with their developmental stage, consultations with the AYA before, during, and after treatment would be vital to their mental health, which includes their outlook on their health situation while they are undergoing the process of receiving and completing therapies.

The Adolescent and Young Adult Oncology Progress Review Group (Albritton et al., 2006) listed six domains of development which individually or in conjunction with each domain may profoundly affect an AYA oncology patient's quality of life (Albritton et al., 2006). They are: (a) intellectual, (b) interpersonal, (c) emotional, (d) practical, (e) existential/spiritual, and (f) cultural. Limited empirical literature currently exists regarding these six domains and the potential

effects a cancer experience may have on them (Albritton et al., 2006). Therefore, more research and information is required in examining such implications in order for medical staff to effectively meet the needs of AYA patients. Addressing the six domains of the AYA development can be accomplished through the practice of patient-centered care. In addition, the patient-centered care model encourages collaboration between health care providers, patients, and families as team members work toward a common goal while incorporating the needs, priorities, and values of the patient (Rosenbaum et al., 1998).

Despite the vulnerability of the AYA population in oncology research and practice, researchers state that this population should be rigorously studied to produce evidence-based practices that appropriately affect care. There is also a call to action for health care providers and consumers to work together to inform administration and government officials of the needed resources (Fernandez, & Barr, 2006).

#### Health Insurance Considerations

On the level of macro practice, the navigation of insurance coverage can be daunting for cancer patients (Mueller, Park, & Davis, 2014; National Children's Cancer Society, n.d.). The population of AYA is historically more vulnerable regarding health care than that of child and adult populations because of their transitional stage of development (Albritton et al., 2006). Due to their age and/or stage in life, most young adults are not employed in positions that offer medical coverage yet they also may be ineligible for coverage under their parent's medical benefits. Recent provisions to the health care system have offered more support to young adults in the event of a medical emergency including adjustments in insurance premiums, health care plans, removing coverage limits, and premium

prices (Mueller et al., 2014, National Children's Cancer Society, n.d.). However, with a new President in office and discussions about changes in federal government legislation, the concerns regarding health care involve possible new limits in healthcare coverage for young adults (Congressional Budget Office, 2017).

While health insurance agencies currently are not allowed to deny coverage to those with pre-existing conditions (Mueller et al., 2014), the revocation of the Restoring Americans' Healthcare Freedom Reconciliation Act of 2015 could affect insurance coverage and premiums (Congressional Budget Office, 2017). It is suspected that within the first full year of revocations, 18 million people will become uninsured (Congressional Budget Office, 2017). This is an active concern for young survivors attempting to transition into adulthood and establish independence. To better understand their needs, the use of valid investigative research tools can assist in identifying AYA's needs as it pertains to the medical care they require.

#### AYA Research Tools

While there are a variety of tools designed to measure patient-centered services for care pertaining to youth, these tools have been used primarily to measure service delivery from the perspective of parents of pediatric patients (Gan et al., 2008). The Measure of Process of Care (MPOC), one of the first tools used in pediatric settings for quality assurance and program evaluation, was used to gather information from the point of view of parents and caregivers of pediatric patients with long term health diagnoses (Klassen et al., 2009). It wasn't until 2007 that the voices of AYA were investigated. The study conducted by Siebes and colleagues (2007) showed that many adolescents believed their lived

experience to be different than what their parents perceived and reported. This led to the recognized need for an instrument which could record youthful patients' specific experiences (Siebes et al., 2007).

In 2008, a tool for measuring the perspectives of the AYA patient was published. The Giving Youth a Voice (GYV) questionnaire was developed through the modification of the MPOC by Gan and colleagues (2008). The GYV questionnaire was initially developed as a 56-item instrument, which after further research was modified to a 20-item questionnaire, the GYV-20. This abbreviated version of the GYV consolidated items of the tool while maintaining its integrity (Gan et al., 2009; Siebes et al., 2007). Continuing research utilizing both forms of the GYV have found both tools to be valid and reliable in gathering the information that the GYV-56 was originally designed to collect (Siebes et al., 2007). Through the development and implementation of the GYV questionnaire, the wants, needs, and experiences of adolescent and young adult oncology patients can be further researched and better understood.

To establish convergent content validity, statistical tests comparing the GYV to the Client Satisfaction Questionnaire (CSQ) were administered. The CSQ is a standardized measure of global satisfaction and has been shown to possess high levels of reliability and validity (Gan et al., 2008). Table 1 shows the Pearson test-retest reliability for the GYV subscales (Gan et al., 2008). Results in Table 2 display that the means for the subscales on both questionnaires are statistically significant in measuring the outlined concepts. Through additional statistical analyses, it has been found that both versions of the GYV are reliable and valid instruments in measuring youth's perceptions (Gan et al., 2008).

Table 1

*Test-Retest Reliability for the Mean of the Responses on the Giving Youth a Voice Questionnaire Subscales*

Subscale	<i>r</i>	<i>p</i>	<i>N</i>
Supportive and respectful	.865	<.0005	49
Information Sharing	.838	<.0005	47
Supporting independence	.840	<.0005	43
Teen centered services	.792	<.0005	31

Adapted from “Giving Youth a Voice: A Measure of Youths' Perceptions of the Client-Centredness of Rehabilitation Services,” by C. Gan, K. Campbell, A. Snider, S. Cohen, and J. Hubbard, 2008, *Canadian Journal of Occupational Therapy*, 75, p. 101.

Table 2

*Correlations Between Mean of Giving Youth a Voice Questionnaire Subscales and the Total Client Satisfaction Questionnaire*

Subscale	<i>r</i>	<i>p</i>	<i>n</i>
Supportive and respectful	.611	<.0005	95
Information Sharing	.509	<.0005	93
Supporting Independence	.514	<.0005	87
Teen centered services	.388	.001	69
Supporting Independence	.514	<.0005	87
Teen centered services	.388	.001	69

Adapted from “Giving Youth a Voice: A Measure of Youths' Perceptions of the Client-Centredness of Rehabilitation Services,” by C. Gan, K. Campbell, A. Snider, S. Cohen, and J. Hubbard, 2008, *Canadian Journal of Occupational Therapy*, 75, p. 101.

