EXPLORING CAMPER PERSPECTIVES ON HEALTH CARE TRANSITION PROGRAMMING OFFERED THROUGH MEDICAL SPECIALTY CAMPS

by

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Planned health care transition from pediatric to adult health care is necessary for adolescents and young adults with chronic diagnoses to have positive health outcomes. Medical specialty camps offer an opportunity for campers to connect with others who have similar conditions, learn about their conditions, and engage in health care transition education. This community engaged qualitative descriptive study aimed to describe how overall participation in medical specialty camps and participation in camp’s transition focused activities are perceived and valued by campers with sickle cell disease or hemophilia. Nine pre-transition youth (16- 22 years) and four post-transition adults (22- 36 years) who attended medical specialty camps run concurrently in southeastern United States participated in semi-structured interviews. Interviews were transcribed verbatim and open coding methods were used to analyze the data. Our research highlights the viewpoints of an underserved and under-researched population. Data analysis resulted in three overlapping themes: Preparing for Adjustment and Independence; Building a Shared Community; and Easing into Transition. Findings suggest that the participants appreciated the opportunity to meet campers with similar health care conditions and often developed long-term friendships. For pre-transition youth, their key transition related concerns

were regarding communicating their condition to others, advocating for themselves, filling out health care paperwork, finding out about their new doctor and clinic team, and even about entering college. Their hesitancy in making the transition stemmed from pre-existing trusting relationships with their pediatric caregivers and comfort in that environment. The post-transition adults emphasized the importance of understanding their health care condition and communicating openly with their new health care providers. Participants advocated for more hands-on learning activities, while acknowledging benefits of camp attendance. They emphasized the need for camp programs to promote connection among youth with sickle cell or hemophilia as well as to improve the process of health care transition. This includes introducing the pre-transition youth to their adult doctor and clinic staff before the transition and discussing their medical condition in advance. Our findings, and feedback from the study partner suggest that using medical specialty camp settings could be viable venues for health care transition programming. Future research should examine the experiences of more medical specialty campers regarding what specific aspects of camp programming helps to prepare them for their health care transition.

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by

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CHAPTER 1: INTRODUCTION

As health care has become more advanced over the years, an increasing number of children and adolescents with chronic health conditions survive into their adult years. In the United States alone, over 500,000 young adults with chronic health conditions reach the age of twenty-one each year (Mahan et al., 2017). By the time that age is reached, it is unlikely that those young adults will be in the same health care clinic that they had attended as a child. This health care transition can be a difficult process for the adolescents, but research has shown that having a structured process for health care transition leads to positive outcomes. There are many methods used for health care transition education such as disease education, creating a plan of care, and familiarizing the adolescent with adult care before their transition (Schmidt et al., 2020). Another resource that may be used more intentionally to further educate adolescents about their health care transition could be through the use of special programming run by medical specialty camps. These camps are able to offer many benefits to their campers, and are in a unique place to help the adolescents learn more about their disease-specific problems. Medical specialty camps help their campers to build self-esteem, independence and self-determination skills, all of which are important for their eventual health care transition (Gagnon et al., 2019). More research from the campers' perspective can add to the literature, regarding the usefulness of medical specialty camp attendance and transition programming toward furthering readiness for health care transitions.

Emerging Adulthood

Emerging adulthood is the stage of life that occurs after adolescence, usually around the ages of 18 – 29 years (Arnett, 2000). During this time, individuals usually go from being dependent on others to becoming more independent and self-focused (Arnett, 2004). This time is

very important for the transition of any adolescent, but this period holds even more significance for adolescents with chronic medical conditions.

Health Care Transition

A health care transition is the process of moving from a child-centered to an adult-centered model of health care (Got Transition, 2021). It is a very difficult time to navigate, with the adolescent going from relying on their parents to help them with their medical condition to becoming responsible for handling many aspects of it on their own. Sawicki et al. (2011) have also found that only around 30% of adolescents with a chronic illness actually had discussed a plan to address transition. With no plan, it has been reported that these adolescents are at a higher risk for negative health outcomes both during their transition and long-term (Kim et al., 2019). It is important for communication about the transition between the adolescent, their parents, and their health care provider, as well as other programs that could help inform them more about their transition. According to Got Transition (2021), the typical time of transition is between the ages of 18 – 21 years, with a pre-transition period from the age of 12 – 17 years where the child is being prepared for their eventual transition, and a post-transition period around the ages of 18 – 23 years, referring to the time after the child starts with the adult-oriented health care system. Fair et al. (2016) described outcomes and skills that adolescents need to develop for a successful health care transition. This included understanding their condition, knowing and adhering to their medications, self-management and self-efficacy, and a strong social network, to name a few. Despite the importance of health care transitions, there are many barriers that can impede the process. Some of these barriers include the relationship with their health care provider, the beliefs they have about adult health care, lack of knowledge on their illness or medications, and a lack of self-management skills, among others (Gray et al., 2017).

Medical Specialty Camps

One of the tools that can help adolescents overcome some of the health care transition barriers are programs in a medical specialty camp. The attendance of a medical specialty camp by children and adolescents with chronic health conditions helps to promote long-term positive changes to self-esteem, self-perception, sociability, and confidence in those campers (Kiernan et al., 2004; Gillard & Watts, 2013). These camps allow their campers to interact with peers with similar opportunities and health care challenges as themselves regarding their disease management, social acceptance, and feelings of loneliness (Meltzer & Rourke, 2005). Desai et al. (2014) found that even shorter weekend camp experiences for children and adolescents with complex heart conditions can help lead to positive benefits such as increased self-esteem and positive emotions, as well as teach coping skills and provide information on their condition that the campers could use to help them outside of camp.

Theoretical Perspectives

The following theories will be used to help guide this thesis in the creation of interview questions as well as content analysis.

Emerging Adulthood Theory

Jeffery Arnett's emerging adulthood theory focuses on individuals in the age range of 18 – 29 years. This is described as a time where the person has moved on from immaturity but not fully taken on the responsibilities of the young adult period (Arnett, 2000). This period is not experienced the same way by everyone, varying across different socioeconomic statuses, cultures, and other contexts making each person's emerging adulthood period face different problems and play out in different ways (Arnett, 2004). This theory is useful for this study since

the process of health care transitions take place during this period, and emerging adult with chronic illnesses must deal with all the issues others in this period confront on top of having their transition to adult-oriented medicine at the same time.

Self-Determination Theory

The self-determination theory focuses on how motivation and personality influence the behavior and development of individuals (Deci & Ryan, 2012). It sorts motivation into autonomous, i.e., when someone does a task by themselves; and controlled, i.e., when someone is influenced by an outside force to complete a task (Gagné & Deci, 2005). This theory is useful for this study due to how it looks at motivation, and can show if individuals going through health care transition are motivated by their own desire to move to adult-oriented health care or if the motivation is coming from outside forces.

Community Engaged Research

Community engaged research refers to a collaborative relationship and joint-decision making between researchers and community personnel (Mikesell et al., 2013). The two groups work together to maximize both of their strengths and create a study that can help answer questions that both parties have. For this thesis I have a community partnership with Camp Hope and Camp Rainbow, camps offered through the East Carolina University Brody School of Medicine's Pediatric Hematology and Oncology Clinic. Camp Hope serves children and adolescents with sickle cell disease, while Camp Rainbow serves children and adolescents with cancer or hemophilia. Serving on the thesis committee for this study as the community partner is the director of Camp Hope and Camp Rainbow.

Purpose of the Current Study

Looking at the literature surrounding medical specialty camps, it is clear camp attendance offers many benefits such as providing campers with new information on their condition, developing coping skills, improved self-esteem, improved self-perception, and more quality social connections (Desai et al., 2014; Kiernan et al., 2004; Gillard & Watts, 2013). The literature has also shown that discussion about a transition prior to it occurring is one of the most important aspects of creating a successful health care transition (Syverson et al., 2016). What is lacking in the current research is information on the programs medical specialty camps use to help educate its campers about health care transition, and if those programs are useful to the youth and adolescents as they begin their own health care transition. The purpose of this current study was to examine what aspects of the health care transition programming by Camp Hope and Camp Rainbow is perceived as being useful by youth in both pre- and post- transition groups, and to provide this information to Camp Hope and Camp Rainbow for transition-related program enhancement.

CHAPTER 2: LITERATURE REVIEW

Emerging adulthood is challenging for everyone (Arnett, 2004), and this is especially true for those with chronic medical conditions transitioning from pediatric to adult health care (Reiss & Gibson, 2002). There are many barriers for these individuals that can affect the success they have with their health care transition, such as a lack of discussion about their health care transition beforehand (Syverson et al., 2016). Medical specialty camps serving adolescents with chronic health conditions create similar conditions to those they will see as an emerging adult such as increased independence and self-management skills (Olsen et al., 2018) and can create more knowledge about their condition and medication (Desai et al., 2014) while increasing their self-esteem and feelings of peer support (Mayo, 2016).

Transition to Adulthood

Emerging Adulthood

Emerging adulthood was described by Jeffery Jensen Arnett (2000) as a time where the person moved on from the immaturity of their youth but before they have fully taken on the responsibilities of the young adult period, usually occurring between the ages of 18 – 29 years. This theory has been used in a wide range of fields, and is continuing to catch on in popularity even now. In it, Arnett outlined five features that separated this period in life from the other periods: identity exploration, instability, self-focus, feeling in-between, and possibilities. Identity exploration is where the person tries to answer the question of "Who am I?" and tries out different life options. Instability refers to how the individual does not yet have a permanent place to live, place to work, or romantic partner. Self-focus describes how the individuals in this stage tend to be concerned mainly with themselves and their own goals rather than the goals of others.

Feelings of in-between refers to how the individual is in a state of transition, where they are neither fully an adolescent nor fully an adult. The final feature, possibilities, refers to how the individual experiences more chances to drastically change and alter their life in this stage more so than any other point in life (Arnett, 2004). To put it simply, emerging adulthood describes the time in a person's life where they are moving away from being dependent on their parental figures, towards becoming a self-sustaining and independent member of society. Arnett (2007) claims that this period is presented positively by most people, and that the ability to focus on oneself leads to satisfaction and a better understanding of who they are as a person. But for those who have a medical condition, the stage of emerging adulthood is much more complicated.

Health Care Transitions

Health care transition refers to the period where an individual with a chronic illness undergoes a change from the health care they were receiving as a child into an adult health care program (Got Transition, 2021). Youth with chronic health conditions are living longer, which has led to an increase in interest in the transition from pediatric to adult health care (Reiss & Gibson, 2002). When an individual turns 18 years old, they are considered an adult and the power of who can make health care decisions transfers from the parents to the now adult patient. This means that the individual will now need to be able to make informed and knowledgeable decisions about their health care themselves (Maradiegue, 2003). This means that for many, their health care transition would take place around the age of 18 years, but depending on their chronic health care condition the transition period could be initiated and completed from any time from 14 – 25 years (Rutishauser et al., 2014).

Fair et al. (2016) attempted to define what could be seen as a successful health care transition. Through a survey given to participants at outpatient, community-based, and primary

care clinics, they came up with a list of ten outcomes that could be used to define what makes up the ideal transition outcomes. The list is as follows:

1) Quality of life: the individual's overall happiness and the ability for them to cope with their condition and have it not impact their daily lives more than it already does.
2) Understands Condition: the individual understands what their medical condition is and understands what complications it could cause in their life.
3) Knows Medication: the individual knows the names of their medications and understands the purposes, doses, and when to use them.
4) Adherence: refers to the ability to continue to take their medications and attend their treatment.
5) Self-Management: the individual is able to take care of their condition themselves without the need of others' help.
6) Attends Appointments: the individual is able to schedule, and makes the effort to attend, their own medical appointments with their primary health care provider.
7) Medical Home: the medical home refers to having a primary health care provider and the appropriate specialists to help the individual when they need it.
8) Avoids Unnecessary Hospitalization: the individual does not hospitalize themselves unless they absolutely have to.
9) Understands Health Insurance Options: the individual knows their options for health insurance and is able to make an informed decision on which option is best for them
10) Social Network: the individual has a social network of friends and family that can help support them when they need it.

This list covers a wide range of aspects for individuals going through a health care transition. Individual outcomes that would be important to the person going through the health care transition, such as quality of life and self-management, ranked highly. This seems to indicate that many of the people going through health care transitions see it as a personal goal and achievement that they want to accomplish. Health service outcomes such as attending medical appointments and avoiding unnecessary hospitalization also ranked highly, showing the importance of learning good habits before the transition. Finally, one social outcome was defined, showing that the individuals still find it important to create a strong social network and that it can have benefits for health care adherence (Fair et al., 2016).

In addition, Got Transition (2021) outlined their six core elements of transition. They state that these six elements define the structure of a basic health care transition process, and can be used by different facilities to accommodate the needs of their patients. They are: developing a transition policy, tracking and monitoring progress, assessing self-care and readiness, developing a health care transition plan, transferring care to an adult-oriented practice, and finally confirming the completion of the transition. They also provide recommended ages for each element, with developing a policy starting around when the child is 12 – 14 years, the next three elements occurring when they are 14 – 18 years, and the transfer of care occurring when they are anywhere from 18 – 21 years, and checking the completion anywhere from when they are 18 – 23 years old.

Reiss et al. (2005) identified multiple practices that help to facilitate a successful health care transition. The first was the idea of understanding that health care transition would be a long-term developmental process that would involve not just the individual, but their family, the health care professionals, and the health care system as a whole. This involved learning more

about the difference between their pediatric medicine and adult-oriented medicine. Another practice that was shown to help was a "transition note", which provided the young adult with the relevant medical information, references, and different strategies that they could use. As stated before, a trusting relationship between the young adult and the health care provider was also important in making sure that the transition experience went well (Reiss et al., 2005).

Marani et al. (2020) reviewed twenty-nine studies focused on health care transition and identified two broad types of models that were commonly used by different clinics. The first was the type that used multiple appointments and a multidisciplinary team comprised of both pediatric and adult health care providers that would educate the individual undergoing the health care transition and help them bridge the gap between the two forms of care. The second was a facilitator-led program, where the facilitator would hold separate appointments to help educate and teach the adolescent the skills they would need for their actual health care transition.

Problems that Arise During Transition

The health care transition process is naturally very complex. There are many different issues that can arise, both expected and unexpected, that can cause the individual to struggle with their transition. One such issue that has been identified as being a barrier to a successful transition is money. As the young adult is undergoing transition, they are also at a time where they may not covered by health insurance. This makes the financial burden on them that much more difficult if they are not prepared to be moved off of their family's health insurance (Reiss et al., 2005; Gray et al., 2017). One issue that could be more easily avoided but is often overlooked is the adolescent discussing the transition process with their physician. Surveys reported that only 50% of parents had discussed transition with their youth's physician and only 30% had an actual plan to address the needs they would have for transition (Sawiciki et al., 2011). Without

having these discussions and a plan, the process of transition comes suddenly to the adolescents, leaving them with little idea of what they should be doing.

While some of these issues can be planned for ahead of time, others are more sudden and can catch a family by surprise. Pediatric care can discharge youth whenever they start to display what they call "adult behaviors". These can include many changes that are sometimes seen with youth aged in their teenage years such as abusing illegal drugs, challenging authority, becoming sexually active, becoming pregnant, or being sent to a juvenile detention system (Sawicki et al., 2011). Many adolescents already view a lack of self-management skills as a potential barrier to their health care transition, so a sudden shift in their health care provider would be even more disruptive (Gray et al., 2017). Another issue that can be identified during transition is having a negative experience with an adult-oriented medicine service. Reiss et al. (2005) found that just one bad experience was enough to have the individual, their family, and even the health care provider become hesitant to continue with the transition process. To help ease this, Reiss et al. (2005) emphasizes the importance of the pediatric health care provider to end the existing doctor-patient relationship in a therapeutic manner to try and implicate that the patient should switch to an adult-oriented health care provider.

Potentially one of the biggest issues that can arise during a health care transition is a lapse in their disease care. Emerging adults are undergoing many different major life changes all at once, such as employment, academic changes, and new social expectations (Arnett, 2000). All of these changes happening at largely the same time is stressful for anyone, but people with chronic diseases have to also now worry about the transition from pediatric to adult-oriented health care. This can lead to lesser adherence to prescriptions and a decrease in attending regular health check-ups for some patients. If the patient is not prepared for this transition, it can lead to a

higher risk of negative health outcomes for the patient both during this time, and long-term (Kim et al., 2019). For these reasons, it is important and necessary for any patient with any chronic health disease to have a health care transition plan so that they can go through this time with minimal problems.

Perceptions of Transition

A poor transition can lead to many negative effects for young adults (Rutishauser et al., 2011). As such, it is important to look at what the youth and parents view as being important to the transition process. According to Rutishauser et al. (2014), most pre-transition youth say that a high barrier to transition is that they feel at ease with their pediatrician, and as a result are hesitant or nervous to switch to an adult physician. This comes from the years of care that leads to strong feelings of trust and comfort towards the pediatrician, that the youth do not yet have with anyone in adult-oriented health care. Interestingly, the post-transition group reported that as not being a particularly important issue. Betz et al. (2013) attempt to explain this by reasoning that pretransition adolescents have less consumer experiences to influence their judgement, so a bad experience affects them more than it would normally. Both the pre- and post-transition groups report that anxiety levels and a lack of information related to health care transition as being highly important to the transition process as well. One factor that could be affecting the pre-transition group's perceptions surrounding transition is if they have had any discussion about transition with their health care provider. Some studies report as high as 64% of adolescents as having no prior discussion with their health care provider about transition (Syverson et al., 2016). This could naturally influence the anxiety levels of those adolescents and their seeming lack of information. By having discussions about their transition with their health care providers, those in pre-transition groups could having more positive perceptions of the transition process.

