

Rural Childhood Cancer in Arizona: A Needs Assessment

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Abstract

Childhood cancer affects nearly eleven-thousand children under the age of fifteen years each year, which launches families into a treatment trajectory of unforeseen complexities in several domains. As pediatric oncology healthcare providers tailor family-centered care for these highly fragile children, it is vital to understand the family's lifestyle and available community resources. Children residing in remote areas may experience more burdensome needs as they progress in the cancer treatment trajectory, which healthcare providers may not be aware of unless the information is specifically solicited or incidentally discovered. Use of an evidence-based needs assessment for families who reside in remote zip codes will aid in identification of unique needs and assist the multi-disciplinary care team to specifically tailor interventions to the family. Forty semi-structured interviews were conducted with parents of childhood cancer survivors using an expert-validated needs assessment tool. The purpose of this Doctor of Nursing Practice (DNP) project is to develop a needs assessment for children with cancer in order to identify which needs are amplified in a remote community in order to match and create resources to meet those needs. *Keywords: Pediatric oncology, needs assessment, rural residence, health disparities*

Rural Childhood Cancer in Arizona: A Needs Assessment

Children and families affected by a childhood cancer diagnosis will face a myriad of needs that may be largely unforeseen to the family. These include socioeconomic, psychosocial, educational, and psychological needs. Children residing in rural or remote areas may experience these needs uniquely as their cancer diagnosis creates demand for multidisciplinary sub-specialty care that is not widely available in rural or remote areas. Knowledge, awareness, and definition of these needs aids in developing interventions and creates opportunity for interdisciplinary provider to support children and families in their childhood cancer journey.

Problem Statement

Childhood cancer is defined as the presence of either solid tumor or liquid neoplasm in a patient under eighteen years of age (American Cancer Society, 2021). Cancer under the age of eighteen years is a relatively rare but a serious incidence, comprising approximately 1% of all cancers diagnosed (American Cancer Society, 2021). A projected 10,500 children under the age of 15 years will receive a cancer diagnosis nationwide in the year 2021 alone and of those diagnosed, nearly 1200 children will die from their disease (American Cancer Society, 2021). The most commonly diagnosed childhood cancer is leukemia (28%), followed by brain cancers (26%). Specifically in Arizona, over 300 children are diagnosed with cancer per year (Arizona Cancer Registry, 2019). While predicted five-year survival is respective to the type of cancer diagnosed, the American Cancer Society (2021) data on five-year survival from a childhood cancer diagnosis is approximately 84%.

Childhood cancer affects patients of diverse socioeconomic and ethnic groups, subsequently creating a variety of unforeseen needs which correlate with the patient's culture, geographic location, socioeconomic status, and family unit arrangement (Delvar, Feng, & Johnson, 2019). Children with cancer residing in rural and remote areas are widely understudied, as the population is small due to rarity of disease. Interestingly, Gila County in Arizona has the highest rate of childhood cancer diagnoses

per capita each year, and is designated as rural county according to the Health Resources and Services Administration (HRSA). This data further demonstrates the vital need to understand how families residing in rural and remote areas can best be supported during their cancer treatment trajectory. Other counties designated as “rural” in Arizona, according to the HRSA, include Apache County, Graham County, La Paz County, Navajo County, and Santa Cruz County.

Purpose and Rationale

Robust knowledge about children with cancer living in rural areas can positively affect the quality of healthcare provided on both micro and macro scales. The gap of knowledge pertaining to the care of rural childhood cancer patients is known in a specific tertiary care facility serving these children in Arizona, however this gap is present at the state level as well. The Arizona Department of Health Services (ADHS), Cancer Control Plan is a document that is edited and updated every four years and published for healthcare professionals and the public in order to better understand cancer in Arizona. Historically, this document has neither reported nor discussed any childhood cancer related data or topics. An addendum to the 2014-2018 Arizona Department of Health Cancer Control Plan included the first community report on childhood cancer. Increased knowledge of the needs of children facing a cancer diagnosis while residing in a rural area would aid in a robust and accurate understanding of the current state of childhood cancer in Arizona. This information will aid in developing targeted interventions to best support childhood cancer patients and their families through treatment. The data collected in this project can aid the ADHS Childhood Cancer Coalition workgroup in identifying ways to better serve this patient population in addition to creating further awareness of childhood cancer and acting as a voice for a patient population who is too young to speak for themselves.

The purpose of this DNP project is to use a systematic and exhaustive literature review to create and implement an evidence-based needs assessment which will accurately identify the multi-faceted and unique needs of pediatric oncology patients residing in a rural or remote setting.

Background & Significance

The body of evidence surrounding needs specifically associated with childhood cancer is limited; and even more limited when the search is narrowed to specifically rurally-residing children. Through synthesis of evidence, the impact of unforeseen needs affecting childhood cancer patients are well-identified. These include psychosocial functioning, lack of financial resources, psychological impacts, and increased parental/sibling general needs. The general needs of pediatric oncology patients are relatively easily identified in the literature as is the incidence of extended burden on rurally-residing families. Identification of specific comprehensive healthcare needs unique to pediatric oncology patients and families residing in rural areas is scarce in the literature.

Sample

Unique to children who live outside of urban areas, a new cancer diagnosis and subsequent treatment will likely require either relocation or frequent transportation to a tertiary care center, which may potentiate changes in home and family structure. Fluchel et al. (2014) found that social and financial burdens of caring for a childhood cancer are compounded by residing rurally, specifically among children who lived two hours or further from a pediatric oncology specialty care facility. A study performed by Walling (2019) also identified that distance to both emergent care and specialty care was a unique burden to families, affecting socioeconomic factors and psychosocial coping factors. Daniel et al. (2013) found that patients residing in rural locations needed the most assistance with arranging for lodging accommodations surrounding tertiary care facilities. Of note, children residing in rural areas are more likely to live in low-income homes and there is high-quality evidence indicating that these children often experience worse health outcomes than urban-residing peers (Peltz et al., 2018).

Intervention

Due to the relatively small incidence of childhood cancer and, specifically, rurally-residing children, current evidence is widely outdated and very limited in quantity. While specific surveys found

in the literature are varied, the general consensus of collected current information pertains to parental presence, employment status, and income level (Daniel et al., 2013; Fluchel et al., 2014; Hall & Gardner, 2019; Karlson et al., 2013; Ramsey et al., 2019, Roser et al., 2019). Additionally, familial support structures, identifying who else is residing with the child, and potential barriers the family foresees are also widely studied. A study by Kerr and colleagues (2007) identified that needs could be well-defined by a multi-question paper survey supplemented by personal interviews with families. Another study by Wakefield et al. (2013) found success in assessing rural needs pertaining to accommodation specifically via telephone. A study by Qi et al. (2017) used a questionnaire known as the Cancer Patient Needs Questionnaire which was completed by parents of pediatric oncology patients. A study by Karlson et al. (2013) was able to accurately identify needs of pediatric oncology patients by utilizing the Psychosocial Assessment Tool 2.0 during routine clinic visits.

Current Practice

Evidence-based standards for psychosocial care during the pediatric oncology treatment process are well-studied, but are not specific or explicitly inclusive of children living geographically removed from a tertiary care facility. A study by Kazak et al. (2015) indicated that psychosocial screening of pediatric oncology patients and families is commonly not standardized or considered to be up to expectations with evidence-based psychosocial care. Scialla and colleagues (2017), used a healthcare provider survey to assess perceived level of psychosocial care success. The results indicated that while provider perception indicated that psychosocial care in the facility met standards of care, there were gaps in care standards for psychosocial and risk assessment of pediatric oncology patients (Scialla et al., 2017).

Outcome

The body of evidence supports identification and definition of pediatric oncology-patient needs through use of a standardized needs-assessment tool via questionnaire, interview, or phone (Kerry,

2007; Qingying et al., 2017; Wakefield, 2013). Knowledge of needs aids in more family-centered care as education and resource allocation is tailored to what is necessary to support the family as a unit (Daniel et al., 2013; Fluchel et al., 2014; Hall & Gardner, 2019; Karlson et al., 2013; Ramsey et al., 2019).

Internal Evidence

In a large urban, metropolitan city in the Southwestern United States, a free-standing pediatric academic medical center serves children and families facing an oncologic diagnosis from the entire southwestern region of the United States. This includes children residing locally and in surrounding urban areas, children residing in rural regions of the state, and children residing on neighboring Native reservations.

A multidisciplinary subspecialty team routinely addresses needs the patient's cancer journey may elicit during their inpatient hospital stays and outpatient clinic appointments, including physical daily needs, mental health needs, health literacy-needs, educational needs, and coordination of follow-up throughout the cancer treatment process. The child and family's needs are typically assessed by a social worker using a standardized assessment at the time of diagnosis, and later the child and family are followed by a social worker assigned by diagnosis throughout the child's oncology journey. The existing tool screens families for many risk factors such as living situation, method of transportation, insurance status, school support, family mental health needs, and existing support systems. This psychosocial screening tool is not designed to capture needs specific to families traveling to Phoenix for treatment from a remote or rural location.

Use of standardized social work assessments may or may not capture needs unique to families residing outside of the urban area, further augmenting the need for this project. Currently, social workers, nurses, and physicians who educate patients prior to hospital discharge must synthesize information collected during the family's care to ascertain readiness and resource availability in the home setting as a trajectory for long-term care success.

PICOT Question

The specific needs of rurally-residing pediatric oncology patients in Arizona are widely unknown. This gap in our knowledge has led to the PICOT question: Among rurally-residing pediatric oncology patients, what intervention could be used to accurately identify needs that municipally-residing children may not experience?

Search Strategy

In order to answer the aforementioned PICOT question, an exhaustive literature search was performed, including databases and thorough searches of pertinent scholarly journals. Four databases were searched: PsycInfo, Medline, and PubMed, and CINAHL. These specific databases were chosen for their pertinence to the topic and availability of high-level studies. The databases were searched by each keyword in the PICOT question, including *pediatric oncology*, *childhood cancer*, *pediatric cancer*, *rural*, *rural-residence*, *needs-assessment*, and *psychosocial needs*.

