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The Social Networks of Adolescents with Chronic Illness: An Exploration of Social Support During Hospitalization

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2022

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By Kaitlyn Brus

Background: Consistency and reliability of social support networks during adolescents is important for personal growth, building and maintenance of self-esteem, and preparation for the transition into adulthood. For adolescents with life-long chronic illness, such as sickle cell disease or cystic fibrosis, frequent hospitalization can be disruptive to normal socialization, which may affect this period of self-actualization and self-determination. Despite this knowledge, there has been little research to conceptualize the role of inpatient hospitalization on social networks of adolescents with genetic chronic illness.

Objectives: This analysis aimed to describe the social networks of adolescents with sickle cell disease and identify changes in social support during in-patient hospitalization and the impact these changes had on adolescents with sickle cell disease.

Methods: Ten semi-structured qualitative interviews with adolescents aged 14-19 who were diagnosed with sickle cell disease, were hospitalized within the prior six months, and lived in the United States were conducted through Zoom software. All participants were recruited via parent-targeted digital recruitment flyers shared through sickle cell advocacy organizations and pediatric clinics. Audio-recorded interviews were transcribed verbatim using Descript. Template analysis was conducted using NVivo 14 for data management and coding.

Results: Analysis produced three major themes among participants: (1) Development of a personal identity shaped by their disease and their surrounding network; (2) How participants' self-perception dictates how they socialize and vice versa; and (3) Defining relationship types, describing barriers and facilitators of these relationships and what modalities of support from these relationships are meaningful for young people with sickle cell disease.

Conclusions: The architecture and adaptability of the social networks of adolescents with sickle cell disease are dependent on a variety of factors including the individual's self-relationship and aptitude to socialization, family dynamics, perception of community empathy and understanding, and experiences, expectations, and receptiveness of support. While appreciative of support received, most participants felt that their needs were unmet at some levels of their social ecosystem (the culmination of an individuals' relationships, social interactions, and communication channels), necessitating the development of programs or intervention to improve in-patient social support for this population.

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1: Introduction

Introduction and Rationale:

The presence of a stable social support network throughout the transition from childhood to adulthood is critical for development.[1-2] For adolescents with life-long chronic illness, such as sickle cell disease or cystic fibrosis, frequent hospitalization can be disruptive to normal socialization, which may affect this period of growth and self-actualization.[3-5] Despite this knowledge, there has been little research to conceptualize the role of inpatient hospitalization in the social network dynamics of adolescents with inherited chronic illness. Furthermore, although these conditions share similarities as chronic genetic disorders, there is reason to believe that systemic healthcare inequalities stemming from historical racial inequities faced by the predominately Black sickle cell disease community may impact their social networks differently compared to the majority White population of individuals with cystic fibrosis. This necessitated a comparative analysis. Therefore, this study was initiated to explore the role of social networks among adolescents with these two conditions during in-patient hospitalization.

Problem Statement:

The social support mechanisms and social networks surrounding adolescents with chronic illness experiencing frequent hospitalization is irrefutably understudied, with a focus over the last few decades almost exclusively centered on young people with later-onset or potentially curable diseases, such as cancer.[6-9] The additional layer of technology as a facilitator of socialization and support for these young people creates yet another dynamic which is lacking in the literature. In the absence of this study, it is unclear the

extent to, or the ways in which, social networks adapt to the needs of teens with sickle cell disease and cystic fibrosis during periods of hospitalization and what psychosocial needs are unmet. Without a clear understanding of the mechanisms of, and gaps in, support that persist in the social networks of adolescents with chronic illness in the current age of technology, we risk perpetuating the long-observed cycle of their unmet psychosocial needs and delayed personal development. [1-3] This underscores the necessity of conducting this research.

Purpose Statement:

The parent study seeks to explore the pathways of social support and the architecture of the social networks, including in-person and virtual networks, of adolescents with chronic illnesses, particularly sickle cell disease and cystic fibrosis, to understand how their networks adapt, or fail to adapt, to their needs during periods of inpatient hospitalization. This thesis details the findings from the first ten interviews with participants living with sickle cell disease.

Research Objectives:

This analysis assessed the role of social networks among adolescents with sickle cell disease with frequent in-patient hospitalization through the following aims:

1. To describe the social networks of adolescents with sickle cell disease.
2. To identify changes in social support during in-patient hospitalization and the impact this has on adolescents with sickle cell disease.

Future analysis will expand the sample size of sickle cell affected participants and include participants living with cystic fibrosis. In addition, future analyses will compare

experiences of social support and the make-up of social networks between sickle cell disease and cystic fibrosis patients.

Significance Statement:

Results from this study, and the larger parent study, are intended to provide evidence for more effective, holistic, and disease- or population-specific care that could expand beyond the individuals within this study and have broadscale public health impacts among these disease groups, or at minimum create a foundation for further investigations.

2: Background

Late adolescence is a crucial time for development: physically, socially, mentally, and emotionally.[1-2] This transitional phase from childhood to adulthood is defined by immense personal change facilitated by the perception and presence of one's social network; however, for teenagers living with chronic illness, disruption of socialization due to frequent hospitalization can have serious adverse effects including increased anxiety, depression, loneliness, and identity loss which can exacerbate physical symptoms and treatment noncompliance.[3-5] The role of social support has been investigated in adolescents with acute chronic diseases such as cancer,[6-9], and though over 40,000 adolescents within the United States are living with life-long chronic disease,[10-11], this same analysis has not been extended to investigate their experience. Findings about social networks and development among adolescents with genetic conditions can inform equitable, whole-person care.

Sickle cell disease and cystic fibrosis are similar in terms of etiology and frequency of hospitalization;[12-14] however, vast differences exist in regard to symptom manifestation, treatments, and demographics. Furthermore, historical interactions with the healthcare system could potentially lead to variability in the role and presence of social networks during in-patient stays for patients with each condition. The period of late adolescence, age 14-19, among those with sickle cell disease and cystic fibrosis is a time in which both populations are entering or beginning to explore palliative care.[15-16] Simultaneously, this age group is experiencing a transition in care from pediatric to adult which, especially for these lifelong disease populations, can be incredibly difficult and place a strain on socialization and confidence in care during hospitalization.[2]

Disease Epidemiology, Etiology, and Progression

Sickle Cell Disease

Sickle cell disease is the most common genetically inherited blood disorder globally and results from a mutation in the HBB gene which encodes for hemoglobin.[17] Sickle cell disease predominately impacts individuals of African descent, with millions suffering globally and approximately 1 in every 365 Black infants born within the United States diagnosed with the disease.[17-18] Individuals with sickle cell disease have red blood cells with a characteristically 'sickled' shape that yields chronic hemolytic anemia, organ dysfunction, vaso-occlusive crises, severe pain, delayed physical development, and an increased risk for other co-morbidities such as stroke, aseptic necrosis, and psychosocial distress among other issues.[15, 17] Among these, vaso-occlusive episodes are the most common reason for hospitalization for people living with sickle cell disease of all ages. Vaso-occlusive episodes are caused by the blockage of blood flow throughout the body due to the build-up of sickle shaped blood cells which can lead to excruciating full body pain, difficulty breathing, high fever, swelling, jaundice, and loss of consciousness. [15, 17]

There is no widely available cure for sickle cell disease, and although curative treatments such as stem cell therapies and bone marrow transplants have begun to show promise in recent years, the vast majority of people living with sickle cell disease are focused on symptom management and preventative medicine inclusive of blood transfusions, medications targeting the production of hemoglobin F, and prescription opioids. The necessity of opioids for pain relief throughout the life-course for individuals with sickle cell disease yields high dose tolerance from a young age.[19] This, coupled with

the historical mistreatment of Black individuals by the healthcare system through the construct of structural racism, has manifested in the stereotype of "drug-seeking behavior" which lends itself to undertreatment of sickle cell disease symptoms, perpetuates mistrust of the medical community among minority populations, and exacerbates the already present challenges of those living with sickle cell disease.[20]

Cystic Fibrosis

Cystic fibrosis, like sickle cell disease, is a genetically inherited condition resulting from gene mutation. However, in the case of cystic fibrosis, these mutations occur within the cystic fibrosis transmembrane conductance regulator gene, and the clinical manifestations of the disease and the afflicted population differ significantly from those with sickle cell disease.[11, 12] Clinically, cystic fibrosis primarily affects the respiratory and digestive systems, producing a characteristic thick sticky mucus within the lungs and other major organs which can cause difficulty breathing, recurrent lung infections, and, within the digestive system, reduced absorption of nutrients leading to malnutrition among other issues. Respiratory and digestive dysfunction resulting from cystic fibrosis contribute to additional co-morbidities such as sinopulmonary complications, developmental delays, and, similar to sickle cell disease, psychosocial distress. [21] Hospitalization among people with cystic fibrosis is often necessitated due to complications related malnutrition, respiratory infection, and/or pulmonary exacerbation due to pneumothorax, hemoptysis, or decreased lung function among other related issues. In the United States, just over 30,000 people are living with cystic fibrosis, and the majority, approximately 85%, are White; however, over

the past decade there has been a significant increase in racial diversity within the cystic fibrosis population. [11]