Parents Role in Health Care Transition

The adolescents are not the only stakeholders invested in the transition process. The parents' perceptions could be just as important. The emerging adulthood period is particularly important in how the parents go from being their child's primary caregiver to the adult-aged child becoming more independent and taking care of themself (Arnett, 2000). As such, the parents are often worried with their emerging adult's ability to become independent and manage their disease by themselves (Delaney et al., 2021). As such, the parents can become invested in preparing their child to become independent and wanting to set them up for success. This leads to concerns about replacing a relationship with a pediatric health care provider with a new health care provider, as well as locating a suitable replacement provider and making sure their child has proper health insurance (Gaydos et al., 2020). It has also been found that the parents with greater role overload, when they must fulfill multiple roles at once beyond their capacity, tend to perceive their youth as less-prepared for their health care transition (Hart et al., 2019). This shows that their own fears and anxieties play a direct role in how confident they are in their child's ability to transition. Knowing what worries the parents hold may help to give us some insight into why children may experience anxiety for the health care transition process.

Current Efforts to Educate about Health Care Transitions

With the importance of health care transitions being more recognized, it is important to look into the current efforts to educate the transitioning adolescents. Currently it is mostly left up to the physicians to educate the adolescent about the transition process, but this responsibility may often fall upon the nurses due to the limited time many physicians have (Callahan et al., 2001). One of the more difficult aspects of health care transitions is that there is no one-size-fits-all age when transition occurs, so the education differs for individuals with different chronic

illnesses. Furthermore, every person is different, and those individual differences can affect what information they need to learn. There are some programs that work with clinics to introduce the youth and their families to their new adult care providers before the actual transition, which helps to ease their anxieties and create familiarity before their transition (Dogba et al., 2014). Other clinics have the adult health care take place in the pediatric clinic for the first year of their transition to help ease the patients into adult care. These methods all proved to be fairly effective in increasing rates of a successful transition, which was measured mostly by continued attendance of appointments and surveys of the transitioned young adults asking if they believed their transition was successful (Bloom et al., 2012). This information provides evidence to the idea that early education is one of the best ways to prepare adolescents for their health care transition, and that the earlier they start to think about it, the better off they most likely will be.

Camps

Summer Camps

Summer camps have been shown to have many positive effects on a person's development and way of thinking. This includes increased independence, perseverance, self-identity, an appreciation of others' differences, and a willingness to try new things (Warner et al., 2021). Readdick and Schaller (2005) found that attending summer camp for just twelve-day sessions raised the camper's self-esteem and self-image. Other research has been conducted finding an improvement in behavior for some children, as well as improvements in the relationships that the child had (Buskirk-Cohen, 2015). Camps are able to offer an opportunity to teach youth and adolescents skills they could use in the future. Camps also have many similarities to the transition from high school to college. This includes the youth being in an environment away from home and their parents that they are not used to, interacting with those

that have different viewpoints from their own, the need for rapid adaptation to a new environment, and similar opportunities for social, emotional, and intellectual development (Olsen et al., 2018). These similarities help make camps a good place to introduce the ideas of transition and prepare the campers for future life experiences that they may have.

Medical Specialty Camps

There have been a growing number of camps that are focusing on working with children and adolescents with chronic illnesses. These camps work with children and adolescents with illnesses such as asthma, cancer, HIV, inflammatory bowel disease, sickle cell disease, congenital heart defects, musculoskeletal diseases, and many more (Sendak et al., 2018). These kinds of camps will be referred to in this thesis as medical specialty camps. It has been found, such as in Guest et al. (2017) that these camps deliver growth in the same areas that other, non-medically focused camps have. Due to their nature as specialty camps, these camps are able to target other, often disease-specific education benefits that general camps do not. This means that these camps can look to help their campers focus on aspects such as their disability management, communication skills, and other disease-specific problems (Gagnon et al., 2019).

Positive Effects of Medical Specialty Camps

Medical specialty camps have been shown to provide a wide range of benefits to their target audiences in both short-term and long-term capacities. Kiernan et al. (2004) found evidence that attendance in a medical specialty camp led to positive long-term changes in the campers' self-esteem and self-perception. It has also been found that the camps are able to provide these children with experiences that they could not normally receive, such as

experiencing more freedom than they are used to and helping them increase their sociability and confidence (Gillard & Watts, 2013).

Studies have also shown benefits to the campers' social lives as a result of attending medical specialty camps. Gillard and Watts (2013) examined a medical specialty camp that focused on children with cancer. The study noted that due to the environment created by the camp, the children were able to become more independent as well as develop deep connections with their peers and the staff members. Another study focusing on an oncology summer camp examined how the adolescent campers viewed themselves in comparison to others. By giving the adolescents the chance to compare themselves to others with the same disease, they were given a better comparison for self-evaluation. This led to improved psychosocial outcomes in those campers such as better confidence, perceived social acceptance, and global self-worth (Meltzer & Rourke, 2005). Another group looked into a camp serving children with spina bifida and found that the campers were able to gain more independence and gains in their own individual goals. Furthermore, they even showed better management of the responsibilities that came with having spina bifida (O'Mahar et al., 2010).

Perhaps one of the greatest benefits that medical specialty camps have is the ability to help these children learn the skills that they will need to help live with their condition and take better care of themselves. Hill et al. (2015) observed a camp for children with Type 1 diabetes, and found that the campers gained more knowledge about their illness, including skills such as how to monitor their blood glucose levels. Similarly, Lawton (2017) observed that after attending a camp for children with Pediatric Inflammatory Bowel Disease (PIBD) the campers were better at coping with the stress that the disease had brought into their lives. A similar effect

was found by Kiernan et al. (2004) where they reported children were able to better manage the anxiety they felt from their condition after attending a therapeutic recreation camp.

Transition and Camp

Summer camps have many similarities to the experiences that emerging adults experience as they leave home. The nature of camps requires the camper to adapt to a new social and physical environment quickly, much like an emerging adult has to do as they leave home for college in their first-year. Olsen et al. (2018) expands upon these similarities further by showcasing how camps and colleges create similar skills and environments. They identify five areas where these comparisons are most apt: the setting, physical development, social development, emotional development, and intellectual development. Both camps and college are in unfamiliar environments, force the individual to adapt to new physical challenges, develop a social climate different from the one they had at home, role models and opportunities for emotional growth, and the potential to learn new skills that they would not have learned otherwise. Overall, the skills that can be learned at a summer camp can also be directly correlated to skills that can help a student be successful in college.

Though not much, there has been some research conducted the examines the potential effects that summer camps can have on preparing children for health care transition. Desai et al. (2014) were interested in the effects that medical specialty camps have on children with complex heart defects (CHD). It was found that even during shorter weekend camp experiences campers were able to create friends and increase self-esteem and positive emotions. A social support network has been shown to be an important factor in a successful health care transition (Fair et al., 2016), and building friendships at a camp of people with a similar condition makes it more likely that the child will have someone to share their experiences with that will understand what

they are going through (Children's Hospital of Philadelphia, 2012). The camp was also able to help provide the campers with more information on their condition and developed coping skills that they could use to help them outside of camp (Desai et al., 2014). Mayo (2016) found that medical specialty camps also increase the self-esteem of campers that attend them, along with an increase in feelings of peer support. This once again shows that there are benefits gained by attending a medical specialty camp that will help the adolescents when they begin their health care transition. On top of these benefits for the campers, the parents benefit as well. Seeing their child succeed at camp can help them to realize that they can do all the activities typical children and adolescents enjoy and still be safe, even with their condition (Children's Hospital of Philadelphia, 2012). Camps are in a unique place where they can help prepare their campers with information about their condition and medication that they can then apply to when they are undergoing health care transition themselves. The camp can also inform the campers as to what the transition from pediatric to adult-oriented health care will look like so when the time comes, they are prepared.

Community Engaged Research

Community engaged research is a collaborative relationship between community personnel and researchers to help answer questions that both groups may have. Through this collaboration, community engaged research helps to create trust through shared power and joint decision-making between the two groups (Mikesell et al., 2013). This does not mean both groups have equal roles at all stages of research but rather they work with each other, maximizing each of their strengths, to help create stronger studies. This includes both sides collaborating on what kinds of questions they seek to answer and the ways in which the research is conducted (Ross et

al., 2010). For this study, the community partnership is with Camp Hope and Camp Rainbow, and the partner is the director of the camps.

Camp Hope and Camp Rainbow

Camp Hope and Camp Rainbow are two medical specialty camps that are offered by East Carolina University Brody School of Medicine and uses the Camp Don Lee facility in Arapahoe, North Carolina. Camp Hope is for children and adolescents aged 6 – 18 years with sickle cell disease and Camp Rainbow is for children and adolescents aged 6 – 18 years with cancer or hemophilia. The camps' goals are to help the campers build self-confidence, develop stronger social and emotional wellbeing, create independence, and learn more about not only their chronic blood disorders but other campers' chronic blood disorders as well. Both camps take place concurrently over the course of the same week and the campers from both interact and take part in activities together. Some of these activities are typical summer camp programming such as canoeing, sailing, arts and crafts, and campfires. Both camps also have activities that specifically teach the campers more about their disease, and work to help prepare them for their eventual health care transition. Specific examples are included in the next section. Furthermore, both camps are overnight and the campers' parents are not in attendance, which allows the campers to experience some of the conditions they will face during their health care transition (East Carolina University Department of Pediatrics, n.d.). This study will only be including the campers with sickle cell disease or hemophilia due to how cancer patients often remain with the clinic until they are 26 - 30 years old, making their transition markedly different from the sickle cell and hemophilia groups (Personal Communication, J. Sauls, 2021).

Transition Education Activities Conducted at Camp Hope and Rainbow from 2016 – 2021 (Personal Communication, J. Sauls, 2021)

2016 – The campers played a modified version of the board game "Life". The normal board game usually consists of players spinning a wheel to move their car through the different sections of life, such as college and getting a job. The players take turns trying to earn as much money as possible before reaching the end of the board, usually labeled "retirement." The campers played this modified version using large dice where they had to answer questions or do whatever action was on the space that they landed on. Each player was given play money before the game and had to decide if they would go to college or straight to work. College players had to pay for tuition or take loans that they would have to pay back. Issues they dealt with included: getting married, going to the hospital whenever they were sick or felt pain, get insurance, pay bills, and having children, among others. The game took around an hour and a half to complete and afterwards the adolescents had a discussion on what they learned, how they managed their money, and the other life experiences that impacted them during the game.

2017 – The campers were divided into groups and discussed what it meant to become an adult. They also discussed what transition meant to them, and these discussions were supported by the volunteers, who were also previous campers at the camps (with the same medical diagnoses).

2018 – This year the format was based around the wheel from the Wheel of Fortune, a game show where contestants spin a giant wheel with multiple values of money labeled on different sections, and they would play for however much money a pointer next to them pointed at after the wheel finished spinning. For the activity, the money was replaced with questions related to transition. The adolescents would spin the wheel and then answer the question that was on the part of the wheel that the pointer landed on. The staff and former patients would clarify any information the adolescents were confused by and the former campers that were

volunteering were also able to provide information they learned during their own experiences with health care transitions.

2019 – The Wheel of Fortune format was once again used as listed in 2018. In addition, the campers also filled out the TIP Transition Readiness Assessment from the Patient-Centered Outcomes Research Institute (PCORI) transition study.

2020 – Due to COVID-19 restrictions no camp could be held, but camp activity packets were sent to all the prospective campers. These packets had activities such as word finds and matching activities that were related to their diagnosis.

2021 – A discussion was held about the transition from pediatric to adult care and what that means and looks like, as well as questions posed to individual campers about transition responsibilities. Staff and volunteers were able to answer questions and provide their own experiences. The campers then watched some of the staff members who had recently been through their own health care transition perform skits depicting several scenarios of a patient going to the emergency room. The staff members acting out the skits used their real-world experiences to help them perform and help the pre-transition adolescents understand the importance of clear communication and a need to understand their diagnosis and be able to explain it to others.

In addition to the camps, East Carolina University Brody School of Medicine's Pediatric Hematology and Oncology Clinic offers other programming outside of the summer camp dates called "Teen Transition Trips" to both the campers and non-campers that it serves. This programming includes college tours to show them around different campuses, clinics where they provide additional transition assessment and education, and teen weekends where the adolescents

can get together to learn more about health care transitions while creating social support networks. One of these programs was a Sickle Cell Transition Retreat, an overnight program where 14 adolescents with sickle cell disease attended alternative pain pool therapy and toured two college campuses. They also played a real-world simulation game where they had to budget play money for services they would need in the real world such as health insurance. More information on these programs is forthcoming (Personal communication, J. Sauls, 2021).

Living with Sickle Cell Disease

Sickle cell disease is a common chronic illness. It is estimated that around 300,000 infants are born with sickle cell anemia worldwide each year, and that number is only expected to rise in the future (Piel et al., 2017). Sickle cell disease is caused by the mutation of just a single gene, and it can affect every organ in the body. Failure to treat the disease regularly could lead to effects such anemia, blocked blood vessels, severe pain, or even organ failure (Piel et al., 2017). In younger patients, sickle cell disease can lead to cerebrovascular disease and cognitive impairment, with blood transfusions still being studied to see what effects they may have (Rees et al., 2010).

Early identification of sickle-cell disease is one of the most important factors in survival. Through the use of penicillin, the child is able to develop more typically, and with regular screenings the risk of stroke is greatly decreased. Blood transfusions are also used in limited situations to help lower the risk of strokes (Meier & Miller, 2012). Children with the sickle cell disease are patients for life, so it is important for them to learn how to live with their condition and be prepared for when they switch from their pediatric health care provider to an adult-oriented health care provider.

Living with Hemophilia

Hemophilia is a bleeding disorder caused by a deficiency of coagulation factor VIII or factor IX in the blood. Due to the hereditary nature of hemophilia, it is most common in men, while many women are carriers that experience no effects (Plug et al., 2006). Due to the disease, many patients with hemophilia end up experiencing ischemic cardiovascular diseases later in life, as well as an increased likelihood for infection (Tuinenburg et al., 2009). Patients with hemophilia live their entire lives with the disease, so it is necessary for youth to go through a health care transition in a timely manner.

Since the 1960s, the life expectancy of patients with hemophilia has gone from less than thirty years to now being well over seventy years. (Tuinenburg et al., 2009). As such, hemophilia patients must also prepare for a health care transition like those with many other types of chronic illnesses. The adolescents in these groups that undergo the transition process are faced with many challenges. Some of these challenges are experienced by anyone going through a health care transition such as switching from pediatric to adult care, and building new relationships. Other challenges are more unique though, such as a higher risk of being infected with HIV or arthritis (Witkop et al., 2015). Some teens also report a lack of social support and that they have a hard time discussing their disease with others, which makes the process of becoming independent even more difficult (Sterling et al., 2013). The transition process is just as important in patients with hemophilia as it is for anyone else with a chronic illness. But with the proper information and time to prepare, the transition process can be a great opportunity to help them becoming more independent and begin their lives in the adult world.

Theoretical Framework

Emerging Adulthood Theory

Emerging adulthood is a theory of development created by Jeffrey Jensen Arnett (2000) which focuses on young adults from the age of 18 – 29 years. It is described as a time where the person moved on from the immaturity of their youth but before they have fully taken on the responsibilities of the young adult period. Arnett (2007) claims that this period is presented positively by most people and that the ability to focus on oneself leads to satisfaction and a better understanding of who they are as a person. This theory is particularly relevant to transition in how it covers the time in one's life where they start to make independent decisions, become financially independent, and take responsibility for themselves (Arnett, 2004). This is especially true for patients with sickle cell disease and hemophilia who not only are transitioning developmentally, but in the health care system as well.

Self-Determination Theory

The self-determination theory focuses on human's own motivation and personality and how those factors impact one's development and behavior (Deci & Ryan, 2012). Self-determination theory differentiates motivation into two categories: autonomous and controlled motivation. Autonomous motivation means that the person is doing something by their own choice and without any outside influence. Controlled motivation refers to the opposite, and is when the person is doing the task due to some outside reason (Gagné & Deci, 2005). Many adolescents view the process of a health care transition as a source of controlled motivation. They may not want to stop going to see their pediatrician or have their parents make appointments for them, but they recognize that it is something that they will inevitably have to

do. Self-determination theory also recognizes that internal motivation is needed to influence one's decisions. How well health care transition goes for any adolescent is largely dependent on how much they care to invest their attention into it. Kim et al. (2019) described how having a plan and adhering to that plan was important for a successful transition, and only the adolescent can decide how closely they will adhere to that plan. The adolescent needs to have the sufficient internal motivation to want to be an active part of the transition process, and that is what can help lead them to a successful health care transition.

Gaps in the Literature

The current literature covers a lot of the benefits that camps can have for youth attending medical specialty camps. The benefits that these camps provide to their campers are well defined, and well documented, despite there still being more information that can be learned. There is a lot of information on what factors go in to creating a successful health care transition, as well as what potential factors could lead to an unsuccessful one, such as lack of communication and prior talks with the adolescent's health care provider (Syverson et al., 2016). Organizations such as Got Transition (2021) outline what factors can help lead to a successful transition. Despite all this, there has been a lack of information on how adolescents view the process of transition versus what post-transition groups look back on and see as important. Knowing this can be useful to research in many ways. It would allow us to identify misconceptions about the transition process are held by those yet to go through the process, or if what they believe to be important lines up with what those who have already completed their transition believe to have been important. This information can help refine our current understanding of what is important in health care transition as well as show what aspects should be focused on when explaining the health care transition process to those in the pre-transition

phase. This study investigates if attending a medical specialty camp and other transition programs has any influence towards health care transition readiness. The study is also interested in the difference between the aspects of health care transition programming pre-transition adolescents and post-transition adults view as being useful, and comparing what the two groups report.