Due to limited amount of research on the topic, other search terms included *pediatric medically fragile needs*, *complex childhood illness needs*, *rural residence and chronic pediatric illness*. MeSH terms were utilized to widen the search. Exclusion criteria included articles older than 2005, lack of peer review, articles whose interventions focused on cancer survivors, and articles not written in English. Inclusion criteria for the literature search focused on needs assessments of children affected by cancer or children residing rurally with a chronic illness requiring ongoing support and supervision by a tertiary health facility.

In PubMed, an initial search of “pediatric OR childhood” and “cancer OR oncology” and “needs assessment” resulted in 502 articles. Narrowing the search terms to “pediatric or childhood” and “cancer OR oncology” and “rural” within the last five years resulted in 209 articles. A search of “pediatric or childhood” and “cancer OR oncology” and “needs assessment” and “rural” resulted in 15 articles.

The initial search in CINAHL included the terms “pediatric oncology OR pediatric cancer OR childhood cancer OR children with cancer” and was limited to the last five years, resulting in 5550 articles. That search was narrowed by the addition of “needs assessment OR needs analysis” which resulted in 63 results, still limited to the past five years. Further adding “rural or remote OR isolated OR regional” narrowed the results down to seven articles.

The PsycInfo database search was limited to the past five years of literature and the initial search using keywords or phrases of “pediatric OR childhood” and “oncology OR cancer” and “needs” resulted in 507 articles. Using the keywords or phrases “Pediatric OR childhood” and “oncology OR cancer” in addition to “needs assessment” resulted in 109 articles. The search was narrowed with the addition of “rural” which resulted in 30 articles.

Medline database initial search using the keywords or phrases of “pediatric OR childhood” and “oncology OR cancer” and “needs assessment” resulted in 678 articles. The second search consisted of “pediatric OR childhood” and “oncology OR cancer” and “rural” and “needs” and resulted in 58 articles. Data search saturation was reached as the several of the same articles appeared across the databases.

In addition, grey literature was searched from Arizona State Department of Health and Center for Disease Control and Prevention well as assimilated epidemiological data. Ancestral literature search was performed on the ten articles selected for synthesis and several others throughout the search. The highest-level studies were selected from quantitative literature, and the most recent and relevant qualitative literature. Each article was critically appraised and placed in evaluation and synthesis tables (Appendix A, B and C).

Critical Appraisal & Synthesis of Evidence

In order to review the body of evidence, a rapid critical appraisal checklist was used to evaluate quality and level of evidence of each article utilized. The majority of studies were low level evidence and studies were a heterogenous mix of quantitative and qualitative data, with primarily qualitative data.

Study designs included mixed-method research and cross-sectional analysis, one systematic review, and one randomized-controlled trial. Qualitative designs used to examine the phenomena included ethnography, phenomenology, and grounded theory.

Measurement tools commonly utilized included in-person semi-structured interviews, open-ended interviews with parents or key informants, questionnaires completed by parents at varying appointments throughout cancer treatment and use of telephonic questionnaires. Validated and evidence-based questionnaires utilized were the Psychosocial Assessment Tool (PAT) and Cancer Patients Needs Questionnaire (CPNQ). Other interventions included a Distress Scale (DS) tool, and research study specific tools interviews with parents (Appendix B).

Several pertinent common themes were identified throughout the literature synthesis, including incidence of disproportionate burden for rural families due to travel, loss of financial stability/income potential, and challenge in ability for the parent to be physically present when the child received treatment or was hospitalized. Among families with a childhood cancer diagnosis, regardless of geographic location, highest needs were consistently seen between educational needs and emotional support needs. While this trend in research results was not localized to rurally-residing families, it could also be reasonably inferred as an increased burden due to distance traveled and lack of local support system (Appendix A & B).

The samples in each study were heterogenous, including variations in parent education, marital status, gender of parent participating, distance of residence from the tertiary care facility overseeing care, and age/gender of the pediatric oncology patient. Additionally, there is heterogeneity of assessed needs whether the data was collected retrospectively during a later phase of the cancer treatment trajectory, or initially at onset of new diagnosis.

The most commonly identified theoretical framework used in the critically appraised research studies was the Pediatric Psychosocial Preventative Model (Kazak et al., 2016; Walling et al., 2019;

Warner et al., 2015) with additional articles applying the Shared Care Model (Daniel et al., 2013), Chronic Care Model (Martinez-Donate et al., 2013; Thewes et al., 2016;), Orem's Theory of Self Care (Fluchel et al., 2014), Supportive Care Framework for Cancer Care (Kerr et al., 2007; Ugalde et al., 2019) and the Health Belief Model (Graves et al., 2015). Qualitative studies grouped findings by common and recurring themes within several domains of need – including psychosocial, emotional/coping, health literacy/education needs, and financial needs.

Analysis of Evidence

Childhood cancer is a rare diagnosis, and children residing rurally with a childhood cancer diagnosis are even rarer. This presents a challenge to healthcare providers of all disciplines as these children and their families may commute for treatment, may choose to reside locally for treatment, and do experience compounded complexities related to rural residence. While there is limited research available pertaining to these children and the needs they face as they fight cancer, they often present to tertiary clinic care centers or regional care centers for unforeseen medical needs. This incidence demands that the healthcare team identify their needs and consequently develop interventions and processes to alleviate burdens throughout the cancer treatment process, thus reducing rural health disparities for this vulnerable population.

Use of methods based on the best evidence for the development of a rural needs assessment will require cultural humility, a large time investment, physical and emotional presence, and willingness to empathize, hear and understand the family's needs. Use of qualitative and quantitative research strategies such as semi-structured interviews, self-administered questionnaires, and telephonic data collection are effective in capturing, defining, and categorizing needs of highest incidence in families who face a childhood cancer diagnosis in a distant location.

Theoretical Framework

The Pediatric Psychosocial Preventative Health Model (PPPHM) was originally designed by Kazak in 2006 for the purpose of general pediatric psychosocial needs assessments in social work. It was then adapted by Kazak and Noll (2015) to focus specifically on the needs of pediatric oncology patients (Appendix D). This framework was selected to guide this DNP project because it identifies that universal psychosocial screening is indicated, but as risk factors are identified (such as rural residence, low literacy, or socioeconomic struggles), the care allocated and care delivery is honed-in and targeted specifically to the needs of the family. The PPPHM is a triangular framework which allows the family to move fluidly between groups as their risk factors change throughout the treatment trajectory (Kazak & Noll, 2015). This framework has successfully been utilized in several pediatric oncology-specific studies, allowing familial needs to be identified as they evolve and change due to compounding effects of cancer treatment. Utilizing this framework for rurally-residing children allows for equitable identification of risk factors for the purpose of allocating resources maximally for the best interest of the patient. The results from this needs assessment will also help the organization and the state of Arizona develop interventions to meet needs that may be presently unknown or unaddressed.

Implementation Framework

Within the guiding theoretical framework of the PPPHM, Lean Six Sigma can be utilized to implement an evidence-based quality improvement project. Lean Six Sigma (Carreira, 2006) framework operates to define needs through the data collection process, measure the incidence and prevalence of identified needs, analyze the needs assessment process and subsequently make improvements. The ultimate goal is to improve efficacy and cultural humility in serving children in rural areas throughout the trajectory of their cancer treatment (Appendix E). Lean Six Sigma allows for each step to fluidly flow into the next in a unidirectional fashion, allowing the process to be repeated in order to best quantify and define the gap of knowledge pertaining to pediatric oncology patients residing rurally. The steps are simple in concept and are directly transferrable to this project specifically. Lean Six Sigma could be

utilized for staff education prior to launching the DNP project in order to unify team members, engage stakeholders, and promote personal investment in the success of developing this needs assessment. Should this initial process of developing a needs assessment be unsuccessful, Lean Six Sigma guides the user in a repeat process allowing room for improvement and re-implementation with evaluation and sustainability built into the model.

Implications for Practice Change

Synthesis of evidence supports implementation of a rural-specific needs assessment for children diagnosed with cancer, preferably within the first six months of diagnosis. The results of this needs assessment will serve as a model of a method to assess ongoing needs in this population. The results of the needs assessment, ultimately, may enhance an intervention to match needs to existing resources, or highlight areas where interventions require honing to best serve this fragile sample. By analyzing the results of semi-structured interviews and self-administered needs assessment questionnaires, most common needs can be defined and categorized to tailor interventions from all members of the multidisciplinary hematology/oncology treatment team. The results of the needs assessment will be examined for the highest prevalence of needs in specific domains (such as psychosocial, literacy, travel/accommodation), and parental perception of needs assessment adequacy.

Stakeholders for this intervention would include hematology/oncology physicians, bedside nurses, outpatient clinic nurses, nurse practitioners, social workers, and therapists of varying disciplines. Engaging stakeholders may require initial education and legwork to combat preexisting perceptions that needs are already assessed by social workers on a standardized basis, which would hypothetically require no further intervention. Stakeholder intervention is crucial to the success of this project as the manpower required to collect data is crucial in order to define needs, develop interventions and eventually allocate resources.

Methods

An evidence-based and expert-validated psychosocial screening tool was designed specifically to capture the unique needs and increased burden experienced by families traveling to Phoenix, Arizona for treatment (see Appendix G). Experts who validated the tool included a hematology/oncology social worker, psychologist, physician, two pediatric nurse practitioners, and an outpatient clinic nurse coordinator. The questionnaire was evaluated especially for cultural humility and sensitive handling of delicate topics contained within the survey. The questionnaire was designed to compare self-reported needs from both locally-residing families and families residing in rural or remote areas. Rural areas were counties designated by the United States Health Resources and Services Administration (HRSA) and include the following counties: Apache, Greenlee, Graham, La Paz, Navajo, and Santa Cruz. In order to capture families who still traveled long distances for treatment but did not reside in a formal rural-designated county, families residing greater than 50 miles from the designated tertiary care facility were considered “remote” and included in the sample.