There is currently no cure for cystic fibrosis, with treatment focusing on symptom management and infection prevention; however, it is important to note that there are various mutations of the CFTR gene and therefore different treatment options based on this genetic variability. Modulator therapies are the most effective cystic fibrosis treatments at present, particularly the newest drug Trikafta, but due to the mutation specific nature of these modulators, they are not compatible for all people living with cystic fibrosis.[22-24] Aside from incompatible mutations, factors such as age, disease severity, and status of co-morbidities may make individuals with cystic fibrosis ineligible for modulator therapies.[22] Other treatment options for those ineligible for modulator therapies, or to be used in tandem with modulators, include chest physiotherapy, anti-inflammatory and other symptom-specific medications, enzyme replacement therapy, pulmonary rehabilitation exercises, and in more extreme cases lung transplantation.[21, 23] Differences in mutation of the CFTR gene echo disparities in disease progression, with those incompatible with modulators experiencing a more “traditional” progression characteristic of a gradual decline in lung functionality coupled with an increase in other associated morbidities. Individuals who are responsive to and benefit from modulators, especially due to the advancements of the past decade, are experiencing slowed disease progression, symptom stabilization, and for some even health improvement.[11, 22-24]

The Psychology of Adolescence and Chronic Disease

Adolescence is characterized by major developmental changes and associated complexities as young people being to acquire the personal values, social capital, attitudes, relationships, and competencies that will carry them through into adulthood.[2] Early work from German-American psychoanalyst Erik Erikson outlined these developmental changes with an eight phase construct from birth through death including acquisition of trust-building skills and autonomy, recognition of personal positionality, and reflexivity. [25] In addition to Erikson's developmental tasks of adolescence, inclusive of mastery of personal identity and socio-relational intimacy, psychologists have identified more specific challenges of young people in the new millennium.[25] These expounded tasks of adolescence included navigating shifts in dependency within the parent-child relationship, exploration of new and evolving roles, socially and sexually, future planning, and subsequent goal pursuit.[26] The execution and timeline of these undertakings are confounded by the challenges associated with chronic illness for young people with sickle cell disease and cystic fibrosis.[3] Navigation of adolescence is extremely complex and crucial to psychosocial development, but when modified by the experiences and adversities associated with living with chronic diseases like sickle cell disease and cystic fibrosis, these challenges can be intensified and give rise to additional issues, often health related, which their peers will not encounter.

Adolescence, among those with sickle cell disease and cystic fibrosis, often coincides with disease progression and exacerbation of symptoms. For the majority this results in continued delays in growth and physical development which, during a time when your

peers are maturing through puberty, can be incredibly frustrating and take a toll on one's self-esteem.[9, 17, 27] This biopsychosocial degradation, for many, contributes to more serious mental health issues like depression and anxiety which can act as a mediator to medication non-adherence and worsen present physical symptoms. Young people with sickle cell disease and cystic fibrosis, regardless of treatment compliance, find themselves in and out of the hospital in their teen years due to the nature of their disease progression and aforementioned psycho-physical complexities.[17, 27] Extended periods of hospitalization yield disruptions in the formation of substantiative and meaningful interpersonal relationships with peers, often resulting in a diminished sense of self and stalling of the completion of Erikson's "adolescent tasks".[9. 17, 25, 27] This reduction in socialization with peers due to frequent school absence, often abstaining from traditional extracurricular activities, and, for many, the choice to complete grade school virtually widens a social gap which cannot be easily bridged by parental, familial, or tertiary bonds.[17, 26] Tertiary bonds within this context refer to individuals with which you have a relationship with, but the connection itself is less intimate than a family member or friend, such as those with members of your religious or spiritual community or neighbors. The increased reliance on, and time spent with, parental figures due to the medical decision-making barriers of minors creates an additional social variation among teens with chronic illness. This additional parental involvement in disease management makes the move toward independence in adolescents incredibly difficult, and for some almost impossible, yielding increased frustration and late term shifts in parent-child dependency.[9, 17, 26] However, teenagers today have the advantage of unbridled connectivity through technology and social media which, in some cases, can act as a buffer to the consequences of this lack of

interpersonal connection with peers traditionally gained through school and related activities. [28]

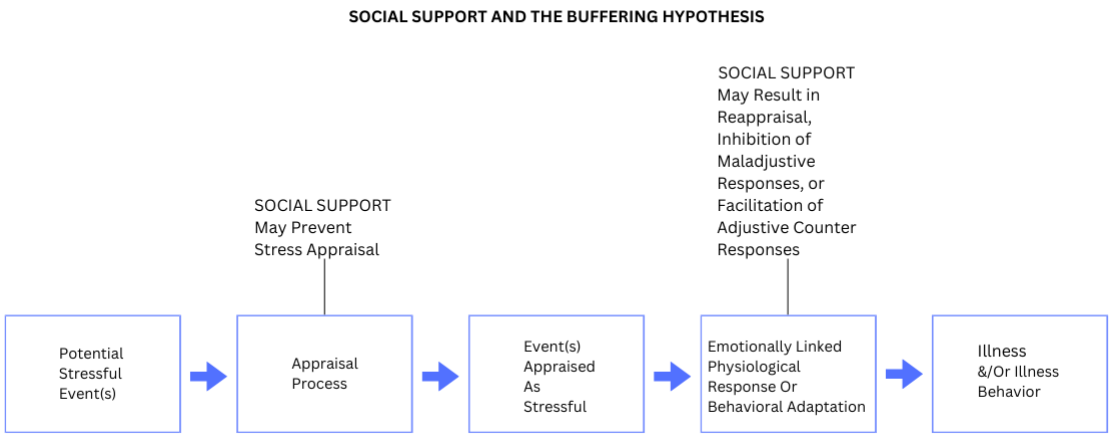
Aside from familial and peer relationships, those social connections formed between young people with chronic illnesses and their medical teams are crucial to treatment adherence and trust-building with the health system.[8] Teens with sickle cell disease and cystic fibrosis approaching late adolescence, aged 17-19, are entering a transitional period from pediatric to adult care, which for many is not facilitated in an intentional, tactful manner.[29-31] Negative perceptions of these newly introduced care providers can lead to the underuse of medical care despite need, inadequate symptom management, and general patient distress over the unknown, particularly among those with sickle cell disease who face the additional barrier of racial discrimination in healthcare settings.[20, 29-32]

Social Support Theory and Types of Social Support

The concept of social support theory is commonly attributed to Dr. Sheldon Cohen whose work on the relationship between perceived social support and health and well-being published in 1985 began the conversation of how relational stability, or the lack thereof, can have tangible physical manifestations.[33] Cohen's work centered on three key aspects of social support including the buffering hypothesis, direct and indirect effects of support, and the notion of subjective versus objective support.[33-35] The buffering hypothesis indicates that the presence of strong perceived social support, particularly among friends and family, can have a protective effect on mental and physical health outcomes, with support acting as a "buffer" to the negative effects of stress on health. This relates to the discussion of subjective versus objective support, as the influence of social

support on health is largely due to the perception of the individual rather than the objective amount of support given (figure 1).[33]

Figure 1: Social Support and the Buffering Hypothesis



*Adapted from Cohen (1985)

Objective support is the tangible actions or assistance from one's support network, which can include anything from a phone call to dropping off a homework assignment to a friend. In addition to objective support Cohen defines subjective support, or the way in which an individual conceptualizes and feels about the support they receive from their network.[33-34] The final piece of Cohen's focus is the nuances of direct and indirect effects of support. Direct effects refer to the immediate impacts of social support on health. such as the alleviation of stress or enhanced emotional well-being; compared to indirect effects, which are often behavior changes influenced by the presence of support that have long-term effects on one's health, such as reducing risky behaviors or adhering to medical treatments.[33]

Following this initial work, the objective categorization of social support has been at the forefront of literature; while this breakdown is still evolving and numerous variations

have been published, a widely used construct simplifies social support into four types: informational, emotional, instrumental, and appraisal support (figure 2).[36]

Figure 2: Types of Social Support Among Adolescents

Type of Support	Definition	Examples Relevant to Teens with Chronic Illness
Informational	the provision of information, advice, or guidance to help with decision-making or problem solving	• Texting a friend about a homework assignment that was assigned when they were absent • Reminding their friends to keep up their treatments
Emotional	includes verbal affirmation of care, physical intimacy, empathy in listening, and the provision of understanding and compassion for an individual	• Calling a friend to talk about their day • Reaching out/keeping up with friends through social media (DMing, sending TikTok's, etc.) • Listening to their friend talk about their struggles and providing reassurance
Instrumental	a physicalized display of support through assistance with practical tasks or provision of resources	• Visiting friends when they are in the hospital • Getting/providing help for their friend if they have an episode at school
Appraisal	the offering of encouragement and validation to raise an individual's self-esteem, confidence, and self-worth.	• Validating their friend's frustrations/concerns • Applauding a friend's strength and resilience

*Adapted from Uchino (2006)

These four types of support can be translated to represent different relationship types and scenarios. The emotional support from parent to child, for example, versus between friends may look very different despite having a similar effect on biopsychosocial well-being.

