Bringing Visibility to Pediatric Sickle Cell Disease: A Needs Assessment to Inform Camp Programming

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Author Note

I have no known conflicts of interest to disclose.

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Abstract

Sickle cell disease is a genetic hemoglobinopathy resulting in chronic and daily pain, risk of serious sequelae, and altered activities of daily living. Resources dedicated to helping individuals with sickle cell disease are lacking, especially compared to other chronic diseases. Children with sickle cell disease experience school absence, fractured peer relationships, frequent healthcare visits, stigma, and feelings of isolation. Additionally, chronic pain decreases developmentally important play and physical activity in these children. The purpose of this Doctor of Nursing Practice (DNP) project is to conduct a needs assessment to inform sickle cell disease family camp programming in southern Arizona. Once a camp experience can be safely implemented, the effects of a camp experience on knowledge, empowerment, and disease management in children with sickle cell disease will be investigated. Research specific to camps for children suffering from sickle cell disease is lacking, however ample evidence suggests the benefit of disease specific camps. Medical specialty camps provide an opportunity for children and families to normalize their condition, participate in activities, and form peer relationships in an environment that safely accommodates their unique needs. This has led to the initiation of an evidence-based project to develop a needs assessment for families affected by sickle cell disease and community partners to inform camp activity development guided by Bandura's theory of self-efficacy and the Centers for Disease Control and Prevention (CDC) Framework for Program Evaluation.

Keywords: sickle cell disease, medical specialty camp, self-efficacy, children

Support for Children with Sickle Cell Disease

Children with chronic diseases have complex medical and psychosocial needs, however resources are limited for most of these conditions. Pharmacologic treatments fall behind those for adults with similar conditions and developmentally appropriate interventions for psychological well-being are scarce. Local non-profit organizations often fill gaps in the community and are typically founded by parents who have identified a need after they have lost a child. Sickle cell disease (SCD) is one of many chronic conditions that interferes with daily life. Children experience chronic and often daily pain in addition to periodic pain crises, require daily medications, have frequent healthcare appointments or hospitalizations, and must exercise caution with activity. For these reasons, quality of life is frequently negatively affected and opportunities afforded to healthy children such as traveling, sports involvement, or summer camp are challenging to accommodate to meet the child or adolescent's medical needs.

Problem Statement

Sickle cell disease is a genetic hemoglobinopathy and the first known molecular disorder, identified in 1910 (National Heart, Lung, and Blood Institute [NHLBI], 2018). This condition affects up to 100,000 people in the United States (US) and seven million people worldwide (Bulgin et al., 2018). In SCD, deoxygenation causes red blood cells to change from round to sickle-shaped, causing impaired blood flow, breakdown of red blood cells, and anemia (Narcisse et al., 2018). The most well-known effect of this sickling is acute pain crises; however, effects of these vaso-occlusive events are seen throughout the body and lead to long term consequences such as chronic pain, organ failure, infection, or stroke (American Society of Hematology [ASH], 2016; Narcisse et al., 2018). This lifelong disease primarily affects minority groups and

requires continued, comprehensive medical care to manage the disease and its complications (Bulgin et al., 2018).

Life expectancy for individuals with SCD in the US has increased from adolescence to adulthood since the 1970s when newborn screening was introduced and early interventions decreased complications in young children (Derlega et al., 2016). While significant advancements have been made over the past century, progress has lagged behind other chronic illnesses such as cystic fibrosis or pediatric cancer (Farooq et al., 2020; McGann, 2016). Few treatment options exist and those that do are not widely available to all individuals (ASH, 2016).

Sickle cell disease is often referred to as a hidden, invisible, or forgotten disease. National and local resources for education, advocacy, research, and support for SCD are lacking. The Sickle Cell Disease Association of America provides access to information and resources, however only 26 states currently have active chapters (Sickle Cell Disease Association of America, n.d.). Many states have organizations dedicated to SCD, which are often created by affected individuals or families, but their impact varies greatly. Federal and state funding is also limited, especially compared to other chronic conditions such as cystic fibrosis (Farooq et al., 2020).

Individuals with SCD often encounter health-related stigma that can lead to isolation, hesitance to disclose diagnosis, delayed medical care, and medication adherence issues. Stigma surrounding race, opioid use, and pain is experienced from family, friends, healthcare providers, healthcare institutions, the general public, and affected individuals (Bulgin et al., 2018). Children with SCD require accommodations at school and home to help manage complications, however the isolation and fear of disclosure paired with the lack of outward signs of this condition and

lack of bonding experiences for children can lead to increased emergency room visits, hospitalizations, and school absence (ASH, 2016).

Purpose and Rationale

In Arizona, conditions such as pediatric cancer and hemophilia have a well-established social network and organizations that help provide a sense of community, emotional support, financial assistance, and the ability for individuals and families to share information and resources. The purpose of this paper is to review the current literature and develop a needs assessment survey in order to develop programming for a future camp experience for children with SCD in Arizona. Evidence has shown the benefit of camp experiences. Camp experiences are available to children and families with other chronic health conditions such as childhood cancer, diabetes, and asthma (Bultas et al., 2015; Faith et al., 2019; Odar et al., 2013). If the unique needs of children and families affected by SCD are not addressed and opportunities for education, networking, normalcy, and fun are not afforded to this population, quality of life will suffer. Feelings of stigma, peer relationships, medication adherence, school attendance, and family dynamics will also be affected (ASH, 2016; Bulgin et al., 2018).

Background/Significance

An estimated 15-18% of children have a chronic illness, which can affect quality of life and psychosocial health (Pecker & Darbari, 201). Individuals with SCD have a higher risk of experiencing depression, sleep disturbance, anxiety, isolation, and catastrophizing, all of which can negatively affect health outcomes (Pecker & Darbari, 2019).

Children with Sickle Cell Disease

Each year an estimated 1,000 children are born with SCD in the US (Narcisse et al., 2018). In Arizona, current data is not readily available, however between 2011 and 2015, 605

children with SCD were discharged from hospitals in Arizona (Cabasag et al., n.d.). These children often miss school due to medical appointments or frequent illness, contributing to social losses and altered friendships (Narcisse et al., 2018). The physical effects of SCD throughout childhood combined with fear of triggering a pain crisis can limit the child's ability to play, an important part of development (Nijhof et al., 2018).

Camp Experience

Camp experiences in the US began in the late 1800s and have demonstrated efficacy in improving the lives of healthy children and those with chronic illness. Medical specialty camps have been heavily researched and provide support, education, and can increase self-esteem while uniting children with special health needs (Narcisse et al., 2018; Odar et al., 2013; Rea et al., 2019). Camps for various conditions such as pediatric cancer, asthma, obesity, heart conditions, diabetes, and hematological conditions have increased across the country, with nearly 300 accredited camps in existence (Faith et al., 2019). These specialty camps take into account the needs and limitations of different diagnoses and can modify experiences appropriately in ways that camps for healthy children cannot. They also provide the benefit of experienced health care providers on site to deliver care and provide ongoing health education pertaining to the disease process and treatment.

Longstanding fear that physical activity contributes to vaso-occlusive episodes has placed activity limitations on people with SCD. As previously mentioned, this has contributed to decreased play in childhood and adolescence and affects normal socioemotional, language, and cognitive development (Nijhof et al., 2018). Newer research has revealed that exercise over exertion may lead to a pain crisis and even low levels of physical activity and sedentary lifestyles are associated with higher pain (Karlson et al., 2020). However, this research also suggests that

moderate amounts of physical activity may improve health outcomes in this population (Karlson et al., 2020). Using this information, camps that feature modified physical activity can be of even more benefit to youth with SCD to safely increase play and physical activity while reaping the other known benefits such as socialization, disease knowledge, and self-esteem.

Current Affairs

The first camp dedicated to children with SCD was established in California in 1967 and has grown significantly. Approximately ten camps dedicated to children with SCD are easily located online, with many accepting campers only from the hosting state. Some do accept national enrollment, but traveling is costly and may not be an option for many. Other camps, mainly those for pediatric cancer patients, invite children with SCD to join. This represents an inclusive and cost-efficient strategy, however there is questionable benefit of mixed diagnoses camps compared to disease specific experiences (Faith et al., 2019).

Benefits of Camp

The widespread benefits of camp are well known and include improved confidence and self-esteem, development of coping strategies, improved hope, and changes in attitude related to illness (Faith et al., 2019; Odar et al., 2013; Rea et al., 2019; Wu et al., 2016). In disease specific camps, children have demonstrated an improved sense of meaning and purpose, peer relationships, and feelings of security along with normalization of their condition (Kelada et al., 2020; Meltzer et al., 2018). From a health standpoint, knowledge of their disease and self-management techniques improve after these camp experiences (Bultas et al., 2015; Hill et al., 2015; Weissberg-Benchell et al., 2019).

