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# Follow Up Care, Cancer Treatment Summaries And Patient Centered Communication

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# FOLLOW UP CARE, CANCER TREATMENT SUMMARIES AND PATIENT CENTERED COMMUNICAITON

by

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# DEDICATION

To Dr. Joe L. Cole and Dr. Amanda Mary Dove

# FOLLOW UP CARE, CANCER TREATMENT SUMMARIES AND PATIENT CENTERED COMMUNICATION

by

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# FOLLOW UP CARE, CANCER TREATMENT SUMMARIES AND PATIENT CENTERED COMMUNICATION

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The adolescent and young adult (AYA) age group is the cohort of individuals who have been diagnosed with and/or are survivors of cancer. It is recommended they receive lifelong follow up care to prevent or mitigate late health effects associated with cancer and treatment. However, AYAs are caught between the pediatric and adult healthcare systems and they may not be able to fully advocate for their healthcare needs. Some factors that may be associated with AYAs survivorship care are treatment summaries and where they receive follow up care.

This study aimed to identify if receipt of a treatment summary and if receipt of follow up care at a survivorship clinic are associated with positive patient centered communication (PCC). Participants were recruited from the Texas Cancer Registry and included adolescents aged between 15-18 living in Texas with a prior diagnosis of acute lymphoblastic leukemia (ALL). They were sent a survey pertaining to their cancer history, survivorship care plans, general health status, current medical care, patient centered communication, late effects from cancer treatment, patient-child relationship and demographics. A multiple regression analysis was used to identify if receipt of a treatment summary and receipt of follow up care at a survivorship clinic were associated with positive PCC. Receipt of a treatment summary was

significant and associated with positive PCC ($\beta$=0.68; p=0.001); receipt of follow up care at a survivorship clinic was not significant and not associated with positive PCC ($\beta$=-0.065; p=0.787). The receipt of a treatment summary associated with positive PCC is consistent with other findings in similar studies.

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# BACKGROUND

## Literature Review

### *AYA Cancer Population*

Cancer is a group of diseases caused by a loss of control of cell division, which may spread to surrounding tissues.[1] The abundance of cancer afflicts any organ and anybody. The adolescent and young adult (AYA) age group is the population of people aged 15 to 39 diagnosed with cancer.[2] Approximately 70,000 AYAs are diagnosed with cancer yearly, which is ultimately 5% of all cancer diagnoses.[2,3] However, AYAs diagnosed with cancer have worse outcomes and higher uninsured rates than children and older adults diagnosed with cancer.[4,5] Furthermore, cancer is the leading cause of disease-related death in AYAs.[4] For AYAs who become survivors, they enter the survivorship phase of care that lasts their entire life and includes follow up healthcare in the forms of physical exams, identification and/or surveillance of potential health care problems, medical care provided by specialists, healthy lifestyle habits and additional support extending beyond one's health (i.e. social, financial, legal needs).[6]

### *Transition of Care & Late Effects*

Transition of care involves two aspects: 1) a patient having one's care transferred between physicians and 2) AYAs assuming responsibility and managing their healthcare.[7] Additionally, transition readiness includes one's self-efficacy in the prevention of late effects related to cancer treatment.[7] As recommended by the Institute of Medicine, cancer survivors should receive long term care that includes “surveillance, prevention and treatment of late effects” since there is an increased risk for acquiring them from the initial diagnosis.[8] Approximately 73% of pediatric and AYA survivors will develop a chronic health issue 30 years post diagnosis and 42% will develop a life-threatening or disabling medical illness.[3] Furthermore, the Childhood Cancer Survivor Study cohort followed 14,000 survivors, of which 2/3 had at least one chronic condition 25 years after the initial diagnosis.[7] Such conditions include, but are not limited to: cardiovascular disease, hypertension, dyslipidemia, diabetes/insulin resistance, obesity, secondary cancers, endocrine disorders, renal dysfunction, musculoskeletal problems and infertility.[9-11] However, several obstacles complicate long term care for survivors, including lack of health insurance and lack of knowledge about their medical history, treatment and consequences.[12-15]