Social Support Research and Programming Among Adolescents with Cancer

There is a significant body of literature outlining the social support needs of adolescents with cancer, yielding decades of data from social intervention trials which could help contextualize next steps in the formulation of supportive programming for young people with sickle cell disease and cystic fibrosis. The wealth of information surrounding psychosocial interventions among young people with cancer is attributable to the high prevalence of cancer in comparison to other life-threatening diseases, the extensive funding allocated to cancer research, and the pronounced nature of the socio-relational shifts among those who develop cancer.[37-40] While the biological changes associated with the development of cancer are different than those with sickle cell disease or cystic fibrosis, the psychosocial impacts among adolescents with each of these diseases are relatively similar; for example, young people with any of the following will likely face difficulties maintaining peer relationships and experience emotional distress stemming from treatment burden, transitions in family dynamics, etc. [27, 31, 37] Therefore, by highlighting the results of social support programming developed for teens with cancer, we can learn what interventions may be beneficial for teens with sickle cell disease and cystic fibrosis and what program components may not be efficacious.

Common issues identified by teens with cancer include: feeling distant from friends and peers due to changes school and extracurricular attendance, feelings of frustration stemming from shifting family dynamics and dependency, and increased anxious and depressive symptoms related to fears of disease trajectory, changes in the physical body

and its' effect on peers' perception of them, and general fear of missing out on, or falling behind in regard to activities and milestones associated with adolescence.[6, 9, 37]

To address these psychosocial concerns several types of interventions have been successfully implemented including individual, group, and family talk therapy, peer support events, academic continuity and school reentry support, social palliative care programming, and online community support, with the most successful combining these elements. [5, 37-38, 41] Two notable multi-component programs are the *Teenage Outreach Program (TOP)* and *13Thirty.* The development of TOP was based upon literature outlining issues affecting teens with cancer and systems theory, a common theoretical framework in social work which emphasizes the interconnectedness of the individual and their environment, with a focus on networking and social support systems.[42] This program was the first of its kind, in that it created a space for young people with cancer to socialize and engage in normal activities with their peers with the intention of facilitating and upkeeping meaningful relationships. Previous programs were short in duration, only available in-hospital, and did not integrate a component of support with both healthy peers and others living with cancer.[42] TOP separated their participant pool by sex and designed two pilot interventions: *"Funky Young Women"* and *"Boys Night Out".* Both included a full day of activities which allowed the participants the opportunity to bring a friend along for the day and meet others with cancer and yielded positive outcomes. Some examples of themes which emerged in evaluation include broadening and solidifying their peer support network, feeling less alone in their experiences as teens with cancer, and increased confidence and comfortability in approaching other teens in the hospital when receiving in-patient

treatment.[42] The TOP has now expanded into several large-scale projects which still integrate aspects of this initial pilot program.

13Thirty is an organization made up of several smaller programs for adolescents and young adults (AYAs) with cancer, their families, and other members of their support system initially developed more informally than that of TOP, beginning in the year 2000 as a peer support group in Rochester, NY.[42-43] It has since expanded its programming to include virtual and in-person arts, wellness, and social peer programs for AYA with cancer to enhance self-esteem and coping skills through peer relationship building, supportive initiatives for parents and families, and trainings with educators and physicians in the Rochester area to facilitate effective school continuity and AYA-specific care.[43] 13Thirty was among the first programs to integrate a virtual platform for AYA to share their experiences with one another, providing early evidence that digital connectivity can have a protective effect in the same way that face-to-face interaction does.[43]

Conclusion

Social support is vital to adolescent maturation and psychological development.[2] Literature suggests that among adolescents with chronic illness, such as sickle cell disease and cystic fibrosis, social support networks play an integral role in maintaining one's biopsychosocial well-being and can help mitigate associated challenges.[26, 33] Despite this, a gap in knowledge surrounding the architecture of social networks surrounding these young people and their adaptation during period of hospitalization persist; therefore this study aims to address this and garner evidence for more targeted and effective supportive programming for adolescents with life-long. chronic illnesses.

3: Methods

An exploratory qualitative study was conducted to elucidate the architecture of the social networks of adolescents with sickle cell disease and cystic fibrosis and describe if and how these networks adapt to support the needs of these young people during periods of hospitalization. Funding for the parent study was obtained by the principal investigator, Kaitlyn Brus, from the Global Field Experiences award in April of 2023. Study conceptualization and design, as well as all instrument and recruitment material design, and analysis was conducted by the principal investigator.

Study Population

The study population included adolescents, aged 14 to 19, with sickle cell disease or cystic fibrosis that have experienced at least one in-patient hospitalization in the last six months. Additionally, all participants had to have reliable internet or phone access as all study components were conducted virtually; those without were excluded. Individuals who could not provide parental consent and assent or consent were excluded. This is a small, exploratory study. We did not believe the sample size would be sufficient to conduct sub analyses of linguistic distinctions with non-English speakers; therefore, adolescents without English proficiency were excluded from this study.

Recruitment of Participants

We recruited adolescents aged 14 to 19 with either sickle cell disease or cystic fibrosis with a hospitalization within the last six months through outreach, in the form of parent-targeted digital recruitment flyers shared through sickle cell disease and cystic fibrosis advocacy organizations and pediatric clinics (see appendix A). All entities aiding in

recruitment sent out digital flyers via email to potentially eligible parties and posted the flyer on their respective social media accounts and listservs. Interested parties were directed to scan the QR code on the flyer which opened a brief screening survey on Qualtrics, an Emory supplied, secure software system. This survey asked for the name of the adolescent and parent or guardian, age of the would-be participant, and parent email and phone number for further contact.

Interested potential participants, alongside their guardian, were contacted by the principal investigator who described the study in more detail and conducted an eligibility screening based on inclusion and exclusion criteria. Eligible individuals and their guardian were then invited to complete the consent and assent or consent process over the phone and accompanied electronic signatures via REDCap.

A recruiting database linking study identifiers with identifiable information including participant and guardian name, guardian phone number and email, eligibility status, and consent status was kept in a secure cloud-based server separate from study data.

Data collection

The principal investigator conducted thirty semi-structured qualitative interviews with teens living with sickle cell disease or cystic fibrosis regarding their social networks, experiences with social support both in and out of the hospital setting, and how they conceptualize their experiences with socialization and hospitalization through the recounting of their most recent in-patient hospital stay (see appendix B). Following each interview, a brief demographics survey was completed verbally with each participant. Interviews were approximately one hour in length and were conducted virtually in order to

expand the participant population to the whole of the United States and collect detailed information on a diverse set of experiences. The participants and their guardians agreed to allow the adolescents to complete the interview with the principal investigator alone on the call prior to completing the consent process in order to facilitate a safe, open, and unbiased space for sharing. Recording of virtual interviews was conducted via an external digital recorder. Immediately following the conclusion of each interview, the audio files were transferred to a secure cloud-based server and deleted from the recording device following successful transfer. The interview guide was piloted by the principal investigator with two team members and an adolescent diagnosed with sickle cell disease who fit the recruitment parameters for this study prior to the initiation of formal data collection.

Data Analysis

This thesis describes an analysis of the first 10 interviews with participants with sickle cell disease. Additional interviews will be analyzed at a different time. Audio recordings of interviews were transcribed using Descript, a HIPAA-compliant, cloud-based automated transcription service. Transcripts were checked for accuracy and completeness and corrected as needed. NVivo software was then used to perform template analysis, a form of modified thematic analysis that incorporates both deductive identification of themes based on pre-established areas of inquiry (e.g. support seeking mechanisms) and inductive analysis of content to identify additional themes.[44] A comparative analysis was then conducted to explore the similarities and differences in the experiences of adolescents with sickle cell disease versus those with cystic fibrosis. Beyond comparison of experience based on disease diagnosis, data was also compared on the basis of participant identified

gender, age, and family structure. Initial inductive coding was conducted separately by the principal investigator and project team. The team met periodically throughout the coding process to discuss their findings and compare their codes. The principal investigator finalized a codebook following this initial coding period which was then used to code all transcripts. The team met following the coding period to discuss meaningful themes constructed from the fully coded transcripts. Once there were no further inductive themes recognized within the data, it was determined that saturation was met, and no further interviews were conducted. Final analysis was completed at this point using the template analytic process described previously.