The availability of funding and resources needed to host a camp can be challenging to obtain. For this reason and the perceived similarity of certain chronic illnesses, it is

understandable that different groups, such as children with cancer and children with SCD would be paired. However, the stigma, experiences, and challenges of children with SCD are vastly different from other disorders and are best addressed as an individual condition.

Internal Evidence

Organizations dedicated to chronic diseases such as hemophilia, pediatric cancer, and cystic fibrosis are well established on national and state levels. One such organization, a nonprofit in Southern Arizona, serves to connect local families affected by childhood cancer. It provides a sense of community, financial support, and emotional support and hosts annual camps for these families as well as local events throughout the year. Outcomes are informally measured through parental feedback and repeat camp attendance.

Approximately 50 children in this area have SCD and are invited to attend all events that are offered in other disease specific camp experiences but are often unable to attend due to local conditions such as elevation change and high environmental temperatures that may provoke a pain crisis. Many families do not attend the local events due to feelings of isolation and the stigma associated with SCD.

Statewide services for SCD are limited, at this time, primarily due to lack of staffing and funding. Families are notified of positive newborn screens by the Office of Newborn Screening within the Arizona Department of Health and referred to a pediatrician. There are two cities within the state that offer specialty care and services for SCD, leaving care gaps in rural areas. Stakeholders are working to increase services, education, and awareness of SCD despite these challenges. This inquiry has led to the PICO question, in children with sickle cell disease (P), how does a camp experience (I) affect knowledge, empowerment, and disease management (O) compared to no camp experience (C)?

Search Strategy

To answer the PICO question, a thorough search for the current evidence was conducted. The search included four databases: the Cochrane Library, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and PsycINFO, in that order. These databases were chosen for their relevance to the PICO question, large research base, and peer review. The search was concluded when no new articles were revealed. Grey literature of publications from the Arizona Department of Health, NHBLI, and ASH were also searched.

Inclusion Criteria, Exclusion Criteria, and Limitations

Inclusion criteria for the searches consisted of children 18 years old and younger with a chronic condition as the primary focus of the study with allowances for studies regarding family camp outcomes. In addition, a camp experience was required with outcomes pertaining to well-being. Studies that were not primary research were excluded. Limits were initially withheld from the searches and added as needed to narrow results and were consistent throughout the databases. The selected limits were English language, peer reviewed articles, and publication dates from 2015-2020 initially. Given the scarcity of data, publication dates were extended to 2013-2020.

Keyword Selection

Given the paucity of data available, the databases were searched using combinations of keywords that addressed all aspects of the PICO question and include: *children, kids, youth, sickle cell disease, chronic illness, chronic disease, minority health, camp, summer camp, recreation therapy,* and *therapeutic camp.* Terms for the outcome such as *quality of life, self-esteem,* and *well-being* yielded minimal results when searched in conjunction with other terms and were used sparingly.

Each database search began using *children, sickle cell anemia, and summer camp* with related terms. Searches were expanded with the addition of the term *chronic illness* and omission of *sickle cell disease* to include research surrounding diagnoses such as pediatric cancer, diabetes, and heart disease. Search terms were consistent in use and order for each database and were searched in various combinations.

Search Results

Utilizing this search strategy, the Cochrane Library yielded results ranged from 16 to 170 articles, CINAHL yielded between four to 42 articles, PubMed ranged from six to 71 articles, and PsycInfo provided 20 results. Given the low search yield in each database, titles and abstracts were reviewed for relevance, inclusion criteria, and outcome measurement. The "similar article" search function in PubMed was utilized to expand results. All references in the systematic reviews were hand searched for relevant articles and to ensure primarily original references were selected. There were article duplications among the databases searched.

Sixteen articles were reviewed and after careful consideration, ten were selected for this review based on the study population, measured outcomes, methodologies, and application to the PICO question. The selected studies consist of one meta-analysis (Odar et al., 2013), two systematic reviews (Kelada et al, 2020; Rea et al., 2019), four quasi-experimental studies (Bultas et al., 2015; Faith et al., 2019; Hill et al., 2015; Weissberg-Benchell et al., 2019), two cross-sectional studies (Karlson et al., 2020; Wu et al., 2016), and one study with mixed-methods design (Meltzer et al., 2018).

Critical Appraisal and Synthesis

The selected studies were evaluated using the Melnyk and Fineout-Overholt's (2019) rapid critical appraisal to determine the strength of evidence. While three studies were high-level

evidence, the majority consisted of lower-level evidence lacking randomization and control groups (see Appendix A, Table A2). Minimal bias was recognized in the studies. All but one study included a multi-day medical specialty camp intervention for children with chronic conditions and four included the effects of a sibling or family camp experience. Karlson et al. (2020) was the exception and evaluated the effect of physical activity on pain and pain interference in children with SCD (see Appendix A, Table A2). Two studies had large sample sizes, however the remaining studies had relatively small samples (see Appendix A, Table A1). Given the type of intervention and population of interest, lack of randomization and control groups, and smaller sample sizes was deemed reasonable.

Heterogeneity was observed in the measurement tools and included a variety of validated and unvalidated questionnaires, focus groups, and interviews. Despite the variance in measurement tools, common outcomes emerged. Eight studies reported on self-esteem or self-perception, six focused on social skills and support, five measured respite or camp satisfaction, four measured self-care and disease management skills, and four measured attitudes towards illness (see Appendix A, Table A2). Data regarding outcome endurance is lacking, however evidence supporting short-term improvements is robust.

Conclusions from Evidence

The evidence suggests positive effects of camp experiences in children with chronic illness (see Appendix A, Table A1). Eight studies demonstrated improvements in at least one outcome measure. The study by Faith et al. (2019) was the one exception. The authors found no significant changes and proposed that benefits of camp are seen in disease specific settings and outcomes lose power when children with a variety of conditions are grouped together. Bringing children with a chronic condition together provides a unique opportunity to exchange ideas, form

peer relationships, learn how others manage their condition, and improve self-perception. Family camps can provide these benefits to children affected by chronic illness and their siblings while providing social support and respite for parents (see Appendix A, Table A2). While none of the camp intervention studies were specific to SCD alone, similar effects were seen in multiple diagnoses and it is reasonable to extrapolate these findings. For a community experiencing isolation and stigma, interventions to combat these feelings are imperative.

Theoretical Framework and EBP Model

Self-efficacy theory was only used in one of the selected studies, however it was chosen as the theoretical framework for this DNP project given the applicability to several outcome measures. Developed by Albert Bandura, the theory describes relationships between individuals, environment, and behavior and holds the assumption that an individual can influence and control their behavior based on reflective thought, use of knowledge, and skills (Bandura, 1977; Resnick, 2014). Bringing children and families affected by SCD together provides opportunities to improve individual self-efficacy, or the belief a person can accomplish their goals. Self-efficacy is influenced by individual actions, observing others, verbal feedback, and physiologic feedback all of which will occur at camp and guide future behavior (Bandura, 1977; Resnick, 2014).

The Centers for Disease Control and Prevention (CDC) Framework for Program Evaluation was chosen to guide the needs assessment and subsequent program implementation (Centers for Disease Control and Prevention [CDC], 1999). The six-step approach of this evaluation model provides a methodical approach to conducting a needs assessment to inform camp structure and activities (see Appendix B). The evaluation model provides four categories of standards to meet and a straightforward, stepwise approach involving stakeholder engagement, a

description of the program, evaluation design, a review of evidence, summary of conclusions, and information sharing (CDC, 1999). The framework is continuous and once the camp has been implemented, evaluation of the program and outcomes can be conducted using the same model to determine if the program met the desired goals and help guide changes moving forward.

Methods

Human Subjects Protection

Institutional review board expedited approval was obtained through Arizona State University prior to project launch. Participants were asked to sign an electronic consent and for those under the age of 18, parental permission and child assent were obtained electronically. Participants were informed that survey completion was voluntary and they could withdraw at any time. The survey did not collect any identifiable information, excepting the option to input an email address to obtain the survey results, however this was not linked to individual survey answers. Aggregate data was analyzed and will be reported to both organizations and participants as requested.

Population and Setting

Due to the Covid-19 pandemic, hosting a SCD family camp was not safe or feasible due to social distancing and virus mitigation requirements. To mitigate this concern, an online survey was created to assess the needs of the pediatric SCD population in Southern Arizona and inform camp development. In an effort to comprehensively understand varying perspectives, the needs assessment was targeted to several audiences. Parents of children with SCD, young adults and adolescents aged 12 years or older with SCD, healthcare workers affiliated with this population, and community partners were invited to complete the survey.