### *Health Insurance*

Lack of health insurance is a known barrier to receiving healthcare services.[13] AYAs are the largest group of uninsured individuals and this may stem from “aging out of parental/public insurance” after age 26, lacking full time employment and not having jobs that provide health insurance.[14,16] Thus, this leads to the AYA cancer survivors not receiving their survivorship care.[13]

### *Barriers to Transition of Care*

During the adolescent time period, parental figures have control of the AYAs’ healthcare, however during the transition process AYAs must take control of their own health.[17] AYA survivors lack basic information about their previous cancer treatment and future cancer surveillance and therefore must be informed about late effect risks and health promotion.[13,18] Ultimately, AYAs will experience an improved quality of life when they have "necessary skills for healthcare self-management in adulthood."[19]

### *Transition into Survivorship*

AYA cancer survivors are at risk for long term health effects, due to cancer and cancer treatment, which include developing second cancers, cardiac conditions, psychosocial problems, endocrinopathy, cognitive problems and poor mental health.[13,16,18] Due to this, current recommendations include maintaining life-long survivorship care for surveillance, prevention, early detection and treatment of late effects.[8,18] Overall, AYA cancer survivors are transitioning into survivorship from active disease treatment and into adult healthcare from pediatric healthcare. Thus, they must have access to care through insurance coverage and they must have the necessary skills for self-management of their health.

### *Demographics of ALL*

The most common cancer for children <20 is acute lymphoblastic leukemia (ALL), however, AYAs aged 15-24 also may be diagnosed with leukemia, which is one of the three commonly diagnosed cancers within this age group.[2,20] According to the Adolescent and Young Adult Oncology Progress Review Group, the AYA population includes those patients between the ages of 15-29.[21] In the United States between 2003-2014, the southern region had the highest cancer incidence of children aged <20, with 61,998 out of 171, 432 new cases; specifically, Texas had the highest incidence with 16,368 cases and the 15-19 age group accounted for 18,933 cases.[22] Recently between 2012 and 2016, the incidence rate for leukemia was 4.6 per 100,00 children/year.[23] In Texas, between 2012 and 2016 for all cancer types, Non-Hispanic Whites and Hispanic Whites aged <20 had an incidence rate of 20.4 per 100,000 people, while Bexar County, had an incidence rate of 21.3 per 100,00 people.[24] Furthermore, it was estimated there were 379,000 childhood cancer survivors in 2010 and it is estimated there will be 500,000 survivors by 2020.[25]

Table 1. Pediatric cancer incidences by age and region between 2003-2014.[22]

| | Incidences |
|---|---|
| US Southern Region Children <20 years of age | 61,998 |
| US Southern Region 15-19 year of age | 18,933 |
| Texas Children <20 years of age | 16,368 |

Table 2. Leukemia incidence rates nationally, statewide and locally.[23,24]

| | Incidence Rates per 100,000 |
|---|---|
| Nationally (2012-2016) | 4.6 |
| Texas, Non-Hispanic White and Hispanic White <20 year of age (2012-2016) | 20.4 |
| Bexar County, Non-Hispanic White and Hispanic White <20 year of age (2012-2016) | 21.3 |