The sample was derived from an existing database of childhood cancer survivors whose guardians consented to future research when they were added to the ongoing database. The database has an existing Institutional Review Board (IRB) approved protocol at the project site, to which a modification was approved by the IRB for this project. The Arizona State University IRB deferred to the project site’s IRB oversight (see Appendix G).

In order to capture accurate recall for this retroactive cross-sectional study, the sample of childhood cancer survivors studied completed active cancer treatment within the last seven years. Phone calls (n = 105) were made to parents of childhood cancer survivors. Forty interviews were completed for a response rate of 38%. Voicemails were left when able, and two follow-up phone calls were made if a voicemail was left. Completed phone interviews lasted between seven minutes and thirty-three minutes. Due to the small sample size, both patients in rural-designated counties and patients who live greater than 100 miles from the tertiary care facility overseeing their cancer treatment

were included in the sample. Half of the 40 patients interviewed resided in Maricopa County, and half of the patients resided in either a rural-designated county or greater than 100 miles from the project site. Interestingly, approximately twice the number of telephone calls were made to metropolitan families in order to obtain at least twenty parents in the urban group. This included twice as many voicemails left for metropolitan families. Families residing in rural areas were more likely to answer on the first call and be willing to answer questions without scheduling an alternate time. Both groups of parents expressed eagerness to share their journey in hopes of helping other families gain support and resources.

Data collected was analyzed and aggregated using descriptive statistics, and Chi-square tests of independence to identify relationships between variables. Data analysis was specifically done to identify and define needs reported by parents of children residing in an urban area versus parents of children residing in a rural or remote area. There was no funding received for this project.

Results

Demographics

Captured data represents ten counties in the state of Arizona, including the rural counties of Navajo (10%), Apache (5%), Gila (2.5%), and remote residences in Coconino County (5%), Mohave County (5%), Pima County (7.5%), Yuma County (10%), and Yavapai County (5%) (See Appendix H, Table 1). Average travel distance to the tertiary care facility overseeing cancer treatment was 105 miles for the entire patient sample. Average patient age at diagnosis was nine years of age, and most common diagnosis was leukemia. Average patient age at the time of the survey was fourteen years of age. Most significant domains reported from the survey data analysis were financial burden, need for school support, relocation needs, travel/transport needs, regional healthcare use, changes of job for caregivers, and mental health needs. Fifty percent of patients in the sample were residing in a rural/remote area at diagnosis (N = 20), and the other fifty percent in metropolitan Phoenix (N = 20). Results from the needs assessment survey are detailed in Appendix H, Table H1-H24.

Survey Results

Quantitative Data Collection

Regional Healthcare Use

Regional healthcare use was statistically significant between groups ($p < .001$) based on residence location. Eighty five percent of families in remote/rural areas took their child to a local or regional medical facility during treatment while only 5% of metropolitan families took their child to a local or regional medical facility. Families in rural/remote areas lived an average of 20 miles from the closest healthcare facility (range 5 miles to 153 miles), whereas metropolitan families lived an average of five miles from a healthcare facility (range < 5 miles to 10 miles). Rural families who did utilize local and regional medical facilities were asked to rate their level of comfort in these facilities caring for their child on a Likert scale of zero “not at all comfortable” to five “extremely comfortable”. The mean score on this item was a two, “uncomfortable” among families whose children did present to a regional medical facility. Specifically, families reported that the regional healthcare facilities were not comfortable doing anything besides transporting ($n=2$), uncomfortable accessing a port ($n=8$), or not aware of neutropenic precautions for PPE/hand hygiene ($n=3$). By contrast, reported mean level of comfort with the urban families’ tertiary care facility managing the cancer treatment was a 4.8, “very comfortable”.

Emergent Transport and Medical Transport Use

Families in remote or rural areas were statistically more likely to use emergent transport ($p < .001$) via air or ambulance during treatment. Sixty percent of families residing in a rural or remote area did utilize emergent transport at least once during treatment. The average number of unplanned, emergent transports was two to three times during active treatment. Families in rural or remote areas were also more likely to use non-emergent medical transport, such as medical taxis or medical transport vans ($p < .001$) Families traveling for care from rural/remote locations reported concerns for the safety of their immunocompromised child during medical transport trips (10%), and long travel times due to

multiple stops picking up other patients (10%). Thirty seven percent of neighborhoods across the entire sample do not have public transportation.

Relocation

Relocation was not statistically significant in relationship to residence location between the urban and remote/rural families ($p=0.73$). Thirteen families relocated during cancer treatment (32.5%) across the entire sample, however rural/remote and metropolitan families reported different reasons for relocating. Families in rural/remote areas relocated to be closer to the hospital overseeing care or closer to family (35%), while families in metropolitan areas moved to be closer to the tertiary hospital (15%), to decrease financial burden (10%), and for environmental safety concerns (5%). Relocating permanently versus temporarily was also statistically significant by residence ($p=0.002$). Among families who did move or relocate, families in rural areas were much more likely to move temporarily (35%) as opposed to permanently (0%), while families in metropolitan Phoenix moved permanently (20%) as opposed to temporarily (5%).

Caregiver Employment Changes

Change or loss of employment for the patient's primary caregiver in both the metropolitan and rural/remote groups was extremely common in the sample with 70% of primary caregivers reporting loss or change of employment due to caregiving demands during treatment. Employment change or loss occurrence was not statistically significant based on location of residence ($p=1.000$). Change or loss of employment varied from resigning altogether (67%), significantly reducing hours (25%), or changing roles (8%). There is a statistically significant relationship between loss of caregiver employment and reported financial burden ($p=.007$) for families in rural/remote areas as opposed to metropolitan families. In metropolitan families, the relationship between loss of caregiver employment and reported financial burden was not statistically significant ($p=.767$).

Financial Burden

In order to assess financial burden, primary caregivers were asked to rate the amount of impact the cancer diagnosis had on their financial stability, with a score of zero being “not at all” and a score of five being “very much”. The average reported score was four, and perceived needs in the financial domain did not differ between rural/remote families and metropolitan families ($M = 4.0$; $p = 1.000$). Families from both parent groups reported maxing out credit cards (7%) and taking out loans (5%) during active treatment. Additionally, there is a statistically significant relationship between distance traveled to tertiary care facility and reported financial burden ($p < .001$).

Academic Support

Lack of school support was statistically significant in relationship to geography of residence ($p=0.038$), with 30% of parents reporting a lack of adequate school support across the entire sample. Across the entire patient sample, 47.5% of children experienced an educational delay due to their diagnosis (i.e., repeated a grade, started school late, or graduated later than anticipated). Children across the entire sample (62.5%) have or had an Individualized Education Plan (IEP) or 504 plan for additional academic support. Parents in rural/remote areas reported that schools did not have adequate resources to assist their child during active treatment (44%), were not understanding of the demands that come with a childhood cancer diagnosis (22%), or were not able to provide extra accommodations due to chemotherapy schedules, surgical procedures, and trips to Phoenix for care (22%).

Mental Health Concerns

Mental health concerns were reported among 50% of caregivers across the entire sample. Of the 20 who reported mental health concerns, 55% reported new onset mental health concerns in themselves as a result of their child’s diagnosis. Parent reported mental health concerns were not statistically related to location of residence ($p = .527$). As for the child, 50% of children have reported mental health conditions. Fifteen of those mental health conditions, according to the parents, were

related to the childhood cancer diagnosis. The onset of the mental health condition occurred during or immediately after treatment. Of the caregivers interviewed, 37.5% of children in the sample currently see a mental health professional. There is no statistically significant relationship between use of mental health services and location of residence ($p = .327$) however parents in rural or remote areas did report difficulty finding mental health care in their areas (26%).

The burden and stress of the diagnosis also placed strain on intimate partner relationships between caregivers of pediatric oncology patients in both parent groups. At time of diagnosis, 27% of caregivers were single and did not have a partner. Twenty two percent of parents across the entire sample also had a change of spouse/partner during or immediately after the cancer diagnosis.

Discharge Education & Provider Accessibility

Seventy percent of patients across the entire sample utilized an on-call line to reach a provider when they were outside of the hospital setting, and caregivers reported they were able to talk with a provider 100% of the time without difficulty. Ninety percent of patients reported receiving discharge education in their primary language, and the 10% of patients who did not receive discharge education in their primary language spoke French, Thai, Romanian, and Spanish. Caregivers were asked to rate their ease of understanding on a Likert scale with zero being “not at all understandable” and five being “extremely understandable”, and the mean score was 4.4 with no statistically significant relationship to geography of residence. Caregivers were also asked on the same Likert scale how comfortable they were taking their child home at diagnosis after discharge education, with a mean score of 3.7 and no relationship to geography of residence. The mean level of comfort in asking questions of the hematology/oncology team during inpatient stays was 4.97 across the entire patient sample where 5 indicated “extreme comfort”.