Ethical Considerations

There was no risk of physical harm within this study. There was a risk of confidentially being breached if identifiable details about participants' social relationships and health status were shared. Participant information used in recruiting was housed in a local screening database housed on a secure Emory cloud server and was deleted immediately following analysis. Screening was performed by the principal investigator who completed human subjects' protection training through Emory's HIPAA and CITI courses. Identifiable data remained separate from study data (transcripts, memos); therefore, the final data analysis set contained no patient identifiers. Interview transcripts were labeled with unique participant identification numbers, and all data identifying participants, or their social networks was manually removed from transcripts.

An additional risk related to participant distress during or after interviews. Reflecting on previous hospitalizations and social support during these times had the potential to be distressing for participants. To address this, during the consent and assent process and following their interview, each participant was provided with contact information to Teen Line, which offers a mental health hotline for teens where they can connect with trained teen counselors and engage with outreach activities that de-stigmatize conversation surrounding mental health.

The consent process and interview guide explained the purpose of the study and guidance that participants need not answer questions that are uncomfortable as part of the study process. Participants had the opportunity to ask questions about the research and their rights again before beginning the interview. Participants had the opportunity to withdraw from the study at any point up to two weeks following interview completion. This study protocol was granted approval from the Emory University IRB (Study #00006211).

4: Results

This analysis includes data from ten interviews with young people with sickle cell disease from across the United States. The majority of those interviewed identified as male (8 male, 2 female), were between the ages of fifteen and eighteen, and currently attended high school in-person (7 in-person, 3 online). All participants identified as Black or African American. An additional demographic question related to quality of life and disease burden was asked prior to the formal interview to contextualize how chronic illness was affecting the participants in real time. In response to the following, 'on a scale from 0-10, with 0 being not at all and 10 being significantly, how much has your sickle cell disease affected your quality of life and ability to participate in regular activities over the last two weeks?', all but one participant responded with a score of seven or higher, suggesting that at the time of interview the majority of participants were experiencing significant disease burden.

A template analysis inclusive of deductive and inductive refinement generated over one hundred codes related to socialization and support experienced by adolescents living with sickle cell disease, both in and out of the hospital setting. Successive rounds of analysis organized these codes into subthemes, and ultimately three major themes which encapsulate the social experience of teens with sickle cell disease, represented in figure 3.

Figure 3: Themes

Theme	*Supporting Subthemes*
Sickle Cell Disease Identity	Disease Conception Limitations and Accommodations Social Network Architecture
Self-Relationship and Communication	Pity & Burden Alone vs Loneliness
Defining Relationships: Socialization and Support	Barriers and Facilitators of Support Socialization & Support Outside of Hospitalization Socialization & Support During Hospitalization What is Meaningful Support

Sickle Cell Disease Identity

Within the context of this study 'disease identity' is the subjective perception of an individual's health condition, in this case sickle cell disease, and how this diagnosis alongside it's symptomology affect one's sense of self, pursuit and maintenance of relationships, and activities of life and leisure. The disease identities of the young people in this study are a direct reflection of their unique experiences and emotionality in response to their personal, medical, structural, and societal relational constellations.

Disease Conception, Limitations & Accommodations

Adolescent participants characterized shortcomings in their experience living with sickle cell disease by three primary parameters: time and opportunities lost due to hospitalization and disease related complications, social and physical limitations, and internalized cynicism related to societal perceptions of people living with sickle cell disease. The idea of losing out on childhood was a consistent discussion across interviews when participants spoke about disease management in their early years. They explained

that the frequency of hospitalizations coupled with their parents' general cautiousness and/or inability to guide the participants' care for their sickle cell disease left them, now as teenagers, feeling as though they have missed opportunities for socialization and other milestones of childhood. This isolation in early years caused by medical adversities yielded accommodations and limitations for all participants in many aspects of life including within their education, extracurricular and leisure activities, familial relationships, and socialization broadly. Two participants shared the following:

> It was just like really hard for me to kind of, uh, have a great, great come up like, as a child coming up to adulthood. My parents didn't know much about how to handle my sickle cell or put things in place to make sure I was able to handle myself and my health physically. [Male, age 16]

> I can do and I can't do certain things for the sake of my health, you know? I can't go to parties. I cannot spend late nights. I cannot drink anything. I don't, I cannot eat everything, play sports, you know? [Male age 18]

All participants discussed accommodations in relation to their education, with some describing simple instances of teachers providing extensions on assignments or sharing their missed work during periods of absence, and others to the extreme of switching to homeschooling to capitalize on its flexibility. At the time the interviews were conducted six out of ten participants were either homeschooled full-time or had been homeschooled for some portion of their academic career. Across the board, while the advantage of scheduling leniency was notable, participants felt as though the frustration from the stark reduction in socialization with peers and lack of accessibility to sports and clubs outweighed the benefits of self-pacing academics. For many, over time, this social dissonance resulted in an intentional shift toward the lone wolf archetype whereby they begin to think of this isolation as a positive outcome because it allowed them to avoid placing emotional burden

on peers, pitying behavior from others, and alleviated them from having to disclose their diagnosis and related vulnerabilities to peers.

Participants reported feeling that were treated differently by their family because of their condition. Instances of parental permissiveness, augmented parental availability, and variability in expectations compared to participants' healthy siblings were pervasive throughout the interviews. This dissimilarity in treatment was deemed necessary and understandable amongst the participant pool, explaining that more time, attention, and tolerance from their parents provided them the opportunity to thrive in the way that their siblings can without additional accommodations. However, some participants expressed that this "preferential" treatment opened the door for resentment to build within their siblings. One male participant described this situation within his familial milieu, where he is one of eleven boys living in a foster household as:

> Some of my siblings snare, they perceive the fact that I'm being given some sort of preferential treatment just 'cause of my health condition. A lot of people see me as a fragile person and you know, I don't really engage in, in, in physical, in physical altercations and there's a lot of them in the house, it's a lot of boys, teenage boys. [Male, age 18]

Additional accommodations related to avoidance of strenuous play, having to opt out of desired sports teams and physical activities with friends, and dietary restrictions were notable alienating factors identified amongst this cohort.

Social Network Architecture

When asked to talk about their close social ties, all ten participants identified a member of their immediate family as their primary social relationship. This is attributed to the intimacy of their relationship in terms of their comprehensive knowledge of their

health needs and well-being, daily activities, personalities and interests, and the erasure of socialization barriers stemming from disclosure apprehension. Of the eight participants who indicated a parental figure as their closest relationship, seven of them pinpointed their mother or maternal guardian. For the majority, maternal relationships tended to be deeper in terms of emotional vulnerability and sharing; paternal relationships were more often a source of instrumental and informational support, if present at all. Nine out of ten participants had at least one sibling, with two out of these nine having a sibling who also lived with sickle cell disease. All participants with siblings noted strong bonds with their siblings with similar justification to their relationship with their parents, with the caveat of recognizing differing power dynamics and role expectations. Those with siblings who also had sickle cell disease described their bond as more profound and empathetic in comparison to their relationships with their healthy siblings:

> I think having sickle cell kind of strengthens our relationship. I know he learns a lot from me and, you know, I kind of, like, show him a lot of things and I give him advice about what to do and what not to do and how to handle himself his health. [Male, age 17]

Tangible friendships were the closest connection following immediate familial relationships across the board. Tangible friendships within this context refer to those which involve palpable expressions of support, meaningful emotional connectivity, and time spent together in-person. Those who sought out these connections found them to be incredibly motivating and fulfilling, indicating that time spent with their friends more often than not allowed them a sense of normalcy that they were not often afforded:

> I have the best friends and they have been like that all, all this while… we attend the same school, we are in the same grade, we do pretty much everything together. So, um, during times when I am hospitalized, they are always in touch and if like their schedule, you know, school allows it, they visit…Just like their presence, just being around is like enough to, you know, for you to want to fight, fight harder ….I really, really appreciate their presence anytime…People that have a chronic illness appreciate true friendship the most because it is rare, you know, for someone to say, oh, I'm gonna be a friend even though you're not the coolest person, you're not the most fun person to be around with, but you know, I, I just care about you and I would want to see you be better. And, you know have a great normal life. That's something that's very rare. [Male, age 18]

Institutional and supplemental support, including healthcare relationships, religious affiliations, academic aids, and hobby or extracurricular mediated bonds served as a tertiary level within the social ecosystem of the participants.