Project Description

An online needs assessment survey was developed with questions focusing on areas of disease knowledge, medication management, self-care techniques, school and social relationships, and camp programming. Data collection began on 18 January 2021 and was completed on 22 February 2021. Recruitment was primarily via email using a consolidated list of 96 email addresses from two nonprofit organizations serving this population. The nonprofit organizations are located in Southern Arizona in a large urban area. The needs assessment was delivered via email with a direct link to the survey. Two reminder emails were sent during the data collection period. The first email was sent one week after the initial email and the second was sent one week prior to survey closure. Additionally, both organizations also placed a link to the survey on their websites and created social media postings with a survey link at the same intervals as the emails. Additionally, a flyer with a quick response (QR) code was placed in outpatient hematology offices in both Phoenix and Tucson. This project did not require any funding given the online nature of instrumentation development and survey distribution.

Instrumentation and Data Collection

The 79-question assessment survey was created based on input from the literature and stakeholders from both organizations. The survey utilized primarily multiple-choice questions with both Likert scale answers and the option to select multiple answers. Select questions allowed for free text clarification to obtain subjective data about subjects such as self-care techniques utilized by the respondents, the decision to disclose their diagnosis, concerns regarding their child's health, and camp programming. Descriptive statistics was the primary data analysis technique utilized. Qualitative data were analyzed through thematic analysis.

Results

Survey Data

Analysis began at the conclusion of data collection. The survey was viewed 244 times, but was started by only 41 respondents with 31 completed surveys, for a completion rate of 75.6%. Respondents took an average of 35 minutes to complete the consent process and 79 questions. Using email did not appear to be a strong recruitment tool as only 13 individuals viewed the emails and seven completed the survey. This indicates that other recruitment methods, including informal recruitment done at the organizational level, are better suited to this population.

The survey was completed primarily by women who identify as black or African American from the Tucson area. Respondents were mostly aged 25-54 years old, have sickle cell trait, and a child with SCD, although four individuals with SCD aged 15-24 years participated (see Appendix C, Table C1).

Disease Knowledge

Nine questions assessed perception of disease knowledge and included information on care providers. All but 3.2% of participants felt that they have a strong understanding of SCD as a whole with 100% reporting a strong understanding of the complications associated with this condition. It is interesting to note that only 51.7% of respondents want more SCD education and 19.3% are uncertain of available education and resources. All respondents report feeling comfortable discussing concerns with their child's hematologist, however 35.7% of participants feel that their child's primary care provider does not have adequate knowledge of SCD (see Appendix C, Table C2).

Medication Management

The next nine questions of the survey assessed attitudes towards treatment and yielded positive findings. The majority of respondents felt strongly that they were educated on management options, were comfortable with prescribed medications, and agreed with the

management plan. Those that did not agree with these statements responded as neutral at 3.2%, 6.5%, and 9.7%, respectively (see Appendix C, Table C3). Another positive finding is the lack of perceived difficulty obtaining prescribed medications where 6.4% of respondents reported trouble obtaining medications and 22.6% responded neutrally.

Self-Care Techniques

Ten questions on the survey assessed both quantitative and qualitative data regarding health status in the past twelve months, current self-care practices, hydration practices, and physical activity. All but 16.1% of respondents felt that they had a strong understanding of self-care modalities and reported themes such as religion and spirituality, outdoor activities and exercise, time with friends and family, involvement in hobbies, and meditation and mindfulness practices (see Appendix C, Table C4). Most respondents (74%) reported that their children were active for at least 30 minutes three or more times per week and approximately half (51.7%) reported daily consumption of non-caffeinated beverages to be 24 ounces or less (see Appendix C, Figure C1 and C2).

Respondents were asked to report the number of pain crises, emergency department (ED) visits, urgent care (UC) visits, hospitalizations, and instances requiring opioid pain management over the past 12 months. Only 35.5% of respondents deny experiencing a pain crisis; 38.7% had two or fewer, and 25.9% experienced three or more in the past year. Emergency room visits were divided with nearly half (48.4%) reporting no ED usage and 41.9% utilizing ED services once or twice over the past 12 months. Urgent care services were was rarely utilized with only 19.3% of respondents seeking this level of care. Hospitalizations were also evenly divided with 51.6% of respondents not requiring a hospital stay in the past year. The range of 1-2 hospitalizations in the past year aligns with participant experiencing a pain crisis two or fewer times in the last year at

38.7%. Finally, the results indicate that most respondents (61.3%) utilized opioid pain management at least once in the past year with only 22.6% denying any usage (see Appendix C, Table C5).

School and Social Relationships

Twenty-four questions on the survey assessed experiences with stigma, comfort disclosing a SCD diagnosis, concerns for health and wellbeing, school experiences, and self-efficacy. Most respondents reported experiencing stigma related to SCD in at least one area of life (61.9%) with only 23.8% of respondents denying any stigmatization (see Appendix C, Figure C3). Contrary to the literature, 67.7% of respondents reported comfort disclosing a SCD diagnosis to others for reasons such as spreading awareness and educating others or creating a support network. Those that were not comfortable disclosing this information reported concern for being treated differently, felt isolated or unrelatable due to their diagnosis, or opted not to disclose due to experiences surrounding stigma (see Appendix C, Table C6). Unsurprisingly, most participants reported worrying about their child's health (76.6%) given the risk of complications, future ramifications of their diagnosis and fear of pain, medication adherence, and transition to adulthood. Additionally, 17.2% of parent participants feel overwhelmed by their child's health needs and 31% had a neutral response (see Appendix C, Table C7). These participants reported a fear of the unknown as well as the complexity of the diagnosis as driving factors for their fear.

The majority of participants noted that their child enjoys school (58%) and is academically successful (64.5%), however only 41.9% felt that their child is supported in school. Reported self-efficacy was high with all but 12.9% of respondents reporting confidence in their child's ability to achieve their goals and 61.3% reporting high self-esteem. Most children had a

positive outlook on life (67.7%) and enjoy playing with friends (70.9%). Despite these high indicators of self-efficacy, only 35.5% report that their child does not feel limited by SCD (see Appendix C, Table C8).

Camp Programming

The final section of the needs assessment consisted of 11 questions to assess knowledge of the project site and inform camp programming. While 80.7% of respondents were familiar with the community nonprofit organizations and 77.4% had attended events hosted by these organizations, only 22.6% had attended a family camp. The majority of participants (77.4%) were interested in attending a SCD family camp (see Appendix C, Table C9). The survey revealed that the participants desired that the educational camp content should have a fairly equal distribution for the topics of general SCD education, medication and management modalities, self-care techniques, transition of care, pain management modalities, cooperation with schools, financial topics, and nutrition (see Appendix C, Figure C4). Similarly, the reported goals of a camp experience were connection, normalization, fun, education, respite, and bolstering self-esteem, also with a fairly even distribution (see Appendix C, Figure C5). When asked about camp venues, there was a preference towards unique indoor venues and hotel or resort settings compared to traditional outdoor camps. Finally, when queried about camp activities with the ability to select multiple answers, there were 221 responses in eleven categories with no clear theme.

Clinical Significance and Impact

This assessment is the first of its kind in Arizona to gather data on the specific needs of the SCD population. Prior to this assessment, support, events, and resources for this population were offered by community organizations based on perceived needs or on an individual level.

Support has been intermittently offered and with low attendance by the nonprofit organizations. Despite the low number of completed assessments compared to the known number of families with children affected by SCD, this project has given direction to community organizations on how best to serve this group.

The community organizations often pair with pediatric hematologists in the state when providing educational content and with the high perception of current strong disease knowledge of these participants, education can be better tailored and focus on identified areas of need such as pain management strategies and the development of pain management plans. Additionally, the need for primary care provider education and school support has been identified and could lead the way for provider outreach events to increase professional knowledge and collaboration. Now that preferred self-care modalities have been identified, events that focus on these themes, the importance of hydration, and safe physical activity can be developed. Finally, a common theme in the literature, and within the survey results, indicate the desire for a network of support.

Families with children affected by SCD would benefit from a camp experience and the reported goals of camp align well with the literature (Bultas et al., 2015; Faith et al., 2019; Hill et al., 2015; Kelada et al., 2020; Meltzer et al., 2018; Odar et al., 2013; Rea et al., 2019; Weissberg-Benchell et al., 2019; Wu et al., 2016). A camp provides the opportunity to bring families together in a fashion that allows for normalization, fun, respite, and education. Medical specialty camps help develop a network of support and advocacy and will facilitate spreading awareness of SCD and combating the stigma that is still prevalent today.

Sustainability

This needs assessment provided initial feedback from Arizona's pediatric SCD population. The needs assessment survey can be easily modified to add, change, or omit

questions as needed and stored as a working document at no cost to the community organizations. Hosting a camp will be more challenging to initiate and sustain as the nonprofit organizations rely on grants to fund such events. One project nonprofit organization is well connected to funding sources within the community and the camp planning process and can help the secondary nonprofit organization develop these connections and adopt the camp initiative. Once the secondary organization is well established, recurrent funding will be easier to obtain, especially as community presence and demand grows.