Purpose of the Current Study

The purpose of this current study was to examine what aspects of the health care transition programming by Camp Hope and Camp Rainbow is perceived as being valuable in both pre- and post- transition groups, and to provide this information to Camp Hope and Camp Rainbow for transition-related program enhancement.

Broad Objective: How do youth and young adults with sickle cell disease or hemophilia perceive the value of attending a medical specialty camp and its transition programming toward their health care transition readiness?

Research Questions: (1) How is participation in Camp Hope and Camp Rainbow perceived and valued by campers? (2) How is participation in the Camp Hope and Rainbow transition activities perceived by campers regarding their knowledge of their health care transition? (3) What aspects of health care transition programing do pre-transition adolescents perceive as being most important? (4) What aspects of health care transition programming do post-transition adults perceive as being most important?

CHAPTER 3: METHODOLOGY

This chapter will provide an overview of the design plan that was followed, participants, instruments, data collection procedures, data management, and data analysis for the present study. This study has been approved by East Carolina University's Institutional Review Board (IRB). The IRB approval letter is located in Appendix A.

Design

To conduct this study, a qualitative descriptive design was used. A qualitative descriptive design is beneficial for this study in how it allowed the use of open-ended interviews to collect data from the participants. In addition, this design provided flexible guidelines that can be followed (Lambert & Lambert, 2012), allowing for the trends found in the responses during the interviews to guide the data analysis.

In addition, this is a community engaged study with Camp Hope and Camp Rainbow, medical specialty summer camps that work with children, adolescents, and youth with sickle cell disease, cancer, and hemophilia, as the partnership entity for this study. Community engaged studies involve a partnership between researchers and the community partnership's goals. This helps to achieve a multi-directional gain of knowledge where both the researchers and the community partnership benefit from the research that is conducted (Ross et al., 2010). Through this collaboration, the administrators of Camp Hope and Camp Rainbow hoped to learn (i) whether camp attendance and transition programming for campers, contributes in some way towards health care transition readiness, and (ii) implications for making improvements in health care transition activities and programming.

Participants

The eligible participants for this study needed to fit a few criteria. There were two groups: a pre-transition youth group and a post-transition adult group. The pre-transition group consisted of the participants that have not yet undergone their health care transition from the pediatric clinic to the adult clinic, and were above the age of 13 years. The post-transition group consisted of the participants that have already completed their health care transition. All participants had to have either sickle cell disease or hemophilia, were current or former campers at Camp Hope or Camp Rainbow, and had participated in the health care transition activity through camp programming in the past, regardless of if they were in the pre-transition or post-transition group. They also had to be able to speak English. Youth with cancer being served by Camp Rainbow were not eligible to participate because they remain with the clinic until the ages of 26 – 30 years, meaning their experience would be substantially different from the participants with sickle cell and hemophilia (Personal Communication, J. Sauls, 2021).

Recruitment Process

Participants were recruited for data collection with the help of the community partnership director of Camp Hope and Camp Rainbow. For initial interest, a flyer was sent to eligible participants detailing the information of the study along with a letter from the clinic's medical directors expressing their support of the study. All potential participants were first screened by the community partner. There were two methods of recruitment used to recruit participants. The first was by contacting eligible participants through the mail or by phone, providing details of the study and what the next steps would require to participate. Then, interested participants were asked to contact the principal investigator, the thesis chair or the community partner. The principal investigator then contacted the potential participants by phone to answer any questions they have, and set up an appointment for an interview if they were still interested in participating

in the study. If they expressed interest in participating in the study, a study packet including consent and assent forms were sent through the mail as appropriate. The study packet also included the demographic survey (Appendix N & O). A second method of recruitment was also done on the day the youth arrived to camp. Eligible participants, along with their parents or guardians if they were under the age of 18 years, were informed about the study and asked if they wanted to participate. If they desired to do so, they were given a copy of the necessary consent and assent forms along with the demographic survey to fill out. Due to the qualitative design, the goal was to recruit and interview until thematic saturation had been reached in both the pre- and post-transition groups. Information about this study was shared with 27 potential pre-transition participants and their parents, as well as 26 potential post-transition participants. Thematic saturation was met with 9 participants in the pre-transition group and 4 participants in the post-transition group.

Data Collection Instruments

Demographic Questionnaire. The demographic questionnaire was focused on learning more about the participant. There were two versions of the questionnaire, one for pre-transition adolescents and the other for post-transition adults. Both included questions about their age, ethnicity, gender, and the years they had attended Camp Hope and Camp Rainbow. The pre-transition questionnaire had questions about the grade of school they were in and asked about other camps they have attended besides Camp Hope and Camp Rainbow. The post-transition questionnaire asked about the participants work status, marital status, education background, and if they had volunteered at Camp Hope and Camp Rainbow in the past.

Semi-Structured Interview Questions. [See Appendix P] These questions were categorized based on the four research questions of this research with the goal of learning about

their general experiences with the health care transition and the programs that they have participated in during their time throughout Camp Hope and Camp Rainbow. The tool consisted of 33 questions organized by the four research questions of this study. These questions were adapted to this study using examples from the Got Transition Sample Transition Readiness Assessment for Youth (Got Transition, 2020). The assessment looked at how important the youth think transition is, their confidence in their ability to move to adult-oriented health care, and their knowledge on what is involved in a successful transition (Got Transition, 2021). The questions in this study aimed to learn more about if camp attendance increases levels of self-determination, if the programming is targeting the parts of health care transitions that the campers are most interested in, and what aspects of health care transition the post-transition adults report as being most important. Some example questions include:

> Can you think of any ways that your experience at camp has been useful outside of camp?
>
> What topics do you think would be helpful to discuss during Transition Education at Camp?
>
> If you had to move to an adult-oriented doctor right now, what would be your biggest concern?
>
> Was there anything about the health care transition that surprised you or you wish you knew earlier?

Data Collection Procedures

As this was a qualitative descriptive study, data collection continued until thematic saturation was reached. In this study, interviews with the participants were conducted either in

person at Camp Hope and Camp Rainbow, or virtually over the internet using the WebEx video communication software. This helped to reduce any travel expenses for the participants, and allowed for more flexibility in interview scheduling. Prior to the beginning of any data collection appropriate assent and consent forms were signed and collected. During the virtual WebEx interviews, the principal investigator was located in the East Carolina University Graduate Assistant Lab, using a password protected personal laptop. The participants were ideally in a private room in their home for the interview, but they were allowed to conduct it in whatever space was most comfortable for them. The video and audio was recorded using the WebEx software to provide facial and auditory information (Cresswell, 1998). The in-person interviews took place in a safe space at Camp Don Lee, where Camp Hope and Camp Rainbow are held, that provided both privacy but still a line of sight for the staff. These interviews were recorded using the WebEx tool so that they could be transcribed for analysis. This method was used for all the pre-transition participants and one post-transition participant. A second research team member was present for the in-person interviews at Camp Hope and Rainbow to help with probing questions as well as allowing an amplified rapport with the participants as they would feel more at ease during the interview (Monforte & Úbeda-Colomer, 2021).

Data Monitoring and Management

Once each interview was completed, their responses were stored on the secure ECU OneDrive. These interviews were transcribed using the closed caption feature of WebEx that converts spoken words into a script. Afterwards, the transcriptions were checked by the principal investigator and another research team member to make sure that they were completely accurate. During the transcribing process, the data were monitored for thematic saturation. Access to the transcribed data was granted to only members of this thesis committee.

Data Analysis

This study follows a qualitative descriptive design. As such, the analysis of the data began to take place as the data were being collected (Lambert & Lambert, 2012). Open coding method was used to find themes in the data in an inductive manner. Quotes extracted from the participants' interviews were used to develop codes, which were then used to create themes for the data (Creswell, 1998; Morse & Richards, 2002). All interview transcripts were coded by the principal investigator and a member of the thesis team. For rigor of data analysis, a sample of the interview transcripts were also coded by the thesis advisor and the community partner. This is done so there were multiple perspectives on the data, to create inter-rater reliability and to see which codes were most agreed upon (Elliott, 2018). The coders met when the principal investigator believed thematic saturation had been reached to compare their coding and discuss any similarities or differences. The analysis and data collection were both done simultaneously so it is known when data saturation was reached. To know that thematic saturation was met, the criteria of reliability and validity were considered. Reliability and validity of these results would be met when it was found through reoccurring or similar answers being given in response to the interview questions (Cypress, 2017). Thematic saturation was met with nine participants in the pre-transition group and four participants in the post-transition group. Once thematic saturation was met, the principal investigator, community partner, and two other members of the research team all coded the interview transcripts individually to find themes among the responses. After they all coded individually, a meeting was held to discuss the themes they had found individually in the interviews and to reach an agreed upon set of themes for the data (Morse & Richards, 2002). The community partner was asked for further interpretation of the interviews or for clarification whenever was necessary (Ross et al., 2010).

Considering that this study is a using a qualitative descriptive design, it is important to adhere to the rigor of qualitative studies. To verify rigor this study used the four criteria outlined by Cypress (2017): credibility, transferability, dependability, and confirmability. Credibility was achieved in this study through the use of in-depth interviews to learn about the participant's experiences. Throughout the interview the principle investigator (PI) listened authentically to the participant's responses and conducted simultaneous member checking to ensure that the PI understood exactly what they were conveying. Additionally, three additional researchers from different disciplines provided their perspectives on the interview transcripts during data analysis. Transferability was achieved through the recognition of the similarities among the participants, notably their attendance at the medical specialty camp. This means that the findings of this research are generalizable to health care transition education programming run by medical specialty camps not included in this study. Dependability was achieved by having the data analysis and results confirmation include a member of the study team who was not involved in the data collection. Any new themes brought up by this team member was greatly considered and helped to shape the final list of themes. Finally, confirmability was met by listening authentically to the responses of the participants and by re-listening and re-coding the interviews several times each as to best reflect their experiences in the themes of this study.

Sharing Findings with the Community Partnership Entity

Being a community engaged study, it was important to present these findings to the partnership entity. The findings of this study were presented to the interdisciplinary clinical team at the Brody School of Medicine's Hematology and Oncology clinic on November 21, 2022. This team consisted of 21 individuals including physicians, nurses, nurse educator, child life specialists, social workers, and research coordinators.

CHAPTER 4: RESULTS

The purpose of this study is to examine what aspects of health care transition programming used by Camp Hope and Camp Rainbow are perceived as being valuable by both pre- and post- transition groups, and to provide this information to Camp Hope and Camp Rainbow for transition-related program enhancement. In the present study, participants took part in an interview that addressed the following research questions: (1) how participation in Camp Hope and Camp Rainbow is perceived and valued by campers, (2) how participation in the Camp Hope and Rainbow transition activities is perceived by campers regarding their knowledge of their health care transition (3) what aspects of health care transition programing pre-transition adolescents perceive as being most important and (4) what aspects of health care transition programming post-transition adults perceive as being most important. These research questions were answered through the three major themes of preparing for adjustment and independence, building a shared community, and easing into transition. The details are provided in the remained of this chapter.

General Demographic Information

All of the participants were either current or former campers at Camp Hope and Camp Rainbow. Table 1 shows the demographic characteristics of the participants. In the pre-transition group there were nine participants, all having sickle cell disease and identified as African American. The pre-transition participants included six males and three females. Five pre-transition participants reported their education level as having at least a high school degree. Seven reported as still living with either their parents or grandparents.

In the post transition group there were four participants, three with sickle cell disease and one with hemophilia. All of the post-transition participants were male, and three of the four were African American while the other was White. Two of the post-transition participants reported between the ages of 18 and 24 years while the other two reported as being above the age of 25 years. All four of the post-transition participants had at least some college experience and were employed for pay.

Table 1

Demographic Characteristics of Participants with Sickle Cell Disease or Hemophilia

Baseline Characteristic	Pre-Transition *n*	Post-Transition *n*
Sex		
Female	3	0
Male	6	4
Age		
Under 18 years	4	0
18 – 24 years	5	2
25 years or more	0	2
Race		
African American	9	3
White	0	1
Highest Education Level		
Some High School	4	0
High School Graduate	2	0
Some college credit, no degree	2	3
Bachelor's Degree	1	1
Employment Status		
Student	3	0
Employed for pay	5	4
Self-Employed	1	0
Who do you live with		
Parents/Grandparents	7	3
Roommates	1	0
Alone	1	0

Spouse/Significant Other	0	1
Name of Diagnosis		
Sickle Cell Disease	9	3
Hemophilia	0	1

Table 2

Demographic Characteristics of Participants

	Age (years)	Participant Gender	Race	Education Level	Diagnosis	Years at Camp
Pre 1	17	Male	African American	Some High School	Sickle Cell	11
Pre 2	20	Male	African American	Some College Credit	Sickle Cell	13
Pre 3	22	Male	African American	Some College Credit	Sickle Cell	14
Pre 4	17	Male	African American	Some High School	Sickle Cell	6
Pre 5	16	Male	African American	Some High School	Sickle Cell	3
Pre 6	20	Male	African American	High School Graduate	Sickle Cell	6
Pre 7	17	Female	African American	Some High School	Sickle Cell	3
Pre 8	18	Female	African American	High School Graduate8	Sickle Cell	7
Pre 9	21	Female	African American	Bachelor's Degree	Sickle Cell	5
Post 1	36	Male	African American	Bachelor's Degree	Sickle Cell	10
Post 2	35	Male	African American	Some College Credit	Sickle Cell	1
Post 3	22	Male	African American	Some College Credit	Sickle Cell	12

Post 4	24	Male	White	Some College Credit	Hemophilia	12

Thematic Results

Thematic analysis of the interviews revealed three major themes: Preparing for Adjustment and Independence, Building a Shared Community, and Easing into Transition. This next section will present these themes with examples taken from quotes from the participants, as well as explore the various sub-themes that were found in the data (See Table 3).

Table 3

Themes of Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps

Theme	Subthemes and Supporting Quotes
Preparing for Adjustment and Independence	**Shifting of Health Care Responsibilities from Parent to Self** "Your parents can't call in for your payment no more. You got to do it yourself because you'll be eighteen. And then like your parents can't talk for you anymore. You're grown." – Pre 1 "Independence, I think that is one thing that camp has offered a Sickle Cell patients is independence, because you gotta, like, make sure you keep up with your stuff when you go shower or activities, they lead you in it, but you gotta learn how to do it on your own." – Pre 9 "I understand that, like my mom ain't going to be there, like, you know, like, with the appointments and stuff I want to, like, you know, have to step up and do the stuff that she usually does. Like, making my appointments, going to my appointments, answering-answering some questions or whatnot and you know." – Pre 4 "I learned that it wasn't hard and, uh, yeah. I overcame that that fear and then I never went back" – Post 4 **Sharing Information with Others** "Being aware that everybody don't understand like, the level of pain, or what like, might help me ease my pain and whatnot." – Pre 4 "You should tell your roommate what your condition is and how, if you start hurting where they need to take you if you can't drive yourself" – Pre 1 "I didn't want to share the fact that I had Sickle Cell to my coaches or my trainers or my teammates, because I didn't want to be treated differently. But, I wish I'd known it, it's okay to do that" – Post 1

	"Advocate for yourself, like not letting them talk to you out of how much pain you may be in, knowing your medication and speaking up" – Pre 9 "Go ahead and tell them [the emergency room staff] like 'I got this, this and all that'. So you won't be waiting in the hospital for long and you won't keep hurting." – Pre 5 **Reluctance to Leave Pediatric Care** "Are they going to care for me like they do the clinic? I mean are they going to take the time and get to know me?" – Pre 2 "The relationship is based off of years and years, we've known them for years" – Pre 3 "Just dealing with the fact that I won't be able to just go to the clinic anymore. And stuff like that. I like going to the clinic and seeing the little fish on the wall and stuff. So when I go to the adult world, its not going to be like that anymore" – Pre 6 "Like physically I was ready because I've already had everything, you know organized. … Well, mentally I just wasn't ready. Because you have to meet new people." – Post 3 "Nervous, intimidated, um, not knowing what to expect. Um, because I didn't know anybody on the adult side at that time." – Post 2
Building a Shared Community	**Feeling Understood and Included** "Before I went to camp I would have said, I thought I was the only person going through something like this. When you go here, you meet people who are doing the same thing, who could talk to you when you are in the hospital." – Pre 1 "We close like we stay with each other when we're back home, hangout, pretty much literally every day" – Pre 2 "Just like that relatedness from these with other people of what you're going through and just makes you feel included like, "Okay, I'm not so different from the world." – Pre 9 "It just gives me an environment where I'm not, you know, I don't feel alone. I can go to somebody that's experiencing the same thing as me." – Pre 4 "One of my best friends will hopefully be in my wedding when I get married. Because I'm getting engaged soon. We met at camp… and we still call each other all the time." – Post 4 **Learning Directly from Persons with Lived Experience** "When I see somebody else that's gone through it and I see they're doing pretty fine it kinda gives me a sense of relief" – Pre 6 "The people that was actually giving us the advice about transitioning and things, they were the people that actually made me feel at home when I first came to camp." – Pre 2 "It feels good cause what they tell you, they already been through it. And so they just trying to get you ready for it." – Pre 5 "Even though we all have sickle cell, some people are, they're very different. Like some are, we have the same type of sickle cell but it can be way worse for somebody else, because it's not that bad for me. But, for others, it's like, they really constantly be in pain and be in the hospital all the time" – Pre 7 "We grew up with them, so they already know how we react to certain stuff" – Pre 1

Easing into Transition	**Self-Reflection and Acceptance of Inevitable Transition** "You progress into it. You don't just jump straight in. You gotta crawl before you walk" – Pre 6 "I… have to step up and do the stuff that [Mom] usually does" – Pre 4 "It's not fun thinking about switching over to [the adult clinic] and pediatrics is fun. So we think about the adult world [and] its like intimidating, so to speak" – Pre 6 "You gotta call your own medicine in and everything like that. You have to do things like, you have to start doing it by yourself" – Pre 7 **Practical Preparation for the Transition Process** "Who are they, how well do they-I know they know more about it than me because they're doctors but like, mainly, just, I-I just I need to get to know them" – Pre 8 "While you're still in pediatric, you need to go ahead, and try to advocate for yourself even if your parents come with you. I mean, even if your parents are with you, so you can go ahead and get yourself ready for when they're not there." – Pre 6 "Our parents are not gonna be able to help us with that paperwork as soon as we transition" – Pre 1 "It kinda helped me to decrease my anxiety a little bit because I can kind of know what to expect when I come in" – Post 2 "One of the advice that we… got was making that note to give to our friends. I would say, right whenever she said it 5 minutes later, we'd go ahead and make a note." – Pre 2 "Just adding more… stuff that grabs their attention to try to reel them into getting to know the process better" – Pre 6 "Just challenge us with games. You got a shot to win as a group" – Pre 5 "Being able to provide those essential details so that your, your doctor knows exactly what's going on… I think that's very important" – Post 1 "Because you do something that's entertaining, they gonna love it. And they gonna take more from it. They gonna keep it in their brains." – Post 3 "I think insurance is definitely one of the big things. I know that's not anyone's favorite topic" – Post 4 "We did a college tour, and they gave us fake money. And it was like: the food is over here. You can go shop over there. It's like they, it was a budget type of thing" – Post 3

Preparing for Adjustment and Independence

The preparation for adjusting to a post-transition life and becoming independent is a process that takes a long time. They understood that transition was a big step, and one that required a certain amount of preparation and practice before transferring to the adult clinic. The responses related to this preparation could be split into three subtheme categories: Shifting of

Health Care Responsibilities from Parent to Self, Sharing Information with Others, and Reluctance to Leave Pediatric Care.