### *Survivorship Guidelines*

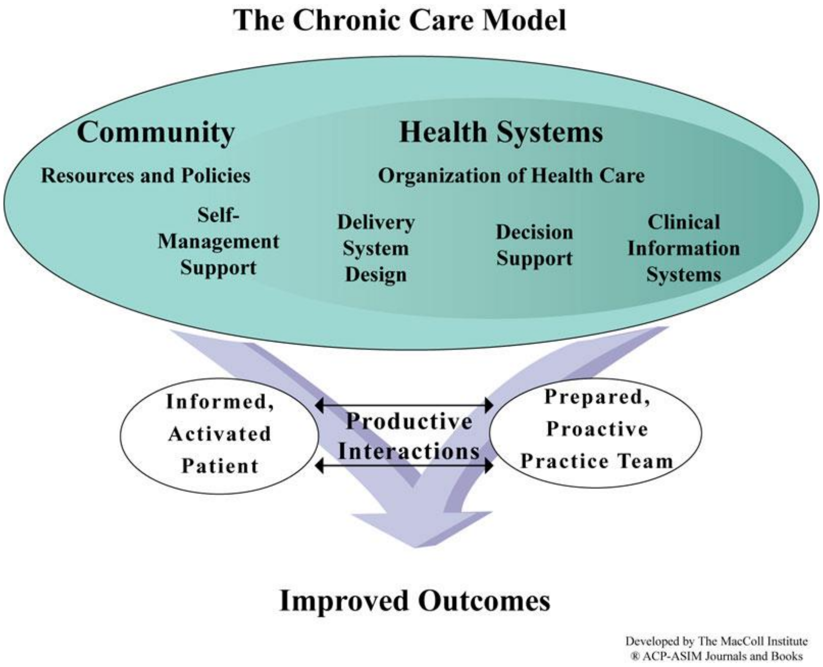
The Children's Oncology Group (COG) created a health screening guideline, based on previous treatment type, that details providing long term follow-up care and health supervision for pediatric cancer survivors.[26] Additionally, the National Comprehensive Cancer Network (NCCN) has created their version of guidelines for AYA follow-up care, which is to be used in conjunction with the COG guidelines.[21] As recommended by the Institute of Medicine and COG, survivors are recommended to have annual follow up care for life.[27] Survivors <39 year of age are recommended to have some of, but not limited to, the following screenings: annual physical exam with blood pressure check, vaccination history discussed and informed about pneumococcal/meningococcal/flu vaccines, routine labs-complete blood count, differential, platelets, chemistry panel, cholesterol, fasting glucose, thyroid stimulating hormone, urinalysis- electrocardiogram, pulmonary function tests, mammogram and breast MRI  (for females only), colonoscopy, ophthalmologic exams, DEXA, neurocognitive testing, cervical/endometrial screening (for women only), lung screening and prostrate screening (for men only).[21]

### *Chronic Care Model*

The Chronic Care Model is a model for managing chronic disease and is separate from the acute healthcare system. Six elements comprise the Chronic Care Model: health systems, decision support, clinical information systems, patient self-management support, community resources and delivery system designs.[28,29] The health system includes a combination of tangibles and intangibles, such as staff, values, goals and operations which function together ranging in the form of a simple family practice to a complex healthcare system.[28] Decision support includes scientific based literature as the foundation to the practice of medicine and the inclusion of patient participation in one's healthcare. Clinical information systems include access to database for certain diseases, which provides information on required tests and tracking, and the interaction between patient and physician regarding medical information.[28] Patient self-management support includes the patient's responsibility for managing one's health; elements may include, but are not limited to, goal setting and action planning. Community resources are resources utilized by communities to "support healthcare efforts by clinicians" and include, but are not limited to, support groups, health programs and community interventions.[28] Delivery system design includes how the healthcare system is implemented (i.e. elements of organization, staffing and delivery) and this aspect has the potential to improve patients' quality of care and health outcomes.[28]

Cancer is one of four main types of chronic diseases and it is recommended that AYA cancer survivors follow a chronic disease model to receive preventative care.[21,28] By providing follow up care, the late health effects may be reduced by prevention or early detection.[30] The first principle in the Chronic Care Model includes having a primary care physician as the main contact for the patient. Ultimately, following the Chronic Care Model provides patients with chronic illness better health outcomes, especially when emphasis is on comprehensive care and overall health of the patient.[28]

Figure 1. Overview of the Chronic Care Model.[31]



*Models of Survivorship Care*

There are two types of models that have been proposed for AYA survivorship care: Multidisciplinary Care Model and the Shared Care Model.[32] The Multidisciplinary Model is centered on care being provided by a specialized team (such as oncologist, cardiologist, etc.) in separate clinical areas and communication with a PCP. The Shared Care Model is centered on coordination between an oncologist and PCP and is the only model to have the options of transition of care.[33] The Shared Care Model has improved health outcomes for patients with chronic illness and it allows for communication and knowledge/information transfer between the oncologist and PCP during and after treatment.[3] For the pediatric oncologist, there is a preference to observe survivors for as long as possible, however some oncologists may not be comfortable caring for survivors as they age.[34] Conversely, PCPs can offer holistic care and are willing to provide survivorship care; however most PCPs may not be comfortable caring for survivors independently and may prefer sharing care with a follow up program or oncologist.[35,36]