Qualitative Results

Miscellaneous needs reported by families traveling for parents treatment included better care coordination to decrease trips between Phoenix and their home, assistance with grocery shopping/meal planning, childcare support for siblings who cannot be at the bedside, financial resources for housing and travel, and mental health resources for parents and counseling to improve caregiver relationships. During interviews, parents expressed difficulties and needs similar to the quantitative findings:

Care Coordination Needs

“Help with coordinating appointments between different doctors would have saved us several trips” –

Mother of 6-year-old leukemia patient, rural

Financial Burden:

“Cost of treatment caused us to lose our house” –Father of 5-month-old ATRT patient

“We are still paying off credit card debt from maxing out our credit cards, six years later” –Father of 16-month-old Leukemia patient, metropolitan

“We exhausted our savings, lost our 401Ks, and burned through a vehicle commuting to PCH” –Mother of 13-year-old brain tumor patient, metropolitan

“Relocation funds were needed, we used \$80,000 in stock market assets in six months” –Father of 15-month-old brain tumor patient, metropolitan

“We maxed out our credit cards and wish we would have shut down our business” –Mother of 4-year-old leukemia patient, rural

“We struggled a lot with resources being in Phoenix and we are in Yuma” –Mother of 12-year-old leukemia patient, remote

Education Needs

“The school didn’t even pay attention to the 504, there are no resources for children with cancer” –

Mother of 12 year old leukemia patient, remote

“Teachers just didn’t understand, they required excess proof of doctors notes and didn’t believe us when she missed school” –Father of 13 year old Leukemia patient, remote

“_____ was bullied for having cancer at school, there was no cancer awareness for other kids at school” –
Mother of 12 year old Leukemia patient, remote

Regional Hospital Use

“Regional hospital has no experience treating kids, they are not comfortable with ports” –Mother of 12 year old leukemia patient, remote

“The local facility would not even touch his port” –Mother of 4-year-old Leukemia patient, rural

“My kid was neutropenic, and they didn’t know handwashing” –Mother of 12 year old leukemia patient, remote

“The regional facility was very uncomfortable, too scared to touch her, did not know how to access port and tried for 3 hours, we just decided to only use PCH instead.” –Mother of 3-year-old patient, remote

Travel and Transport Use

“Medical transport was never concerned if my three-year-old had to stop and pee, they were always running late, and had multiple other patients on board” –Mother of 3-year-old Lymphoma patient, remote

“We took eight trips to Phoenix in two months over three hundred miles each way” –Mother of 10 year old Leukemia patient, rural

“His constipation was bad, he slept in the outhouse after we requested a septic tank and it wasn’t able to be built...we ended up building it ourselves” –Mother of 23 year old Leukemia patient, rural

Housing Accommodations

“We were too far away from PCH to use a hotel or qualify for Ronald McDonald house, but the drive was still nearly an hour which was many miles and tanks of gas” –Father of 14 year old leukemia patient, remote

“We needed closer housing outside of Ronald McDonald due to the size of our family being too large for the space” – Mother of 6 year old Leukemia patient, rural

Mental Health

“We would have loved if someone checked in on us as parents for processing trauma of diagnosis” – Mother of Leukemia patient, remote

“We wait a month for any specialty services, psych especially” –Mother of 12 year old leukemia patient, remote.

Conclusions & Implications

Children and families residing in rural areas facing an oncologic diagnosis experience compounded burdens. There is a high cost to the family economically, educationally and emotionally. The results of this evidenced-based needs assessment aids the multidisciplinary team in targeting interventions to the unique needs families may face. By using a needs assessment questionnaire at time of diagnosis, time of first hospital admission, or time of social-work evaluation, interventions could be developed, processes enhanced and the allocation of resources could be better guided. If rural-specific needs are known and evaluated as families complete these assessments, the multidisciplinary team will be better able to target education and care-plan designs to be specifically centered to each family for children in the inpatient setting and home setting alike. The acquisition of the data for the needs assessment for families residing in rural areas can be implemented in a cost-effective manner utilizing existing resources within the tertiary care center, such as social workers, medical assistants, or registered nurses.

Data could be provided to charitable organizations and hospital administration and government organizations who oversee funding allocation and budgeting. Knowledge of the needs families are experiencing can also impact policy changes which would affect accessibility and program eligibility for families in need.

Discussion

Identifying and defining needs for these families is only the initial step in the comprehensive care continuum for children with cancer. The results indicate that there is need to identify existing resources that could be matched to the needs families are experiencing. After existing resources are exhausted, this data could be utilized to support the need for additional resource creation by private sector and government organizations alike.

Data collection for this project was limited greatly by the COVID-19 pandemic, which prevented all in-person research from occurring. Additionally, data collection was limited by a small database to draw potential participants. It was difficult to reach families by phone and the obtained data was biased due to caregiver difficulty in recalling events surrounding the initial and ongoing treatments of their child due to length of time since cancer diagnosis. For this initial data collection, only English speaking caregivers were surveyed. To overcome language barriers, the needs assessment survey would need to be translated into Spanish and a Spanish-speaking team member would need to administer the survey. Strengths for this DNP project included strong site support, stakeholder investment, creation of an expert-validated and transferrable needs assessment survey, and eagerness by survey participants to contribute data which may help other families.

Findings from this project are complimentary to other findings in the literature. A literature review Roser et al. (2019) found a high rate of job loss among primary caregivers, and also found an inverse relationship between geographic residence and reported financial burden. Peikert and colleagues (2020) found that approximately 25% of parents had interruptions in intimate partner relationships due to a childhood cancer diagnosis, and that 70% of parents reported difficulties surrounding work and finances during childhood cancer treatment. Ugalde et al. (2019) found a high need for an affordable and accessible housing accommodation plan for families of cancer patients when living geographically isolated from the hospital.

Recommendations for future research would be to utilize this needs assessment survey at the beginning of treatment in order to meet the child's and family's needs in an anticipatory nature, as opposed to retroactively. There is also need to revise the needs assessment survey for efficiency, ease of use, and to increase reliability. The survey needs to be adapted to a Spanish version and would require a bilingual clinician or use of clinical interpreter to broaden the use of the survey to include the Spanish-speaking sample in Arizona. Additionally, the survey could be utilized in other pediatric patient populations who experience chronic and complex illness in order to identify if similar identified needs are present beyond pediatric oncology patients.

This needs assessment has provided a more robust understanding of day-to-day life for children facing a cancer diagnosis in the rural or remote setting and provided valuable data that can be utilized by the tertiary facility whose patients were included in this survey. Additionally, this data can be shared with the Arizona Cancer Coalition's Childhood Cancer workgroup in order to begin to represent childhood cancer at the state level.

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Appendix A

Table 1

Qualitative Evaluation Table

Citation	Theory/ Conceptual Framework	Design, Method, & Sampling	Sample & Setting	Major Themes Studied & Definitions	Measurement & Instruments	Data Analysis	Findings & Themes	Level of Evidence Application to practice Generalization Feasibility Limitations
Daniel et al.,(2013) Accommodation in pediatric oncology: parental experiences, preferences and unmet needs	Shared Care Model	Method: Cross-sectional study design: Semi-structured interviews with parents of POPs treated at TCC within the past five years. Purpose -Explore accommodations utilized by RR	N=42 parents of POPs. 23 mothers, 19 fathers -- parents from 25 families. Demographics: Marital status - 87% mothers married, 94% fathers married Education level- , 50% with college education, Employment status – 73% employed full time.	Major Themes: Accommodations used by RR POPs and their families. -Assess FB of accommodation, DT, and mode of transportation -Parents accommodation needs and assessment of bedside/comunal facilities.	Instrumentation: SSI occurred and were coded line by line, and categorized based on RR as categorized by DT. Areas Assessed: MOT, Travel time in hours, location of accommodations for other family members,	Statistical Analysis Themes were numerically assessed to reduce likelihood of researcher bias.	Major Findings -FB associated w DT and accommodations were major concern. -Most families did not receive aid money for accommodations. -Parents felt that better decisions were made by medical staff when families were in closer proximity.	LOE: VI ATP: This study directly answers the PICOT and identifies that SSI are an effective needs assessment strategy. Feasible but requires manpower. Generalization/Feasibility: Able to be reproduced without difficulty. Requires man power and ability to contact/see families during clinic encounters to carry out interview.

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Bias: None Declared	POPs/families . -Assess financial burden of travel, travel time, MOT. -Understand parents preferences for staying at bedside/in alternate accommodation.	MOT: 95% of families traveled by car.	cost of travel between home/TCC.	-There is a need for greater access to accommodation for rural families. -Data suggests that close proximity for family & POP recovery can decrease LOS. -Symptoms related to CTT exacerbated by travel. -RR causes separation from family members, loss of home environment, loss of existing support network, loss of privacy.	Limitations: -Minimal statistical analysis -Single study, single sample			
Fluchel, et al. (2014) Geography and the burden of care in pediatric cancers	Inferred: Orem's Theory of Self Care	Method: Cross-sectional SAS to identify Phenomenology Purpose: Identify if RR and DT	N=356 caregivers of POPs who were diagnosed within the past three months. Demographics 87% English speaking, 13%	Major Themes: Identify Impact on family and FB based on >1 hr DT and >2 hours DT from TCC.	Instrumentation: 48-question SAS in Eng/Span. Stratified by Dx to prevent confounding: ALL, AML,	Multivariable regression models: Comparison of geographic groups and POP demographics – two-	Approximately 1/3 of families relocated due to cancer dx, 1/3 of caregivers quit or changed jobs P <0.01, children residing rurally	LOE: III ATP: This is a rural-focused study that directly compares increased burden due to DT, cost of travel, loss of income potential. Fits PICOT seamlessly.

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Country: USA	greatly impacts FB during CCT.	Spanish-speaking caregivers.	Measures: Relocation, Employment, Schooling Finances	brain tumors, solid tumors.	sample t test. Wilcoxon-Mann-Whitney test for categorical variables, chi-square for non-ordered categorical variables.	reported greater FB as well as increase in missed school days P = 0.01. Use of emergency or air transport to TCC was nearly 25% in POPs living rurally. -Pts traveling 2+ hours experienced significant academic delays (28%) – including being held back a year or feeling unable to keep up with peers.	Generalization/Feasibility: Must identify sample of children in RR and non-RR for sake of comparison, but targeted SAS is reasonable to complete needs assessment and identify unique needs to RR POPs. Limitations: Only one sample from one clinic Only 18.6% of participants in this study lived rurally/remotely Study not stratified by phase of treatment which could impact perceived needs Missing representation from many minority groups.
Funding: NIH Grant		Mean pt age: 8.8 years					
Bias: None identified		1+hr DT: 39.3% of pts 2+hr DT: 25.7% of pts 20% Hispanic, 82% Caucasian Income level: Median of \$20,000-\$39,000 annually. Education: 42% reported college education Insurance: Majority Medicaid-insured MOT: 98% by car.					