Most researchers investigating the effects of patient-centered care in oncology patients have utilized qualitative research in the form of semi-structured interviews and focus groups to gather information about their lived experiences as cancer patients (Farjou et al., 2014). The voice of adolescent oncology patients was first investigated with the creation of a new quantitative questionnaire. In 2015, the population of AYA oncology patients were surveyed utilizing the GYV to explore patient-centered care as experienced by the patients (Klassen et al., 2013). In the act of collecting the perspective of youth patients, patients receive the message that their concerns are as important as that of their parents and families (Gan et al., 2008). This tool was employed in hopes of confirming that the conceptual framework used in adult patients was applicable to childhood cancer patients and survivors (Klassen et al., 2013).

### Chapter Summary

This chapter addressed the theoretical and empirical literature which informs this study. Understanding the complexities of human development in the AYA population is pertinent in providing responsive care in the medical arena. Though the needs of the individual AYA is constantly evolving as they develop, the static level of patient survivorship for this group exposed a degree of deficiency in healthcare services for the AYA population. Due to the complexities and limited data regarding this population, it may be difficult to identify areas of concern. This research study aimed to collect information that contributed to the existing body of knowledge with the hopes of improving patient-centered care for AYA oncology patients. Chapter three details the methodology of the research study, including sampling criteria, instrumentation, and data analysis.



## CHAPTER 3: METHODOLOGY

This study explored the current practice of patient-centered care in the Valley Children's Hospital (VCH) oncology unit with a focus specifically on the AYA population. Individuals in this age group have a specific set of emotional, physical, and psychosocial needs due to their life course development. To address the needs of this population, VCH created the Childhood Cancer Survivorship Program. This program serves the at-risk population of pediatric cancer survivors by providing them with education, treatment, and support (Valley Children's Hospital, 2016a). Over 60% of childhood cancer survivors will later develop chronic long term complications directly resulting from their cancer treatments (Mitka, 2012; Valley Children's Hospital, 2016b). The Childhood Cancer Survivorship Program was established in 2009 with two goals in mind: to promote healthy lifestyles for childhood cancer survivors as they mature and become adults, and to utilize information gathered to expand research on creating the most effective cancer treatments while minimizing late effects (Valley Children's Hospital, 2016b). This program strives to be inclusive, welcoming patients who have been treated within the unit, as well as those treated at other medical institutions (Valley Children's Hospital, 2016b). Cancer-free patients are monitored for at least three years from their final cancer treatment (Valley Children's Hospital, 2016b). This study attempted to understand the perspectives of AYA patients currently enrolled in the Childhood Cancer Survivorship Program in an effort to learn more about their experiences with patient-centered care.

### Research Study Question

The research question was: What is the current level of patient-centered care being practiced in the oncology unit at Valley Children's Hospital?

## Methodology

In this section, criteria for study subjects and the research instrument are discussed. With limited existing studies investigating the area of patient-centered care with AYA oncology patients, a valid tool was identified and researchers were granted access by the tool's author. Following the discussion of the study instrument, the data analysis process, limitations, reliability, and validity will be explained and discussed.

### Sampling Criteria for Study Subjects

Due to the sensitivity and increased vulnerability of patients currently on active treatment, enrollment of subjects was restricted to those no longer receiving active cancer treatment. Inclusion criteria for study subjects were limited to those diagnosed with cancer between 12 and 21 years of age and were between 18 and 30 years of age at the time of study enrollment. Both male and female patients enrolled in the Childhood Cancer Survivorship Program were invited to participate in the survey. This program requested, but did not require, that patients be at least three years off treatment prior to their enrollment. Utilizing a non-probability sampling method and based on their qualifying criteria, 131 subjects were invited to participate in this study.

The research instrument, the GYV-20, was originally designed and validated for surveying adolescents between 13 and 21 years of age. However, the Survivorship Clinic sees patients who are up to 30 years of age, so the upper range for current age was extended to 30 years old. There were no exclusion criteria regarding diagnosis, ethnic background, or gender. Based on the number of patients currently enrolled in the Survivorship Program, the accrual goal was 50 subjects.

### Research Instrument

The GYV-20 questionnaire was selected to evaluate current practice of patient-centered care. The GYV-20 was designed to measure adolescent and young adult perceptions of medical services with an emphasis on patient/family-centered services (Gan et al., 2008). An evaluation of the tool found it to have a strong construct validity and good reliability (Gan et al., 2008; Klassen et al., 2013; Siebes et al., 2007). Though the GYV was originally designed for its use with AYA in a rehabilitation setting, it has been used with various populations of adolescents and young adults across the globe (Gan et al., 2008; Klassen et al., 2013; Siebes et al., 2007).

### Research Procedures

All members of the Childhood Cancer Survivorship Program who met the study criteria were mailed an information sheet by postal mail informing them of the research study (see Appendix A). To maintain patient confidentiality and protect anonymity, a VCH research coordinator, the only person who had access to patient protected health information (PHI), addressed and mailed the cover letters.

VCH's Institutional Research Board waived the requirement for the researcher to obtain signed consent under 45CFR46.117(c) – “research will not involve greater than minimal risk to the children.” Additionally, an informed consent form was not utilized since no PHI was collected in the questionnaire. Subjects acknowledged their consent by completing the questionnaire. When patients gave consent to participate in the study, they were able to complete the survey online through a link provided in the information sheet. The link directed subjects to a website, which was housed on an easily accessible URL. The URL was created in an effort to increase accessibility. When accessing the website, subjects were first welcomed and then asked to select a posted link directing them

to a second website where the survey questions were presented. When arriving at the second website, subjects were asked to first complete a few short questions regarding their demographics (see Appendix B). Subjects then proceeded to the GYV-20 questionnaire (see Appendix C).

Surveys were administered and data gathered during a three-week period in January 2017. Approximately half way through the data collection period, a follow-up letter was sent out to remind patients of the study and encourage participation (see Appendix D).

The data was collected through Qualtrics, which is an electronically-based and password protected online statistics software package that allows for data that is collected to be housed on their website, as well as exported into analysis software. Qualtrics also provided functions to anonymize data and control for repeated entries, allowing data collections to be reliable and valid (Qualtrics, 2015).