Healthcare relationships were particularly critical, with six of ten participants suggesting a close tie with their hematologist and noting the value of having consistency in their care teams during routine visits and hospitalization. Healthcare team consistency allowed for the initiation and preservation of emotional attachment to key team members, encouraging admittance of treatment deviations, sharing personal information outside of the health context, and establishment of relationships between care team members and the family beyond the healthcare setting. One participant shared:

> I love my doctor. I love her. He's, uh, she is very, very, patient with me. I love her and I feel like she's one person that I can confide in, you know, uh, when it comes to maybe I did something I was supposed to do, you know, that kind of like affected my health. She's someone that I can talk about things too, apart from like my mom. [Male, age 15]

The remaining four participants did not receive care from a hospital with a sickle cell unit or specialized staff, creating friction with hospital personnel due to a lack of urgency in care, attentiveness, and poor holistic care. This stark contrast in treatment has

blocked the formation of meaningful relationships with healthcare providers and affects how the individuals' social ecosystem interact with them during periods of hospitalization. One participant shared:

> When I was younger, you know, before the time my dad kind of like moved to [city with a sickle cell treatment center], it was terrible. To be honest, it was terrible. I remember one time my dad sort of like, really got angry at hospital staff because I was in pain and I think all they did a simple blood, blood test, and like, they didn't really treat…or tend to me as, as well as, like, my dad had wanted so he sort of like, flared up, and got really angry at the staff. It was really bad because like, hospitals, especially ones that are not dedicated to treating sickle cell, they don't really do much to address the long-term effects of the disease. They just kind of like treat immediate symptoms and try to calm you down and offer you stuff that is going to get the situation taken care of temporarily and get you to leave. [Male, age 18]

Adolescents who found comfort and community in religious or spiritual organizations characterized this relationship as supportive, but not social. Instances of emotional and appraisal support, such as prayer and messages of encouragement, from spiritual community members were appreciated; however, these relationships differed from tangible friendships and even close relationships with healthcare providers because participants noted that they were not socially tied to these individuals due to lack of commonalities and age differences among other factors.

Virtual relationships were prominent across all interviews. This type of relationship includes communities or individuals the participant has met in person before but are too far away to meet in-person regularly and connections which are exclusively online. Virtually mediated relationships included interest-based communities, informational support related to sickle cell disease, and parasocial relationships with artists or influencers and their fellow followers. In some cases, participants shared personal information and disclosed their sickle cell disease status within these virtual relationships, but the majority

of these virtual communities served as a form of social escapism. Regardless of the extent to which the participants shared personal information, all found virtual connectivity to be a crucial aspect of socialization within their identified networks.

Societal perception of sickle cell disease and individuals living with sickle cell disease pervaded all aspects of socialization among the adolescents interviewed, modifying who they chose to engage with, how they interacted with them, and for many, why they opted for social avoidance. Perceived fragility of participants, unpredictability of disease and consequent unreliability of participants, as well as perceptions of symptom exaggeration were all reported by participants as ways they are viewed by society at large. These sentiments are inherently shaped by social discourse, personal experience, and relayed narratives, uniquely altering the social motives and actions of each participant. For example:

> I wish people would stop blaming. I'm not trying to be a victim, but like, I feel like people kind of like discriminate a bit against people that have sickle cell because like, they feel like you're the cause of your own misfortune, like people look at you and think, like, the pain is not real…I just wish people knew that the pain was serious and took it seriously…I think people don't take it seriously because like, it's mostly a black problem. [Male, age 17]

Self-Relationship & Communication

Self-relationship encompasses the interplay of one's psyche, including their convictions, emotions, and actions, and their presentation of this amalgamation to others. This presentation of the self-relationship materializes as self-esteem, self-awareness, self-compassion, and self-confidence among other traits. The quality of one's self-relationship is inextricably linked to their ability to, and interest in, relationship building and

communication; self-relationship quality in this context is confounded by adolescence and identity building concomitant to the challenges of living with sickle cell disease.

Pity & Burden

Avoidance of engaging in self-pitying, receiving external pity, and imposing burden was at the forefront of participant social concerns, suggesting that these factors contribute significantly to their socially evasive behaviors and emergence of self-reliant coping behaviors. Among the participants, eluding pity was operationalized differently than burden. Burden circumvention often centered on omission of information (e.g. not sharing symptoms or frustration with limitations) or lack of emotionality (e.g. avoiding expressing negative emotions stemming from lack of freedom), Pity evasion, on the other hand halted transparent relationship building entirely. For those who sought tangible friendships, it was important that they refrain from inconveniencing these friends with their accommodations. One participants' narration of this emphasized that putting herself in the position of inconvenience was preferrable to asking that her friends alter their plans in order for her to be included in activities she was unable to due to sickle cell related limitations:

> They try to involve me in everything and they try not to make plans for, you know, they're not, uh, they don't feel different about making plans for something that they know I will not be able to join them because the worst thing that's gonna happen is I'm gonna go with them and, you know, just watch them, cheer them on and not participate actively, and they're fine with doing that. So, you know, it just makes me feel like I'm not a liability for them. [Female, age 18]

Abstaining from oversharing unfavorable news or depressive thoughts, and subsequently avoiding their friends having to cope with the participant's mental or physical struggles, for many, was deemed integral to relationship preservation. By downplaying symptoms and severity of complications related to their sickle cell disease, one participant avoided self-

pity and depressive thoughts. Mitigation of the negative information her friends were privy to offered her an alluring form of escapism within their relationship:

> I'm okay to talk to them about it [her SCD], but I don't usually do that because, you know, I think that when I start talking about myself, because I tried it, like, in the past, I was really depressed, I was, really having this like period of depression thinking about my condition. So whenever I talk about myself and feel sorry for myself, I know everyone else is like, just, you know, feeling sorry for me. And then they tried to avoid the topic as much as possible. And then, you know, it just gets awkward and the whole situation is ruined. [Female, age 17]

The compulsion to conceal or trivialize aspects of their life with sickle cell disease with friends was consistent across interviews.

The perceived barrier to entry to maintain friendships was deemed insurmountable by most participants. Furthermore, the idea of sickle cell disease stopping them from being cool or fun enough to warrant friendship, coupled with burden-avoidant behaviors, left participants with few or no tangible friendships. Participants patched this void in the secondary level of the social ecosystem by leaning on their familial bonds, initiating virtual relationships, or, more often, looking inward for support and succumbing to introversion. Adopting a lone wolf persona characterized by increased self-reliance, independence, and dependence on self-coping mechanisms.

Given that the adolescents in this study are in high school, questions related to their views and pursuit of romantic relationships were included. Two of ten participants reported having a romantic partner. The remaining eight participants rationalized their choice not to pursue dating or explaining that it was not something they had put thought or energy into with two of the unpartnered participants conveying considerable concerns with engaging in romantic relationships. Some unpartnered participants feared placing

emotional burden on a romantic partner and believed that people their age would be unwilling to invest effort to understand their needs given the optional for a more "conventional" partner, leading them to avoid dating outright. One participant could not envision a partner capable or willing to provide the magnitude of unconditional support and patience received from family, leaving them pessimistic towards dating and relationships in general:

> "I would hate a lot is being a burden to somebody else. No, you know, I've never had, I've never had like a girlfriend in my life. I can't imagine having a girlfriend because, you know, lot of people won't be as patient dealing with me as like my parents would be. And I would hate people that are not my parents to take on a lot of burden on their shoulders just because of me, you know, so I think at the end of the day, I recognize that I am all I got." [Male, age 16]

Alone vs Loneliness

Distinguishing between the experience of being alone and dealing with loneliness was instrumental in the participants' navigation of building interpersonal bonds, maintaining connection, and coping with the obstacles of traversing adolescence while living with chronic illness. The alone versus loneliness dichotomy permeated throughout the interviews, relevant to participant social circumstances both in and out of hospitalization. Several of the adolescents described a social architecture inclusive of minimal peer interaction, by their own volition, parental dictation, and or disease related circumstance, leaving them either alone or surrounded by exclusively immediate family most of the time. The choice to be alone, while not explicitly positive, was not regarded as an issue amongst those who opted for social withdrawal but more so as a matter of circumstance, asserting that that is just how it is. Participants maintained that, for them, there is a clear distinction of being alone versus feeling lonely which held true in and out of

the in-patient setting. Being alone refers to the physical state of having no one around, intentionally, or otherwise. The feeling of being alone was not exclusive to isolation; however, but also included feeling that no one around them could truly empathize with their situation, merely sympathize.