Graves et al., Community-Based Participatory Research: Toward Eliminating	Inferred: Health Belief Model	Method: MM CBPR randomized phone calls, in person-interviews,	Mixed – included 774 randomized community members via phone (random-digit-dialing	Major themes: Perception of health status within the county, perception of biggest	Instrumentation OES - questions w 9 key informants in community.	No statistical analysis, data was independentl y evaluated due to mixed-method and	Valuable findings from multiple experts, including HCPs, community members.	LOE: IV ATP: -Rural Focused -Identifies difficulty w follow through
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Rural Health Disparities (2015)	survey of HCPs	within the rural area)	healthcare need in county, perception of biggest barrier to health status.	774 randomized telephone calls, disproportionately to white females	small sample size.	Highlights difficulty with attrition rates of rurally-residing individuals who have low literacy.	of low-income/low education populations -Multimethod, multi-informant approach.	
Country: USA	Purpose: Identify perceptions and unique needs of pts who are RR both POP perspective and HCP perspective.	9 key informant interviews. Written HCP surveys – 45 surveys returned of 150 distributed	Demographics:	Written survey to HCPs, only 30% completion.			Limitations: -Not pediatric focused -Very subjective, not standardized. -No statistical analysis	
Funding: Not identified								
Bias: None								
Martinez-Donate et al. (2013)	Chronic Care Model	Method: Mixed-Method – interviews, health literacy assessments, phone surveys with cancer patients.	N: 53 patients treated in 5 oncology clinics. N=41 HCPs Focus group with HCPs: 7 oncologists, 32 oncology nurses, 5 other RNs, 2 Medical assistant. Average years experience: 10	Major Themes: -Community resources -Self-management support -Delivery system design -Decision support	Instrumentation Interviews w patients and Short Test of Functional Health Literacy in Adults Semi-structured interviews with HCPs.	Statistical Analysis: Descriptive statistics computer for demographic data and results were integrated with qualitative analyses.	Findings: Patient findings: Half of full-time employed patients quit their jobs due to diagnosis. 57% indicated that HCPs used words they did not understand. 54% of patients signed a consent form they did not read or understand.	LOE: VI ATP: Matches PICOT besides being pediatric, but specifically analyzes gaps due to DT/RR. Generalizability/Feasibility: Labor intensive due to mixed-method and multiple population data collection. Limitations:

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<p>Enhancement Study (ROLES)</p> <p>Country: USA Funding: NIH & University of Wisconsin School of Medicine Bias: Declared as none</p>	<p>Patients: 63% female, 96% non-Hispanic, 71% married. 49% high school education, Median income level \$30,000-50,000. 45% full time employed prior to cancer dx, 20% at time of survey.</p> <p>HCPs: 90% female.</p>	<p>Staff findings: Patients would rather not be “needy” so hesitant to report needs. Patients are too overwhelmed to know what to ask HCPs feel that POP needs are not routinely or adequately assessed. Disjointed care coordination</p>	<p>-Rural focused but not pediatric focused</p>					
<p>Thewes et al., (2016)</p> <p>Routine Screening of Indigenous cancer patients’ unmet support needs: a qualitative study of patient and clinician attitudes</p>	<p>Inferred: Chronic Care Model</p>	<p>Method: Brief SSI with indigenous oncology patients treated at one of four sites.</p> <p>Purpose: Identify the role of screening for unique needs in indigenous oncology patients.</p>	<p>N=34 patients 18+ years Australian indigenous POP <5 years from diagnosis Able to understand English Able to give informed consent</p> <p>Demographics: Mean age: 54 years 68% female,</p>	<p>Major Themes: -Physical and psychological needs -Hospital care needs -Practical and cultural needs -Information and communication needs</p>	<p>Instrumentation Supportive Care Needs Assessment Tool for Indigenous People administered by interviews. 27-item open ended verbally administered, average length of time 23 minutes.</p>	<p>Statistical Analysis: Transcripts coded and thematic analysis performed.</p>	<p>Findings: -Widespread distrust of medical community -Pts appreciated needs assessment process as it links them to resources and allows them to be heard. -Pts reported that needs assessments done at</p>	<p>LOE: VI ATP: Directly answers PICOT question, elicits unique needs RR patients face. Generalizability/Feasibility: Time consuming and requires man power and time before/after appointments</p>

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Location:							beginning of treatment was most helpful. -High staff satisfaction due to knowledge of needs	for data collection. Limitations: -Not pediatric focused -Single study/sample -Some POP struggled to interpret questions
Funding:								
Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research								
Bias: None declared								
Ugalde et al., (2019) Supportive Care Framework for Cancer Care Rural Caregivers' Experiences of Cancer Care when accessing metropolitan qualitative study	Supportive Care Framework for Cancer Care	Method SSI with caregivers of oncology patients and social workers.	N=21 caregivers. 16 female, 5 male of cancer patients who lived 60+ miles from TCC. Also included 5 social workers.	Major Themes Rural culture and community Life adjustments and available support	Instrumentation SSI which was audio-recorded, average length 32 minutes. Caregiver areas assessed: -MOT, DT -How travel impacts care -Information and support given for trips/travel expectations	Statistical Analysis Descriptive statistics were used to code pt's based on sociodemographic data and results were analyzed and grouped by theme by author.	Major Findings: Caregivers feel geographic isolation. Caregivers reported that long DT required lots of coordination/high cost. Some assistance finding a MOT. Accommodations were an additional burden of availability and cost.	LOE: VI ATP: Understanding needs of RR patients & families is the PICOT, so while this study is not pediatric-focused the findings are transferrable. Generalizability/Feasibility: SSI can be time intensive and require
Country: Australia								
Funding: a Victorian Cancer Agency								

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<p>Early Career Seed Grant</p>	<p>Bias: Declared as none</p>	<p>spent as a caregiver was an average of 1-2 years. Social workers: 100% female, median age 45, average of 5 years of experience as social worker.</p>	<p>patients as opposed to urban residents? What is the impact of traveling? Do you feel caregivers have adequate information/knowledge of travel expectations.</p>	<p>-Early screening is key to tailor interventions to the patients need.</p>	<p>extensive manpower, however it is a valid strategy for needs assessments. Limitations: Not specifically pediatric focused. Very small sample size.</p>			
<p>Walling et al., Challenges Associated With Living Remotely From a Pediatric Cancer Center: A Qualitative Study (2019)</p>	<p>Inferred: Pediatric Psychosocial Preventative Health Model</p>	<p>Method: Interviews with caregivers of POPs over a 16 week period, once saturation of data was reached interviews were discontinued. Purpose: Assess incidence of increased burden due to RR.</p>	<p>N=16 caregivers) of POP who lived in a rural area 2+ hours from TCC overseeing CCT. 14 were married and 14 reported an income of <\$80000 per year.</p>	<p>Major Themes: -Experience at RCC hospital -Interaction between RCC and TCC. -Impact on Family -Family/Pt relationship with cancer center -General CCT management</p>	<p>Instrumentation SSI w OE questions (12 with mothers, 6 with fathers), majority in person and a small percentage by phone.</p>	<p>Patient responses and sociodemographic details were presented using descriptive statistics. Participants were not stratified, but interviews were coded by two authors separately.</p>	<p>Major Findings: -Increased FB related to DT and relocation -Loss of income potential due to increased work absenteeism -Increase in stress due to receiving emergent care by RCC hospitals with limited resources. -Increased stress secondary to TCC and RCC communicating -Perceived increase in</p>	<p>LOE: IV ATP: -Can be feasibly reproduced to accurately identify the needs of children residing in rural areas. Generalizability/Feasibility: Low cost, but requires manpower Limitations: Small, single</p>

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						Thematic analysis was performed.	suffering to the child due to aforementioned finding.	clinic sample size.
Warner et al., 2015 Financial Burden of Pediatric Cancer for Patients & Their Families Country: USA Funding: Translational Comparative Effectiveness Research Grant, Huntsman Cancer Institute, Hyundai Hope on Wheels Foundation, NIH through grant. Bias: Declared as none	Pediatric Psychosocial Preventative Health Model	Method: Single-site, cross-sectional surveying parents of POPs who were less than five years post diagnosis. Purpose: Evaluate caregiver burden in relation to socioeconomic and healthcare utilization factors.	N=254 Demographics Mean POP age: 8.9 years of age. Mean time since diagnosis: 1.6 years Race: 90.3% non-Hispanic, 9.7% Hispanic. 9.1% with just high school education, 90.9% with some college, Median household income: 40,000-59,000 annually. 16.8% RR, 83.2% urban residents. 75% private insurance	Major themes: Financial burden outcome Socioeconomic factors – Insurance status Rural residence status Parental employment issues related to CTT Healthcare use – unexpected hospitalizations	48-item SAS to evaluate burden of cancer care.	Multivariable linear regressions were utilized to determine the outcome variable.	Caregivers in RR reported higher financial burden than caregivers residing in urban areas. Loss of income potential due to unexpected hospitalizations, increased appointment, 32% of caregivers have changed/quit jobs during CTT.	LOE: VI ATP: Use of an evidence-based way to collect, analyze, and determine relationships between variables – including rural residence and financial burden in addition to unexpected hospitalizations. Generalization/Feasibility: Questionnaires can be provided to families at appointments. Limitations:

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-This study was not solely focused on POPs In RR, however there is valuable information about increased financial burden.
-No name of survey/tool or details about what specific questions were asked

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Appendix B

Table 2

Quantitative Evaluation Table

Citation	Theory/ Conceptual Framework	Design, Method, & Sampling	Sample & Setting	Major Themes Studied & Definitions	Measurement & Instrumenta- tion	Data Analysis	Findings & Themes	Level of Evidence Application to practice Generaliza- tion Feasibility Limitations
<p>Kazak et al., (2016) Psychosocial assessment as a standard of care in pediatric cancer: Psychosocial assessment standard.</p> <p>Country: USA</p> <p>Funding: Mattie Mira-</p>	<p>Pediatric Preventative Psychosocial Health Model</p>	<p>Method: Literature search by pediatric oncology psychologists, social workers, psychiatrists, counselors, & one parent of POP. IV: PAT, Distress thermometer DV: distress, quality of</p>	<p>N=149 studies based on a systematic, comprehensive literature review.</p>	<p>Major themes: -Child/Family psychosocial adjustment -Family resources -Family/ Psychosocial support -Previous history/premorbidity functioning -Family structure and function</p>	<p>Instrumentation: This study identified 2 evidenced-based psychosocial assessments: <i>Distress Thermometer</i> questionnaire – LS assessment of general distress level. <i>Psychosocial Assessment Tool</i> – parent</p>	<p>No specific statistical data reported for this literature review, but statistics of reviewed literature are well-analyzed and evidence table makes strong</p>	<p>-Children and families facing oncologic dx report increased distress, poorer quality of life, and hardships in psychosocial arenas. -Family voice in psychosocial assessment</p>	<p>LOE: I ATP: -Strong evidence for two well-validated psychosocial assessment tools. Limitations: While this study did not specifically identify families residing rurally, this could easily and feasibly be translated to assessing the needs of those families. This study likely captured some of those families without specifically identifying them.</p>