#### Data Analysis

As stated earlier, the information collected was anonymized as part of the registry. The researcher was not given a list of patient names or any identifiable information. Instead, VCH took responsibility for addressing and mailing all information sheets and follow-up reminders to ensure patient confidentiality. All data was collected through the password protected website and transferred into a password-protected Excel spreadsheet on the researcher's personal computer. The only people who had access to the de-identified reported scores were the researcher, the researcher's chairperson at California State University, Fresno, and the statistician contracted through the Graduate Statistics Studio at California State University, Fresno. To further anonymize the data, the Qualtrics software allowed

for IP addresses to be hidden so that the subjects' information could not be traced back to a single individual or setting.

Once the data was collected through the Qualtrics website and exported into Microsoft Excel Spreadsheet Software, the data was scored by a statistician at the Graduate Statistics Studio at California State University, Fresno. Reported scores measured the extent to which AYA patients reported their experiences of patient-centered care.

#### Limitations, Validity, and Reliability

The GYV measures four subscales of patient-centered care as it applies to AYA: (a) *supportive and respectful relationships*, (b) *information sharing and communication*, (c) *supporting independence*, and (d) *teen centered services* (Gan et al., 2008). These subscales of the GYV were found to be appropriate as related to quality improvement (Klassen et al., 2013). In addition, this questionnaire had been tested for its validity and reliability with individuals 13-21 years of age and with specific approval from the authors of its use in subjects up to 25 years old (C. Gan, personal communication, January 12, 2017). One subject was 27 years of age; however, their data was included in the data analysis as they are still being seen by the survivorship clinic for annual follow-up care. Typically, the GYV is administered immediately upon medical discharge in AYA patients. However, because of the increased vulnerability of patients who are minors and who are still receiving treatments for their cancers, the GYV was utilized to retroactively account for the care subjects received.

According to the manual designed to guide the administration and use of the GYV, for a survey response to be acceptable, 66% of a subscale must have

been completed and at least 50% completion of the questionnaire was required (Gan, Campbell, Snider, Hubbard, & Wright, 2013).

### Chapter Summary

This chapter presented the methodology of this study, which included the research question, purpose of study, sampling method, inclusion criteria, study instrument, research procedures and limitations. The goal of the study was to conduct a quantitative study of female and male AYA who are cancer survivors. This study utilized a valid and reliable questionnaire known as the GYV-20, which measured patient-centered care across four subscales. While patient-centered care has received wide recognition in research, limited attention has been given to the AYA population of cancer survivors in regard to their emotional, physical, and psychosocial development. Next, chapter 4 presents the results of this study, including findings generated from the analysis of data collected.

## CHAPTER 4: RESULTS AND DISCUSSION

This chapter presents the key findings from surveys completed by 11 subjects identified as patients who underwent cancer treatment during their adolescence or young adulthood. Demographics of the study subjects will be presented first to establish knowledge of the population polled. The second section presents the findings generated from the data analysis and statistical results of this study. Lastly, the research question will be addressed in the light of the data.

### Demographics

A total of 131 information sheets were mailed out to qualifying subjects. Eleven of the 131 sheets were returned due to incorrect mailing addresses for the identified subjects. Ten of the eleven returned sheets were readdressed with the patient's current addresses and mailed the same day they were returned. The final returned sheet was delayed 4 days before re mailing due to the time needed to locate the updated address of the patient. Since reminder sheets were to be sent out the following day to the other patients, this single patient only received the initial information sheet. Thus, 130 reminder forms were sent out approximately 10 days into the collection period reminding subjects to complete the online survey. A total of 13 responses were collected. However, due to completion percentage, two entries were deleted as the subjects did not complete at least 50% of the survey (Gan et al., 2013). With a goal of 50 subjects, this study failed to meet its accrual goal.

Table 3 displays the subject demographic information collected in the survey. Of the 11 study subjects, 7 were female, 2 were male, and 1 subject preferred not to answer. Within the population of subjects, 8 self-identified to be of Hispanic or Latino ethnic descent, which is approximately 73% of the subjects.

Doctors of the VCH oncology unit report that these findings are reflective of the total population of oncology patients in Central California (J. D. Ozeran, Personal Communication, March 18, 2017). The age of diagnosis ranged from 13 to 19 years of age with a mean of 15 years of age for this group. Current age of subjects was also collected, with the subjects being between the ages of 20 and 27 years of age and a mean age of 22 years of age at the time of survey completion.

Table 3

*Demographics of Study Subjects*

Subject Number	Current Age	Gender	Ethnicity	Age at Diagnosis
11	22	Female	Hispanic or Latino	13
10	22	Female	Asian	13
9	20	Male	Hispanic or Latino	15
8	25	Female	Hispanic or Latino	15
7	23	Female	Hispanic or Latino	14
6	21	Female	Hispanic or Latino	17
5	27	Female	Hispanic or Latino	16
4	21	Male	Hispanic or Latino	15
3	20	Female	Caucasian/White - Non-Hispanic	13
2	22	Male	Hispanic or Latino	19
1	24	Prefer not to answer	Prefer not to Answer	17



## Results

The research question guiding this study was: What is the current level of patient-centered care being practiced in the oncology unit at VCH? To better understand the current level of patient-centered care practiced within the oncology unit of VCH, the GYV-20 questionnaire was employed to measure patient-centered care across four subscales as reported by AYA. Though the responses to the study were limited (n=11), it was believed that the data yielded information that acknowledged the strengths and weaknesses of the care unit investigated.

The GYV-20 measured four subscales: (a) *supportive and respectful relationships*, (b) *information sharing/communication*, (c) *supporting independence*, (d) and *teen-centered services*, which have all been found to be significant in providing patient-centered care to AYA (Gan et al., 2008). Responses were prompted through use of a seven-point Likert-like scale ranging from *a lot*, a score of 7, to *sometimes*, a score of 4, to *never*, score of 1, with an option of *does not apply to me*, score of 0, to indicate those who have never completed a questionnaire. Each subscale was evaluated parametrically by computing the mean of all entries of each select subscale. The standard deviations of each mean within each subscale were also calculated to measure within a 68% margin of error.