Discussion

Limitations

While this needs assessment provided important insight to the pediatric SCD population in Arizona, there are limitations to the data. Based on low completion rates from emailed surveys, there is a potential that the results are not reflective of the large SCD community. The overall low completion rate paired with the large number of participants that have attended events hosted by the project site raises concerns over the representativeness of the sample as many more of these individuals are already active in the community. In addition, the length of the survey may have deterred participants based on the number of times the survey was viewed and the near 25% dropout rate. By increasing stakeholder involvement in future survey distribution and adapting the survey as needed, a larger sample size would identify additional needs of this community.

Summary

Medical specialty camps normalize chronic conditions, improve self-perception, and provide social support. Stigma and isolation affect people with SCD, which leads to delayed care, medication adherence issues, and decreased quality of life. Expanding opportunities to

engage, educate, and empower this population in a community can improve family dynamics, peer relationships, school attendance, pain symptoms, and decrease healthcare costs. The results of this needs assessment highlighted opportunities for education and insight on what these families need and want from educational and camp programming. By addressing these needs, one of the most important and likely outcomes is providing these children the opportunity to have fun and learn how to safely play despite having SCD while increasing awareness of this forgotten disease.

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Appendix A

Evaluation and Synthesis Tables

Table A1

Evaluation Table Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Bultas et al., (2015). Psychosocial outcomes of participating in a pediatric diabetes camp. **Funding:** School of Nursing at Saint Louis University **Country:** US **Bias:** All authors are employed by the university that funded the study.	Self-efficacy theory- inferred	**Design:** Quantitative, quasi-experimental (pre- and posttest) **Purpose:** To evaluate the effects of a camp experience for children with type 1 DM.	**n=** 38 **Demographics:** Mean age: 12.53 years Male: 50% Mean time since diagnosis: 4.57 years Previously attended overnight camp: 65.8% **Setting:** Week-long overnight camp for children with DM. **Inclusion criteria:** Diagnosis of DM, aged 8-17 years, attend camp	**IV:** Camp experience **DV1:** ATI **DV2:** Confidence in self-care management **DV3:** Perception and satisfaction with camp	**CATIS:** Reliability: IC α= 0.8 TR t= 3.1, p< 0.01 Validity: GFI= 0.86 **SED:** Reliability: α= 0.9 **PCOM:** Reliability: IC α= 0.93	Descriptive statistics, paired samples *t* test, and independent samples *t* tests to compare campers by characteristics. Pearson's correlations to evaluate relationships between variables. Shapiro-Wilk goodness of fit	**DV1:** Pre-camp M= 3.68 Post-camp M= 3.89 t= -2.781, p= 0.008, r= 0.42 **DV2:** Pre-camp M= 4.92 Post-camp M= 5.31 t= -5.89, p= 0.00, r= 0.76	**LOE:** III **Strengths:** Adequately powered and results are consistent with other studies. **Limitations:** Convenience sample, small n, limited generalization, no comparison group, and no long-term follow up.

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			overnight, child and parent agree to participate, and can read and understand English. **Attrition:** 0			test assessed instrument normality.	**DV3:** Total M= 4.04 Self-esteem M= 4.63 Social functioning M= 3.52 Emotional functioning M= 4.19 Physical functioning M= 4.10	**Conclusions:** Campers and parents reported an increase in self-care management, self-efficacy, and significant improvements in ATI. **Feasibility:** Camp provides an opportunity to increase self-management techniques and improve ATI.
Faith et al., (2019). Improvements in hope and beliefs about illness following a summer camp for youth with chronic illnesses.	Hope Theory	**Design:** Quantitative, quasi-experimental (pre- and posttest) **Purpose**: To evaluate changes in	**N**= 62 **Demographics:** Mean age: 13.45 years Cancer: 34.4% SCD: 13.1% Renal disease: 26.2% Heart disease: 6.6% Other chronic illness: 19.7%	**IV**: Camp experience **DV1**: HA **DV2**: HP **DV3**: ATI **DV4**: BBSC benefit **DV5**: BBSC burden	**CHS** Reliability: IC r= 0.77 TR r= 0.73, p< 0.001 Validity: r= 0.61 **CATIS** Reliability: IC α= 0.8	Paired-samples t-tests to compare HA, HP, ATI, and perceptions of illness benefit and burden from	**DV1**: Pre-camp M= 13.16 Post-camp M= 12.82 t= 0.73 d= 0.09 **DV2**: Pre-camp	**LOE**: III **Strengths**: Diverse sample, camp shared common features of illness specific camps, and provided a

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Funding: None, camp hosted by non-profit **Country:** US **Bias**: None		hope, attitude toward illness, and perceptions of illness following participation in a SC for youth with a variety of chronic illnesses.	**Setting**: Five-day SC for youth with chronic illness. **Exclusions**: Individuals that did not complete both pre- and post-camp measures. **Attrition**: 14 campers	**DV6:** Number of camp activities **HA:** Youths' beliefs about ability to accomplish goals. **HP:** Youths' confidence that actions will help them achieve goals.	TR t= 3.1, p< 0.01 Validity: GFI= 0.86 **BBSC** Reliability: IC benefit α= 0.85, burden α= 0.80 TR benefit r= 0.74, burden r= 0.78 Validity: r≥ 0.5, p< 0.001	beginning to end of camp. Hierarchical regression to examine whether participation in optional camp activities predicted changes in dependent variables.	M= 12.05 Post-camp M= 12.02 t= 0.07 d= 0.01 **DV3**: Pre-camp M= 3.69 Post-camp M= 3.36 t= 4.14 d= 0.41 **DV4**: Pre-camp M= 32.83 Post-camp M= 32.92 t= -0.09 d= -0.01 **DV5**: Pre-camp M= 23.00 Post-camp M= 23.57 t= -0.64 d= -0.06	unique contribution to the literature. **Limitations**: Small N, no follow-up data collected, no control group, and self-reported data instead of objective, observable data. **Conclusions**: There were no changes in campers' hope, ATI, or perceptions of illness benefit or burden. These findings are contrary to findings of illness specific camps.

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							DV6: β= -0.46 t= -1.55 p= 0.13	**Feasibility**: Camps for youth with chronic illness require extensive resources. This study does not show the benefit of a camp for those with a variety of chronic illnesses.
Hill et al., (2015). Measuring the impact of a medical specialty camp. **Funding**: None, camp was volunteer run **Country**: US **Bias:** None	Self-Determination Theory	**Design:** Quantitative, quasi-experimental (Pre- and posttest) **Purpose**: Determine the efficacy of a diabetes camp in terms of development of camper competency,	**N**= 23 completed pretest, 34 completed posttests **Demographics:** Mean age: 10.63 years Male: 46.7% Mean time since diagnosis: 3.61 years Mean HbA1C: 7.78 **Setting**: Three-day family camp.	**IV1:** Campers with 0-24 months since diagnosis **IV2:** Campers with 25-48 months since diagnosis **IV3:** Campers with 49-160 months since diagnosis **DV1**: Competence	**BPNS** (Post-test only) Reliability: α= 0.49 Validity: CFI= 0.59 **PCS** Reliability: α= 0.904 Validity: r= 0.54 **DSPSA** (Post-test only)	Pearson's correlation to determine if there was a statistical relationship between pre-camp and post-camp perceived competence levels. One-way ANOVA to determine if	**DV1**: Pre-camp M=5.11 Post-camp M= 5.15 F=8.56 r= 0.662 p= 0.014 IV1: M=5.61 IV2: M=5.31 IV3: M=4.25 F= 5.25 p= 0.013 **DV2**: PCS effect on	**LOE**: III **Strengths**: Reinforced prior studies and sample size was acceptable for statistical analysis. **Weaknesses**: Small n, 33% of participants did not complete the pre-test, BPNS IC was weak,

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
		autonomy, and relatedness.	**Exclusions**: Campers without an adult family member. **Attrition**: 0	**DV2**: Relatedness **DV3**: Autonomy **Competence:** sense of mastery **Relatedness:** sense of connectedness to the learning environment. **Autonomy:** perceived origin or source of one's own motivation.	Reliability: α= 0.968 Validity: CVI= 0.8	levels if autonomy support were different for groups with different levels of experience managing DM. Linear regression to examine the effect post-camp perceived competence had on relatedness and to examine the relationship between camper satisfaction and relatedness.	relatedness F= 7.32 t= 2.705 p= 0.011 Relatedness effect on satisfaction F= 9.21 t= 3.035 p= 0.005 **DV3:** IV1: n= 9 M= 1.61 IV2: n= 10 M= 2.28 IV3: n= 9 M= 2.13 F= 0.367 p= 0.7	sample was not diverse. **Conclusions**: There was an increase in perceived competence in managing DM with newly diagnosed campers gaining the most benefit, increased competence predicted relatedness, and those with higher levels of relatedness were more likely to be satisfied with camp. Autonomy score increased; however, the difference was not statistically significant.