Key: **ALL:** Acute Lymphoblastic Leukemia **AML:** Acute Myeloid Leukemia **ATP:** Application to Practice **CCT:** Cancer Care Trajectory **CPBR:** Community-Based Participatory Research **DT:** Distance traveled **Dx:** Diagnosis **Eng:** English **FB:** Financial burden **HCP:** healthcare provider **KI:** Key informant **LOS:** Length of stay **LS:** Likert scale **MM:** Mixed Method **MOT:** Method of transportation **OEI:** Open-ended Interviews **OES:** Open-ended survey **PAT:** Psychosocial Assessment Tool **POP:** Pediatric Oncology Patient: **RCC:** Regional Care Center **RCT:** Randomized-Controlled Trial: **RN:** Registered Nurse **SAS:** Self-administered survey **Span:** Spanish **SSI:** Semi-structure interview **SW:** Social Worker **TCC:** Tertiary care center **Tx:** Treatment

cle Founda- tion & NIH		life, psycho- social hard- ships due to cancer diag- nosis. Purpose: Identify standard- ized use of psychosocial screening for POPs.		report, identi- fies level of risk in multiple ar- eas.	case for studies chosen.	aids in iden- tifying that stress of dx peaks in ini- tial months and de- creases as disease tra- jectory con- tinues. -Major con- clusion: Children and families facing can- cer dx should rou- tinely re- ceive sys- tematic psy- chosocial assess- ments.		
Kerr et al., (2007)	Supportive Care Framework for Cancer Care	Method: CPNQ was baseline assessment, followed with interview ~3 months later. Purpose:	Sample: Sample of parents whose children were treated at a TCC serving urban and rural POPs N=15. 20	Major Themes: 5 themes: -Psychosocial needs -Health information needs -Physical and daily living needs -Patient care and support needs	Instrumentatio n: Cancer Patient Needs Questionnaire (CPNQ) – 76 item questionnaire (terms were modified to fit pediatric pt	Reliability establishe d using Cronbach’ s alpha coefficien t (.90 to .78)	Major Findings: ½ of parents reported a moderate or high need on the CPNQ, emotional	LOE: III ATP: This study is directly applicable to the PICOT Feasible due to low-cost, low required man power to provide a questionnaire. Generalizability/Feasibili ty: Interviews will require more manpower but aid in family feeling

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to Local Needs Assessment	Identify which domain needs are most prevalent in, and identify which needs were most important to the families.	eligible parents identified, 15 participated (75%)	-Interpersonal communication need	needs filled out by caregiver – Pediatric Oncology Patient Survey)	and information al needs ranking highest.	like needs are seen/heard/addressed.
Country: Canada		Demographic s: 80% married, 73% full time employed 60% high school education or higher		LS of 1 “no need for help” to 5 “high need for help” . in addition to one OES question for parents to fill in any additional un-addressed needs.	1/3 of parents were most concerned about practical needs, most specifically FB of CCT.	Limitations: -Only Eng speaking patients were included -Not specifically rural focused, but RR POPs were captured at an unknown percentage of the sample.
Funding: Ministry of Health in Ontario	IV: CPNQ DV: Identified needs – health education, physical needs, psychosocial needs	Average age of child: 10-11 years.				
Bias: None identified or declare						

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Appendix C

Table 2

Synthesis Table

	Daniel et al.	Fluchel et al.	Graves et al.	Kazak et al.	Kerr eal.	Martinez-Donate et al.	Thewes et al.	Ugalde et al.	Walling	Warner
Year	2013	2014	2015	2016	2007	2013	2016	2019	2019	2015
LOE	VI	III	IV	I	III	VI	VI	VI	III	VI
Country	Australia	USA	USA	USA	Canada	USA	Australia	Australia	USA	USA
Demographics										
N	42	356	774/9 KIs 45 HCPs	149	15	53 Pt/41 HCPs	34	21 pt/5 SW	16	254
Mean Pt Age	-	8.8 years	-	-	10 years	62 years	54.4 years	-	7 years	8.9 years
Majority High School or Higher education	X	X	X	-	X	X	-	-	X	
Majority married	X	-	-	-	X	X			X	
Average level of Income <\$50k	-	X	X	X		X				X
Pediatric-Focused Study	X	X	X	X	X				X	X
Adult-Focused Study						X	X	X		
Setting										
Inpatient Setting				-						
Outpatient Setting	X	X		-	X	X	X	X	X	X
Other/Home			X	-						
Independent variable										
SSI	X		X			X	X	X	X	
SAS		X		X	X		X			X
Telephonic Survey			X							
OES			X		X			X		
HCP/Key informant interviews			X			X		X		

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Dependent Variables										
Financial Burden	X	X		X		X		X		X
↑ Isolation	X				X	X		X		
↑ Psychosocial distress	X	X		X	X	X		X	X	X
↑ Relocation		X		X					X	
Change in parental employment due to dx		X		X		X			X	X
Stressors related to cost of travel/accommodations	X	X		X		X			X	X
Educational burden/need							X		X	

Key: **ALL:** Acute Lymphoblastic Leukemia **AML:** Acute Myeloid Leukemia **ATP:** Application to Practice **CCT:** Cancer Care Trajectory **CPBR:** Community-Based Participatory Research **DT:** Distance traveled **Dx:** Diagnosis **Eng:** English **FB:** Financial burden **HCP:** healthcare provider **KI:** Key informant **LOS:** Length of stay **LS:** Likert scale **MM:** Mixed Method **MOT:** Method of transportation **OEI:** Open-ended Interviews **OES:** Open-ended survey **PAT:** Psychosocial Assessment Tool **POP:** Pediatric Oncology Patient: **RCC:** Regional Care Center **RCT:** Randomized-Controlled Trial: **RN:** Registered Nurse **SAS:** Self-administered survey **Span:** Spanish **SSI:** Semi-structure interview **SW:** Social Worker **TCC:** Tertiary care center **Tx:** Treatment

Appendix D

Theoretical Framework

Pediatric Psychosocial Preventative Health Model

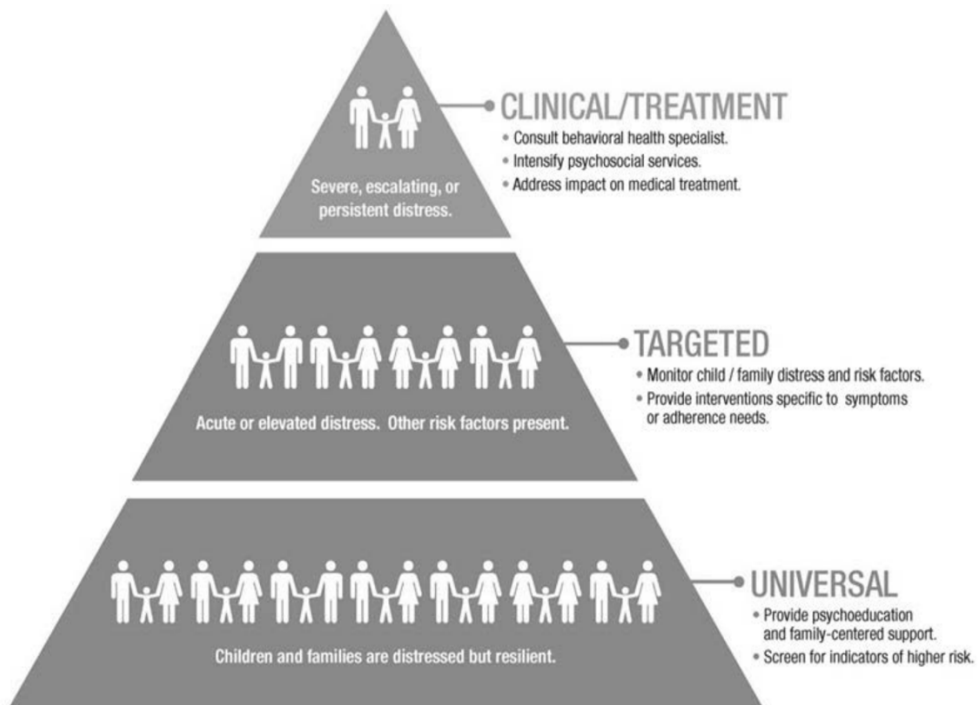


Figure 1. A graphic representation of the Pediatric Psychosocial Preventative Health Model (Kazak, 2006)

Appendix E

Implementation Framework

Lean Six Sigma

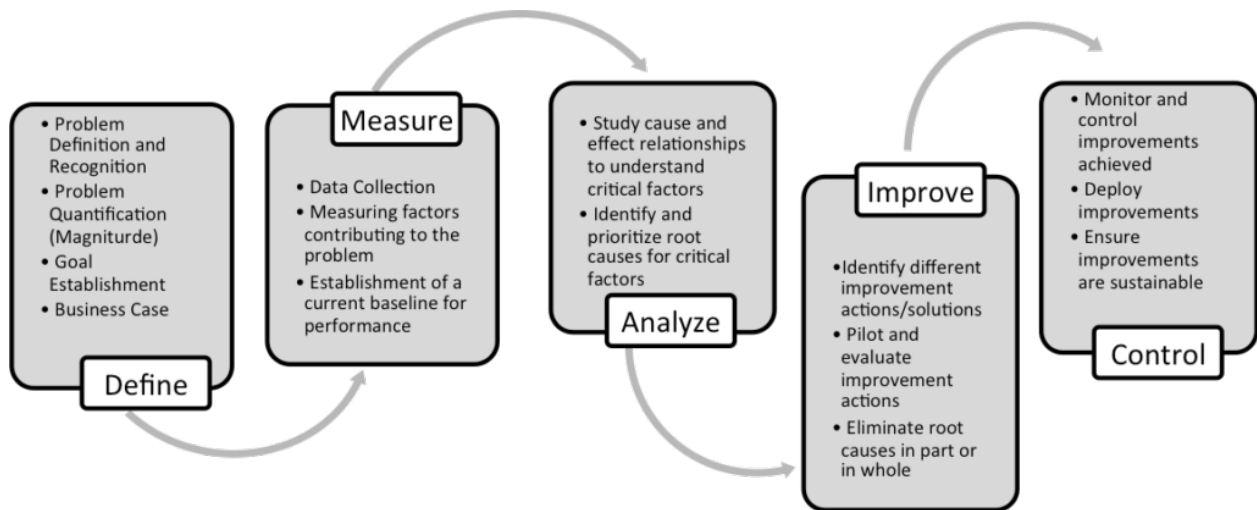


Figure 2. Graphic representation of the Lean Six Sigma Framework for Quality Improvement (Carrera, 2006).