Figure 1 displays the means within each subscale on which data was composed. As seen in the graph, the first three subscales reported receiving high levels of patient-centered care while the final subscale was significantly lower. The first subscale, *measuring supportive and respectful relationships*, resulted with a mean of 6.02 with a standard deviation of 1.87. Subscale two, *information sharing & communication*, was found to have a mean of 6.53 with a standard deviation of .57. Similarly, subscale three, *supporting independence*, concluded

with a mean of 6.71 with a standard deviation of .45. The final subscale, *teen centered services*, however, resulted in a mean 3.91 and a standard deviation of 2.64.

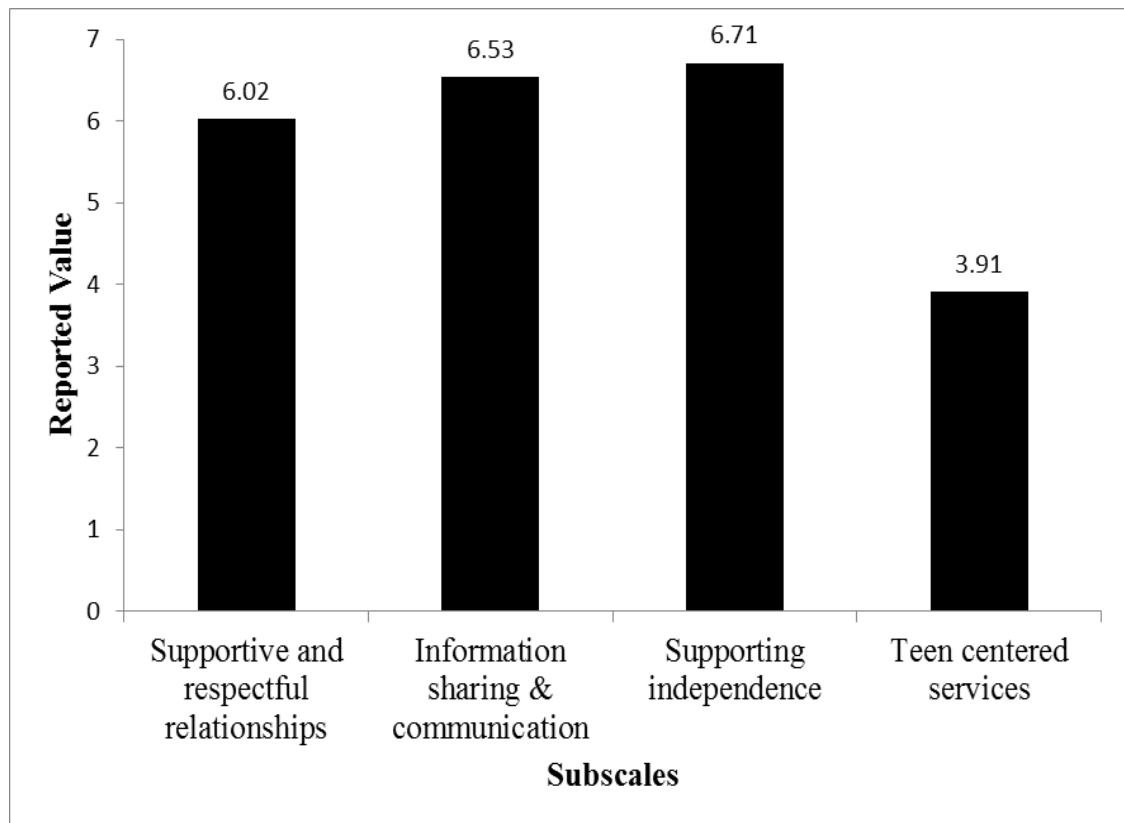


Figure 1. Means reported among four subscales of the GYV-20

#### Research Question of the Study

In answering the research question regarding the current level of patient-centered care practiced in the oncology unit at VCH, this study data indicated that of the four primary areas representing patient-centered care, study subjects reported experiencing high levels of care in three areas. The final subscale was significantly lower and results displayed a high standard deviation in which standard error may occur. However, due to the small sample size, researchers were

unable to attribute the significance of the results to the larger population of AYA cancer patients.

#### Chapter Summary

Chapter 4 presented and discussed the findings of the study data. The responses of 11 adults who underwent treatments for cancer as AYAs were used to establish baseline data for patient interpretations of the care they received. Chapter 5 will further discuss the results, the study's limitations, how these findings apply to the broader scope of research within this population, and concluding with implications and recommendations for the social work profession. References and appendices follow chapter 5.

## CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

Chapter 5 will summarize the contents of the study and discusses considerations for future research and practice implementation. First, the major findings will be discussed in regard to their consistency with existing research. Next, implications of this research study will be addressed with particular attention to its application for the social work profession and policy development. Lastly, the third section will address the study's limitations and conclude with recommendations for future research and practice.

### Major Findings

This study was the first research to utilize the GYV-20 within pediatric oncology in the United States. Consistent with research published from other countries (Gan et al., 2008; Klassen et al., 2013; Siebes et al., 2007), the higher the mean of each subscale, the higher the level of patient-centered care was reported, except for the subscale of *teen centered services*. With all ratings on a seven-point Likert-like scale, it was found that VCH's oncology unit staff provided elevated levels of *supportive and respectful relationships, information sharing/communication, and support for independence*. These scores signify that there were high rates of communication; that the 11 subjects felt supported to be independent; and that they reported having a voice in their care.

The last subscale, however, resulted in low scores, indicating that there were few *teen centered services* available to AYA patients in this unit. As noted in the literature, peer exposure and teen-centered services were reported as key features of patient-centered care with the AYA population. Therefore, the lack of available services can negatively affect the patient's care as experienced from an AYA's perspective. The information found in this study can be used to further

expand research in the unit and provide guidance and direction for necessary services to a vulnerable population.