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								Feasibility: As medical specialty camps increase, self-determination theory can be utilized to measure outcomes.
Karlson et al., (2020). Physical activity and pain in youth with sickle cell disease. **Funding:** None declared **Country:** US **Bias:** None	Fear Avoidance Model	**Design:** Quantitative, cross sectional study **Purpose:** Examine the relationship between physical activity and pain in children with SCD.	**N=** 206 **Demographics:** Mean child age: 11.73 years Female: 54.9% Caregiver: 75.24% mothers **Setting:** Children and caregivers completed questionnaires during regularly scheduled clinic appointments over a three-year period. **Inclusion criteria:** Diagnosis of SCD, children aged 8-18 years, caregiver over	**IV1:** Children with Hemoglobin SS or Hemoglobin SC **DV1:** Physical activity **DV2:** Pain **DV3:** Pain interference **DV4:** Emotional distress **Physical activity**: planned activity consisting of continuous movement,	**Family Symptom Inventory** α= 0.86–0.92 **PROMIS-25** α= 0.87 **Child Physical Activity Questionnaire** α= 0.83	Multiple linear regression to model pain intensity, pain interference, and pain frequency. Wilcoxon Rank Sum test and 2-sample *t* test, χ^2, and Fisher exact test to evaluate the differences between groups. Spearman correlation	**DV1:** 0 days/week: 3.66% 1-2 days/week: 21.95% 3-5 days/week: 40.24% 6-7 days/week: 22.45% **DV2:** Pain intensity M= 4.96 Rarely: 16.4% Sometimes: 46.03%	**LOE:** IV **Strengths:** Large sample size and data collected from child and caregiver. **Limitations:** Cross-sectional survey and self-report on activity level. **Conclusions:** Low rates of physical activity are associated with increased

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			18 years old, ability to read and write in English. **Exclusion criteria:** Significant developmental or cognitive delay limiting the ability to complete questionnaires. **Attrition:** 0	increases in heart rate, and heavy breathing for 30 minutes. **Pain interference:** interferences in daily activities, school, sports, peer relationships, and physical activity.		coefficient to describe the correlations between variables.	Often: 29.1% Most days: 8.5% **DV3:** Pain interference score M= 59.11 **DV4:** Depression and anxiety r=0.63, p< 0.01 Anxiety and pain interference r= 0.32, p< 0.01 Anxiety and pain intensity b= 0.1, p= 0.0014	pain interference and frequency. **Feasibility:** Education regarding moderate exercise in children with SCD could improve pain and pain interference.
Kelada et al., (2020). Camps for children with cancer and their families: A systematic	Not reported	**Design:** Systematic Review of qualitative and quantitative studies	**N=** 19 **DS:** MEDLINE/PubMed, PsycINFO, and Social Work Abstracts	**IV1:** Children's camp **IV2:** Family camp	Interviews, observations, focus groups, and various validated and unvalidated questionnaires.	PRISMA Mixed Methods Appraisal Tool	**DV1:** Females reported increased support, repeat camp	**LOE:** I **Strengths:** Findings were similar throughout

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review of psychosocial and physical impacts. **Funding:** Camp Quality Australia **Country:** Australia and Colombia **Bias:** None		**Purpose:** To provide an updated review of the benefits of child based and family camp.	**Inclusion criteria:** Original articles, camps for children up to 19 years old, camps for children with cancer or their families, published between 2013-2018. **Exclusion criteria:** Articles not published in English and studies that were similar to another in the review in terms of sample, measures, or design. **Countries:** US, Canada, & Hong Kong	**DV1:** Social support **DV2:** Psychological functioning **DV3:** Confidence and self-esteem **DV4:** Social skills and sociability **DV5:** Physical activity and physical functioning **DV6:** Fun and respite **DV7:** Solidarity and reconnecting as a family			attendance related to support, campers felt understood, accepted, and comfortable. Decreased support for adolescent males. **DV2:** Increased QOL, decreased internalizing symptoms, repeat camp related to improved coping strategies, psychosocial adjustment improved for females. Increased internalizing	studies, the findings support previous results, and critical appraisal of studies was discussed. **Limitations:** Lack of comparison groups, no long-term follow-up, use of non-validated measures, small sample sizes within studies, and several articles did not report details of the study. **Conclusions:** There is moderate evidence to support short term benefit of

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
							symptoms for siblings. **DV3:** Mixed results **DV4:** Increased sociability, friendships formed, repeat attendance related to social functioning. **DV5:** Improved activity, activity increased before and after camps, repeat attendance positively related.	children's and family camps for children with cancer. **Feasibility:** Camp offers physical and psychosocial benefits to families and children.

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
							DV6: Fun and respite experienced. **DV7:** Family reconnection	
Meltzer et al., (2018). Benefits of disease-specific summer camps: Results from quantitative and qualitative studies at Roundup River Ranch. **Funding:** None **Country:** US **Bias:** None	Social Comparison Theory and Psychosocial Development Theory	**Design:** Mixed methods. Quantitative, longitudinal study **Purpose:** To examine the benefits of disease-specific SC for children with chronic illnesses.	**N=** 61 **Demographics:** Mean age: 13.3 years Female: 61.6% Cancer/tumors/SCD: 12 Renal disease: 8 Crohn's/celiac/liver disease: 16 **Setting:** Week long camp for children with chronic illness. **Inclusion criteria:** Campers scheduled to attend SC in 2015 and provided consent/assent. **Exclusion criteria:** Those who did not	**IV1:** Time **IV2:** Camper status **DV1:** Positive affect **DV2:** Meaning and purpose **DV3:** Peer relationships	**PROMIS** α= 0.87 **Positive Affect Pediatric 8-item** α= 0.94 **Meaning and Purpose Pediatric 8-item** α= 0.93 **Peer Relationships Pediatric 8-item** α= 0.84	Descriptive statistics to examine demographics. Assessment Center to score the PROMIS banks and create outcome variables. Linear mixed-effects models to examine differences in variables.	**DV1:** IV1: F= 25.09, p< 0.001 IV2: F= 0.01, p= 0.91 IV1 x IV2: F= 1.64 p= 0.2 **DV2:** IV1: F= 5.52, p= 0.006 IV2: F= 0.32, p= 0.57 IV1x IV2: F= 5.26, p= 0.008 **DV3:**	**LOE:** IV **Strengths:** Findings are consistent with past studies, and use of reliable questionnaires. **Limitations:** Small sample size, high attrition, and reliance on self-report measures. **Conclusions:** Children who attended a disease-specific SC had short term improvements

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			complete the three surveys. **Attrition:** 25				IV1: F= 9.64, p< 0.001 IV2: F= 0.14, p= 0.71 IV1x IV2: F= 1.64, p= 0.2	in positive affect, meaning and purpose, and peer relationships. **Feasibility:** A disease specific camp can have positive outcomes.
Odar et al., (2013). Relationship between camp attendance and self-perceptions in children with chronic health conditions: A meta-analysis. **Funding:** None **Country:** US **Bias:** None	Self-esteem Theory and Self-perception Theory- inferred	**Design:** Meta-analysis **Purpose:** To evaluate the relationship between camp attendance and changes in self-perceptions in children with chronic conditions.	**N=** 31 **DS:** PubMed, PsycINFO, ERIC, and Proquest **Inclusion criteria:** Quantitative, original studies, written in English, children and adolescents with chronic conditions, participation in camps designed for chronic conditions, one measured outcome relating to self-perception, and	**IV:** Camp completion **DV1:** Post camp self-perception **DV2:** Follow-up self-perceptions	**Self-Perception Profile for Children and Adolescents** α= 0.81 **Piers-Harris Children's Self-Concept Scale** α= 0.91 **Rosenberg Self-esteem Scale** α= 0.77–0.88 **Culture-free Self-esteem Scale**	PRISMA Cohen's d to calculate ES. Stem and leaf plot to identify outliers. Q-statistics to test homogeneity.	**DV1:** Q (30)= 285.697, p<0.001 d= 0.25, 95% CI [0.16-0.34] **DV2:** Q (10)= 45.38 p<0.001 d= 0.15, 95% CI [0.05-0.26]	**LOE:** I **Strengths:** Use of all quantitative studies with similar methodologies, addressed potential bias, and adequate N. **Limitations:** Limited literature, small sample sizes of individual studies, small

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			studies reporting statistics to calculate ES. **Exclusion criteria:** Not specified		α= 0.81–0.93 **Child Health Questionnaire** α= 0.93			ES, and individual studies were missing statistical data. **Conclusions:** Children and adolescents attending a camp for chronic conditions experienced a small but significant improvement to self-perception post-camp and at extended follow-up. **Feasibility:** Camp may improve children's immediate and prolonged self-perception.