Appendix F
IRB Outcome Notification



February 25, 2021

Alexandra M Walsh, MD
Phoenix Children's Hospital
Hematology/Oncology
1919 E. Thomas Road
Phoenix, AZ 85016

PCH IRB # IRB-09-089: Establishment of a Survivor Program Registry

Dear Dr. Walsh:

On February 25, 2021 the modification request form dated 02/18/2021 01:57:58 PM MST for the above mentioned project received approval by the Phoenix Children's Hospital Institutional Review Board by expedited review under 21 CFR 56.110(b) (2); 45 CFR 46.110(b) (2) because it involves minor changes in previously approved research during the period (of one year or less) for which approval is authorized.

This Expedited Review of Modification request provides an investigator-initiated change to add Lauren Harrell, RN to the study personnel. In addition, a needs assessment questionnaire to be conducted via telephone is being submitted for approval.

This approval includes:

Submission Components		
Form Name	Version	
Phoenix Children's Modification Form	Version 12.0	
Phoenix Children's Pre-Review Correction Form	Version 2.0	
Phoenix Children's Pre-Review Correction Form	Version 1.0	
Study Document		
Title	Version #	Version Date
Rural Cancer Needs Assessment Tool Final_V1_Clean_02.18.21	Version 1.0	02/18/2021
Rural Cancer Needs Assessment Tool Final_V1_Clean_02.18.21	Version 1.0	02/18/2021
Rural Cancer Needs Assessment Tool Final_V1_Tracked_02.18.21	Version 1.0	02/18/2021
DOA updated 18FEB2021	Version 1.0	02/18/2021
Rural Cancer Needs Assessment Tool Final_V1_Clean_02.08.21	Version 1.0	02/08/2021
Rural Cancer Needs Assessment Tool Final_V1_Tracked_02.08.21	Version 1.0	02/08/2021
Rural Cancer Needs Assessment Tool Final_V1_28JAN2021	Version 1.0	01/28/2021
Survivor Protocol_V5_Clean_01_28_21_T	Version 5.0	01/28/2021
Survivor Protocol_V5_Tracked_01_28_21_T	Version 1.0	01/28/2021
Survivor DOA 29JAN2021_Harrell	Version 1.0	01/29/2021



Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited others require full board review. If any adverse events occur, please report them at once to the IRB. The study must be submitted for continuing review approval on or before 02/07/2022 unless closed before that date.

If you have any questions or require further information please contact Shy Walker at swalker@phoenixchildrens.com.

Sincerely,

A handwritten signature in black ink on a light-colored background. The signature reads "Mitchell Shub MD" in a cursive script.

Signature applied by Mitchell Shub on 02/25/2021 04:26:16 PM MST

Mitchell Shub, MD
Chair, PCH Institutional Review Board #1

cc: Dresden Whitehead, Jodie Greenberg

Appendix G

Needs Assessment Tool

Code #:

Rural vs. Non-Rural Needs Assessment Tool

Chart Review

- Pt Gender:
- Race:
- Ethnicity:
- Patient Primary Language:
- Caregiver Primary Language:
- Pt current age:
- Pt age at diagnosis:
- Date of initial diagnosis:
- Diagnosis:
- Zip code at time of diagnosis:
- Current zip code:
- Distance (mi) traveled to tertiary care (PCH) at time of diagnosis
- Distance (mi) traveled to tertiary care (PCH) at current
- Distance (mi) to local/tertiary medical center
- Use of additional services:
 - Psychology
 - PT:
 - OT:
 - Speech:
 - Endo:
 - Ortho:
 - Neuro:
 - Other specialties:

Parent Telephone Interview

"Hi, my name is Lauren Harrell and I am a registered nurse at Phoenix Children's Hospital (PCH) and a pediatric nurse practitioner student at Arizona State University, Edson College of Nursing and Health Innovation. I am working with Dr. Walsh and Kathy Hinkle and the survivorship program at PCH. I am conducting interviews with parents of children who were treated for a cancer in order to better understand the needs and experiences of families during this period of your lives. The goal of this interview is to assist PCH and the Arizona Department of Health to better care for families during and after childhood cancer treatment especially for patients who live in different area of the state. If you are willing, I would like to ask you some questions about your child's cancer treatment. You can answer in as little or as much detail as you feel comfortable with. The interview will take approximately 30 minutes. Is this a good time for you or should be arrange a better time?"

Demographic Data:

- What race/ethnicity do you identify with? Repeat with child's race/ethnicity.
 - a. Black or African American
 - b. Asian or Pacific Islander
 - c. White or Caucasian
 - d. Native American or Alaskan Native
 - e. Multiracial or Biracial
 - f. A race/ethnicity not listed here
- Who lives at home with you and your child?
- What is your level of education?
 - Some high school
 - High school graduate
 - Some college
 - College graduate)

Travel/Regional Health Use:

Code #:

- During treatment, did your child start to have any new mental health concerns or did their existing mental health concerns worsen? Y/N
- If yes, please list:
- At present does your child have a history of any mental health concerns? Y/N
- If yes, please list:
- If yes, have you tried to find a mental health provider in your local area? Y/N
- If yes, were you able to obtain care in your local area? Y/N
- If yes, does your child continue to see a mental health provider? Y/N
- Of the following, which providers did your child see during their initial cancer treatment?
 - Occupational therapy
 - Physical therapy
 - Developmental specialists
 - Speech therapy
 - Other:
- Of the following, which providers does your child see now?
 - Occupational therapy
 - Physical therapy
 - Developmental specialists
 - Speech therapy
 - Other:
- Of the providers your child sees, where are services provided? (PCH, local clinic)
- Have you ever used the PCH on-call hem/onc line? Y/N
- When using the PCH on-call hem/onc line, do you experience any difficulty in reaching a provider? LIKERT (0 none at all, 5 unable to reach provider)

Table 3

0	1	2	3	4	5
None at all	Not very much difficulty	A little bit of difficulty	Some difficulty	Very much difficulty	Unable to reach provider

- How well did the team assess or incorporate cultural and spiritual beliefs or home traditions during your child's care? LIKERT (0 – not at all, 5- very well)

Table 4

0	1	2	3	4	5
Did not incorporate cultural & spiritual beliefs	Infrequently incorporated	Sometimes incorporated	Frequently incorporated	Many times incorporated	Incorporated cultural & spiritual needs at every encounter

Health Literacy: Education at time of discharge

- After receiving PCH discharge education at time of your child's cancer diagnosis, what was your comfort level in caring for your child at home? LIKERT (0 – not comfortable at all, 5 – completely comfortable)

Table 1

0	1	2	3	4	5
Not at all comfortable	Not very comfortable	A little bit comfortable	Comfortable	Very comfortable	Completely comfortable

Code #:

- How easy or difficult was PCH discharge education for you to understand? LIKERT (0 – not at all understandable, 5 – completely understandable)

Table 5

0	1	2	3	4	5
Not at all understandable	Not very understandable	A little bit understandable	Mostly understandable	Very understandable	Extremely understandable

- Did you receive discharge education in your primary language? Y/N
- What comfort level did you feel in asking questions of the health care team? LIKERT (0 – not comfortable at all, 5 – completely comfortable)

Table 1

0	1	2	3	4	5
Not at all comfortable	Not very comfortable	A little bit comfortable	Comfortable	Very comfortable	Completely comfortable

School: Education at present time

- Does your child have a 504 plan or IEP at school? Y/N
- Do you feel that your child's school provides adequate support based on your child's needs? Y/N
- Did your child experience educational delay due to cancer treatment? Y/N
- If so, describe:

Home:

- Does your home and neighborhood have reliable electricity? Y/N
- Does your home neighborhood have reliable running water? Y/N
- Does your neighborhood have reliable public transportation? Y/N
- If yes, explain:

Miscellaneous:

- At diagnosis, was there anything you wish the oncology team was aware of in order to better care for your child?
- What additional ways could we have helped during your child's treatment?
 - Transportation (bus fares, taxi coordination, gas money)
 - Local housing accommodations
 - Food, dietary supplements
 - Cleaning/sanitation supplies
 - Other – Assistance with bills, child care for siblings
- At present, is there anything you wish the oncology team was aware of in order to better care for your child?
- Are there additional ways the team could have supported your family during your child's treatment?**

"Thank you so much for your time and for answering these questions. Your time and experience may help inform and improve the care of children going through cancer treatment. I appreciate your time today."