Hypothesizing that all four subscales would come back with high ratings, the low reported experience of teen-centered care came as a surprise to researchers, while the other three subscales displayed positive results. As research has shown, elevated levels of practiced patient-centered care may improve quality of life for patients (Epstein & Street, 2011). Increasing teen-centered services available to AYA patients can significantly improve the care experienced by this vulnerable population and provide an opportunity for peer support and social engagement. For AYA diagnosed with cancer, the three domains of development, school, family, and peers, must be expanded to include a fourth area for consideration as proposed earlier in the report: the hospital setting. With the extensive medical needs of a youth undergoing cancer treatment, considerable amount of time is spent in the hospital. In this medical setting, AYA interact primarily with adult health care professionals, learn about medical terminology and processes, and live through an important life stage in an environment that is vastly different from that of their healthy peers. These are important considerations for professionals working with the AYA population and specifically for medical social workers as they are often the source of support and connections at the hospital.

#### Implications and Recommendations for Social Work

This section examines the study's results to address how the practice and training needs of medical social workers and interventions for AYA patients may be modified and implemented to appropriately address the needs of the AYA patients.

A cancer diagnosis is not only terrifying for the AYA patient who has been diagnosed, but also for the patient's parents, siblings, extended family, friends, and peers. Medical social workers assess and address all levels of the patient's world by conceptualizing and employing the systems theory. Social workers serve the family as a unit while simultaneously addressing the needs of the individual patient. It is the job of the social worker to explain and assist a family as they navigate through the health care system. It is worth noting that a recent study explored the perceptions of patients by social workers. The study's (Craig et al., 2015) findings consistently paralleled the goals of the social work profession: autonomy and social justice (National Association of Social Workers, 2008). While a single social worker may not be able to support and assist all levels or systems impacted by a diagnosis, social workers can guide families to agencies and other individuals that provide needed support and resources. Gathering relevant information on the needs of adolescent cancer patients is imperative, so that care provided by medical professionals may be tailored to accurately address the needs of the youth.

Understanding the lived experience of a client or patient is critical in providing services that appropriately address their needs and well-being (NASW, 2008). Utilizing an empowerment approach through patient-centered care may be beneficial for social workers working in medical settings. Social workers take a proactive role in understanding the patients they serve and to effectively advocate for their unique needs. Patient-centered care deeply aligns with the ethics and concepts of social work as both approaches emphasize the importance of human relationships, the worth of the person, and human service (Epstein & Street, 2011; NASW, 2008). Social workers are bound by the National Association of Social Workers (2008) Code of Ethics to serve and improve human well-being by

assisting people in meeting their needs. As such, they have an extensive history of being a fundamental part of service delivery in regard to mental and physical care (Craig et al., 2015). With the flexibility to address micro level concerns (i.e., mental health) to macro level concerns (i.e. insurance coverages and costs), social work services are vital in addressing the needs of the patient in a holistic approach. Understanding and practicing patient-centered care with AYA oncology patients can further develop a medical social worker's empathy and ability to effectively serve patients.

Serving as the link between the patient and needed services, medical social workers in pediatric hospitals often provide emotional support. However, the current standard of care does not require social workers to provide emotional support for the patients or families (Craig et al., 2015). Knowing what and how the patients feel throughout the treatment process is critical in assessing and understanding their lived experiences and thus more effectively and holistically address their physical, mental, and emotional needs. For medical social workers working with the population of AYA oncology patients, the results of this study can inform delivery of care in aligning social work services to match the needs of patients and improved quality of care. The field of social work and AYA patients both could benefit from further investigations of this topic to help medical professionals to provide care designed to address the needs of the youth. This study endeavored to address the gaps in literature focusing on the population of adolescent and young adult oncology patients in an attempt to understand their needs. Social workers serve their clients on the basis of empowerment, social justice, and cultural diversity (NASW, 2008). Through training to provide more appropriate teen-centered services, the level of patient-centered care received by

patients may improve and therefore potentially lead to a higher quality of life (Epstein & Street, 2011).

### HIPAA

In 2003, federal legislation enacted the Health Insurance Portability and Accountability Act (HIPAA) which put in place policies to safeguard an individual's health information (U.S. Department of Health & Human Services, n.d.). HIPAA limits what can be shared about a patient's healthcare, including but not limited to whether or not a designated patient is present in the hospital/care unit on a given day. While this policy is beneficial to patients, this may pose a hindrance in addressing the developmental need of peer socialization in AYA oncological care. HIPAA inadvertently restricts the socialization that may occur among AYA oncology patients through the limitation of sharing which individuals are present in the hospital. As socialization is critical in the self-discovery process of the AYA, it is important for medical staff to provide social opportunities for AYA patients.

While data from this study displayed high levels of patient-centered care practiced with respect to medical interventions and interactions at VCH, the area of teen-centered services lacked supporting data. As discussed earlier, peer socialization is fundamental to human development along with the task identity formation at the AYA stage of life. Two identified training areas revolve around HIPAA regulations and teen-centered services.

Because HIPAA policies limit social interactions within a medical unit, training staff regarding HIPAA regulations to better support much needed peer socialization of the patients would be beneficial for this population. One recommendation is to create a waiver for specific clauses of the HIPAA



regulations, allowing medical staff to share information regarding when a patient is present in the unit. This waiver would allow for staff to legally encourage and nurture beneficial socialization among AYA in a unique medical situation while also protecting their medical rights and confidentiality. Unfortunately, HIPAA regulations do not only apply to living patients, but deceased as well.

### End of Life Considerations

With the low survival rate of youth diagnosed with cancer, one outcome of cancer is death. As death is a common occurrence among oncology units, patients may discover the untimely passing of a friend in unexpected and painful ways. Unfortunately, HIPAA restrains medical staff from sharing news of the death of a patient. This lack of sharing crucial information about a peer may lead to harmful implications in a patient's own battle with cancer. Negative outcomes of a peer's death include depression, substance use, and suicidal ideation (Malone, 2012). A study investigating teenage female responses to a peer's death reported that many of their participants experienced difficulty in responding to the grief they felt (Malone, 2012). The female patients stated that they were immediately filled with a mixture of emotions such as immense sadness and physical pain, but they did not understand how to express their bodily sensations.