### *Patient Centered Communication*

Communication between healthcare providers and patients is essential in delivering healthcare. However, communication in cancer care differs vastly from communication in other diseases.[37] Unlike chronic disease, cancer may be fatal, yet curable, includes various types of treatment options, includes post-treatment uncertainty and includes dynamic healthcare providers.[37] Cancer patients experience various transitions within their healthcare, including from active treatment to remission to survivorship. For children and adolescents, they make an additional transition from pediatric healthcare to adult healthcare. Additionally, young adults may not be equipped to solely navigate the health care system. Thus, communication in adolescents and young adults is crucial. Patient centered communication (PCC) is composed of three values and 6 functions and it may improve health outcomes.[37,38] The first value of PCC emphasizes one's experience with disease and specific needs. The second value promotes patients actively engaging in one's healthcare and the last value focuses on strengthening the patient-physician relationship.[37] The six functions of PCC include the fostering of healing relationships, exchanging of information, responding to patients' emotions, managing uncertainty, making decisions and enabling patient self-management.[37]

### *Health Promotion Theories and Follow-up Care*

Health promotion theories are utilized to understand human behavior and to predict future behavioral changes.[39] Such theories include but are not limited to: Health Belief Model, Theory of Reasoned Action/Planned Behavior, Transtheoretical Model of Behavior Change, Communication Persuasion Matrix, and Social Cognitive Theory. The theories listed are further elaborated on in Table 3. The Health Belief Model is used to understand an individual's choice to partake in a health action.[39] The Theories of Reasoned Action and Planned Behavior are two similar theories that originated solely from the Theory of Reasoned Action.[39] The Theory of Reasoned Action originally provided an understanding between one's health risk behavior and one's awareness of the potential negative outcomes associated with such a behavior.[39] The Theory of Planned Behavior is an extension of the Theory of Reasoned Action and identifies one's intention as the predictive factor of behavior.[39] The Transtheoretical Model is a stage theory that is used to understand a person's behavior based on a particular stage and to specifically promote change methods based on the stage one is in.[39] The Communication Persuasion Matrix is used to alter one's attitude through the use of logic and reasoning; it includes steps that are effective with persuasive communication and communication variables.[39] Lastly, Social Cognitive Theory describes how one's behavior, cognition and personal/environmental factors interact to understand human behavior.[39]

Research utilizing such theories to understand survivors' follow up care are prevalent. In one study, the Theory of Planned Behavior was utilized to analyze follow up care attendance in childhood cancer survivors.[40] One aim measured perceived control, intention and attendance; higher perceived control and higher intention were both associated with actual attendance in follow up care.[40] In another study, the Health Belief Model was utilized to identify an association between health beliefs and follow up care.[41] Survivors were more likely to attend follow up care if they perceived benefits in follow up care, which are related to “help[ing] detect late effects and preventing negative consequences of late effects of [one’s] cancer”; additionally, they were also more likely to attend follow up care if perceived benefits included believing “follow up care was suitable to detect and prevent late effects.”[41]

Table 3. Types of theories utilized in health promotion.[39]

| Theory | Description of Theory | Constructs of Theory |
|---|---|---|
| Health Belief Model | Seeks to identify why an individual engages in a health behavior | • Perceived Susceptibility<br>• Perceived Severity<br>• Perceived Benefits<br>• Perceived Barriers |
| Theory of Reasoned Action/Planned Behavior (TRA/TRB) | TRA: Seeks to identify why one engages in a health behavior despite awareness of negative outcomes<br>TPB: Identifies one’s intent as a prediction of behavior | TRA:<br>• Attitude<br>• Subjective Norm<br>TPB:<br>• Attitude<br>• Subjective Norms<br>• Perceived Behavioral Control |
| Transtheoretical Model of Behavior | Utilizes stages to understand one’s behavior; targets intervention based on stage to progress one to the next stage | • Stages of Change<br>○ Precontemplation<br>○ Contemplation<br>○ Preparation<br>○ Action<br>○ Maintenance<br>○ Termination<br>• Process of Change<br>○ Consciousness Raising<br>○ Dramatic Relief<br>○ Environmental Reevaluation |