Loneliness as a concept was far more complex. Loneliness was regarded as not only the emotional response to being alone, but also a culmination of feelings related to lost opportunity and restriction. Within the context of hospitalization, one participant described this phenomenon:

> I feel lonely, but feeling lonely is not necessarily feeling alone. Right? I feel like loneliness being alone is like different in the sense that loneliness is just, um, like a lack of activity… the state of not being able to do what you want to do and have fun and just live life the way you live life. That, that, that sinking feeling is, is sort of similar to loneliness, but I'm not alone. I'm not alone. Obviously, I know they are there, my parents and my family. but they are not in that in that bed and they don't really know what it feels like. They don't experience the suffering the same way I do. [Male, age 17]

More than anything, loneliness was described as frustration with oneself, feelings of helplessness, and vexation resulting from the sensation of misplacement and missing out while their social ecosystem carried on without them. Despite this, for the majority, there was a reversion to burden evasion behaviors which, in turn, reinforced the loneliness narrative, minimizing their expression of suffering in an attempt to absolve their social ties. Participants opted to place their attention on the wants and needs of their network instead of expressing their own needs. This intentional shift in focus allows them the space to deescalate their own negative reactions, circumvent depressive thoughts, and focus on recovery. However, participants did note that there was an expectation that their immediate

circle would provide support within their capabilities and without significant strain, (e.g, messaging, writing cards, visiting), discussed in further detail below.

Defining Relationships: Socialization and Support

The distinction between socialization and support among participants was clear and mandated the way they communicated with each relationship type. Analogous to the notion that all squares are rectangles but not vice versa, all supportive relationships were considered social, but not all social relationships were supportive. However, participants regard both supportive and social relationships as essential pieces of their social constellations, asserting that each have their own roles and expectations. Supportive relationships, for example, were privy to more intimate knowledge of the participants' personality and needs, sickle cell related or otherwise, than social relationships which may serve as a break from reality.

Supportive relationships in this context include familial bonds, tangible friendships, and, for some, tertiary relationships dependent on the breadth and reliability of their primary and secondary relational pools. Exclusively social relationships, in the context of this study, are connections which are low maintenance, born from common interests or hobbies, surface-level relative to personal information sharing, and primarily online. Exceptions to the virtual stipulation in this cohort included peer acquaintances, church members, and personal tutors.

Barriers and Facilitators of Support

Socialization & Support Outside of Hospitalization

Participants outlined barriers and facilitators of socialization, and subsequently support, both within and beyond periods of hospitalization. Instances of bullying, social reduction attributable to homeschooling, and perceived social limitations served as the primary barriers to socialization outside of hospitalization.

The school setting is an obvious facilitator among those who can attend in person, providing daily interaction and additional interest related bonding through academic clubs and extracurriculars permissible for those with physical limitations; however, in-person school also bred an environment for bullying. Bullying was a prevalent issue among the participants, with eight of ten describing at least one instance of bullying related to their sickle cell disease. Harassment from school peers ranged from derogatory remarks to physical attacks, with one participant rushed to the hospital after being beaten by another student. Participants responded to bullying through social reclusion at school and nondisclosure of their sickle cell disease to peers to avoid torment and unwanted attention. One participant shared:

> Um, you know, um, uh, bullying is a thing at my school…people try to use my condition to to make fun of me. Someone said something one time and you know, it was painful to hear. Uh, he said that, you know, a majority of sicklers don't live past 30 and he said something like I'm going to die soon and things like that. And that really, really hurt. That really hurt at that time… so then I really kind of like made the choice to not really associate that much with my peers at school. [Male, age 17]

Two participants, at the discretion of their parents, were removed from in-person school entirely due to safety concerns following attacks, protecting them physically but concurrently inducing complete social isolation through homeschooling.

Beyond safety concerns, homeschooling was utilized by six participants at some point in time to help maintain their academic progress during periods of hospitalization and sickle cell related complications generally. None of the participants with homeschooling experience were involved in a co-op or social group of other homeschooled students, reducing their social circles to their immediate family, tertiary relationships, and any friendships formed prior to leaving school. One participant expressed that he really struggled with this switch, explaining his love for meeting new people and making new connections but, by his mothers' judgement, is now homeschooling and only interacts with his family and private tutors:

> I did experience bullying, I was beat up, I was picked on for nothing…you know, I were points that I bled and went to the emergency room and, you know, my mom had to say no, this is not really healthy for you. And in like, the school district that I am in, fighting and violence, aggressive behavior is really, really rampant. So, she really thought it was not a good idea to let me go to regular school. [Male, age 16]

Frequent absence and self-determined unreliability as a friend, constraints on participation in physical and extracurricular activities, and the assumption that teenagers their age will be unempathetic to their needs and limitations functioned as barriers for socializing for young people with sickle cell disease in this study. Participants expressed that they felt with these perceived barriers there was no point in seeking tangible friendships, reverting to their family and themselves for support and entertainment:

> I had this bout of like hospitalizations where I had to be admitted every now and then. So, um, those periods, they, they, they kind of like, um, kept me away from my friends and you know, I wasn't consistent with my, my presence in school and stuff like that. So I kind of decided that like, since there's no point, you know, trying to make friends at school, if you're going to leave them, like, if there's no certainty that you're going to be there, you're going to do the fun stuff with them, you're going to go to adventures, you're going to spend time together. There's no point. So I just had to, you know, learn to be able to leave by myself and just leave alone. [Male, age 17]

However, three participants with self-identified close tangible friendships show that this assumption that teenagers are apathetic to peers with sickle cell disease is not universal. These participants describe their friends as attentive, thoughtful, and engaged with their needs as someone with sickle cell disease. Their friends' curiosity and openness to learning about their condition made them feel acknowledged and supported without being singled out, facilitating meaningful and inclusive friendships. Additional facilitators of socialization and support outside of the hospital included family cohesion and technology accessibility.

Familial cohesion fostered a supportive home environment for all participants to some degree, with parental availability, strong sibling relationships, and consistency from family relationships creating an environment where participants felt comfortable sharing their needs and seeking help, emotionally or otherwise. All participants identified at least one parent or guardian who they felt they could confide in, described feeling heard and accommodated to by the family unit, and among those with siblings, described a reciprocal sense of respect and understanding. The consistency of comfort and functionality of the family units of those in this study were crucial to support facilitation both in and out of the hospital setting. Participants explained that technology gave them the ability to keep consistent contact with friends and immediate family, extended family, and virtual

communities among others. While technology was noted as a primary facilitator of support during periods of hospitalization specifically, it is important to note its' role in the lives of modern adolescents, with those in this study being no different. Calling, texting, facetiming, and social media were used most frequently for socializing at all levels of the social ecosystem outside of the hospital setting, with TikTok, Discord, Instagram, Snapchat, and Reddit being the most frequently used platforms. Membership in virtual communities enabled participants to construct personal narratives distinct from the disease identity and social identity broadly, connecting with individuals beyond their material social relationships. Technology-based relationships, mediated through Discord, Instagram, and Reddit, comprised of art, poetry, music, sports, and political commentary communities. Online communities were utilized by all participants in various capacities. Those who wrote off intimate relationships with peers used online communities to provide socialization in lieu of real-life friendships while others found online communities focused on interests distinct to those shared with close friends. One frequently mentioned example of the latter was digital content sharing within arts-based online forums. One notable benefit of creating a persona separate from their disease identity within arts-based groups was the receipt of honest criticism of their work from virtual peers. Participants expressed concerns over friends and family not being transparently critical of their work, insinuating that the fragile perception of the participant could impact the sincerity of others' feedback; nondisclosure of their sickle cell within these online forums mitigates this risk of soft-pedaling.

Socialization & Support During Hospitalization

Participants expressed that support from their social networks was a crucial aspect of their recovery during health crises, even though not all participants received sufficient support due to interpersonal and structural barriers. Visitation from friends during hospitalization was a significant issue due to hospital visitation policies for minors, many requiring adult accompaniment, and some prohibiting visitors under the age of sixteen. Accompaniment rules, in this case, place pressure on the parents of the participant's friends to become involved in supporting, which, for the majority, was considered too much of an inconvenience. Friends of participants treated in hospitals that allowed unaccompanied minor visitors still reported transportation barriers, since most of their friends were unable to drive and either did not or could not use public transportation. Two participants described visitation from their close friends accompanied by their parents. In both cases, the participants' guardians were unable to visit due to work responsibilities and preoccupation with their other children, prompting their friends, and the parents of their friends, to offer instrumental and emotional support. Other participants reported that friends' parents reached out to their parents asking for updates on the participant's condition, which was a significant facilitator of support and highly resonant among participants. Prior obligations and responsibilities were the primary barrier between the participants and receipt of support from their networks; however, relative to the amount of time their immediate family had available, most participants felt they received adequate visitation. Three of ten reported having at least one parent visiting in person daily, an additional four participants had one parent consistently present, and the remaining three had at least one parent visiting every other day. Regarding visitation from friends, half of

the participants felt insufficiently supported during their most recent stay, inclusive of in-person visitation and virtual connectivity. This lack of emotional support left participants exceedingly vulnerable, souring an already suboptimal situation. This phenomenon of friends not stepping up, particularly among those who reported frequent hospitalizations, was not uncommon. One participant explained that when hospitalization becomes almost routine, it loses a sense of novelty and is treated less seriously, whether this is reflected medically or not:

> You know, friends, sometimes they come around, sometimes they don't. Like, there was a time where, you know, being hospitalized was like a regular thing for me, so friends really weren't coming that much. You know, they weren't keeping in touch that much because it was like a normal thing for me. So there was a time like, my friends weren't really, really regular in that regard. But, as I've gotten older and have less admissions I've got more people visiting and checking up on me…before when it was like a regular thing maybe they come the first time they come the second time the, by the third or fourth time they might like lose interest. [Male, age 17]

Of the five participants who endorsed sufficient support relative to visitation, three expressed that they either had no friends they anticipated coming to visit or requested that no one outside of immediate family visit until discharged home.