Shifting of Health Care Responsibilities from Parent to Self

As with any child growing up into an adult, that child will gradually start doing jobs that the parent has done for them up to that point. Youth with chronic illness experience this in ways such as taking themselves to appointments and remembering to take their medication on their own once they reach a certain age. Pre 4 shares:

> I understand that, like my mom ain't going to be there… with the appointments and stuff I… have to step up and do the stuff that she usually does. Like, making my appointments, going to my appointments, answering some questions or whatnot.

This helps to illustrate that the pre-transition participants are aware of the tasks they will have to participate in after they transition. The participants were aware that once they reach the age of 18 years their parents can no longer speak for them, and they will have to understand how to navigate the system on their own. Pre 1 states "Your parents can't call in for your payment no more. You got to do it yourself because you'll be eighteen. And then like your parents can't talk for you anymore. You're grown."

Multiple participants reported going to camp as being important to help them learn how to become more independent from their parents. Pre 9 shares "One thing that camp has offered us sickle cell patients is independence, because you gotta… keep up with your stuff when you go shower or activities, … you gotta learn how to do it on your own." A post-transition participant stated that at camp he learned how to treat himself when he got an injury (a major task of managing hemophilia), stating "I learned that it wasn't hard and, uh, yeah. I overcame… that fear

and then I never went back" (Post 4). This shows how being away from their parents can help the participants to learn how to accomplish tasks on their own that they normally would have relied on their parents to complete.

Sharing Information with Others

While all the participants felt confident in the knowledge they had on their diagnosis, they did have concerns on being able to share the details of their diagnosis with others. As one participant states, they had to be aware that "everybody don't understand like, the level of pain, or what like, might help me ease my pain and whatnot" (Pre 4). Explaining their condition to others can be particularly concerning regarding the college experience. Going to college is a large change and one that can be difficult to navigate. There are many people at college who will not understand their condition or how to help if there is a crisis. One participant stated "You should tell your roommate what your condition is and how, if you start hurting where they need to take you if you can't drive yourself" (Pre 1). This extends to teachers and coaches as well. Post 1 shared:

> I didn't want to share the fact that I had Sickle Cell to my coaches or my trainers or my teammates, because I didn't want to be treated differently. But, I wish I'd known it, it's okay to do that.

They came to this conclusion after experiencing the benefits of having others know about their condition and be able to help get them the care they needed when they showed signs of pain.

Being able to properly report their condition is important when it comes to go to the adult clinic and emergency rooms as well. One participant stated that in the emergency room they have to be able to "go ahead and tell them like 'I got this, this and all that.' So you won't be waiting in

the hospital for long and you won't keep hurting" (Pre 5). They need to be able to tell them who they are, what their diagnosis is, and what medications they take for the doctors to be able to help them. It is also important for them to be confident in themselves and their answers. One participant states that it is important to "advocate for yourself, like not letting them talk to you out of how much pain you may be in, knowing your medication and speaking up" (Pre 9).

Reluctance to Leave Pediatric Care

During the many years the pre-transition youth spend going to pediatric care, they grow comfortable and attached to the doctors and nurses that they interact with. As one participant states "The relationship is based off of years and years, we've known them for years" (Pre 3). As they say, some of them have been going to the same pediatric doctor for their entire lives, and it can be hard to leave that comfort. Pre 6 shared that one of the hardest parts of transitioning for them was

> Just dealing with the fact that I won't be able to just go to the clinic anymore.... I like going to the clinic and seeing the little fish on the wall and stuff. So, when I go to the adult world, it's not going to be like that anymore.

These feelings lead into a fear that the doctors at the clinic will not care for them in the same way as what they are used to at the pediatric clinic. Data suggests that even the inviting physical atmosphere provides comfort, and leaving that for the sterile adult clinic leads to feelings of unease. One participant wondered "Are they going to care for me like they do the clinic? I mean are they going to take the time and get to know me" (Pre 2)? The pre-transition participants seemed doubtful that they would be able to build relationships with adult doctors like they had with the doctors they knew in the pediatric clinic. This has led to some of the participants

revealing that they choose to stay in the pediatric clinic even after they felt prepared to transition. As Pre 3 stated, “They shouldn’t push nobody out the clinic yet if they’re not, you know, mentally and physically ready. I've been ready since I was like 20, but I just didn't want to leave.”

Post-transition participants also reported this change being difficult. One post-transition participant recalled “Like physically I was ready because I've already had everything, you know organized. … Well, mentally I just wasn't ready. Because you have to meet new people” (Post 3). Even if they know they are prepared, they are still not confident that they will be able to create a strong relationship with their new caretakers like what they had with the pediatric clinic. Another post-transition participant recalled feelings of being “nervous, intimidated, um, not knowing what to expect. Um, because I didn't know anybody on the adult side at that time” (Post 2). Breaking the ties with the pediatric clinic to go to an adult clinic where they do not know anyone is very difficult for individuals with sickle cell disease and hemophilia, and makes preparing for the health care transition all the more difficult.

Building a Shared Community

One aspect that was clear in every response was how much they appreciated attending camp. Attending camp made the participants feel more independent, learn more about their disease, make friends, and simply have fun. Creating a community where having sickle cell or hemophilia was seen as the norm and they could freely discuss their struggles with their peers was an experience that they did not often get to have outside of camp. This theme has two major subthemes: Feeling Understood and Included, and Learning Directly from Persons with Lived Experience.

Feeling Understood and Included

Every participant highlighted the fact that everyone at camp understood their condition and could empathize with them as a positive aspect of attending camp. One pre-transition camper states that an aspect of camp they appreciate is “Just like that relatedness from these with other people of what you're going through and just makes you feel included like, “Okay, I'm not so different from the world” (Pre 9). Having people around that can understand their condition can help make the campers feel like they are part of a community. As one participant stated, “It just gives me an environment where I'm not, you know, I don't feel alone. I can go to somebody that's experiencing the same thing as me” (Pre 4). Feeling like they have peers that they can discuss their struggles with openly is seen as being very important to these participants.

The participants reported that outside of camp, it was rare to meet anyone else with a health care condition like their own. Pre 1 shares:

> Before I went to camp I would have said, I thought I was the only person going through something like this. When you go here, you meet people who are doing the same thing, who could talk to you when you are in the hospital.

These bonds were strong as well, continuing on outside of camp. One participant reported that the friends they met at camp “we stay with each other when we’re back home, hangout, pretty much literally every day” (Pre 2). This helps to show that the bonds that are formed at camp can extend beyond just the camp gates.

All the post-transition participants that attended camp also reported on how important it was to form these bonds with people they met at camp. Interestingly, these bonds seemed to maintain their strength even after years of not going to camp. One post-transition participant

reported that “one of my best friends will hopefully be in my wedding when I get married. Because I'm getting engaged soon. We met at camp… and we still call each other all the time” (Post 4). The bonds formed at camp through these shared experiences have the potential to last a lifetime.

Learning Directly from Persons with Lived Experience

Every pre- and post-transition participant commented on their positive experiences learning from those at camp who also had sickle cell or hemophilia. One participant recalled realizing at camp that “even though we all have sickle cell, some people are, they're very different… it can be way worse for somebody else… they really constantly be in pain and be in the hospital all the time” (Pre 7). This exposure to others with their condition helps them to better understand their own experiences through observing and listening to the experiences of others. Every year the camp has some staff that were former campers that had already transitioned, and speaking to these staff members had a clear effect on the participants. Just their presence at the camp was reassuring to some of the participants. One participant, when asked about the presence of the volunteers, stated “when I see somebody else that’s gone through it and I see they're doing pretty fine it kinda gives me a sense of relief” (Pre 6). Another participant commented on how they felt when seeing these staff members that have already transitioned. “It feels good cause what they tell you, they already been through it. And so, they just trying to get you ready for it” (Pre 5).

The advice given from these staff members can resonate with the pre-transition campers stronger as well, since it is coming from those who they already knew. One participant recalls “the people that was actually giving us the advice about transitioning and things, they were the people that actually made me feel at home when I first came to camp” (Pre 2). Another

participant discussed how the staff they had already known could explain the aspects of transition better to them. “We grew up with them, so they already know how we react to certain stuff” (Pre 1). This pre-existing relationship lends itself to the campers taking what they say more seriously than a doctor that they barely know.

Easing into Transition

A successful health care transition does not just happen overnight. To help ensure that a health care transition is successful, much time needs to be taken by the person transitioning, their family, and the health care staff to make sure that they are well prepared. This theme is primarily concerned with the participants own reflection and acceptance of their health care transition and the ideas that were presented by both groups of participants on ways to help improve the health care transition programming. This theme is broken into two subthemes: Acceptance of Inevitable Transition and Practical Preparation for the Transition Process.

Acceptance of Inevitable Transition

Self-reflection and acceptance of their transition was something all the participants reported in some form. They understood that they would have to transition to adult care eventually, but that did not mean they wanted to transition right away. As one participant states “you progress into it. You don’t just jump straight in. You gotta crawl before you walk” (Pre 6). The programming at Camp Hope and Rainbow is based around preparing the campers for their transition early, thus helping with this idea of gradually teaching and preparing the pre-transition youth.

The participants also clearly understood that they would have to take over the roles of their parents. Once they reach the age of eighteen, they have to be able to advocate for

themselves without the assistance of their legal guardians. One participant states “You got to do it yourself because you'll be eighteen. And then like your parents can't talk for you anymore. You’re grown. So, at that point, you gotta take over” (Pre 1). Another participant described this change as “I… have to step up and do the stuff that [Mom] usually does” (Pre 4). The pre-transition group understood that they would have to take on the responsibilities that had been left up to their families previously, and were also preparing to do that. “You gotta call your own medicine in and everything like that. You have to do things like, you have to start doing it by yourself” (Pre 7).

This acceptance and self-realization led some of the participants to recall why it is that they did not want to leave the pediatric clinic. When asked about why a participant had not yet transitioned, they stated: “It's not fun thinking about switching over to [the adult clinic] and pediatrics is fun. So we think about the adult world [and] its like intimidating, so to speak” (Pre 6). Transitioning to the adult clinic can be a big change, and the data shows that even though the participants are aware that they will eventually need to transition, many will still want to stay with the pediatric clinic as long as possible.

Practical Preparation for the Transition Process

The participants all had suggestions on different activities that could help better address their concerns regarding their health care transition. Many pre-transition youth were very concerned by the fact that they did not yet know who their doctor would be. One asks “who are they, how well do they-I know they know more about it than me because they’re doctors but like, mainly, just, I-I just I need to get to know them” (Pre 8). Having no familiarity with a doctor after leaving a doctor they’ve seen for often their whole lives is difficult. They also recognize

that when they go to this doctor they are going to have to advocate for themselves. This includes giving them their information, and informing them of their condition. Pre 6 suggests:

> While you're still in pediatric, you need to go ahead, and try to advocate for yourself even if your parents come with you. I mean, even if your parents are with you, so you can go ahead and get yourself ready for when they're not there.

This can help them with feeling more comfortable talking to providers and understanding all their information.

Many pre-transition participants also had suggestions for ways they would change the health care transition activity at Camp Hope and Rainbow to be more engaging. In particular, many participants reported hands-on practice as being a good way to get them more involved. As one participant stated, the campers would remember the activity more by "just adding more… stuff that grabs their attention to try to reel them into getting to know the process better" (Pre 6). The methods of how to deliver these hands-on activities differed. One participant suggested incorporating it into the message of the existing program. "One of the advice that we… got was making that note to give to our friends. I would say, right whenever she said it 5 minutes later, we'd go ahead and make a note" (Pre 2). Another participant was curious about how to fill out the different paperwork that is involved with going to the adult clinic, saying "our parents are not gonna be able to help us with that paperwork as soon as we transition" (Pre 1). A final suggestion given by one of the participants was to turn it into a game. "Just challenge us with games. You got a shot to win as a group" (Pre 5). Using games could be a way to keep it more in-line with other camp programming while maintaining engagement.

The post-transition group had several suggestions to help ease the pre-transition youth into their transition. All of the post-transition participants emphasized the importance of knowing your health care provider as soon as possible, if not even before the transition itself. Two of the post-transition participants reported as having been to the adult clinic prior to their first appointment. One stated "it kinda helped me to decrease my anxiety a little bit because I can kind of know what to expect when I come in" (Post 2). Being able to know how it will look once they transfer over can help ease their anxiety. This extends to meeting their doctors as well. They also emphasized knowing yourself and your condition as being important to the health care transition. As one participant stated "being able to provide those essential details so that… your doctor knows exactly what's going on… I think that's very important" (Post 1).

Interestingly, the post transition group also had similar suggestions to improving the health care activity as reported by the pre-transition group. One of the participants emphasized the importance of making sure the transition education programming was entertaining, "because you do something that's entertaining, they gonna love it. And they gonna take more from it. They gonna keep it in their brains" (Post 3). Paperwork was also mentioned, specifically filling out insurance forms and paying for their own insurance. "I think insurance is definitely one of the big things. I know that's not anyone's favorite topic" (Post 4). Similarly, managing yourself financially was mentioned by two of the post-transition participants. One of the participants described a non-camp activity they did with camp peers, "we did a college tour, and they gave us fake money. And it was like: the food is over here. You can go shop over there. It's like they, it was a budget type of thing" (Post 3). Being able to budget for themselves is important, especially with the medical expenses they will have to make.

Summary of Results

The current study had four major research questions. The first question is "How is participation in Camp Hope and Camp Rainbow perceived and valued by campers?" Campers perceived camp experiences as valuable, as seen through the theme of Building a Shared Community. The campers valued building relationships with other campers, allowing them to feel included and understood by others. The second research question is "How is participation in the Camp Hope and Camp Rainbow transition activities perceived by campers regarding their knowledge of their health care transition?" The subthemes of Learning Directly from Persons with Lived Experience, Shifting of Health Care Responsibilities from Parent to Self, and Self-Reflection and Acceptance of Inevitable transition all help answer this question. Participation in the transition activities allows the campers a chance to learn from those that have already transitioned, understand how to take care of their health care needs on their own without the assistance of their parents, and reflect on what they can do to help prepare themselves for their future transition. The third and fourth research questions were related to what aspects of health care transition programming 3) pre-transition or 4) post-transition youth perceive as important. These questions are answered by the themes of Preparing for Adjustment and Independence and Easing into Transition. In preparing for adjustment and independence self-realization of the importance of taking on the responsibilities that once belonged to the parents was emphasized, as well as the importance of being able to share details on their condition with doctors, roommates, or anyone else that they felt needed to know were stated by both groups. The reluctance to leave pediatric care for adult care was also discovered from pre-transition participants that felt nervous about transitioning to an adult clinic where they did not know who would be taking care of them. Similarly, post-transition participants reported that having some exposure to the adult doctors or a tour of the adult clinic beforehand helped to ease their anxieties. Finally, many suggestions

were given on ways to ease into transition and improve the health care transition activity, as well as suggestions as to what types of information the participants were most interested in learning, which will be elaborated on in the discussion chapter.