Appendix H

Results

Table H1
Descriptive Data

Variable	<i>n</i>	%
County		
Yuma**	4	10.00
Pima**	3	7.50
Navajo*	4	10.00
Gila*	1	2.50
Coconino**	2	5.00
Apache*	2	5.00
Maricopa	20	50.00
Mohave**	2	5.00
Yavapai**	2	5.00
City of residence at diagnosis		
Show Low	1	2.50
Yuma	2	5.00
Kaibito	1	2.50
Tucson	2	5.00
Chinle	1	2.50
New Hampshire	1	2.50
Kayenta	2	5.00
Payson	1	2.50
Scottsdale	3	7.50
Fort Defiance	1	2.50
Somerton	1	2.50
Vernon	1	2.50
Kingman	1	2.50
Flagstaff	1	2.50
Casa Grande	1	2.50
Phoenix	9	22.50
Anthem	1	2.50
Mesa	1	2.50
Lake Havasu City	1	2.50
Clarkdale	1	2.50
Prescott	1	2.50

RURAL CHILDHOOD CANCER

50

Glendale	1	2.50
Gilbert	3	7.50
Chandler	1	2.50
Maricopa	1	2.50
Diagnosis		
Leukemia	20	50.00
Lymphoma	4	10.00
LCH	2	5.00
Medulloblastoma	6	15.00
Rhabdomyosarcoma	1	2.50
Ewing's Sarcoma	1	2.50
Wilm's Tumor	2	5.00
Germinoma	1	2.50
Pineoblastoma	1	2.50
Anaplastic ependymoma	1	2.50
Pituitary Tumor	1	2.50
Patient Gender		
M	19	47
F	21	52
Highest Level of Caregiver Education		
Some college	13	32.50
College graduate	17	42.50
High school graduate	10	25.00

*Indicates rural counties

** indicates remote location

Table H2
Descriptive Data

<i>Primary Language</i>		
Variable	<i>n</i>	<i>%</i>
Caregiver Primary Language		
English	31	77.50
Span	6	15.00
Thai	1	2.50
French	1	2.50
Romanian	1	2.50
Patient Primary Language		
English	35	87.50
Thai	1	2.50
Span	3	7.50
French	1	2.50

Table H3
Descriptive Data

Highest Level of Caregiver Education		
	<i>n</i>	%
Some college	13	32.50
College graduate	17	42.50
High school graduate	10	25.00
Missing	0	0.00

Table H4
Descriptive Data – Remote/Rural

How do you travel to your child's appointments?	n	%
POV	18	90.00
POV, Medical Transport	0	0.00
POV, Taxi, Medical Transport	1	5.00
Medical Transport	1	5.00

Table H5
Descriptive Data – Metropolitan

How do you travel to your child's appointments?		
POV only	17	85.00
POV, Medical Transport	3	15.00
POV, Taxi, Medical Transport	0	0.00
Medical Transport only	0	0.00

Table H6

Care at Regional Health Facilities vs. Care at Tertiary Facility – Likert Scale

Variable	<i>M</i>	<i>SD</i>	<i>n</i>
How comfortable did you feel that regional medical facility staff were in caring for your child?	2.28	1.99	18
How comfortable did you feel that tertiary facility staff were in caring for your child?	4.88	0.33	40

Table H7

Chi Square Test of Independence

Has Your Child Used Emergent Medical Transport?

Rural/Remote Vs. Metropolitan	N	Y	χ^2	df	p
Metropolitan	20[14.00]	0[6.00]	17.14	1	< .001
Rural/Remote	8[14.00]	12[6.00]			

Table H8

Chi Square Test of Independence

Did any primary caregivers lose or change jobs due to diagnosis?

Rural/Remote vs Metropolitan	Y	N	χ^2	df	p
Metropolitan	14[14.00]	6[6.00]	0.00	1	1.000
Rural/Remote	14[14.00]	6[6.00]			

Table H9

*Two-Tailed Mann-Whitney Test for Effect on Financial Stability During Treatment
Remote vs Non-Remote*

Variable	Mean Rank		<i>U</i>	<i>z</i>	<i>p</i>
	Metropolitan	Rural/Remote			
Effect on Financial Stability During Treatment	20.50	20.50	200.00	0	1.000

Variable	<i>M</i>	<i>SD</i>	<i>n</i>	<i>p</i>
Effect on Financial Stability During Treatment – Metropolitan	3.70	1.89	20	0.42

Variable	<i>M</i>	<i>SD</i>	<i>n</i>	<i>p</i>
Effect on Financial Stability During Treatment – Rural/Remote	3.95	1.43	20	0.32

Table H10

Chi Square Test of Independence

Did you relocate or change residences due to the diagnosis?

Rural/Remote vs Metropolitan	N	Y	χ^2	df	p
Metropolitan	14[13.50]	6[6.50]	0.11	1	.736
Rural/Remote	13[13.50]	7[6.50]			

Table H11

Chi Square Test of Independence

Did you move permanently or temporarily?

Rural/Remote vs. Metropolitan	Temporarily	Permanently	χ^2	<i>df</i>	<i>p</i>
Metropolitan	1[3.69]	5[2.31]	9.48	1	.002
Rural/Remote	7[4.31]	0[2.69]			

Table H12

Chi Square Test of Independence

Did you stay at RMH/Hotel/With Family during treatment?

Remote vs. Non-Remote	Y	N	χ^2	df	p
Metropolitan	4[11.28]	16[8.72]	22.13	1	< .001
Rural/Remote	18[10.72]	1[8.28]			

Table H13

Descriptive Statistics – Travel

Rural/Remote	<i>n</i>	<i>%</i>
Did you stay in RMH/Hotel/with family during treatment?		
Y	19	95.00
N	1	5.00
Primary Reason for Moving:		
Closer to PCH	7	35.00
Environmental safety concerns	0	0.00
Finances	0	0.00
Did not move	13	65.00
Did you relocate or change residence due to diagnosis?		
N	13	65.00
Y	7	35.00
Missing	0	0.00

Table H14

Descriptive Statistics – Travel

Metropolitan	<i>n</i>	<i>%</i>
Did you stay in RMH/Hotel/with family during treatment?		
Y	4	20.00
N	16	80.00
Primary Reason for Moving		
Closer to PCH	3	15.00
Environmental safety concerns	1	5.00
Finances	2	10.00
Did not Move	14	70.00
Did you relocate or change residence due to diagnosis?		
N	14	70.00
Y	6	30.00

Table H15

Descriptive Data

Mental Health Concerns—Entire Population

Variable	<i>n</i>	%
At the time of diagnosis did you have mental health concerns (primary caregiver)?		
N	31	77.50
Y	9	22.50
At present do you have mental health concerns (primary caregiver)?		
Y	20	50.00
N	20	50.00
At the time of diagnosis, did you have a spouse or partner?		
Y	29	72.50
N	11	27.50
At present, do you have the same spouse or partner?		
Y	31	77.50
N	9	22.50
Missing	0	0.00
Does your child see a mental health professional?		
N	25	62.50
Y	15	37.50
At present, does child have mental health concerns?		
N	20	50.00
Y	20	50.00
Prior to the diagnosis, did child have mental health concerns?		
N	35	87.50
Y	5	12.50
Missing	0	0.00

Table H15

Descriptive Data

Mental Health Concerns

Rural/Remote	<i>n</i>	<i>%</i>
At the time of diagnosis did you have mental health concerns (primary caregiver)?		
N	16	80
Y	4	20
At present do you have mental health concerns (primary caregiver)?		
Y	11	55
N	9	45
At the time of diagnosis, did you have a spouse or partner?		
Y	15	75
N	5	25
At present, do you have the same spouse or partner?		
Y	16	80
N	4	20
Does your child see a mental health professional?		
N	11	55
Y	9	45
At present, does child have mental health concerns?		
N	8	40
Y	12	60
Prior to the diagnosis, did child have mental health concerns?		
N	18	90
Y	2	10

Table H16

Descriptive Data

<i>Mental Health Concerns</i>		
Metropolitan	<i>n</i>	<i>%</i>
At the time of diagnosis did you have mental health concerns (primary caregiver)?		
N	15	75
Y	5	25
At present do you have mental health concerns (primary caregiver)?		
Y	9	45
N	11	55
At the time of diagnosis, did you have a spouse or partner?		
Y	14	70
N	6	30
At present, do you have the same spouse or partner?		
Y	15	75
N	5	25
Does your child see a mental health professional?		
N	14	70
Y	6	30
At present, does child have mental health concerns?		
N	12	60
Y	8	40
Prior to the diagnosis, did child have mental health concerns?		
N	17	85
Y	3	15

Table H17

Discharge Readiness and Cultural Care – Entire Population

Variable	<i>M</i>	<i>SD</i>	<i>n</i>
Comfort level taking child home at time of discharge after education	3.70	1.74	40
Comfort level asking questions of the hem/oncology team	4.97	0.16	40
Integration of spiritual/cultural beliefs during care	3.63	2.09	35

Table H18

Provider Line Access – Entire Population

	<i>n</i>	<i>%</i>
Have you ever used the hematology/oncology provider on-call line?		
N	8	40
Y	12	60
Have you ever had difficulty reaching a provider?		
N	12	100
Y	0	
N/A	8	

Table H19

Did you receive discharge education in your primary language?

	<i>n</i>	%
Y	36	90
N	4	10

Table H20

Chi Square Test of Independence

Do you feel that your child's school provides adequate support?

Rural/Remote Vs. Metropolitan	Y	N	χ^2	df	p
Metropolitan	17[14.00]	3[6.00]	4.29	1	.038
Remote	11[14.00]	9[6.00]			

Table H21

Chi-square Test of Independence

Did the child experience educational delay due to treatment?

Rural/Remote vs Metropolitan	N	Y	χ^2	df	p
Metropolitan	12[10.50]	8[9.50]	0.90	1	.342
Rural/Remote	9[10.50]	11[9.50]			

Table H22

Access

Metropolitan	<i>n</i>	%
Does your neighborhood have public transportation?		
N	5	25.00
Y	15	75.00
Does your neighborhood have reliable electricity and running water?		
Y	20	100.00
T	0	0.00
N	0	0.00

Table H23

Access

Remote/Rural	<i>n</i>	%
Does your neighborhood have public transportation?		
N	10	50.00
Y	10	50.00
Does your neighborhood have reliable electricity and running water?		
Y	18	90.00
T	1	5.00
N	1	5.00