Familial cohesion and the integration of technology served as primary facilitators of support and socialization during in-patient hospitalization. Adapting daily routines, coordinating childcare for siblings, initiating plans to alternate visitation, and engaging siblings in visitation allowed parents to foster a supportive environment for their teens during in-patient stays, reflecting balance principles. Engagement of siblings in instrumental support contributed to mitigation of resentment building, relationship

strengthening among siblings and the family unit, and enablement of communication between the family unit and healthcare team:

> Assurance, and, motivation, and moral support, and just the feeling that like, you're not alone in all of this and you've got people that really genuinely care about you and are willing to put their jobs at stake just to be with you, like, it's just like really, it feels really good. Like, I might be suffering, but I'm not going through the suffering alone. It's a good feeling, you know?...Imagine being in the hospital alone and, just somebody coming to drop raw food for you, that would be terrible, man. It would be really terrible. So, I really appreciate the fact that my parents are there, and they are attentive and they are available when I am hospitalized. [Male, age 18]

Virtual connection to one's social network was fundamental to maintaining optimism and receipt of objective support during hospitalization. Utilization of technology by participants circumnavigated many of the notable barriers of support and socialization, acting as an independent facilitator accessible at all levels of the social ecosystem. For those unable to visit in person, instrumental and emotional support was supplemented through calling, texting, interactions through social media platforms, shoutouts on classroom message boards, and other means of digital engagement. Tertiary relationships developed and maintained online fulfilled an additional role of support, primarily through distraction versus emotional or appraisal-based relationships formed with in-person relationships.

What is Meaningful Support

Meaningful support from one's relational ecosystem was regarded as any thoughtful attempt to provide emotional, appraisal, or instrumental support during periods of hospitalization, with the context of the capability of individual bearing support considered. The sentiment of network capacity playing a role in participant expectations is modeled through adolescent tangible friendships. Participants recognized that fellow teenagers are unable to make fully autonomous decisions, i.e. visiting in person on their own accord, but

are consistently able to provide emotional support through distraction and digital connection; therefore, they adjusted their expectations of support to reflect individual, even social ecosystem level, capacity. Distraction as a means of emotional support from friends was regarded as highly important, with many participants suggesting that fighting boredom, and consequently pessimism, can be one of the more difficult aspects of extended in-patient stays. Sharing TikTok's, exchanging Snapchats, messaging through Instagram, and texting were the most frequent forms of support via distraction, creating a seemingly unbound connection between participants and their friends. Support through distraction was regarded as a reasonable expectation for friends among participants, explaining that emotional support beyond distraction is better suited for family members who are able to comprehend the breadth of their situation, medically, emotionally, or otherwise.

Support anticipated from immediate family members was more extensive across all participants, inclusive of instrumental, emotional, and appraisal support. Visitation from parents and siblings, regardless of frequency, was valued above all else. Physical presence during hospitalization is a compound form of support, integrating principles of instrumental support via the visitation itself and additional acts of care provided, emotional support through consolation, and sentiments of encouragement serving as appraisal. Actionable displays of care by parents and guardians including coordinating calls with extended family, providing entertainment and distraction through audiobooks, podcasts, playlists, and books, facilitating communication with healthcare personnel and educators, bringing handwritten cards and small gifts, and, among those who identified as spiritual, engaging with scripture and orchestrating prayer circles. Engaging the mind,

whether this be through audible entertainment, conversation, reading, or religious engagement was a priority for participants and their families.

> It's just like the care and the concern and the gifts and the support that they show, it really does help to know, like, that I have people around me and people that show concern. So, every time someone just picks up the phone…my uncle and my cousins, they say hi and of like play around with me on the phone and stuff like that, just seeing their faces on video call makes me feel a sense of belonging. Like, at least I've got some people that look out for me and people that care about me. So, yeah, just the simple act of reaching out is something I really do appreciate and gifts and well wishes that they send over as well. So yeah, those basic acts, I don't think I really anything more, maybe ice cream. [Male, age 16]

Emphatic appreciation of all modalities of support was universal; however, not all participants are awarded the same level of effort and care from their networks. During their most recent hospitalization, three participants experienced periodic visitation from immediate family, two anticipated visitations from friends to no avail, and one, in the span of three weeks, was visited only by his mother and private tutor. Unrequited support from social relationships is painful, and among the adolescents in this study, manifested as overwhelming loneliness and disappointment.

> My mom was always there and she brought some people to come pray and my tutor…Nobody else showed up apart from those two people in like the whole span of three weeks. No, nobody showed up…It made me feel really, really lonely. I really needed, I really needed people at that time, because I didn't know what was going on with me. And, you know, uh, I wish I could've you know, just vented to them [their friends] about, you know, some of my struggles. [Male, age 16]

Additionally, participants raised issue with the notion that some members of their social circles demonstrated evidently heightened engagement with their well-being during health crises, asserting that they should not have to be in critical condition for their friends, loved ones, and tertiary relationships to be in tune.

> I feel like just, uh, showing up when I am sick is like, it's kind of like really discouraging because, you know, I understand that people, everybody has their own problems to take care of, but if my people showed up the same way when I wasn't sick as they, as they showed up when I was sick and hospitalized, I think that would make me feel a lot better because like now I don't, I don't have to feel like I have to be in a critical condition for you to kind of like, reach out…If we really had that strong bond when I'm not sick, I would really, really feel loved and supported. [Male, age 17]

When asked about interest in an in-patient peer support program to supplement this supportive void, all but one participant expressed interest with the caveat that program volunteers be genuine and have similar values. Commentary surrounding authenticity was rooted in ensuring that volunteers were participating in the program for the betterment of those they intended to serve versus their own extrinsic motivations. One participant described a relationship she formed with another teen living with sickle cell disease during a previous hospitalization, expressing that the opportunity to meet more people who understand her situation through a peer-support program would be of significant interest to her and likely other young people with sickle cell disease:

> I think I'm fine talking about my condition and you know, a bunch of other people that I've spoken to who have sickle cell are also fine talking about it because they don't want to feel like there's a stigma, right…There was one time I was admitted and I also met a girl about my age that had sickle cell too and that was amazing because I rely on her support because she understands how I feel…So I actually got her contact and we still talk till today. [Female, age 17]

Informational support was not a significant measure of relationship depth and network connection during hospitalization; however, outside of the in-patient setting, resource sharing from health professionals, friends and family, and others living with sickle cell disease on virtual forums related to health maintenance and management was acknowledged by participants.

5: DISCUSSION

This analysis aimed to qualitatively describe *1) the architecture of social networks of adolescents with sickle cell disease and 2) identify changes in their perceived social support during in-patient hospitalization and the consequent effectiveness of adaptations in maintaining a supportive environment.* The social networks of the adolescent participants living with sickle cell disease were broken down into social and supportive relationships, including immediate and extended family, tangible friendships, tertiary relationships, and exclusively virtual relationships. Relationships at all levels of the social ecosystem were mediated by the individual's self-relationship and their degree of preference for reclusive behavior to avoid social scrutiny, pitying behaviors, and placement of burden on others.