The community partner's questions were also answered. The first question was whether camp attendance and transition programming for campers contributes in some way towards health care transition readiness, which aligns with the second research question of the study, addressed above. The second question related to implications for making improvements in health care transition activities and programming. Results suggested implementing more interactive, hands-on activities such as educational games that relate to the information being taught. As seen with the subtheme Learning Directly from Persons with Lived Experience, it would also be helpful to include advice from the recently transitioned volunteer staff members, when possible, as the participants reported those conversations as being helpful. The subtheme of Practical Preparation for the Transition suggests that providing the participants an opportunity to meet an adult care physician and see examples of future insurance options can be beneficial as well.

CHAPTER 5: DISCUSSION

The findings provide insights into transition programming by Camp Hope and Camp Rainbow are perceived as being valuable in both pre- and post- transition groups. This study is a community engaged study partnered with Camp Hope and Camp Rainbow, and the findings of this study provide information to Camp Hope and Camp Rainbow for transition-related program enhancement. This study aimed to further discover how youth and young adults with sickle cell disease or hemophilia perceived the value of attending a medical specialty camp and participating in its transition programming toward their health care transition readiness. The results found are viewed through the lenses of the emerging adulthood theory (Arnett, 2007) and the self-determination theory (Lee et al., 2021).

Some unique aspects of the population were how they had all attended Camp Hope or Camp Rainbow, or attended transition-based field trips to colleges. This meant that they had been given some formal education on transition in unique settings. Setting this apart from other studies, many of the pre-transition youth were over the age of 18 years, with some being as old as 22 years and still not having yet transitioned. This provided a unique perspective as these participants hold unique insight on the reasons they may be hesitant to transitioning to adult health care. Through this group we were able to better identify what aspects of the health care transition were interested in learning more about before they transfer to adult care. The post-transition adults were more varied in age, providing multiple perspectives on the health care transition, with some having transitioned around ten years ago and others just recently transitioned. Those who had transitioned many years prior had more long-term perspectives on the important aspects of the transition, while those who had transitioned more recently provided

details on the immediate differences and what they missed about pediatric care. In this discussion chapter, further insights into each research question will be elaborated.

Campers Value their Participation in Camp Hope and Camp Rainbow

As shown by the theme of building a shared community, in all the responses from every camper, former or current, there was a clear love for Camp Hope and Camp Rainbow. Every participant reported creating friendships at camp with people who they keep up with outside of camp. Importantly, these friends are those who they can relate to through their shared experiences with their health care conditions, particularly through the pains that they feel. Being around so many with similar health care conditions is a rare experience for most of the participants, and helps them feel like part of a community. Participants stated that being at camp surrounded by people that could relate to helped them "come out of their shell" and become more sociable when they were outside of camp. This lines up with the findings of Gillard and Watts (2013) that attending a medical specialty camp can help to increase sociability among the campers that attend. This also lines up with other findings that youth with health care conditions help each other through sharing their experiences (Children's Hospital of Philadelphia, 2012).

The participants also reported an increase in their communication skills from their time at camp, as illustrated in the "sharing information with others" subtheme. The participants learned to better explain their condition to others, and this naturally helps to improve their communication ability in other areas as well. This supports the findings of Gagnon et al. (2019), who also reported that communication skills increased as a result of attending a medical specialty camp. Gagnon also reported an increase in independence from the campers, which the findings of this study support as well. The theme of preparing for adjustment and independence shows off these skills well, with campers reporting being able to take on more of their parent's

responsibilities as a result of their attendance at camp. Gaining communication skills and becoming more independent line up with the ideas presented by Arnett (2000) on how the emerging adult is gradually taking on the responsibilities necessary for adulthood.

Camper's Perception of Participation in Camp Transition Activities

All the participants seemed to understand the value of the transition activity, and thought that it was beneficial to have. These activities are done every year to help the participants understand more about their upcoming health care transition. The activities that seemed to be the best remembered by the majority of participants were the ones that involved older volunteers that had already transitioned. As one participant stated "the same people that was telling me, like, helping me out through camp my very first year are the same people that are helping me transition" (Pre 2). The subtheme of learning directly from persons with lived experience was readily apparent. Seeing those who were recently pre-transition youth themselves discuss their experiences transitioning to the adult clinic helped to make the pre-transition youth feel reassured that their own transition would go smoothly as well. The advice they gave also seems to have resonated deeper as a result of them being so trusted and having recently gone through the transition experience themselves. This finding appears novel in that it is one not mentioned in past literature, and could be explored further in the future.

While many of the participants reported remembering at least one transition activity, some struggled to find something that they found as being new information from it. One participant states "they always teach us, so it was like. It's like that, the education is already there" (Pre 6). Every participant reported having already spoken either with their family and/or their doctor about their health care transition prior to going to camp. This meant that while these activities were viewed as helpful, a lot of the information did not come as a surprise to the

participants. This information mainly centered around taking medication, and attending appointments. It could be that since they already hear this from parents or doctors they find it to be redundant and lose interest. Looking at this idea through the lens of the self-determination theory, if the participants in the activity are not interested in what is being taught, then they will not feel intrinsically motivated to engage with the activity deeply and will not gain much information from it as a result (Lee et al., 2016).

Aspects of Health Care Transition Programming that Pre-Transition Youth Perceive as Being Most Important

The participants in the pre-transition youth group were largely concerned with the aspects of transition that were related to them becoming more independent. For those that had not yet entered college, they all reported that the move to college and how to manage their condition in college life as important to them. This was seen in having to report their condition to others. Telling new roommates, friends, or teachers about their condition was something that was brought up by all four participants under the age of 18 years. They were curious as to how to best go about informing their new acquaintances of their health care condition and how to help them in case of an emergency. Some participants were also curious as how to navigate their social life when they get older, and if they should take any extra precautions. “when you get eighteen and partying a lot and stuff like how to tell the people you went to the party with… if you start hurting” (Pre 1). This would surely be a tricky conversation to have with a parent, so they would prefer to have it with older volunteers at camp they have most likely already experienced the effects and can help to inform the pre-transition youth not yet in college.

Another reoccurring aspect of the health care transition that interests the pre-transition youth is advocating for themselves and taking over the responsibilities of their parents. This is

most seen in regards to talking to the staff in the adult health care clinics and being able to properly report their health care condition to others. They are aware that if they cannot properly inform the staff about their condition that they will not receive the proper care they need in a timely manner. For this reason, many reported being able to properly explain their condition as one of the top activities they were working on improving for themselves. As such, they would want the transition programming at camp to help them better understand how to properly communicate about their condition to others. This desire to take care of themselves is consistent with some of the aspects Fair et al. (2016) described as being important to a successful transition, such as understanding their condition, adherence, and having a strong social network.

Another topic of interest was that of insurance and other paperwork that they would have to fill out in the future. For their entire lives, the paperwork and insurance has been completed by their parents, so they never had to worry about it. But as they transition, they will have to start taking care of the paperwork themselves and find their own insurance. As discussed by Fair et al. (2016), Reiss et al. (2005) and Gray et al. (2017) this could place a large financial burden onto them if they do not properly understand insurance and prepare to get their own, so it stands to reason that they would want to learn more about it whenever possible.

Finally, the pre-transition participants were very concerned about who their doctor would be after they transitioned. There was a clear feeling of reluctance to leave their pediatric doctor, and a large reason for this was their long-established relationship with those doctors. They did not want to transfer from a doctor they had been seeing for most their lives to a doctor they had never met before and were not comfortable around. From these views, we can see that the health care transition is firmly an idea rooted in the self-determination theory concept of controlled motivation, or one done more from outside influences rather than internal ones (Gagné & Deci,

2005). The youth do not want to leave the pediatric clinic, and maybe they would not transition at all if they were not told they had to. This extends to the environment as well, where multiple pre-transition participants reported preferring the animals on the walls of the pediatric clinic as opposed to the dull walls of the adult clinic. Many reported wanting to have a tour of the adult clinic or meet with their new doctor before transitioning as something that might make them feel more comfortable and prepared for their transition. These findings align with what was found in the literature, where studies such as Rutishauser et al. (2014) and Dogba et al. (2014) have reported that programs focused on introducing the youth to the adult providers can help to ease their anxiety.

Aspects of Health Care Transition Programming that Post-Transition Adults Perceive as Being Most Important

The post-transition adults emphasized the importance of communication between the individual transitioning and their new health care providers. All of the post-transition participants reported having at least some interaction with a doctor from the adult clinic before they transitioned. This provided them with a familiar face that helped make the transition easier. Two of the participants even had tours of the adult clinic before they fully transitioned, helping them even further by understanding exactly where they will be going and what their appointments will look like. This once again lines up with the findings of Rutishauser et al. (2014) and Dogba et al. (2014) showing that being introduced to adult providers earlier is beneficial in creating a smoother health care transition.

All four post-transition adults also emphasized the importance of being responsible for, and knowledgeable about, yourself. They talked on how knowing your medications and taking care of yourself was important in making sure that someone does not have to go to the adult

clinic more than they need to. They stressed the importance of knowing yourself and your limits and being careful so that they could keep on enjoying life. Post 1 even states how "camp taught me the importance of taking care of yourself, before you have to go see a doctor", showing how camp can be a good place to teach this lesson. This lines up with the findings of O'Mahar et al. (2010) that attending a medical specialty camp can lead to better management of disease-specific responsibilities. Viewing these statements through the lens of emerging adulthood, the post-transition group viewed taking care of themselves as being an important part of becoming an adult.

A final point that was mentioned was that it would be beneficial for programs to go over how to manage insurance. The process of selecting a good insurance plan is very important, but also very easy to put off until it is too late. Pre 4 states that they "underestimated how much of a hassle it would be" to find their own insurance provider. This lines up with Fair et al. (2016), Reiss et al. (2005), and Gray et al. (2017) who all emphasized understanding insurance options as being important for a successful health care transition. By educating the pre-transition youth while they are young on how to choose an insurance plan that fits their needs, it will save them a lot of time and potentially money in the future, even if they find it to be a pain in the moment.

Theoretical Insights

As described by Arnett (2004), the emerging adulthood period of one's life is when one starts to make independent decisions and take responsibility for themselves. Through the participants responses, it is clear that they have a desire to gain that independence and be able to take care of themselves. Many of the aspects of transition the participants were interested in learning more about, such as communicating information about their disease to others and filling

out paperwork, were the ones that would make them less reliant on their parents. Through their responses, the participants showed a desire to step into their own.

Looking at the responses through the lens of the self-determination theory provides interesting interpretations of the participant's responses. These participants all have a level of autonomy in deciding when they believe they are ready to transition to adult care, which has led to some staying in the pediatric clinic longer than they may have otherwise. As stated by Pre 3, "They shouldn't push nobody out the clinic yet if they're not, you know, mentally and physically ready. I've been ready since I was like 20, but I just didn't want to leave." Proper intrinsic motivation is important in determining motivation (Lee et al., 2021). The participants were shown to have stronger intrinsic motivations when it came to taking care of themselves and learning how to explain their condition to others. Currently, the health care transition is extrinsically motivated. This means that the health care transition programming done by Camp Hope and Camp Rainbow needs to appeal to the campers to help them better retain the information being taught.

Suggestions for Camp Hope and Rainbow's Programming Related to Health Care Transitions

Overall, campers were satisfied with the health care transition activities that Camp Hope and Camp Rainbow were already providing, but there were a few suggestions that were made on ways to potentially improve it. One suggestion that was brought forth by both pre- and post-transition participants was to include more interactive, hands-on, activities for health care transition education. By providing more interactive programming, it allows for the participants to be more involved with the lesson on transition that is being taught. Some suggestions for this were to play an educational game, or to do an activity after the speaking/questions segment that

is related to what was discussed right before. This could potentially help them retain the information further in the future.

Another commonality among all the participants was that they found the advice given by the volunteers that had already had their health care transition and were attending the adult clinic to be extremely helpful. For this reason, this study recommends that the transition programming involve these post-transition volunteers as much as possible. By having those that have recently transitioned speak on their experiences, it will come across as more relatable to the campers and put their own health care transition into perspective for them.

It was also found that the attachment to the pediatric clinic was making the pre-transition youth more hesitant to transition to the adult clinic. After spending most of their lives with these doctors, it is hard for them to leave those care givers for someone they do not know (Rutishauser et al., 2014). The post-transition adults indicated that having chances to meet with these doctors earlier is helpful in making that process less frightening for the transitioning individuals. Many of the campers transition from the pediatric clinic to the same adult clinic (Personal Communication, J. Sauls, 2022). If it is possible for one of the doctors from the adult clinic to come visit camp and talk to the campers about what to expect, this could help relieve that anxiety and give them a familiar face at the adult clinic for when they go to their first appointment.

Finally, five different participants all mentioned wanting to incorporate learning how to navigate the paperwork better as something they would like to see from Camp's transition programming. This lines up with the findings of Fair et al. (2016), who listed understanding health insurance options as an ideal transition outcome. One participant stated "our parents are not gonna be able to help us with that paperwork as soon as we transition" (Pre 1). This desire to learn. This includes insurance papers and Medicaid forms. This could be achieved by bringing in

example forms and having the campers fill them out, or by having a list of insurance options and having each camper pick the one they feel would be best for them.

Insights from the Community Partner

According to the community partner it had been reported by the adult clinic that the recently transitioned patients did not know enough when they transitioned to the adult clinic. This study suggest that camp is a good starting point in finding what questions need to be answered and what they could be doing better to help better prepare the pre-transition youth for their transition. The data of this study suggest that the pediatric side of the clinic needs to better communicate with the adult side of the clinic, letting the doctors know what aspects of transition the pre-transition youth were interested in and what the post-transition adults reported as being important, which could allow for the opportunity for the doctors to answer those questions before the youth ever transition. Knowing the importance of the relationship to the provider for these youth may also encourage the doctors to meet with them before their first appointment. Importantly, the community partner reported that these interviews uncovered a wealth of good information that will be helpful to use when they are creating future programs. They also reported that through reading the transcripts and the good things the campers, both past and present, say about camp, it helped to make them feel like their work throughout all these years has been validated.

Additionally, following the presentation to the clinical team attendees expressed appreciation for the findings in that they better understood the experiences of the campers and the value of camp attendance for them. They acknowledged gaining insight that the pre-transition youth valued having the opportunity to speak with post-transition adults about challenges and helpful tips for the health care transition process. They then considered the benefit of potentially

implementing a peer mentorship program at the clinic, where recently transitioned adults talk with soon-to-transition youth about different aspects of their transition. On hearing that the participants expressed wanting more preparation regarding managing insurance-related documents prior to their health care transition, they expressed an interest looking into how they may be able to facilitate that in the clinic or through their transition education activities. Finally, based on participants concerns regarding wanting to become more familiar with the adult clinic staff before their transition, they suggested having an adult doctor or someone from their team could participate at camp to potentially increase that familiarity. They expressed wanting the findings disseminated through more formal publications in order to use them as an advocacy tool toward gaining more resources.

Limitations

The findings of this study should be considered within the context of the study's limitations. For the pre-transition youth, the sample was filled with mostly older youth who had been preparing for transition for some time. This meant that many of their questions about their health care transition had already been answered by their doctors or conversations with some of their older peers. There were also no patients with hemophilia in the pre-transition group, meaning their disease-specific experiences are not well documented in this study. As for the post-transition adults, the sample size was largely limited due to the difficulty in contacting the former campers, as well as a low response rate from those that could be contacted. The medical records that the community partner had access to for the post-transition group were older records from when they had not yet transitioned. This meant that the records often had out of date addresses, thus decreasing the pool of potential participants contacted. According to the community partner, another possible reason for this low response rate may have been due to the

post-transition group lack of familiarity with the WebEx software. Participation may have been higher if interviews could have all been in-person, as they were for the pre-transition group. There was a lack of gender diversity in the post-transition participants, with all four participants being male.

Another limiting factor of this study comes from the slightly older age of all the pre-transition participants. There were no participants that were below the age of 16 years, and this increases the chance of them having already had significant transition education from the doctors, families, or past years at camp before. This means that some of the topics discussed in the transition education program, such as taking medications and scheduling appointments, they could have already heard many times before and as a result found them to be not as important.

Implications

The results of this study support the existing literature while contributing new information to the existing literature. The pre-existing relationships with pediatric care staff leading to a barrier to transition reported by Rutishauser et al. (2014) was supported in full. Multiple pre-transition youth discussed how they felt comfortable at the pediatric clinic with the staff they had known for years, as opposed to the adult clinic staff that they did not know at all. The findings of Rutishauser et al. (2014) and Dogba et al. (2014) were supported that introducing the pre-transition youth to the adult clinic through either a tour or meeting a doctor before their transition takes place can lead to better health care transition outcomes. Betz et al. (2013) explained that having less experience with the adult clinic makes the negative experiences stand out more, but the effect is diminished after a few visits, which is supported by this research. This study also supports the findings such as Bloom et al. (2012) that earlier education of transition is what is most effective in preparing the youth for their transition. All of the pre-transition youth

reported having had transition education from their doctors and parents for many years already, before many of them had even begun thinking about transition, and as a result they were much more knowledgeable on the subject.

On the effects of medical specialty camps, the results of this study once again line up with the findings in the existing literature. This includes the findings of Mayo (2016) that attendance at a medical specialty camp increases camper's self-esteem and feelings of peer support, as well as the findings of Olsen et al. (2018) on participation increasing independence and self-management skills. The participants reported being more sociable, having greater communication skills, and understanding their health care condition better as a result of attending the camp, lining up with the findings of studies such as Desai et al. (2014), Gagnon et al. (2019) and Gillard and Watts (2013).