| | | |
|---|---|---|
| | | ○ Self-Reevaluation<br>○ Self-Liberation<br>○ Helping Relationships<br>○ Counterconditioning<br>○ Contingency Management<br>○ Stimulus Control |
| Communication Persuasion Matrix | Promotes changing one's attitude and behavior through logic and reasoning | • Steps<br>○ Attention and Comprehension<br>○ Attitudes<br>○ Social Influence<br>○ Self-Efficacy<br>○ Behavior<br>○ Behavior Change<br>• Communication Variables<br>○ Message Content<br>○ Program Audience<br>○ Communication Channels<br>○ Message Source |
| Social Cognitive Theory | Seeks to understand one's behavior via reciprocal determinism, which demonstrates how behavior, cognitive and environmental factors interact | • Reciprocal Determinism<br>• Outcome Expectations<br>• Self-Efficacy Expectation<br>• Behavioral Capability<br>• Perceived Behavior of Others<br>• Social and Physical Environments |

## Public Health Significance

Determining if survivors receive a cancer treatment summary and identifying where they receive follow up care is important in helping survivors establish sole responsibility of their healthcare. This will contribute to existing literature and elucidate new findings in the emergent field of AYA cancer survivorship care. Ultimately, this will help advance the field by promoting design and implementation of evidence-based survivorship care interventions. These interventions will help improve survivors' quality of life, prevent late health effects or identify them earlier, and prevent early mortality. Lastly, this research may further contribute to health professionals deciding on and establishing a general model of survivorship care for cancer survivors.

### Hypothesis, Research Question, Specific Aims or Objectives

Receiving a cancer treatment summary may improve a survivor's ability to communicate one's healthcare need with a physician.[42] Additionally, survivorship clinics may be more equipped to address survivors' healthcare needs by adhering to screening recommendations from the COG LTFU.[43] However, it is unknown if receiving follow up care at survivorship clinic is associated with patient centered communication. The main research question of this study is:

Is receiving a cancer treatment summary and receiving follow up care at a cancer survivorship clinic associated with positive patient centered communication?

## METHODS

### Study Design

The study was quantitative and it sought to identify if receiving a cancer treatment summary and receiving follow up care at a survivorship clinic were associated with positive patient centered communication (PCC). The study was conducted by utilizing secondary data, in the form of a self-report questionnaire, from acute lymphoblastic leukemia survivors aged 15-18 within Texas. The data was previously collected by Dr. L. Aubree Shay. The independent variables were receipt of cancer treatment summary and receiving follow up care at a cancer survivorship clinic. The dependent variable was the patient centered communication, which centers on the communication between patient and physician. It included 5 statements about how one perceived his/her doctor understanding one's perspective of health, encouraging one to manage his/her health, encouraging one to learn more about his/her health, providing one with options for his/her healthcare and listening to one prior to making medical decisions. The two independent variables were categorical and were coded to reflect this. The dependent variable was continuous and was coded by applying a 5-pont Likert scale.

The hypothesis was tested by utilizing multiple linear regression.

## Study Setting

This study was not conducted in a single setting. Instead, previous data was collected from participants who lived throughout the state of Texas. Most participants lived within or near three of the five largest cities in the state, including Houston, Dallas and San Antonio.

## Study Subjects

Prior approval from the UT Health Institutional Review Board was granted for the survey and recruitment of participants. Participants of the study were recruited from the Texas Cancer Registry. Inclusion criteria were adolescents between the ages of 15-18, living in Texas and with a prior diagnosis of acute lymphoblastic leukemia.

## Sample Size Calculation and/or Study Power

The study utilized a multiple linear regression model with two independent categorical variables and one dependent continuous variable. For hypothesis testing, a 95% confidence interval and a significant p-value less than or equal to 0.05 was utilized.

## Data Collection

The data from the questionnaires was collected by Dr. L. Aubree Shay. The survey gathered data about one’s cancer history, survivorship care plans, general health status, current medical care, patient centered communication, late effects from cancer treatment, patient-child relationship and demographics. The surveys were distributed to acute lymphoblastic leukemia survivors by mail and/or by email and were entered into REDCap. Participants were given a $15 gift card for participating in the survey.