Key: **ANOVA-** analysis of variance; **ATI-** attitude towards illness; **BBSC-** benefit and burden scale for children; **BPNS-** basic psychological needs scale; **CATIS-** children's attitude toward illness scale; **CFI-** comparative fit index; **CHS-** children's hope scale; **CI-** confidence interval; **COCA-I-** Children's Oncology Camping Association International; **CVI-** content validity index; **DM-** diabetes mellitus; **DS-** databases searched; **DSPSA-** diabetes-specific parental support for adolescents; **DSTAR-** diabetes strength and resilience measure; **DV**- dependent variable; **ES-** effect size; **GFI-** goodness of fit index; **HA-** hope agency; **HbA1C-** hemoglobin A1C; **HP-** hope pathway; **IC-** internal consistency; **IV**- independent variable; **LOE-** level of evidence; **N**- number of studies; **n**- number of participants; **PAID-** problems areas in diabetes; **PCOM-** pediatric camp outcome measure; **PCS-** perceived competence scale; **PRISMA-** preferred reporting items for systematic reviews and meta-analyses; **PROMIS-** patient-reported outcomes measurement information system; **QI-** qualitative interview; **QOL-** quality of life; **SC-** summer camp; **SCD-** sickle cell disease; **SED-** self-efficacy for diabetes scale; **TRC-** therapeutic recreation camp; **US-** United States

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Rea et al., (2019). A systematic review of therapeutic recreation camp impact on families of children with chronic health conditions. **Funding**: None **Country**: US, Canada, Australia, and Ireland **Bias**: None	Health Belief Model- inferred	**Design:** Systematic Review of survey and QI studies **Purpose**: To provide a synthesis of research on how TRC impact the parents and siblings of children with a variety of chronic conditions.	**N**= 21 **DS**: PubMed, PsycInfo, SportDISCUS, Health Source Nursing/Academic Edition **Inclusion criteria**: Peer-reviewed, between January 2000 and May 2018, English language, sample including parents and/or siblings of children with chronic health conditions, participation of parents, siblings, and/or patient in TRC, measurement of specific parent, sibling, or family outcome. **Exclusion criteria**: Not related to camp or	**IV1**: Sibling camp **IV2**: Family camp **IV3**: Patient camp **IV4**: Patient & sibling camp **DV1**: Parent outcomes **DV2**: Sibling outcomes **DV3**: Family outcomes **Parent outcomes**: include psychological health, social support, respite, and disease knowledge. **Sibling outcomes:** include psychological health, self-	Semi-structured interviews and a variety of validated and camp created questionnaires.	PRISMA	**DV1**: Parental outcomes improved in 7 studies. **DV2**: Sibling outcomes improved in 6 studies **DV3**: Family outcomes improved in 3 studies.	**LOE**: I **Strengths**: Findings are consistent with previous reviews and expands on current knowledge. **Weaknesses**: Nearly half of the studies did not use validated measures or relied on qualitative interviews, high potential for bias, limited studies available, and results may not be generalizable.

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			did not include a family component.	concept, social support, ATI, and camp experience.				**Conclusions**: Camp has a positive impact on parents and siblings among different chronic illnesses. **Feasibility**: Including parents and siblings in medical specialty camps can be beneficial, however traditional camp duration may be challenging due to work schedules.
Weissberg-Benchell et al., (2019). Diabetes camp still matters: Relationships	Self-care Theory- inferred	**Design:** Quantitative, pre and post-test	**N=** 2488 **Demographics:** Age 8-18 years M= 12.8 years Female: 51.9%	**IV1:** Parents of adolescents **IV2:** Adolescents **IV3:** Parents of children	**PAID teen and child version** α= 0.91–0.96 **Self-care Skills Checklist**	*t*-tests and bivariate correlations to examine relationships between	**DV1:** IV1: d= -0.23, p < 0.001 IV2: d= -0.12, p< 0.001	**LOE:** III **Strengths:** Large sample size, supports prior research,

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
with diabetes-specific distress, strengths, and self-care skills. **Funding:** Leona M. and Harry B. Helmsley Charitable Trust **Country:** US **Bias:** None		**Purpose:** To study the association between participation in diabetes camp and diabetes related distress, self-care, and strengths.	First-time campers: 28.6% **Setting:** Campers from 44 diabetes camps in the US. **Inclusion criteria:** English speaking parent to consent **Attrition:** 20%	**IV4:** Children **DV1:** Diabetes-specific emotional distress **DV2:** Perceived independence in self-care skills **DV3:** Diabetes-specific strengths	α= 0.84– 0.87 **DSTAR** α= 0.77	demographic variables and pre-camp scores of DV. Sidak-Bonferroni correlation to adjust for inflated type 1 error. Independent samples *t* tests to examine the difference between campers and parents on pre-camp measures. Paired *t* tests to examine pre-post changes for parent and youth reports of DV.	IV3: d=-0.23, p< 0.001 IV4: d= -0.13, p= 0.001 **DV2:** p< 0.001 IV1: d= 0.22 IV2: d= 0.11 IV3: d= 0.26 IV4: d= 0.24 **DV3:** IV2: d= 0.07, p= 0.054 IV4: d=0.06, p= 0.168	and consideration of bias. **Limitations:** Low sample diversity, findings may not be generalizable, varied camp programming, and high attrition. **Conclusions:** Campers and parents reported improvements in distress and self-care skills after attending a diabetes camp. **Feasibility:** Camp can provide an opportunity to improve self-

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
								care and reduce distress for children and families.
Wu et al., (2016). A multisite evaluation of summer camps for children with cancer and their siblings. **Funding:** COCA-I, National Cancer Institute of the National Institutes of Health, and University of Sydney Fellowship **Country:** US and Canada **Bias:** None	Self-esteem Theory- inferred	**Design:** Quantitative, cross sectional study **Purpose:** To investigate differences in camp outcomes by demographics, illness, and camp characteristics across multiple sites.	**N=** 2284 Patients= 1230 Siblings= 884 **Demographics:** Patient age M= 12.9 years Sibling age M= 12.0 years Female: 49.3% First time campers: 22.5% **Setting:** Nineteen SC for children with cancer or their siblings held over six- or seven-days during summer of 2012. **Inclusion criteria:** Children aged 6-18 years attending SC for children with cancer,	**IV1:** Patient campers **IV2:** Sibling campers **DV1:** Self-esteem **DV2:** Social functioning **DV3:** Emotional functioning	**PCOM** IC α= 0.93	Descriptive statistics to summarize demographic information. χ^2 analyses and *t*-tests to assess demographic differences between patients and siblings. *t*-tests and ANOVA to determine if PCOM scores differed by camper characteristics and camp setting.	**DV1:** t= -3.26, p= 0.001 d= 0.14 (0.06-0.23) CI= 95% **DV2:** t= -0.1, p= 0.914 **DV3:** t= -4.42, p< 0.001 d= 0.20 (0.11-0.28) CI= 95%	**LOE:** IV **Strengths:** Multiple sites across two countries, standardized measures, and large sample size. **Limitations:** No control group and no long-term follow-up, **Conclusions:** Children with cancer and their siblings benefit from SC and repeated attendance may

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Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			survivors, or siblings, and parental consent. **Exclusion criteria:** Children of an adult cancer patient **Attrition:** 7.5%			Effect size and 95% CI to assess significant differences between groups.		be related to better outcomes. **Feasibility:** Camp provides a positive experience for children with cancer and their siblings and repeated attendance may increase these effects.

Key: **ANOVA-** analysis of variance; **ATI-** attitude towards illness; **BBSC-** benefit and burden scale for children; **BPNS-** basic psychological needs scale; **CATIS-** children's attitude toward illness scale; **CFI-** comparative fit index; **CHS-** children's hope scale; **CI-** confidence interval; **COCA-I-** Children's Oncology Camping Association International; **CVI-** content validity index; **DM-** diabetes mellitus; **DS-** databases searched; **DSPSA-** diabetes-specific parental support for adolescents; **DSTAR-** diabetes strength and resilience measure; **DV**- dependent variable; **ES-** effect size; **GFI-** goodness of fit index; **HA-** hope agency; **HbA1C-** hemoglobin A1C; **HP-** hope pathway; **IC-** internal consistency; **IV**- independent variable; **LOE-** level of evidence; **N**- number of studies; **n**- number of participants; **PAID-** problems areas in diabetes; **PCOM-** pediatric camp outcome measure; **PCS-** perceived competence scale; **PRISMA-** preferred reporting items for systematic reviews and meta-analyses; **PROMIS-** patient-reported outcomes measurement information system; **QI-** qualitative interview; **QOL-** quality of life; **SC-** summer camp; **SCD-** sickle cell disease; **SED-** self-efficacy for diabetes scale; **TRC-** therapeutic recreation camp; **US-** United States