Informing patients of a death in the unit while providing grief services to offer closure is essential and strongly recommended in addressing the emotional distress caused by a friend's death. Coping with a death deprived of closure may lead individuals to unnecessarily and continuously relive the painful memories and loss (Heaman, 2007). In a resource for survivors, *The View from Up Here: Your Guide to Surviving Childhood Cancer* (National Children's Cancer Society. n.d), an AYA cancer patient disclosed, "Sometimes, surviving when others don't cause

a lot of internal stress. There's a feeling of needing to live your life to the absolute fullest to honor them." Most survivors experience depression, anxiety, and fear resulting from their cancer related experiences and all survivors experience some level of grief from the losses they suffer (National Children's Cancer Society. n.d). Surviving cancer may lead an AYA to experience significant gains such as maturity, wisdom and perspective (National Children's Cancer Society. n.d). However, in order for these gains to occur, the grief they experience must be addressed in a healthy way (National Children's Cancer Society. n.d). While many researchers have investigated cancer regarding treatment success, research on cancer deaths remains scarce (J. D. Ozeran, Personal Communication, March 18, 2017). Unfortunately, limited background information currently restricts researchers from further expanding on this information. For the AYA patients who survive their battle with cancer, victory may come as a poignant achievement due to the loss of their peers. It is critical for researchers and medical staff alike to better understand how a death in a pediatric oncology unit can affect the emotional, mental, and physical well-being of other patients.

#### Limitations of the Study

While this study implemented the use of a pre-established tool to measure perceptions of patient-centered care, there were limitations to collecting information that appropriately identified current practices of patient-centered care at VCH. One limitation of this research was the small sample size, which significantly limits the generalizability of the results for this population. As 131 patients met subject criteria, the results of this study represented approximately 8% of the 131 patients. However, this number did not include those who were current AYA receiving active cancer treatments at the time of the study.

Researchers contribute the low number of responses to the study's online platform in which surveys were delivered. Inviting subjects to access the survey on their own volition increased the level of difficulty in comparison to surveys being delivered through social media or email where the participant would only need to select the link to gain access. Upon learning of the study's results, VCH staff reported that the research participation is not surprising and appropriately reflects current knowledge of the AYA population within the unit. VCH medical social workers acknowledge that there is a lack of participation among AYA in age appropriate activities (A. Robertson, personal communication, October 8, 2016). The low response affected the study's ability to accurately interpret the data and generalize the results. For future replications of this study, it is recommended that researchers administer the surveys via emailed links, social media posts or conduct the surveys in person. It is also suggested that an incentive be offered to increase the likelihood of subject participation.

Use of convenience sampling and accessibility were also potential factors contributing to the small sample size. Additionally, the subjects providing data for this study were from one unit within VCH. Based on the narrow scope of the population surveyed, it is unknown whether the results could be applied to other units within the hospital or to other facilities.

Perhaps the most notable limitation of this study was the quantitative nature of the investigative tool. Due to the nature of the data, the tool could not provide information regarding the lived experience of subjects and how they interpreted the care they received. This information may be useful in receiving more specific feedback about the services patients felt were lacking, and how they would have improved their care experiences. Counter to social work values, this method of data collection did not allow for a subject to express their needs or share

experiences. Doing so would provide validation for the feelings they expressed in the questionnaire and inform current practices. Though the tool asked for their input instead of their parents or caregivers, this study did not allow for subjects to add their comments or communicate their concerns. It is recommended that future studies utilizing this instrument to gather data consider the vulnerability and complexity of this population. Perhaps through the incorporation of a mixed methods approach, open ended questions could be incorporated in the tool to provide further explanation to the quantitative data.

### Recommendations for Future Directions

Due to the complexity and limited existing knowledge of this vulnerable population, there are numerous recommendations for improving current standards of care for AYA cancer patients. Most importantly, as the results of this study indicated, an increase in teen-centered services is needed. In order to further encourage patient socialization, adjustments in legislation and policy may be warranted. In this section, both recommendations will be discussed along with suggestions for staff education and further research suggestions.

### Support for Peer Socialization

In order to improve patient-centered care with AYA patients, medical staff should consider expanding their teen-centered services to better address the specific needs of the AYA population. Medical social worker Alistair Robertson (Personal Communication, October 8, 2016) of Valley Children's Hospital further emphasized the importance of peer communication and social connection, stating that experiences of other survivors can assist in inspiring other patients in their progress throughout the various stages of survivorship. The creation of one or multiple cancer support groups could be an appropriate intervention to encourage

essential socialization opportunities among AYA while simultaneously providing supportive care.

Researchers in New Zealand found that providing support groups with the AYA population provided numerous psychosocial benefits such as gaining perspective and enhancing confidence (Kane, Jasperse, Boland, & Herst, 2014). However, physical attendance in the hospital could be difficult based on transportation, status of health, personal insecurities, feeling ill, and commuting to the hospital on days without a medical appointment. Because of the multiple contributing factors of patient absences for support groups, it is suggested that an online forum specific to teens undergoing or recovering from cancer treatment be created at VCH.

The online forum can provide a possible solution to encourage peer interaction. This platform would allow for patients to self-disclose their information and further provide support to each other throughout their cancer treatments using the favored media of today's teens. A 2011 study investigated the use of online support groups in women who had breast cancer (Shim, Cappella, & Han, 2011). Results showed that the disclosure of insightful information, such as experience with stressful situations, strongly effected enhancing health benefits and improving emotional well-being (Shim et al., 2011). The National Children's Cancer Society (n.d.) states that connecting with others who have shared similar cancer experiences and emotions may assist in the healing process.

Currently, online socialization and typed words are the norm of communication (Helm, Möller, Mauroner, & Conrad, 2012). Many youth find communicating online more enjoyable than holding a face to face conversation (Helm et al., 2012). Online forums allow for socialization among patients, providing an opportunity to compare treatments, and to give and receive support.

Studies show that social media platforms provide youth with empowerment, collective action, social justice actions, and educational pathways (Johnston-Goodstar, Richards-Schuster, & Sethi, 2014). Such online forums would require constant monitoring to ensure that the site is being utilized appropriately and that everyone is safe in the online setting.

To further address the specific needs of AYA patients, the VCH oncology unit could benefit from designating a “teen only” area where AYA could congregate to socialize and provide peer support when present in the oncology unit. It may be even more beneficial to establish an entire unit dedicated to AYA. Establishing this unit with a physical space at the hospital could enable medical staff to more skillfully provide appropriate care that reflects the AYA’s needs. Though this would require a financial investment and increase in staffing on the part of the hospital, documentation exists that teen specific units have been successful in other institutions (Teen Cancer America, n.d.). With peer interactions being such a pivotal part of AYA development, it would be wise for VCH to further consider how they can encourage and support these needs.