## Data Analysis

With the data already collected, STATA was utilized to reanalyze data and test the hypothesis. A multiple regression model was utilized to show the relationship between the independent variables, receipt of cancer treatment summary and receiving follow up care at a survivorship clinic, and the dependent variable, patient centered communication. Since the survey indicated three options for response to the variable of receiving a treatment summary (“Yes”, “No”, “I don’t know/I am not sure”), the data was recoded to combine both the “No” and “I don’t know/I am not sure” response into a single response. Additionally, the dependent variable was not part of the original data and was generated. The dependent variable was created by averaging each survivor’s response to the combined 5 statements

("My doctor seems to really understand how I see thing with respect to my health"; "My doctor makes me feel confident in my ability to manage my heath"; "My doctor encourages me to ask questions about my health"; "My doctor listens to what I think before making recommendations and setting goals"; and "My doctor provides me with choice and options and for managing my health"). With all three variables, three regression models were shown: 1) a multiple regression model, 2) a linear regression model with the independent variable of receiving a cancer treatment summary and 3) a linear regression model with the independent variable of receiving follow up care at a survivorship clinic.

Descriptive statistics including current age, race/ethnicity, education level completed, living arrangements, total household income, insurance coverage and type of insurance coverage were also described in STATA.

## RESULTS

In this study, 51 participants completed the questionnaire, however some participants did not answer all the questions. The age range of participants varied from 15-19 with an average age of 16.96 years, 52.94% of participants identified as White, 52.94% of participants were in high school but did not graduate and 84.31% of participants lived with their parents. Further statistics about household income, insurance coverage and type of insurance coverage are further detailed in Table 4.

Model 1 related the receipt of a cancer treatment summary to the average score of patient centered communication (PCC). The relationship between the two variables is significant (*β*=0.68; p=0.001). Additionally, the relationship is positive, yet only 22.45% of the variation seen in PCC is attributed to receipt of a cancer treatment summary.

Model 2 related receiving follow up care at a survivorship clinic to the average score of PCC.  This relationship is not significant (*β*=-0.065; p=0.787). Furthermore, the relationship is negative and only 0.16% of the variation is attributed to receiving follow up care in a survivorship care clinic.

Model 3 related the receipt of a cancer treatment summary and receiving follow up care at survivorship clinic combined to the average score of PCC. This model shows there is only 23.36% of variation in PCC due to both receiving a cancer treatment summary and receiving follow up care at a survivorship clinic. Receipt of a cancer treatment summary is significant (*β*=0.68; p=0.001), but receipt of follow up care at a survivorship clinic is not significant (*β*=-0.065; p=0.787). Table 5 summarizes the statistics of the multiple regression and linear regression data.

Table 4. Characteristics of Participants (N=53)

| | N (%) |
|---|---|
| Current Age (mean, SD) | 16.96 (1.21) |
| Race/Ethnicity | |
| Non-Hispanic White | 27 (52.94) |
| Hispanic/Latino | 18 (35.29) |
| Black/African American | 3 (5.88) |
| Hispanic Black/African American | 1 (1.96) |
| Asian | 1 (1.96) |
| N.H./P.I.* | 1 (1.96) |
| AI/AN+ | 0 (0) |
| Education Level Completed | |