Table A2

Synthesis Table

Author	Bultas	Faith	Hill	Karlson	Kelada	Meltzer	Odar	Rea	Weissberg-Benchell	Wu
Year	2015	2019	2015	2020	2020	2018	2013	2019	2019	2016
LOE/ Design	III/ Quasi-experimental	III/ Quasi-experimental	III/ Quasi-experimental	IV/ Cross-sectional	I/ SR	IV/ Mixed Methods	I/ MA	I/ SR	III/ Quasi-experimental	IV/ Cross-sectional
Diagnosis										
SCD		X		X		X				
DM	X		X				X	X	X	
Cancer		X			X	X	X	X		X
Other		X				X	X	X		
Intervention										
Patient Camp	X	X			X	X	X	X	X	X
Family Camp			X		X			X		
Sibling Camp					X			X		X
Physical Activity				X						
Outcomes										
ATI	X	X				X		X		
Self-care/Self-management	X		X		X				X	
Social skills or support			X		X	X		X	X	X
Physical activity				X	X					
Fun/Respite/Camp Satisfaction	X				X			X	X	X
Self-perception/Self-esteem		X	X		X	X	X	X	X	X
Measurement Tools										
BPNS			X							
CATIS	X	X								
PCOM	X				X			X		X
PCS			X							
PROMIS				X	X	X				
Interviews					X			X		
Other	X	X	X	X	X	X	X	X	X	

Key: **ATI-** attitude towards illness; **BPNS-** basic psychological needs scale; **CATIS-** children's attitude toward illness scale; **CHS-** children's hope scale; **DM-** diabetes mellitus; **LOE-** level of evidence; **MA-** meta-analysis; **PCOM-** pediatric camp outcome measure; **PCS-** perceived competence scale; **PROMIS-** patient-reported outcomes measurement information system;; **SCD-** sickle cell disease; **SR-** systematic review

Appendix B

CDC Framework for Program Evaluation

CDC (1999).

Appendix C

Survey Results

Table C1

Participant Demographics

Demographics	Number	Percent
Gender		
Female	26	84
Race/Ethnicity		
Black/African American	29	93.5
Caucasian/White	1	3
Other	1	3
Respondent Age		
15-17	2	6
18-24	2	6
25-34	6	19
35-44	9	29
45-54	8	26
>54	4	13
Region in Arizona		
Tucson Area	22	71
Phoenix Area	7	23
Other	2	6
Relationship to SCD		
SCT	13	27
SCD	5	10
Child with SCT	7	15
Child with SCD	16	33
Had a child with SCD	5	10
Community partner	2	4
Children's Age		
0-5	6	17

6-10	7	19
11-15	6	17
16-20	10	28
>21	5	14

Note. SCD = sickle cell disease; SCT = sickle cell trait.

Table C2

Disease Knowledge

Question	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
SCD in general	58.1%	38.7%	3.2%	0	0
Role of hemoglobin in SCD	67.7%	25.8%	6.5%	0	0
Complications of SCD	77.4%	22.6%	0	0	0
Available education and resources	51.6%	29%	16.1%	3.2%	0
Desire for more education on SCD	32.3%	19.4%	32.3%	12.9%	3.2%
Perception of PCP knowledge of SCD	35.5%	19.4%	16.1%	16.1%	3.2%
Comfort discussing concerns with hematologist	80.7%	9.7%	0	0	0

Note. PCP = primary care provider; SCD = sickle cell disease.

Table C3

Treatment and Medication Management

Question	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Education on treatment/management	67.7%	22.6%	3.2%	0	0
Comfort with prescribed medication	61.3%	25.8%	6.5%	0	0
Difficulty obtaining prescribed medication	3.2%	3.2%	22.6%	25.8%	38.7%
Agree with prescribed management	51.6%	29%	9.7%	0	0
Child is active participant in health	64.5%	22.6%	6.5%	0	0

Table C4

Self-care Themes

Theme	Number of responses
Religion/Spirituality	15
Outdoors/Exercise	13
Family/Friends	13
Hobbies	6
Meditation/Mindfulness	4
Rest	3
Nutrition/Hydration	3
Pampering	2
Music	2

Figure C1

Number of Days with at Least 30 Minutes of Physical Activity

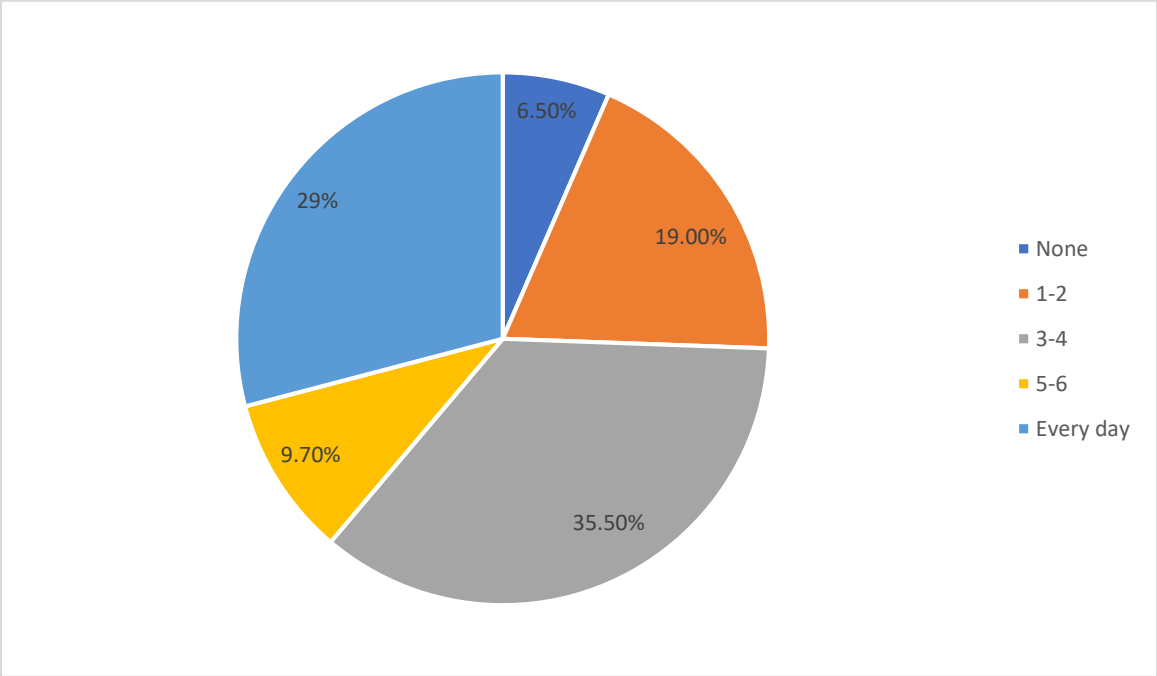

Figure C2

Daily Consumption of Non-caffeinated Beverages

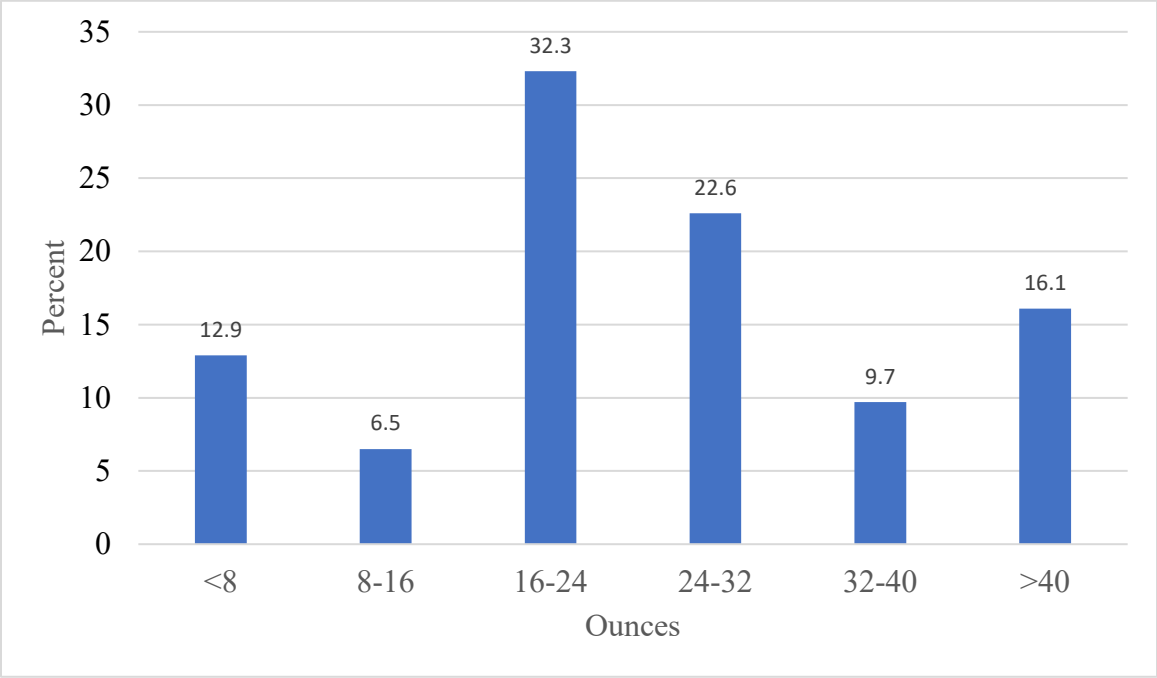

Table C5

Health Status in the Last 12 Months

Question	Never/None	1-2	3-4	5-6	>6
Pain episodes requiring opioids	22.6%	25.8%	16.1%	9.7%	9.7%
Pain crises	35.5%	38.7%	12.9%	6.5%	6.5%
Emergency room visits for SCD	48.4%	41.9%	3.2%	6.5%	0
Urgent care visits for SCD	80.7%	16.1%	3.2%	0	0
Hospitalizations for SCD	51.6%	38.7%	3.2%	6.5%	0

Note. SCD = sickle cell disease.