#### Adjustments in Policy

Peer socialization remains to be a key element in healthy human development. Based on the study’s results, it is recommended that VCH’s Oncology unit provide more teen-based services/activities, allowing for peer socialization and identity development. However, due to HIPAA, socialization of AYA among the oncology unit may be hindered. Allowing staff to be creative and flexible in their service opportunities while recognizing HIPAA regulations may allow them to address this problem. Gan et al. (2009) determined that teen-centered services are a primary pillar of patient-centered care in the AYA

population. However, examples or descriptions of teen-centered services need to be defined and clarified. This critical gap requires the collection of qualitative data from AYA patients as *teen centered services* may vary from unit to unit as well as across geographical and cultural regions.

### Education

Responsible for the medical care of AYA oncology patients, health care staff need to be properly educated in areas of patient-centered care and empowerment techniques. This education does not only benefit the staff but also serves to benefit the patients, with whom staff will be interacting. Workshops introducing the practice of patient-centered care to patients have found that the participants have begun advocating for increased implementation of patient-centered care (Balogh et al., 2011). Trainings for physicians and medical professionals on patient-centered practices have been suggested to further improve care (Balogh et al., 2011). It has been noted that the medical model is deficit-based, leading patients to focus on their diagnosis (Zucca et al., 2014) while patient-centered care allows for holistic care of the individual.

However, medical professionals may encounter barriers to this practice of patient-centered care as some patients may be hesitant to become involved. Viewed as minors, medical decisions and opportunities for dialogue may automatically be given to parents or guardians. As a result, training staff in empowerment strategies may be most appropriate. In the event an AYA is asked for their opinion or feelings, the youth may be hesitant and uncertain how to engage as this may be the first time they are invited to speak for themselves. In this instance, utilizing empowerment strategies can promote patient autonomy and provide a sense of control in their lives (Pulvirenti, et al., 2014).

### Future Research

Investigators suggest that surveys be distributed during routine follow up care with the Childhood Cancer Survivorship Program. This would provide the opportunity for verbal clarification and parental consent for those who are minors but fit population criteria. It is hypothesized that by presenting an opportunity to complete the survey in person, a higher sample size would result. It is the goal of researchers that surveys regarding patient-centered care will be administered as part of routine practice over time. With that goal in mind, it is hoped that this research can serve as a pilot study for further research

Furthermore, this sample of subjects was recruited through one unit of a single pediatric hospital in Central California. In an effort to achieve generalizable results, it is recommended that future researchers expand the population to other units and other hospitals throughout the United States. Utilizing a mixed methods research design may yield additional data that could be beneficial in providing a more holistic image of the care delivered to AYA in the oncology realm. This approach would then be more consistent with the goals and values of the field of social work and patient-centered care.

### Conclusion

Understanding the needs of AYA oncology patients is not only critical in providing positive care, but also in increasing quality of life and supporting healthy development. It is concerning that limited research has been devoted to investigating AYA oncology without focusing on their care experiences. This study explored AYA's perspectives of patient-centered care performed within the Oncology unit at VCH. Though the study's results were limited due to the small sample size, it would be useful to re-consider this research as a pilot study on



which to appropriately adjust and implement future studies in gathering AYA's perceptions about the quality of care they received.

A call to action for AYA patients to speak out and become involved in reporting their experiences is a step in the right direction. Many survivors of cancer can learn to advocate for themselves to successfully meet their needs. As patients and survivors, they possess the knowledge required to influence change and become an effective part of a solution in improving not only their well-being, but the well-being of their peers (National Children's Cancer Society. n.d). As a vulnerable population facing medical crises during a critical developmental period of their lives, it is critical that medical staff are appropriately trained to empower, educate, and most importantly, to listen and respond to the needs of the adolescent and young adult patients. Their lives depend on it.

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## APPENDICES



## APPENDIX A: INFORMATION SHEET

Hello Survivor,

My name is Savannah Gomes and I too, am a cancer survivor. I was diagnosed at age 16 and received my chemotherapy treatments at Valley Children's Hospital. It has now been 8 years since completing my cancer treatments and I am now a graduate student at Fresno State.

I am inviting you to participate in a research study via an anonymous survey. This research looks at the care that takes place in the Oncology Unit at Valley Children's. Since you are now in the Childhood Cancer Survivorship Program, your input is important in my research and I would like to know more about your experiences with Valley Children's oncology staff.

Specifically, I want to learn more about the care patients' ages 13-30 years old receive. The survey will take approximately 10 minutes to complete. This research study is completely voluntary. You may choose not to participate or withdraw from the study at any time.

You will not receive any direct benefit from participating in this study. However, information collected has the potential to positively influence patient experiences in the future. There will be no cost to you to participate and you will not be paid to participate. There will not be any identifiable information collected for your participation in the survey. I will not have access to your medical records, and neither your name nor your personal information will ever be connected to your survey responses.

You may skip any of the survey questions if you choose not to answer them. A potential risk of completing the survey is that recalling your experience as a patient may cause some emotional upset. If this were to happen, I encourage you to follow up with your primary care physician or the staff at Valley Children's Oncology Unit at 559-353-5480 for further emotional support services as needed. If these support services are needed, they may be covered by you or your insurance.

By filling the online survey, you are giving your consent to participate. If you agree to participate in this questionnaire you, the survivor, can submit your answers through the following:

- ❖ Online Survey Questionnaire at <http://teencancer.wixsite.com/survey>

If you choose to participate, please submit your survey by FEBRUARY 10, 2017.

If you have any questions related to the study, please feel free to call Valley Children's Oncology Research Coordinator, Neil Manibo 559-353-5480.

For any questions regarding your research rights, you may contact the Valley Children's Hospital Institutional Review Board (IRB) at 559-353-5171 and you will be directed to the Chairperson of the Human Subjects Committee. This individual is an impartial third party not associated with the research study. The IRB has approved the research study and works to protect the rights and welfare of people who participate in research.