| | |
|---|---|
| 1-8 years (grade school) | 5 (9.8) |
| 9-12 (HS, but did not graduate) | 27 (52.94) |
| Completed HS/GED | 13 (25.49) |
| Training after HS, other than college | 1 (1.96) |
| Some college | 5 (9.8) |
| Living Arrangement | |
| Live with parents | 43 (84.31) |
| Live with roommates or other family member | 5 (9.8) |
| Other~ | 3 (5.88) |
| Total Household Income | |
| <$19,999 | 9 (17.65) |
| $20,000-$39,999 | 5 (9.8) |
| $40,000-$59,999 | 6 (11.76) |
| $60,000-$79,999 | 7 (13.73) |
| $80,000-$99,999 | 2 (3.92) |
| Over $100,000 | 9 (17.65) |
| Don’t know | 13 (25.49) |
| Insurance Coverage | |
| Yes | 48 (94.12) |
| No | 3 (5.88) |
| Type of Insurance Coverage | |
| Through your place of employment | 0 (0) |
| Through your spouse/parent | 26 (49.06) |
| Through a self-purchased policy | 1 (1.89) |
| Through Medicaid | 16 (30.19) |
| Through Medicare | 3 (5.66) |
| Through military dependent/veteran benefit | 1 (1.89) |
| Other^ | 3 (5.66) |
| Received Cancer Treatment Summary | |
| Yes | |
| No (includes responses I don’t | 35 (66.04) |
| know/I am unsure and no | 18 (33.96) |
| response) | |
| Received Follow Up Care at Survivorship Clinic | |
| Yes | 11 (20.75) |
| No | 42 (79.25) |
| Average score of PCC (mean, SD) | 4.59 (0.67) |

Abbreviations and Symbols

HS=High School

PCC= patient centered communication
*=Hispanic Native Hawaiian/Other Pacific Islander
+= American Indian/Alaskan Native
~=Other Includes dorm, grandparents and with living only with mom
^=Christian Healthcare Ministries

Table 5. Multiple regression analysis predicting patient centered communication (PCC).

| | $R^2$ | $\beta$ | t | *P* |
|---|---|---|---|---|
| Model 1 | | | | |
| Received cancer treatment summary | 0.2245 | 0.68 | 3.69 | 0.001 |
| Model 2 | | | | |
| Received follow up care at survivorship clinic | .0016 | -0.065 | -0.27 | 0.787 |
| Model 3 | | | | |
| Received cancer treatment summary | 0.2236 | 0.696 | 3.73 | 0.001 |
| Received follow up care at survivorship clinic | | -0.158 | -0.74 | 0.463 |

## DISCUSSION

The primary purpose of the study presented was to identify whether receiving a cancer treatment summary and receiving follow up care at a survivorship clinic was associated with positive patient centered communication (PCC). The results of this study indicate that receiving a cancer treatment summary is associated with positive PCC.

The treatment summary is one component of the survivorship care plan (SCP), which serves to inform the patient's oncologists and primary care providers (PCPs) about her/his survivorship care.[44] Treatment summaries include information such as one's specific cancer diagnosis, the stage of disease at diagnosis, type of treatment (chemotherapy, radiation or surgery) and potential late health effects stemming from the type of treatment.[44] In a study by Blanch-Hartigan et al,[42] having a treatment summary may improve PCC "through better care coordination, more survivor involvement, and less uncertainty about survivorship care." According to the American College of Surgeons' Commission on Cancer, receiving a treatment summary is a requirement.[45] However, survivorship care plans, which may contain a treatment summary, are not always delivered to survivors and/or their primary care physicians.[46] Additionally, 1,850 cancer programs across the United States were assessed to identify if survivorship care plans were implemented with patient care; of the 1,850 programs, only 44% utilized survivorship care plans. Furthermore, for programs who did provide survivorship care plans, half or less than half were given to survivors.[46] Lastly, Forsythe et al[47] showed that 49.1% of oncologists always or almost always provided treatment summaries while only 34.2% of primary care physicians always or almost always received treatment summaries.

This study is consistent with other study findings. Blanch-Hartigan et al[42] studied the relationship between receipt of a treatment summary, PCC and quality of care. Data from the Health Information National Trends survey from October 2012-January 2013 was utilized and receipt of treatment summaries was significantly associated with higher overall PCC and quality of care. Of the 6 functions of PCC, five functions were associated with higher PCC when given a treatment summary. The five functions include: exchanging information, making decisions, enabling self-management, managing uncertainty and fostering healthy relationships. Additionally, survivors who received a cancer treatment summary were three times as likely to describe excellent/very good quality of care.[42]

Swoboda et al[45] also sought to determine a relationship between receipt of treatment summaries, quality of life and PCC. The study utilized data from the Health Information

National Trends Survey for 2012, 2014, and 2017 and it showed a significant association between receipt of treatment summary and PCC. Furthermore, the functions of responding to emotions and managing uncertainties were significantly associated with receipt of a treatment summary.[45] Both studies utilized a survey to collect data to measure the relationship between receipt of a treatment summary and PCC in adult survivors of various cancers; yet, this is a novel study that has not been previously investigated among AYA survivors of acute lymphoblastic leukemia.