The new findings from this study include the perceived value of the experiences of recently transitioned peers to pre-transition youth, and the areas pre- and post-transition find to be most important. Every participant interviewed commented on how they found the experiences of recently transitioned peers to be helpful in understanding what to expect, learning what they need to work on, and feeling more confident in their own transition. Pre-transition youth perceived aspects of independence, such as going to college; self-advocacy and understanding their condition; and insurance and paperwork as being important to their eventual health care transition. Post-transition adults perceived communication with adult care providers, being responsible for yourself, and selecting an insurance plan as being important for a successful health care transition. Finally, future research could further examine the impact of having recently transitioned adults discussing their transition with pre-transition youth on their health care transition knowledge and readiness.

Conclusion

This study contributes to the present literature by examining the perceptions that campers at a medical specialty camp have on the health care transition specific programming, and examining what aspects pre-transition youth and post-transition adults perceive as being most important to their health care transition. These differing perspectives on transition help us to see what parts of the health care transition the pre-transition youth are most concerned with learning as opposed to what aspects the post-transition adults report as being the most important. The study found that the campers greatly value their time at camp and the community that camp builds, allowing them the rare opportunity to meet people with similar health care conditions to them. It was found that by participating in the camp's transition activities, the campers particularly found advice from recently transitioned staff to be beneficial. The aspects of health care transition programming that the pre-transition youth were most interested were adapting to college, telling others about their condition, filling out paperwork and finding out who their doctor would be after they transitioned. The aspects of health care transition the post-transition adults reported as being most important was communication between the individual and their new health care staff, being knowledgeable about themselves, and managing insurance. Suggestions for our community partner to help further refine their transition programming include having more interactive activities, include the recently transitioned volunteers more, explaining the adult care clinic more in-depth, and showcasing how to navigate the paperwork that they will be required to complete once they transition. In conjunction with future research, the findings of this present study speak to the importance of introducing the pre-transition youth to their adult care doctor before they transition and early transition education on ensuring a successful health care transition. These findings also speak to how medical specialty camps can

increase feelings of self-esteem, peer support, communication skills, and independence. Findings suggest that medical specialty camps are a viable venue for health care transition education and facilitating meaningful relationships among campers with similar conditions as a support system for each other as they move through the health care transition process.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **rede.ecu.edu/umcirb/**

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB

To: Tripp Chesnutt

CC: Priti Desai

Date: 4/20/2022

Re: UMCIRB 22-000075
Exploring Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 4/20/2022. The research study is eligible for review under expedited category # 6 & 7. The Chairperson (or designee) deemed this study no more than minimal risk.

As the Principal Investigator you are explicitly responsible for the conduct of all aspects of this study and must adhere to all reporting requirements for the study. Your responsibilities include but are not limited to:

1. Ensuring changes to the approved research (including the UMCIRB approved consent document) are initiated only after UMCIRB review and approval except when necessary to eliminate an apparent immediate hazard to the participant. All changes (e.g. a change in procedure, number of participants, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the UMCIRB before they are implemented;

2. Where informed consent has not been waived by the UMCIRB, ensuring that only valid versions of the UMCIRB approved, date-stamped informed consent document(s) are used for obtaining informed consent (consent documents with the IRB approval date stamp are found under the Documents tab in the ePIRATE study workspace);

3. Promptly reporting to the UMCIRB all unanticipated problems involving risks to participants and others;

4. Submission of a final report application to the UMICRB prior to the expected end date provided in the IRB application in order to document human research activity has ended and to provide a timepoint in which to base document retention; and

5. Submission of an amendment to extend the expected end date if the study is not expected to be completed by that date. The amendment should be submitted 30 days prior to the UMCIRB approved expected end date or as soon as the Investigator is aware that the study will not be completed by that date.

The approval includes the following items:

Name	Description
Assent Form for Pre-Transition Adolescents	Consent Forms
Consent Form for Post-Transition Young Adults	Consent Forms
Parent Permission Form for Parents of Pre-Transition Adolescents	Consent Forms
Phone Script for Post-Transition Adults	Recruitment Documents/Scripts
Phone Script for Pre-Transition Parents	Recruitment Documents/Scripts
Post-Transition Cover Letter	Recruitment Documents/Scripts
Post-Transition Demographic Survey	Surveys and Questionnaires
Post-Transition Recruitment Flyer	Recruitment Documents/Scripts
Pre- and Post-Transition Interview Question Guide	Interview/Focus Group Scripts/Questions
Pre-Transition Cover Letter	Recruitment Documents/Scripts
Pre-Transition Demographic Survey	Surveys and Questionnaires
Pre-Transition Recruitment Flyer	Recruitment Documents/Scripts
Signed Recruitment Letters (Pre and Post-transition) from Dr. Fuh	Recruitment Documents/Scripts
Thesis Proposal Chapters 1 - 3	Study Protocol or Grant Application
Waiver of Authorization	HIPAA Documentation

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B: PRE-TRANSITION INFORMED CONSENT FORM

Parent/Guardian Permission to Allow Your Child to Take Part in Research

Information to consider before allowing your child to take part in research that has no more than minimal risk.

Title of Research Study: Exploring Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps

Principal Investigator: James Warren Chesnutt III (Tripp) (Person in Charge of this Study)

Institution, Department or Division: Department of Human Development and Family Science

Address: 1000 East 5th St. ECU Building 112W Greenville, NC 27858

Telephone #: 252-328-4630

Other Personnel: Jacque Sauls

Telephone #: 252-744-3304

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why is my child being invited to take part in this research?

The purpose of this research is to find out what aspects of the health care transition programming by Camp Hope and Camp Rainbow is perceived as being useful by pre-transition youth and post-transition adults. A health care transition refers to the period where your child will move from their pediatrician to an adult-oriented healthcare provider. Your child is being invited to take part in this research because they are a sickle cell or hemophilia patient that has attended Camp Hope or Camp Rainbow in the past. The decision for your child to take part in this research will also depend upon whether your child wants to participate. By doing this research, we hope to learn what aspects of the health-care transition programming is seen as being most important by campers.

If you and your child agree for him/her to volunteer for this research, your child will be one of about 20 people to do so.

Are there reasons my child should not take part in this research?

Your child should not take part in this research if they are not a sickle cell or hemophilia patient, or if they have not attended Camp Hope or Camp Rainbow at least once in the past. They should also not take part in this research if they attended the camp but for whatever reason did not take part in the transition activity. They should not participate if they cannot read, write, and speak in English.

What other choices do I have if my child does not take part in this research?

Your child can choose not to participate. You do not need to make any other choices.

Where is the research going to take place and how long will it last?

The research will be conducted virtually from East Carolina University's Rivers building office, utilizing an online meeting video platform called WebEx. Your child will need to have means to access this, either through a personal computer, smart phone, or tablet. Interviews will take place only one time during the study. The total amount of time your child will be asked to volunteer for this study is between 20 minutes to 1 hour for each interview. If clarification is needed will we reach out for a shorter second interview.

What will my child be asked to do?

You will be asked to do the following:

- Read the study information: you can contact either myself or my thesis director with any questions.
- Please talk to your child about the study.
- If you and your child agree to participate, you will be asked to read and sign the consent form

Your child will be asked to do the following:

- Read and sign the assent form
- Complete a questionnaire about basic demographic information, such as their age and grade in school, and their participation with Camp Hope and Rainbow.
- A brief interview over WebEx covering topics such as Camp Hope and Camp Rainbow, the programming they participated in both at camp and after camp, and their health care transition. These interviews would be recorded via WebEx and kept secure until the research is completed. If your child is attending Camp Hope or Camp Rainbow this summer they can choose to participate in the interview while at camp if they prefer.

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. As a parent, you would be supporting a research study that may be helpful for your child or other children with sickle cell disease or hemophilia.

Will my child be paid for taking part in this research?

We will not be able to pay your child for the time you volunteer while being in this study.

Will it cost me anything for my child to take part in this research?

It will not cost you any money to be part of the research. Your child will need to be able to access the Internet and complete a virtual interview, using either a computer, smartphone, or tablet.

Who will know that I took part in this research and learn personal information about me?

The research team associated with this study may know that your child took part in this research and may see information about your child that is normally kept private. ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.
- People designated by Camp Hope and Camp Rainbow

All the information you and your child share will be kept confidential, except for disclosures regarding child abuse, elder abuse, abuse towards a person with a disability, or threat to harm self or others. Such information is required to be reported to appropriate authorities for safety concerns.

How will you keep the information you collect about my child secure? How long will you keep it?

There will be two pieces of data generated from this study: audio/visual interview data and a printed transcript. Electronic data will be stored in a password-protected Pirate Drive that is accessible through a password-protected computer. This will help ensure no breach in confidentiality occurs. The deidentified printed transcript will be kept in a secure, locked cabined in a locked office at East Carolina University and will be kept following University guidelines.

What if my child decides he/she doesn't want to continue in this research?

Your child can stop at any time after it has already started. There will be no consequences if he/she stops and he/she will not be criticized. Your child will not lose any benefits that he/she would normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator via email at chesnuttj16@studnets.ecu.edu or Camp Director Jacque Sauls at 252-916-0051 or email saulsj@ecu.edu, or Tripp's researcher chair's office at 252-328-2866 or email at desaip.ecu.edu.

If you have questions about your child's rights as someone taking part in research, you may call the University and Medical Center Institutional Review Board (UMCIRB) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of Human Research Protections, at 252-744-2914

Is there anything else I should know?

Your child's information collected as part of the research, even if identifiers are removed, will not be used or distributed for future studies.

I have decided my child can take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that my child can stop taking part in this study at any time.
- By signing this informed consent form, my child is not giving up any of his/her rights.
- I have been given a copy of this consent document, and it is mine to keep.

_____

Parent's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

_____

Person Obtaining Consent (PRINT) **Signature** **Date**

APPENDIX C: ASSENT FORM

Assent Form

Things You Should Know Before You Agree To Take Part in this Research

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IRB Study #22-000075

Title of Study: Exploring Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps

Person in charge of study: James Warren Chesnutt III (Tripp)
Where they work: East Carolina University Department of Human Development and Family Science
Other people who work on the study: Jacque Sauls, Priti Desai

Study contact phone number: 252-328-2866, 252-744-3304
Study contact E-mail Address: chesnuttj16@students.ecu.edu or saulsj@ecu.edu or desaip@ecu.edu

---

People at ECU study ways to make people's lives better. These studies are called research. When teenagers switch from their pediatric child doctor to adult care, this is called health care transition. This research seeks to find out what aspects of the health care transition programming by Camp Hope and Camp Rainbow is perceived as being useful by pre-transition youth and post-transition adults.

Your parent(s) needs to give permission for you to be in this research. You do not have to be in this research if you don't want to, even if your parent(s) has already given permission.

You may stop being in the study at any time. If you decide to stop, no one will be angry or upset with you.

Why are you doing this research study?
The reason for doing this research is to understand the experience of adolescents attending a camp with other teenagers with similar diagnoses. We also want to understand how transition activities at camp are experienced by adolescents. It will also help provide information to Camp Hope and Camp Rainbow staff to help them improve the health care transition activity for the future.

Why am I being asked to be in this research study?
We are asking you to take part in this research because you either have sickle cell or hemophilia and attended Camp Hope or Camp Rainbow at least once in the past.

How many people will take part in this study?
If you decide to be in this research, you will be one of about 20 people taking part in it.

What will happen during this study?
If you decide that you want to be in this research study, this is what will happen:
Your mom or dad will:

1. Complete a form giving their permission for you to participate.

You will:

1. Complete a form stating that you wish to be a part of this research.
2. Complete a questionnaire about yourself, who you live with, and your experience at Camp Hope or Camp Rainbow.
3. Work with your mom or dad to schedule a time for you to complete the virtual interviews, or conduct the interview during camp. During the interview you will answer questions about your time at Camp Hope or Camp Rainbow, your thoughts on your health care transition, and your thoughts and memories about the Camp's health care transition activities.

Your interviews will be recorded. At any time, you may ask to take a break, skip a question you do not wish to answer or to come back to, or to be done with the interview. If you do not wish to keep talking at a certain point, you also have the option to reschedule your interview.

These interviews may take place virtually through a platform called Webex. You will need to have access to the Internet as well as a computer, smartphone, or tablet to complete this interview. There is also the option to do an in-person interview if you plan to attend Camp Hope or Camp Rainbow this summer. Each interview will last approximately 20 to 60 minutes.

Who will be told the things we learn about you in this study?

The things that we learn about you in this study will only be shared with the research team. In case you tell me about an adult currently or previously hurting you; if you tell me about an adult hurting an elder; if you tell me about an adult hurting a person with a disability; or if you tell me about any threat or intention to hurt yourself or somebody else, this information will have to be told to your parents as well as professionals who can get you the right kind of help. ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.
- People designated by Camp Hope and Camp Rainbow

What are the good things that might happen?

Sometimes good things happen to people who take part in research. These are called "benefits." The benefits to you of being in this study may be that the health care transition programming at Camp Hope and Camp Rainbow is improved and is able to help more young people better understand transition. There is a chance you will benefit from being in this research.

What are the bad things that might happen?

Sometimes things we may not like happen to people in research studies. These things may even make them feel bad. These are called "risks." These are no known risks to this study at this time. Things may also happen that the researchers do not know about right now. You should report any problems to your parents and to the researcher

Will you get any money or gifts for being in this research study?

You will not receive any money or gifts for being in this research study.

Who should you ask if you have any questions?

If you have questions about the research, you should ask the people listed on the first page of this form. If you have other questions about your rights while you are in this research study you may call the Institutional Review Board at 252-744-2914.

If you decide to take part in this research, you should sign your name below. It means that you agree to take part in this research study.

_____	_____
Sign your name here if you want to be in the study	Date
_____	
Print your name here if you want to be in the study	
_____	_____
Signature of Person Obtaining Assent	Date
_____	
Printed Name of Person Obtaining Assent	

APPENDIX D: POST-TRANSITION INFORMED CONSENT FORM

Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Exploring Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps

Principal Investigator: James Warren Chesnutt III (Tripp) (Person in Charge of this Study)
Institution, Department or Division: Department of Human Development and Family Science
Address: 124 Rivers West
Telephone #: 252-328-2866
Study Coordinator: Priti Desai
Telephone #: 252-328-2866
Other Personnel: Jacque Sauls
Telephone #: 252-744-3304

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

This research is interested in what aspects of the health care transition programming used by Camp Hope and Camp Rainbow is valued by current and former campers. Health care transition refers to the time when a teen with a disability switches from their pediatric child doctor to adult care. The reason for doing this research is to understand the experience of adolescents attending a camp with other teenagers with similar diagnoses. We also want to understand how transition activities at camp are experienced by adolescents. It will also help provide information to Camp Hope and Camp Rainbow staff to help them improve the health care transition activity for the future.
Eligible participants must have been a camper at the camps in the past, participated in the health care transition activity, and be either a sickle cell or hemophilia patient. We ask that you participate in an interview that should take around 20-60 minutes to complete. We do not foresee any notable risks that you may encounter during this interview.

Why am I being invited to take part in this research?

The purpose of this research is to learn what aspects of the health care transition programming used by Camp Hope and Camp Rainbow are valued the most by former campers. A health care transition refers to the period where an adolescent moves from their pediatrician to an adult-oriented healthcare provider. You are being invited to take part in this research because you are a sickle cell or hemophilia patient that has attended Camp Hope or Camp Rainbow in the past. The decision to take part in this research is yours to make. By doing this research, we hope to learn what aspects of the health-care transition programming is seen as being most important by campers.

If you volunteer to take part in this research, you will be one of about 20 people to do so.

Are there reasons I should not take part in this research?
You should not take part in this research if you are not a sickle cell or hemophilia patient, or if you have not attended Camp Hope or Camp Rainbow at least once in the past. You should also not take part in this research if you attended the camps but for whatever reason did not take part in the transition activity. You should not participate if you cannot speak in English.

What other choices do I have if I do not take part in this research?
You can choose not to participate. You do not need to make any other choices.

Where is the research going to take place and how long will it last?
The research will be conducted online on WebEx. You will need to log in to WebEx 1 time during the study. The total amount of time you will be asked to volunteer for this study is about one hour over the next month.

What will I be asked to do?
You will be asked to do the following:

- Complete a questionnaire asking for some basic demographic information such as age and ethnicity about the participant and their participation with Camp Hope and Rainbow.
- A brief interview over WebEx covering topics such as Camp Hope and Camp Rainbow, the programming they participated both at camp and after camp, and their health care transition. Only if clarification is need will we reach out for a shorter second interview. These interviews would be recorded via WebEx and kept secure until the research is completed.

What might I experience if I take part in the research?
We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others with sickle cell disease or hemophilia in the future.

Will I be paid for taking part in this research?
We will not be able to pay you for the time you volunteer while being in this study.

Will it cost me to take part in this research?
It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?
ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.
- People designated by Camp Hope and Camp Rainbow

How will you keep the information you collect about me secure? How long will you keep it?

The demographic questionnaires and interview recordings will be kept on a password protected hard drive. Only members of the research team will be able to access the information on these drives. This information will be deleted upon the completion of the research.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator via email at chesnuttj16@students.ecu.edu or his researcher chair's office at 252-328-2866 or email at desaip.ecu.edu, or Jacque Sauls at 252-916-0051 or email saulsj@ecu.edu.

If you have questions about your rights as someone taking part in research, you may call the University & Medical Center Institutional Review Board (UMCIRB) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director for Human Research Protections, at 252-744-2914 or desaip.ecu.edu.

Is there anything else I should know?