For any questions regarding your de-identified anonymous responses, you may contact chair of my research committee, Dr. Nancy Delich, California State University Fresno, at (559) 472-9917.

Thank you for your time. Your input on this survey will be used to improve the care that teens receive in the Valley Children's Hospital Oncology Unit.

Savannah Gomes, BA  
Graduate Student at California State University, Fresno

## APPENDIX B: RESEARCH SUBJECT DEMOGRAPHICS

How old are you currently? \_\_\_\_\_

What Gender do you currently identify as?

- Male
- Female
- Prefer not to answer

What is your racial/ethnic background?

- White/Caucasian-Non-Hispanic
- Hispanic or Latino
- Black or African American
- Native American or American Indian
- Asian
- Pacific Islander
- Middle Eastern
- Other
- Prefer to Answer

How old were you when you were diagnosed with cancer? \_\_\_\_\_

APPENDIX C: GIVING YOUTH A VOICE QUESTIONNAIRE-  
BRIEF (GYV-20)

**Giving Youth a Voice Questionnaire-Brief (GYV-20)**

Caron Gan, Kent Campbell, Andrea Snider, Janine Hubbard, and Virginia Wright

Holland Bloorview Kids Rehabilitation Hospital

We would like to understand and measure the experiences of youth who have a cognitive or physical disability. In particular, we wish to know about what you think of the services you have received over the past year from your **Rehabilitation Centre**.

The questions in this section are based on youth, like yourself, have told us about the way services are sometimes offered. We would like you to indicate how much the event or situation happens (or doesn't happen) to you at your Rehabilitation Centre. You are asked to answer each question on a scale from 7 (A Lot) to 1 (Never).

The following is an example of the kinds of questions you will be asked. This example also shows what your answer could mean.

<i>How much do the <b>people</b> who give you questionnaires...</i>	A lot		Sometimes			Never		Not Applicable
... provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (A lot), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Does not apply to me), it means that you have never received a questionnaire and so you cannot answer the question. We would like you to think about your experiences with \_\_\_ (name of program or service) over the past year. We are interested in your personal thoughts and would appreciate your own answers to the questions below.



For each question, please indicate how much the event or situation happens to you by circling **one** number (from 1 to 7) that you feel best fits your experience. When answering these questions, we would like you to think about \_\_\_\_ (name of program or service).

PEOPLE refer to those individuals who work directly with you. These **may include** teachers, psychologists, therapists, social workers, doctors etc.

**IN THE PAST YEAR**      Indicate how much the event or situation happens to you.

<i>How much do the <b>people</b> who work with you...</i>	A lot		Sometimes			Never		Does not apply to me
1. ... give you enough time when you need to make choices in treatment?	7	6	5	4	3	2	1	0
2. ... make sure you have a chance to say what is important to you?	7	6	5	4	3	2	1	0
3. ... help you feel more sure of yourself?	7	6	5	4	3	2	1	0
4. ... tell you details about your treatment, such as the reasons for it, what is being done, and for how long?	7	6	5	4	3	2	1	0
5. ... talk to you honestly?	7	6	5	4	3	2	1	0

**IN THE PAST YEAR**

Indicate how much the event or situation happens to you.

<i>How much do the <b>people</b> who work with you...</i>	A lot			Sometimes			Never	Does not apply to me
6. ... treat you as a young adult rather than a child?	7	6	5	4	3	2	1	0
7. ... trust that you know yourself best?	7	6	5	4	3	2	1	0
8. ... recognize that you and your family have the final say when making decisions about your treatment or services?	7	6	5	4	3	2	1	0
9. ... show an understanding of your feelings?	7	6	5	4	3	2	1	0
10. ... show they care about you?	7	6	5	4	3	2	1	0
11. ... inform you of how treatments might harm you or help you?	7	6	5	4	3	2	1	0
12. ... look at all of your needs (e.g. cognitive, emotional, and social needs), as well as your physical needs?	7	6	5	4	3	2	1	0
13. ... treat you as an individual rather than like all other youth with a disability?	7	6	5	4	3	2	1	0
14. ... answer your questions?	7	6	5	4	3	2	1	0

**IN THE PAST YEAR**

Indicate how much the event or situation happens to you.

<i>How much do the <b>people</b> who work with you...</i>	A lot			Sometimes			Never	Does not apply to me
15. ... seem aware that your needs change as you get older?	7	6	5	4	3	2	1	0
16. ... get along well with youth?	7	6	5	4	3	2	1	0
17. ... give you a chance to say what you want to get out of treatment?	7	6	5	4	3	2	1	0
18. ... explain what they are doing?	7	6	5	4	3	2	1	0
19. ... make you feel that you can trust them?	7	6	5	4	3	2	1	0
20. ... offer you useful information about how you are doing?	7	6	5	4	3	2	1	0

## APPENDIX D: FOLLOW-UP REMINDER

Hello Survivor,

This is a reminder that you previously received an information sheet notifying you about a research study taking place in the Oncology Unit. If you have already completed the survey, please disregard this letter.

If you have not completed the survey, I just wanted to remind you that your opinion is valued and would be appreciated. However, this research study is completely voluntary; you may choose not to participate or withdraw from the study at any time. The survey will take approximately 10 minutes to complete. There will not be any identifiable information collected.

By filling out the online survey, you are giving your consent to participate. If you agree to participate in this questionnaire you, the survivor, can submit your answers through the following:

- <http://teencancer.wixsite.com/survey>

If you choose to participate, please submit your survey by FEBRUARY 14, 2017.

If you have any questions related to the study, please feel free to call Valley Children's Oncology Research Coordinator, Neil Manibo 559-353-5480.

For any questions regarding your research rights, you may contact the Valley Children's Hospital Institutional Review Board (IRB) at 559-353-5171 and you will be directed to the Chairperson of the Human Subjects Committee. This individual is an impartial third party not associated with the research study. The IRB has approved the research study and works to protect the rights and welfare of people who participate in research.

For any questions regarding your de-identified anonymous responses, you may contact the chair of my research committee, Dr. Nancy Delich, California State University, Fresno, at (559) 472-9917.

Thank you for your time.

Savannah Gomes, BA

Graduate Student at California State University, Fresno