Figure C3

Experiences of Stigmatization

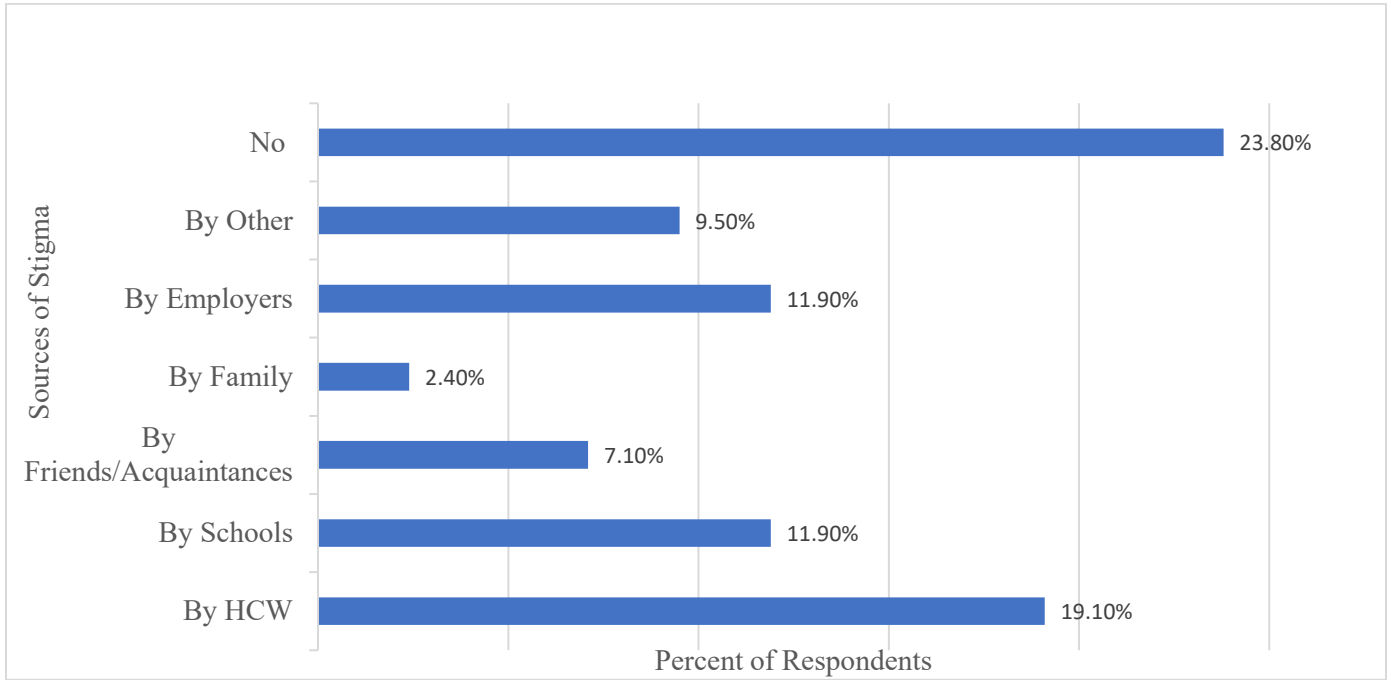

Table C6

Diagnosis Disclosure Themes

Theme	Number of responses
Comfort Disclosing	
Spread awareness/education	8
Build support network	4
Discomfort Disclosing	
Being treated differently	4
Isolation/unrelatable	2
Stigma experience	2

Table C7

Diagnosis and Health Concerns

Question	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
Comfortable disclosing SCD diagnosis	41.9%	25.8%	16.1%	6.5%	0
Worry surrounding child's health	63.3%	13.3%	16.7%	0	0
Overwhelmed by child's health needs	6.9%	10.3%	31%	37.9%	6.9%

Note. SCD = sickle cell disease

Table C8

School and Social Needs

Question	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
Feels supported in school	29%	12.9%	25.8%	3.2%	0
School nurses are knowledgeable about SCD and child's needs	9.7%	6.5%	19.4%	9.7%	0
Academically successful	35.5%	29%	12.9%	0	0
Enjoys schools	29%	29%	16.1%	3.2%	0
Comfortable playing with friends	54.8%	16.1%	9.7%	3.2%	0
Experienced bullying related to SCD	6.5%	9.7%	3.2%	16.1%	29%
Successfully achieves goals	41.9%	38.7%	12.9%	0	0
High self-esteem	32.3%	29%	25.8%	3.2%	0
Positive outlook	29%	38.7%	19.4%	3.2%	0
Feels limited by SCD	3.2%	22.6%	25.8%	22.6%	12.9%

Note. SCD = sickle cell disease

Table C9

Knowledge of Organization

Question	Yes	No	Unsure
Familiar with project site	80.7%	19.4%	0
Attended events hosted by site	77.4%	22.6%	0
Knowledge of existing camps	64.5%	35.8%	0
Prior camp attendance	22.6%	77.4%	0
Interest in attending SCD camp	77.4%	3.23%	19.4%

Note. SCD = sickle cell disease

Figure C4

Desired Camp Education

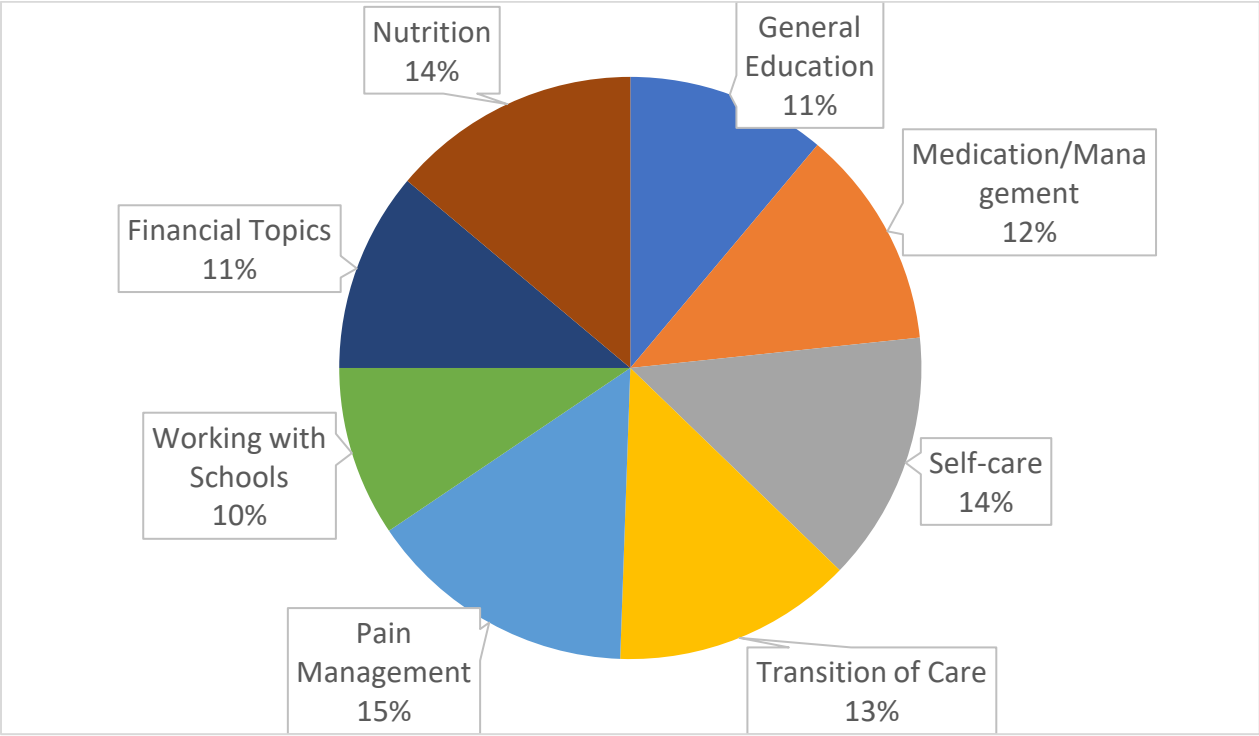

Figure C5

Goals of Camp