Your information collected as part of the research, even if identifiers are removed, will not be used or distributed for future studies.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

_____ _____ _____

Participant's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT)	**Signature**	**Date**

APPENDIX E: WAIVER OF AUTHORIZATION

UMCIRB #22-000075 PI: Trip Chesnutt

University and Medical Center Institutional Review Board
Application for Waiver or Alteration of Authorization

1. Select the types Protected Health Information (PHI) to be collected:
   - [☐] Billing records
   - [☐] Mental Health records
   - [☒] Physician/clinic records
   - [☐] other:
   - [☐] Hospital/medical records (in and out-patient)
   - [☐] Lab, pathology and/or radiology results
   - [☐] PHI previously collected for research purposes

2. Select the responses below for all the identifiers to be captured in the research study:
   - [☒] Postal address
   - [☒] Account /medical record number
   - [☐] Certificate/license number
   - [☐] Name of relatives
   - [☐] E-mail address
   - [☐] Health plan numbers
   - [☒] Name
   - [☐] Name of employers
   - [☐] Photographic images
   - [☐] Finger or voice prints
   - [☐] Telephone number
   - [☐] Internet Protocol (IP) address number
   - [☐] Web universal resource locator (URL)
   - [☐] Fax number
   - [☐] Any device or vehicle identifiers and serial numbers, including license plate numbers
   - [☐] Date of birth, admission date, discharge date, date of death, all ages over 89
   - [☐] Any other unique identifying number, characteristic or code

Please note: Pursuant to North Carolina law, **social security numbers are not permitted to be collected in reliance on this waiver of authorization**. Unless social security numbers are required by law to be collected, the study subject must be given a written disclosure which (i) states that providing social security number is not required; and (ii) describes the purpose for which the social security number will be used.

3. Select the response below on how participant's Protected Health Information (PHI) is protected against improper use or disclosure:
   - [☐] Research team members will sign a Confidentiality Agreement.
   - [☒] The information will not be shared unless it is stripped of all 18 identifiers.
   - [☐] The information will be shared with a random code as outlined in the research protocol.

4. Explain the data management measures to protect the confidentiality of participant's data such as storage and access issues, including (i) safeguards for storage of any identifiers on computer workstations; and (ii) safeguards for storage of any identifiers on laptop computers, flash drives or any other portable electronic device, as applicable.

The PHI pulled from the medical documents will be stored on the password protected secure department PirateDrive.

5. Data will be stripped of all identifiers upon completion of:
   - [☐] subject participation
   - [☐] FDA approval
   - [☒] other (please specify): Upon closure of study recruitment
   - [☐] data analysis
   - [☐] specimen processing

   OR

   Identifiers will be retained indefinitely because:
   - [☐] the study is longitudinal
   - [☐] of federal requirements (specify):
   - [☐] other (specify):

6. Provide any additional explanations on why the use/disclosure of PHI involves no more than minimal risk to participant privacy

Access to the medical records is only for the purpose of updating camp participant's addresses for a subset of post-transition participants to be mailed information on the study. Once that information is received, should they want to participate, all information will come directly from the study participant and no medical records will be accessed for data. All data afterwards will be self-reported by the participant and no PHI will be involved.

7. Explain why the participant's Authorization cannot be attained and, therefore, research cannot be practicably carried out without the Waiver or Alteration of Authorization. If required elements of a valid HIPAA Authorization are being omitted from the Authorization process, please list them and justify their exclusion.

Previous camp participants are also patients of ECU. Access to the medical records is necessary to gain accurate addresses to get the recruitment fliers. PHI is used to obtain contact information for a subset of the post-transition potential participants only. Without the Waiver or Alteration of Authorization those participants will not be able to be contacted by the study at all, making it impossible to gain their Authorization without use of this waiver.

8. Select the response or explain why research can not practicably be conducted without the participant's PHI.
   - [ ] PHI is needed to identify eligibility for the study
   - [ ] PHI is the focus of the study (e.g. – epidemiological studies)
   - [x] Other (specify): Addresses are need to send the recruitment fliers to potential participants

I verify that protected health information will not be re-used or disclosed to any other person or entity, except as required by law, research oversight, per the terms of a valid HIPAA authorization or those uses outlined above. I will only collect the information as specified above, and limit access to that information to the greatest extent possible as previously described. I will destroy the identifier at the earliest opportunity consistent with the conduct of the research as specified above.

Principal Investigator's signature — Date: 4/7/22

References: 45 CFR 160 and 164, Standards for Privacy of Individually Identifiable Health Information; Final Rule NC Gen. Stat. Sect. 132-1.10 (Social Security Numbers and Personal Identifying Information)

APPENDIX F: LETTER OF SUPPORT FROM DR BENG FUH: DIRECTOR OF PEDIATRIC HEMOTOLOGY AND ONCOLOGY, ECU

ECU BRODY SCHOOL OF MEDICINE

Department of Pediatrics
Brody School of Medicine
Section of Pediatric Hematology/Oncology

600 Moye Blvd
Vidant-MA Suite 333
Greenville, NC 27834

Phone (252) 744-4676
Fax (252) 744-8199
Nights/Weekends
(252) 744-7676

Beng Fuh, MD
Director /Professor

Sarah Leonard, MD
Assistant Professor

Andrea Whitfield, DO
Assistant Professor

Cathleen Cook, MD
Assistant Professor

Rachael Davis, MD
Assistant Professor

Jessica Veale, PA
Physician Assistant

Chelsea Rivenbark, FNP
Family Nurse Practitioner

Katie Venters, RN, BSN
Nurse Specialist

Kalen Sugg, RN, BSN
Nurse Specialist

Michael Mintz, RN
Nurse Specialist

April Gay, NA
Clinic Nursing Assistant

Aimee Smith, PhD
Psychologist

Lora Joyner, MS, PT, PCS
Pediatric Physical Therapist

Mary Lynn Harrell, BS
Research Specialist

Hillary Weismiller, MPH
Research Specialist

Jacque Sauls, MS, CCLS
Dir. Rainbow Serv./Child Life

Tamika Mackey, BS
Child Life Specialist

Charmaine Bond, MSW, LCSW
Social Worker

Marcus Perry, MSW, LCSWA
Social Work

Scott Miller Jr, M.Ed.
University Program Specialist

Candace Rouse
Administrative Assistant

January 31, 2022

ECU University & Medical Center
Institutional Review Board
4N-70 Brody Medical Sciences Building
600 Moye Blvd
Greenville, NC 27834

To Whom It May Concern:

Mr. James Tripp Chesnutt, III is planning a Master's Thesis exploring the value of health care transition programming offered for campers as perceived by pre and post transition youth. Participants will be pre and post health care transition sickle cell and bleeding disorder patients ages 14 - 29 who have attended ECU Pediatric Hematology/Oncology's Camp Rainbow or Camp Hope programs and have participated in transition educational sessions conducted at camp. Eligible adolescents and young adults will be identified by ECU Pediatric Hematology/Oncology and if interested, the patient and parents of underage participants, will be consented and participate in an interview conducted by Mr. Tripp and trained Research Assistants.

It is our hope that this research will generate valuable information regarding the benefits of providing health care transition educational programing for adolescents who are attending medical specialty camps. We fully support Mr. Chesnutt in pursuing this important research study.

Please feel free to contact us if you have questions or need additional information.

Sincerely,

Beng Fuh, MD
Professor,
Director Pediatric
Hematology/Oncology

Jacque P. Sauls, MS, CCLS
Director Camp Rainbow/Camp Hope
Child Life Specialist

APPENDIX G: LETTER OF SUPPORT FROM CAMP DON LEE

From: Kate Metts <kate@donleecenter.org>
Sent: Wednesday, March 9, 2022 4:40 PM
To: chesnuttj16@ecu.edu <chesnuttj16@ecu.edu>
Subject: Camp Don Lee Permission

To whom it may concern:
We would be happy to help and provide some space for ECU master's student Tripp Chesnutt to conduct 1-1 interviews at Camp Don Lee facility for his titled: **Exploring Camper Perspectives on Health Care Transition Programming Offered Through Medical Specialty Camps.**
We understand he will be interviewing pre-and post-transition adolescents and young adults who are either campers or counselors attending Camp Hope and Camp Rainbow between June 15-17th, 2022. We understand his study will be approved by ECU's IRB in order to complete these onsite interviews and I will be provided a copy of this IRB approval letter.
We wish him the best for his research.
Kate Cooper Metts
Director
Don Lee Center
315 Camp Don Lee Road
Arapahoe, NC 28510
252-249-1106 ext. 23

Kate Cooper Metts
Director
Don Lee Camp & Retreat Center
Arapahoe, NC
www.donleecenter.org

Sent from my iPhone

APPENDIX H: PRE-TRANSITION RECRUITMENT LETTER FROM DR BENG FUH:

DIRECTOR OF PEDIATRIC HEMOTOLOGY AND ONCOLOGY, ECU

Department of Pediatrics
Brody School of Medicine | 3E-142 Brody Medical Sciences Building | Mail Stop 703
East Carolina University | Greenville, NC 27834-4354
252 744 2540 office | 252-744-1116 fax

Dear Parent or Caregiver,

I invite you to consider participating in a research study, which may improve knowledge regarding the perception of health care transition among adolescents and young adults. Health care transition refers to the time when a teen or young adult with a chronic health condition moves from their pediatric doctor to adult care. With this information we would help programs better understand what your views on transition currently are. Your participation may also provide insight for future health care transition educational activities at clinic and at Camp Hope and Camp Rainbow.

Tripp Chesnutt is a Master's student in the Human Development and Family Science Department at East Carolina University and will be conducting this research. He will be working under the guidance of Priti P. Desai, PhD, MPH, CCLS, Associate Professor in the department. While he is conducting research interviews at camp, he will be under the supervision of Jacque Sauls, our ECU Camp Hope and Camp Rainbow Director.

Tripp will be recruiting current and former Camp Hope and Camp Rainbow campers diagnosed with either sickle cell disease or hemophilia aged 13 years and higher to serve as participants. If you agree to have your child participate in this study, they will be asked to engage in an in-depth interview to share their knowledge on health care transition as well as their thoughts on the camps' health care transition educational activities. Interviews will be scheduled on a first come, first serve basis until the necessary data are collected. Please see the enclosed flier regarding study details as well as contact information for the thesis team.

Please consider allowing your child to participate in this upcoming study, which will hopefully generate valuable information regarding the views of pre-transition adolescents and post-transition young adults have on their health care transitions, as well as helping to further refine the health care transition educational activities at Camp Hope and Camp Rainbow. The study has been approved by the Institutional Review Board (IRB) of East Carolina University. If you are interested in participating, please contact Tripp, Jacque Sauls or Dr. Desai; their contact information is provided on the attached study flier. They will also be happy to provide more detailed information regarding the study.

Our team wholeheartedly supports this research project. Please contact Tripp at chesnuttj16@students.ecu.edu or Jacque Sauls at saulsj@ecu.edu or by phone at 252-744-3304 or Dr. Priti Desai at desaip@ecu.edu or by phone at 252-328-2866 if you have further questions about this study.

Date: April __, 2022

Sincerely,

Beng Fuh, MD
Chief and Associate Professor
Pediatric Hematology/Oncology
Brody School of Medicine
East Carolina University

APPENDIX I: POST-TRANSITION RECRUITMENT LETTER FROM DR BENG FUH:

DIRECTOR OF PEDIATRIC HEMOTOLOGY AND ONCOLOGY, ECU

ECU

Department of Pediatrics
Brody School of Medicine | 3E-142 Brody Medical Sciences Building | Mail Stop 632
East Carolina University | Greenville, NC 27834-4354
252-744-2540 office | 252-744-1376 [illegible]

Dear Potential Participant,

I invite you to consider participating in a research study, which may improve knowledge regarding the perception of health care transition among adolescents and young adults. Health care transition refers to the time when a teen or young adult with a chronic health condition moves from their pediatric doctor to adult care. With this information we would help programs better understand what your views on transition currently are. Your participation may also provide insight for future refinement of the health care transition educational activities in clinic and at Camp Hope and Camp Rainbow.

Tripp Chesnutt is a Master's student in the Human Development and Family Science Department at East Carolina University and will be conducting this research. He will be working under the guidance of Priti P. Desai, PhD, MPH, CCLS, Associate Professor in the department. While he is conducting interviews at camp, he will also be under the supervision of Jacque Sauls, our ECU Camp Hope and Camp Rainbow Director.

Tripp will be recruiting former Camp Hope and Camp Rainbow campers and camp volunteers diagnosed with either sickle cell disease or hemophilia aged 18 years and higher who have transitioned to adult care to serve as participants. If you agree to participate in this study, you will be asked to engage in an in-depth interview to share your knowledge and experiences about health care transition as well as your thoughts on the camps' health care transition educational activities. Interviews will be scheduled on a first come, first serve basis until the necessary data are collected. Please see the enclosed flier regarding study details as well as contact information for the thesis team.

Please consider participating in this upcoming study, which will hopefully generate valuable information regarding the views of pre-transition adolescents and post-transition young adults have on their health care transitions, as well as helping to further refine the health care transition educational activities at clinic and at Camp Hope and Camp Rainbow. The study has been approved by the Institutional Review Board (IRB) of East Carolina University. If you are interested in participating, please contact Tripp or Dr. Desai; their contact information is provided on the attached study flier. They will also be happy to provide more detailed information regarding the study.

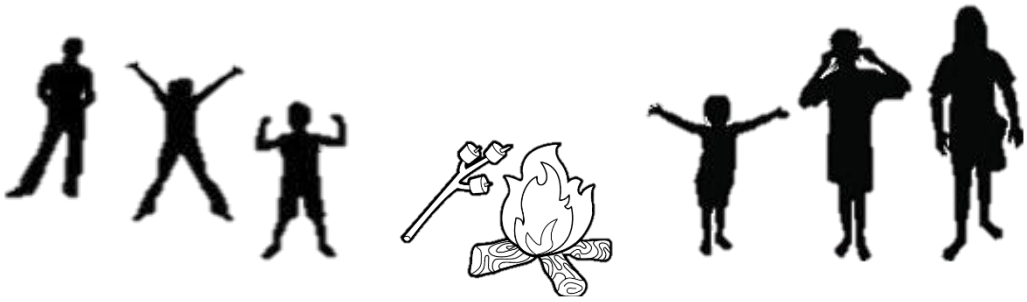
Our team wholeheartedly supports this research project. Please contact Tripp at chesnuttj16@students.ecu.edu or Jacque Sauls at saulsj@ecu.edu or by phone at 252-744-3304, or Dr. Priti Desai at desaip@ecu.edu or by phone at 252-328-2866 if you have further questions about this study.

Date: April __, 2022

Sincerely,

Beng Fuh, MD
Chief and Associate Professor
Pediatric Hematology/Oncology
Brody School of Medicine
East Carolina University

APPENDIX J: PRE-TRANSITION RECRUITMENT FLYER



Are you the parent or guardian of an individual living with sickle cell disease or hemophilia that has gone to Camp Hope or Camp Rainbow?

We need YOUR help for a research study!

We are seeking your help in a graduate-level research study being conducted at East Carolina University. This study aims to understand the value of attending Camp Hope and Rainbow and how participation in transition programming/activities feel useful to you regarding your health care transition. Health care transition refers to the time when teenagers switch from their pediatric child doctor to an adult health care provider. Your participation can help us further refine the health care transition programming at Camp Hope and Camp Rainbow.

If you consent to your child participating, you will be asked to:

1. Sign a consent form stating you give permission for your child to participate in this study

Your child will be asked to:

1. Sign an assent form stating they wish to participate in this study
2. Complete a questionnaire about your family demographics. This includes questions such as who lives in the home, education and income, and your child's camp history
3. Complete a virtual interview that will last approximately 20-60 minutes using WebEx, an online meeting space. If they are attending Camp Hope or Camp Rainbow this summer they can choose to conduct the interview there if they prefer.
   All interviews will be recorded. The research team will follow all research ethics to protect each participant's identity, and their identity will never be revealed during the reporting of findings.

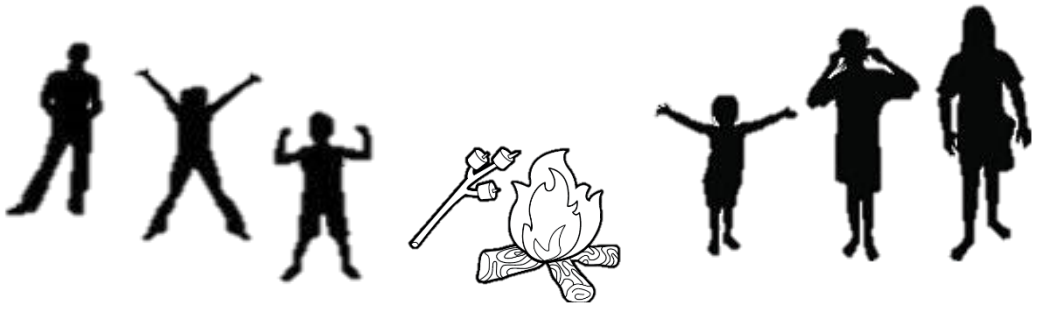
Your child is eligible to participate if:

1. They are living with either sickle cell disease or hemophilia and have attended Camp Hope or Camp Rainbow in the past
2. They have not yet transitioned from their pediatric health provider to an adult-oriented health care provider
3. They have access to the Internet and a computer to participate in a virtual video interview
4. They speak, read, and write in English

For more information, contact Tripp Chesnutt at chesnuttj16@students.ecu.edu or Jacque Sauls at saulsj@ecu.edu or 252-744-3304 or Dr. Priti Desai at desaip@ecu.edu or at 252-328-2866. Tripp Chesnutt is a current student and Dr. Desai is a faculty member at East Carolina University.

Thank you for your consideration to participate in this important study!