Patient centered communication has been studied in other disease models among adolescents. In one study, Croom et al[48] sought to determine the perceptions of PCC in adolescents and parents regarding empowerment and diabetes management. The study identified that an adolescent's perception of PCC is associated with increased perception of competence and control in managing one's Type I Diabetes. Additionally, adolescents' perception of PCC correlated to higher self-efficacy, self-competence and better adherence. Such higher PCC scores reflected adolescents' adherence 6 months after their initial appointment. Lastly, adolescents' and parents' perceptions of heightened adolescent competence influences diabetes management. This PCC perception may encourage adolescents to be involved in their medical care and by them assuming responsibility to manage their healthcare, including managing one's illness and being more involved in her/his medical care.[48]

In another study involving adolescent and young adult (AYA) patients with chronic kidney disease, the amount of communication time and topic of communication was studied between physician, caregiver and AYA.[49] Coburn et al[49] identified that the proportion of overall talk by age group increased; adolescents aged 11-14 talked 9.2% of the time during nephrology visits, adolescents aged 15-17 talked 13% of the time, and young adults aged 18-20 talked 23.75% of the time. Nevertheless, providers spoke the most during appointments, regardless of age group, with approximately 60% of the time.[49] Additionally, information discussed during appointments include biomedical information related to one's illness and therapeutic regimens, including type of medication taken and adherence to medication. Young adults aged 18-20 demonstrated more responsibility for their healthcare by discussing their therapeutic regimen and medical information more than any other age group. Despite that young adults spend more time discussing their healthcare with providers, the study suggests that patients in middle adolescence (ages 15-17) may be the time for patients to begin assuming independence. Patients in middle adolescents may become responsible for all aspects of her/his therapeutic regimen, which includes knowing the names of medication, knowing doses of medication and understanding the function of the medications. By doing this, patients may then build upon this knowledge and gradually learn her/his medical history, ultimately leading to more involvement during medical appointments.[49]

This study hypothesized that receipt of a treatment summary and receipt of follow up care at a survivorship clinic is associated with positive PCC; the study only found that receipt of a treatment summary is associated with positive PCC.  Despite the results of the study, they must be understood within the context of the research.  This study utilized data from adolescent survivors of acute lymphoblastic leukemia, thus, the results may not be applicable to other adolescent with non-leukemia cancers. There are many different types of cohorts of cancer survivors and certain needs and challenges may also differ by age group. Patient centered communication and how it is measured may differ based on such cohorts and their needs; therefore, the results of the study should be expressed within the adolescent cohort. Additionally, this study was cross sectional and causality may not be inferred. Lastly, the survey had a small sample size and a low response rate, thus it may not represent non-responders.

Conversely, a strength of this study is it contributes to the minimal, but growing evidence of research to further understand PCC in adolescents. Additionally, this is a novel study that assessed receipt of a cancer treatment summary and PCC in adolescent survivors of acute lymphoblastic leukemia and the findings in this study are consistent with other similar studies in adult survivors of cancer.

## CONCLUSION

In our study of adolescent survivors of acute lymphoblastic leukemia, receipt of a cancer treatment summary was associated with positive PCC. These findings are novel for the survivors in the adolescent age group and are also consistent with findings in similar studies of adult survivors of various cancers. Further research, both quantitative and qualitative, should be conducted to understand how treatment summaries are related to PCC. Additionally, more studies should identify how the patient-parent-physician relationship (triad) impacts quality of care, how the triad influences AYAs assuming responsibility of their healthcare and ultimately, how well young adults exert autonomy for their healthcare and manage it. If possible, more research is also needed to identify other support to the AYAs, which may be provided through social workers or a navigator familiar with the healthcare system. Conducting research in these areas will elucidate findings and promote healthcare management skills to AYAs. Ultimately, such skills may be able to empower AYAs with managing their health and prevent or mitigate late health effects associated from their previous cancer and cancer treatment.

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