APPENDIX K: POST-TRANSITION FLYER



Are you an individual living with sickle cell disease or hemophilia that has gone to Camp Hope or Camp Rainbow?

We need YOUR help for a research study!

We are seeking your help in a graduate-level research study being conducted at East Carolina University. This study aims to understand the value of attending Camp Hope and Rainbow and how participation in transition programming/activities feel useful to you regarding your health care transition. Health care transition refers to the time when teenagers switch from their pediatric child doctor to an adult health care provider. Your participation can help us further refine the health care transition programming at Camp Hope and Camp Rainbow.

You will be asked to:

4. Sign a consent form stating you wish to participate in this study
5. Complete a questionnaire about your family demographics. This includes questions such as who lives in the home, education and income, and your child's camp history
6. Complete a virtual interview that will last approximately 20-60 minutes using WebEx, an online meeting space.
   All interviews will be recorded. The research team will follow all research ethics to protect each participant's identity, and their identity will never be revealed during the reporting of findings.

You are eligible to participate if:

5. You are living with either sickle cell disease or hemophilia and have attended Camp Hope or Camp Rainbow in the past
6. You have transitioned from your pediatric health provider to an adult-oriented health care provider
7. You have access to the Internet and a computer to participate in a virtual video interview
8. You can speak, read, and write in English

For more information, contact Tripp Chesnutt at chesnuttj16@students.ecu.edu or Jacque Sauls at saulsj@ecu.edu or 252-744-3304 or Dr. Priti Desai at desaip@ecu.edu or at 252-328-2866. Tripp Chesnutt is a current student and Dr. Desai is a faculty member at East Carolina University.

Thank you for your consideration to participate in this important study!

APPENDIX L: PHONE CALL SCRIPT FOR PARENTS OF CHILDREN WITH SICKLE CELL DISEASE OR HEMOPHILIA

Hello! My name is Tripp Chesnutt, and I am a current Master's student at East Carolina University. I would like to speak with the parent or guardian of *(child's name)*. I am following up regarding information that you received from your camp director Jacque Sauls.

As you read in the recruitment information, I am currently conducting a research study about the effects that camp attendance and transition programs can have towards health care transition readiness. I have received permission from your child's camp director and my university's research regulatory team for this study. First, I would like to thank you for expressing interest in allowing your child to participate in this study would like to answer any questions you may have.

Before we continue, I want to verify if your child is eligible to participate in the study. To do this, I will ask you a few questions.

1. Do you have a child with either sickle cell disease or hemophilia?
2. Does this child currently attend, or have they previously attended, Camp Hope or Camp Rainbow?
3. Do you have access to the Internet and a computer, smartphone, or tablet to complete virtual video interviews?
4. Does your child speak, read, and write in English?

If the answer to any of the screening questions is "no":

Thank you for your time. Unfortunately, part of the criteria for my study is *(insert reasoning based on answer to question*). Since *(reason)*, we no longer need your participation in this study. I appreciate you taking this call and speaking with me and hope you enjoy the rest of your day.

If the answer to all of the screening questions is "yes":

I am calling to provide information about the study and answer any questions you may have. I hope you and your family will consider participating in the study by completing a demographic survey and a virtual video interview on a date and time that works well for you. I would like to give you some more information about the study. Do you have a few minutes for me to discuss this with you?

If the answer is "yes":

I would like to learn more about the effects that camp participation and transition programs can have towards an adolescent's health care transition readiness. I am interested in learning about both their current knowledge as well as what they believe is needed to be sufficiently prepared for a health care transition.

There is no financial cost for participating. Your child's interviews will take place using a virtual video system called WebEx. During these interviews, I am hoping to speak with your child about

their time at Camp Hope or Camp Rainbow, their current knowledge on health care transition, and any activities they have done to help prepare themselves for their transition. Do you have access to the Internet and a computer, smartphone, or tablet to complete this interview?

I will be sending you more detailed information about the study, but at this time, do you have any questions regarding this study?

Do you think you might still be interested in allowing your child to participate in this study? After this phone call, I will be emailing you the consent and assent forms, and the demographic questionnaire. The demographic questionnaire will ask questions about your household makeup and some general questions about your child's age, grade in school, and participation with Camp Hope or Camp Rainbow.

The *consent form* is **yours** to complete; the *assent form* and *demographic questionnaire* are **your child's** to complete. Before we can complete an interview, I will need to have these completed and returned via email. Do you give me permission to send you this information via email?

What is the best email address for you to receive these?

I will email you my availability so that we can schedule a date and time for an interview.

If you and your child decide to participate, you are still able to drop out of the study at any point in time.

I appreciate your time. Please let me know if you have any questions regarding the study, either now or at any point of time in the future. You can reach the camp director, Jacque Sauls, at 252-916-0051 or by email at saulsj@ecu.edu, or my thesis advisor, Dr. Priti Desai, at 252-328-2866, or you may email me directly at chesnuttj16@students.ecu.edu. All of this contact information is also available on the flier that was sent via email.

Thank you so much for your time today!

APPENDIX M: PHONE SCRIPT FOR ADULT PARTICIPANTS WITH SICKLE CELL DISEASE OR HEMOPHILIA

Hello! My name is Tripp Chesnutt, and I am a current Master's student at East Carolina University. I would like to speak with *(participant's name)*. I am following up regarding information that you received from your camp director Jacque Sauls.

As you read in the recruitment information, I am currently conducting a research study about the effects that camp attendance and transition programs can have towards health care transition readiness. I have received permission from your camp director and my university's research regulatory team for this study. First, I would like to thank you for expressing interest in participating in this study and would like to answer any questions you may have.

Before we continue, I want to verify if you are eligible to participate in the study. To do this, I will ask you a few questions.

1. Do you have either sickle cell disease or hemophilia?
2. Have you previously attended, Camp Hope or Camp Rainbow?
3. Do you have access to the Internet and a computer, smartphone, or tablet to complete virtual video interviews?
4. Does you speak, read, and write in English?

If the answer to any of the screening questions is "no":

Thank you for your time. Unfortunately, part of the criteria for my study is *(insert reasoning based on answer to question*). Since *(reason)*, we no longer need your participation in this study. I appreciate you taking this call and speaking with me and hope you enjoy the rest of your day.

If the answer to all of the screening questions is "yes":

I am calling to provide information about the study and answer any questions you may have. I hope you will consider participating in the study by completing a demographic survey and a virtual video interview on a date and time that works well for you. I would like to give you some more information about the study. Do you have a few minutes for me to discuss this with you?

If the answer is "yes":

I would like to learn more about the effects that camp participation and transition programs can have towards an adolescent's health care transition readiness. I am interested in learning about what those who have already completed their transition believe is needed to be sufficiently prepared for a health care transition.

There is no financial cost for participating. Your interviews will take place using a virtual video system called WebEx. During these interviews, I am hoping to speak with you about your time at Camp Hope or Camp Rainbow, your current knowledge on health care transition, and what you

believe impacted your own transition. Do you have access to the Internet and a computer, smartphone, or tablet to complete this interview?

I will be sending you more detailed information about the study, but at this time, do you have any questions regarding this study?

Do you think you might still be interested in participating in this study? After this phone call, I will be emailing you the consent form and the demographic questionnaire. The demographic questionnaire will ask general questions about your age, ethnicity, and camp participation.

The *consent form* and *demographic questionnaire* are **yours** to complete. Before we can complete an interview, I will need to have these completed and returned via email. Do you give me permission to send you this information via email?

What is the best email address for you to receive these?

I will email you my availability so that we can schedule a date and time for an interview.

If you decide to participate, you are still able to drop out of the study at any point in time.

I appreciate your time. Please let me know if you have any questions regarding the study, either now or at any point of time in the future. You can reach the camp director, Jacque Sauls, at 252-916-0051 or by email at saulsj@ecu.edu, or my thesis advisor, Dr. Priti Desai, at 252-328-2866, or you may email me directly at chesnuttj16@students.ecu.edu. All of this contact information is also available on the flier that was sent via email.

Thank you so much for your time today!

APPENDIX N: PRE-TRANSITION DEMOGRAPHIC QUESTIONNAIRE

Participant Code: _____

Instructions: ***Please circle the most appropriate answer choice for you or fill in the blank where necessary***

1. What sex do you identify as?
    a. Male
    b. Female
    c. Other (Please Specify) _____
    d. Prefer not to answer
2. What is your age?
    a. _____ years
3. What is your race?
    a. African American
    b. White
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Other Pacific Islander
    f. Other (Please Specify) _____
    g. Prefer not to answer
4. What is the highest degree or level of school you have completed?
    a. No schooling completed
    b. Up to 8th grade
    c. Some high school
    d. High school graduate, diploma or the equivalent (GED)
    e. Some college credit, no degree
    f. Trade training
    g. Associate degree
    h. Bachelor's degree
5. What is your employment status?
    a. A student
    b. Employed for pay
    c. Self-employed
    d. Out of work and looking for work
    e. Out of work but not currently looking
    f. A homemaker
    g. Unable to work
    h. Not working currently
6. Who do you live with?
    a. Parent(s)
    b. Roommate(s)
    c. Spouse/Significant other

    d. Alone
    e. Other (Please specify) _____
7. What is the name of your diagnosis?
    a. Sickle Cell Disease
    b. Hemophilia
8. How many years have you attended Camp Hope or Camp Rainbow?
    a. _____
9. What (if any) other medical specialty camps or overnight camps have you attended besides Camp Hope and Camp Rainbow? (Please list all)
    a. _____
    b. _____
    c. _____
    d. _____
10. What topics do you think would be helpful to discuss during Transition Education at Camp and elsewhere? (Choose all that apply)
    a. Description of Adult Medical Care System
    b. Making Appointments
    c. Knowledge about your health condition
    d. Location of adult clinic
    e. Adult medical services provided
    f. Managing your insurance
    g. How to contact the adult providers
    h. Managing your own health care
    i. Managing a Budget, Coping with Stress
    j. Alternative Methods to cope with Pain and symptoms
    k. Living Wills and Advance Care Directives
    l. Establishing a Primary Care Physician
    m. Going to College
    n. Career Exploration
    o. Adult Relationships
    p. Building Independence from Parents
    q. Work issues
    r. Other: _____

APPENDIX O: POST-TRANSITION DEMOGRAPHIC QUESTIONNAIRE

Participant Code: _____

Instructions: ***Please circle the most appropriate answer choice for you or fill in the blank where necessary***

1. What sex do you identify as?
    a. Male
    b. Female
    c. Other (Please Specify) _____
    d. Prefer not to answer
2. What is your age?
    a. _____ years
3. What race do you identify as?
    a. African American
    b. White
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Other Pacific Islander
    f. Other (Please Specify) _____
    g. Prefer not to answer
4. What is the highest degree or level of school you have completed?
    a. No schooling completed
    b. Up to 8th grade
    c. Some high school
    d. High school graduate, diploma or the equivalent (GED)
    e. Some college credit, no degree
    f. Trade training
    g. Associate degree
    h. Bachelor's degree
    i. Master's degree
    j. Doctorate degree
5. What is your employment status?
    a. A student
    b. Employed for pay
    c. Self-employed
    d. Out of work and looking for work
    e. Out of work but not currently looking
    f. A homemaker
    g. Unable to work
    h. Not working currently
6. Who do you live with?
    a. Parent(s)
    b. Roommate(s)

    c. Spouse/Significant other
    d. Alone
    e. Other (Please specify) _____
7. What is your marital status?
    a. Single, never married
    b. Married or domestic partnership
    c. Separated
    d. Divorced
    e. Other (Please specify) _____
8. What is the name of your diagnosis?
    a. Sickle Cell Disease
    b. Hemophilia
9. How many years did you attended Camp Hope or Camp Rainbow?
    a. _____
10. What (if any) other medical specialty camps or overnight camps have you attended besides Camp Hope and Camp Rainbow? (Please list all)
    a. _____
    b. _____
    c. _____
    d. _____
11. Did you ever volunteer at Camp Hope or Camp Rainbow?
    a. Yes
    b. No
12. If you answered yes to the previous question, what years did you volunteer? (Please list all years)
    a. _____
13. What topics do you think would be helpful to discuss during Transition Education at Camp and elsewhere? (Choose all that apply)
    a. Description of Adult Medical Care System
    b. Making Appointments
    c. Knowledge about your health condition
    d. Location of adult clinic
    e. Adult medical services provided
    f. Managing your insurance
    g. How to contact the adult providers
    h. Managing your own health care
    i. Managing a Budget, Coping with Stress
    j. Alternative Methods to cope with Pain and symptoms
    k. Living Wills and Advance Care Directives
    l. Establishing a Primary Care Physician
    m. Going to College
    n. Career Exploration
    o. Adult Relationships
    p. Building Independence from Parents

q. Work issues
r. Other: _____

APPENDIX P: PARTICIPANT INTERVIEW SCHEDULE

Introductions

Thank you for agreeing to participate in this study. Before we move forward with the interview, I would like to provide you with a brief introduction. My name is Tripp Chesnutt and I am a graduate student at East Carolina University. I am currently doing research on health care transitions, which refers to when teenagers switch from their pediatric child doctor to adult care. I am interested in how attending a medical specialty camp and participating in transition programming is related to your health care transition readiness. I want to learn about how participating in Camp Hope and Camp Rainbow has impacted you personally and your knowledge and perceptions surrounding your health care transition. I will be recording your interview so that I will be able to remember all of the information that you share during this time, but your responses will be kept confidential and will not be shared with anyone not involved with the study. You have control over what you choose to share during this time, and do not have to answer any question if you are not comfortable with doing so. You have a right to stop the interview at any time if you wish. To protect your identity, your name will not be used during the transcription of this interview and any data analysis. Do you have any questions? Are you ready to begin?

*Questions may be modified or added for probing per study goals based on the individual's responses.

RQ 1: How is participation in Camp Hope and Camp Rainbow perceived and valued by campers?

1.1) What were your top three activities that you did at Camp Hope and Camp Rainbow over the years?
1.2) Did you make any friends while at camp that you keep in touch with outside of camp, please do not use any names of friends for confidentiality?
   a. How do you stay in touch with those friends?
1.3) What was your experience with being away from home for multiple nights before you went to camp?
   a. Were you nervous before the first day?
   b. How did that change during the course of the camp?
1.4) What surprised you most about camp when you first arrived?
   a. Was there anything that you struggled to adjust to at first?
1.5) Was there any moment at camp where you overcame a challenge that you did not believe was possible at first?
   a. What was that challenge?
   b. How did you overcome it?
1.6) Was there anything about camp that you did not like?
1.7) Can you think of any ways that your experience at camp has been useful outside of camp?

RQ 2: How is participation in the Camp Hope and Rainbow transition activities perceived by campers regarding their knowledge of their health care transition?

2.1) Do you recall if there was any activity you participated in at Camp or with other campers that taught you about your future health care transition to an adult care provider?
   a. Can you describe that activity?
   a. Was there anything in particular you remember learning from that activity?

2.2) During the health care transition activity, was there anything that stood out to you about being ready for health care transition?

2.3) Was there anything else you were hoping would be covered in the activity that was not?

2.4) What was helpful or enjoyable to you about the transition activity?
   a. What suggestions do you have, if any, to improve the activity?

2.5) What topics do you think would be helpful to discuss during Transition Education at Camp and elsewhere?
   a.

2.6) What was helpful being around other campers with similar health care conditions and situations?
   a. How did you feel seeing other campers who seemed further along in the transition process from you? How did that help you in any way?

2.7) What effect did meeting counselors who were past campers have on you?

2.8) Was there anything about transition in particular that you found to be easier or understood better after your time at Camp Hope or Camp Rainbow?

RQ 3: What aspects of health care transition programing do pre-transition adolescents perceive as being most important? (Only use with the pre-transition group)

3.1) What is your understanding of health care transition when you become an adult?
   a. When do you expect your transition to happen?
   b. How long do you think Preparation for Transition from Pediatric Health Care to Adult Health Care should take?

3.2) Have you discussed your health care transition with your parents at all? What are their thoughts on the process?

3.3) Have you begun discussing your health care transition with your doctor or other health care staff?
   a. If yes: when and with whom?

3.4) What parts of the health care transition have you focused the most on so far (if applicable)
3.5) How knowledgeable do you feel about your diagnosis?
    a. What, if any, information do you wish you had more of?
3.6) How confident do you feel in your ability to take care of yourself in terms of your medications and medical appointments?
3.7) What part of your health care transition are you the most confident in?
3.8) What part of the health care transition do you want to work to improve the most?
3.9) If you had to move to an adult-oriented doctor right now, what would be your biggest concern?

RQ 4: What aspects of health care transition programming do post-transition adults perceive as being most important? (Only use with post-transition group)

4.1) When did you first start to discuss your health care transition with your parents and doctor?
    a. Who was it that started the discussion?
4.2) Do you remember what you thought or felt about transitioning to adult health care before you started the health care transition process?
    a. At around what age did you transition from pediatric to adult-oriented health care?
    b. How do you think your transition went overall?
    c. Were there any specific activities you participated in that helped prepare you?
    d. Who helped you learn about your transition?
4.3) In your opinion, what was the easiest part of your health care transition?
4.4) What was your biggest struggle in regards to your health care transition?
4.5) How did you feel about managing your transition overall?
    a. How did you feel about scheduling your own appointments?
    b. What, if any, were some of your struggles in regards to transition?
4.6) What part of the health care transition would you say was the most important?
4.7) Was there anything about the health care transition that surprised you or you wish you knew earlier?

Open Ended Questions

5.1) Is there anything else you would like to share about your experience at Camp Hope and Rainbow or about your health care transition?
5.2) Do you have any suggestions of how to improve future transition camp programming?