Adaptation of Social Patterns

For adolescents with sickle cell disease in this study who adoption of a burdensome self-image was precursor to social isolation thereby. This social isolation, which ranged from keeping all or some friends ignorant of their condition to choosing not to engage in tangible friendships with peers entirely, prevented participants from expressing themselves and their struggles related to their condition to friends and receiving social support from a friend group. Participants maintained that there were benefits of concealment from friends, including circumvention of pity receipt and burden placement, as well as having a space within friendships to exist outside of their health issues. However, the belief that sharing little or sugarcoating their struggles to be more digestible is necessary to uphold friendships may be reflective of a strained self-relationship, indicative of diminished self-esteem and self-worth. Additionally, the creation of a burdensome self-image, particularly

when hospitalized, may be reflective of a lack of self-empathy and understanding. [2, 45] Insecure attachment with one's self-relationship, stemming from aforementioned fears and social disinterest, for most participants, steered them away from traditional socialization patterns of adolescents. Mid-adolescence is characterized by a shift toward increased involvement with friends and social detachment from parental figures.[45] Stagnation in this transition is present within the participants of this study, which may yield poor social development and slower maturation of skills necessary to navigate into adulthood.

Furthermore, engaging with different social groups with varying interests and attitudes throughout adolescence allows teenagers to experiment with different identities before ultimately finding a sense of belonging and self-identity. [45] For the young people in this study, this opportunity to shop around social groups during school was stunted by bouts of hospitalizations, homeschooling, torment from peers, and self-inflicted emotional and social restriction; however, this was supplemented through identity building within virtual communities. Virtual community building within this cohort, in part, models traditional peer selection, with participants befriending peers they find similar to themselves either through interests or in their experience with sickle cell disease.[46] However, virtual community did not imitate peer socialization, or the increase in similar attributes between friends over time, as defined by developmental psychologists because of nondisclosure of personal information by participants within these virtual communities.[45] Even among participants who described strong tangible friendships, peer socialization was not fully actualized due to the aforementioned deficiency in open dialogue with friends.

Given the marked disparities in social availability and priorities of young people living with sickle cell disease and their healthy peers, one could anticipate differences in social behaviors. However, when compared to teens diagnosed with cancer, an acute chronic condition which, like sickle cell disease requires a high degree of medical management, significant and discernible distinctions in social mobility among those with sickle cell disease remain evident. Literature surrounding adolescents living with cancer indicated that, similar to participants in this study, instances of bullying from peers, issues with self-image and identity, changes in peer relationships, and increased reliance on immediate family members were pervasive social challenges.[9, 47-49] Bullying among teenagers with cancer was primarily verbal and related to physical appearance changes from treatment, with a systematic review of bullying in this population reporting no published instances of physical violence from peers, only "teasing."[48] Participants in this study indicated much more severe harassment from peers, including physical assault. This discrepancy could be attributed to the fact that the general public, including their healthy peers, have a knowledge base of what cancer and its associated symptoms and treatment might entail versus sickle cell disease which is less widely understood.[50] This may be leading to othering, or treatment of someone as fundamentally different that oneself, and contributing to mistreatment and discrimination from peers.

The phenomenon of nondisclosure of sickle cell disease serving as an opportunity for normalcy or social distancing from peers among participants is not echoed in cancer literature. Teens with cancer reported that they felt as though they did not have the option not to disclose their diagnosis, as the physical changes in their appearance due to treatment and the changes in their social lives and priorities generally to accommodate treatment

made it obvious to their peers. [47-49] This however pushed them to continue to pursue friendships with peers, explaining that while this changed their social availability, it did not stop them from establishing new relationships or upkeeping those which they had prior to their diagnosis, contrary to the experiences and beliefs of participants with sickle cell disease in this study. [9, 47, 49] Related to relationship upkeep, studies on teens with cancer reported that pitying from peers was a significant issue, however, expressing that this type of attention was unwanted and requesting distraction or emotional support quelled this issue.[47,49] Participants in this study also experienced issues with pity from peers, however for most participants, the fear of receiving pity in the future kept them from creating social connections. Related to burden in cancer literature, no publications describe concerns of placing burden on friends or restriction of relationship building or sharing to avoid burdening their social networks.

Social Network Architecture & Adaptability Expectations & Realities

Participants' social networks were segmented into primary, secondary, and tertiary relationships with each level of this relational constellation incurring a different expectation of support. For example, parents and siblings, the primary relationships for participants, were expected to provide support differently than members of a participant's church congregation (tertiary relationships). Understanding expectations of relationships allows for the recognition of unaddressed needs, and subsequently how interventions could be developed to fulfill these during periods of hospitalization.

Adaptability among the family unit was consistent, with parents and siblings making the time and effort to visit in person, stay connected digitally, and mediate support from

other outlets including communicating with health care teams, bringing members of the church to pray, coordinating calls from extended family, and updating school administration and teachers. Instrumental support, in addition to visitation, which was adapted for hospitalization and participant limitations included reading to them, playing audiobooks, music, and podcasts, and bringing them food. This primary relationship and the support provided through it was highly appreciated among participants. In cancer literature, a similar increase in time spent with parents was noted; however, this was a point of tension among parent-child dyads. Adolescents living with cancer reported feeling a loss of independence after their diagnosis, forcibly growing closer with their parents as they became more intimately in tune with their needs, medically, socially, physically. [9, 50, 52] Adolescents living with sickle cell disease spend equal if not more time with their immediate family members; however, unlike peers with cancer, harbor no resentment towards this dynamic as they have lived their entire lives highly dependent on parental support, unlike individuals with cancer who experience a sudden shift in the parent-child relationship after disease diagnosis.

The nature of in-born genetic conditions like sickle cell disease versus later onset conditions like cancer yields differences in social network architecture beyond parental involvement. The social networks of individuals diagnosed with cancer as teens mimic those of healthy peers, with tangible friendships fulfilling the bulk of their social and supportive needs.[47] Studies indicate that some teens with cancer felt even more supported by friends during treatment than before, with one study reporting that, when matched on age, they had higher social health-related quality of life scores than their healthy peers.[51] However, social withdrawal among teens with cancer due to frustration with separation

from friends during treatment, changes in self-image, and lack of peer understanding was noted.[9, 47, 52] Conversely, the adolescents with sickle cell disease in this study placed more attention on familial relationships out of fear of burdening friends and experiencing a lack of empathy from peers, resulting in a lack, or complete absence, of peer relationships in and out of the hospital setting. Among participants who did engage in close tangible friendships, adaptability during hospitalization was minimal, with most checking in virtually, if at all, leaving a void in instrumental support from peers which could not be fulfilled with parental support.

Technology as a means of adaptation was prevalent within this study and among young people with cancer, as reflected in literature. Technology and virtual community for both groups of teens allowed for upkeep of tangible friendships, creation of relationships with peers living with the same condition, and as a means of emotional support through distraction from healthcare/illness.[52] However, seemingly unique to adolescents with sickle cell disease, was the use of online communities as a means of social escapism and avoidance of their disease identity. In this case, there was no change in these connections during periods of hospitalization due to nondisclosure, presenting a distinct form of socialization which allowed study participants to take on a different identity, one unencumbered by their condition.

Contribution to Literature

Amidst the growing body of knowledge related to the experiences of adolescents living with sickle cell disease, this study, to our knowledge, is the first to qualitatively assess specific attributes of the social network adaptability of teenagers with sickle cell disease in

the United States. Previous work has described social isolation and difficulties with relationship navigation during adolescence as components of living with sickle cell disease, highlighting how physical needs, disease progression, treatment adherence or the lack thereof, and recurrent hospitalizations may contribute to isolation.[17, 50, 53-54] Results from this analysis are consistent with literature related to social pitfalls (e.g. exposure to bullying, pitying);[17, 50] however, this analysis introduces the concept of burden as an emotional barrier to socialization and subsequent social mediation through virtual community building. Additionally, the discussion of virtual community in this analysis sets the stage for further research on how technology accessibility and modern social dynamics have successfully mediated aspects of isolation or contributed to these issues (e.g., adding new opportunities for socializing versus virtual connection replacing close in person relationships yielding socioemotional stunting). Furthermore, this analysis expands on research regarding actionable traits of adaptability among the networks of teens with sickle cell disease, identifying which traits were considered meaningful to this community and what needs were unaddressed with a specificity absent in current literature. Additional analysis being conducted in the parent study for the analysis reported here, will provide additional clarity to these issues by allowing a comparison with teens affected by a different genetic disorder, cystic fibrosis.

Public Health Implications & Recommendations

Given the results from this analysis and related literature, future research may address the incorporation of social workers, interdisciplinary healthcare teams, and disease-specific advocacy organizations into initiatives to mitigate the social reclusive

behaviors and encourage open expression among teens with sickle cell disease. This could be addressed through the integration of talk therapy in care plans, the creation of opt-in virtual communities facilitated by treatment centers or advocacy groups, and or the initiation of social programming modeled after those created for adolescents living with cancer.[42-43] Related, the expansion of peer social palliative programming within in-patient care facilities, such as Streetlight, will enable support, or at minimum distraction, for young teenagers living with chronic illnesses who experience frequent hospitalization.[5] Utilization of online community should be considered when designing social programming for teens living with sickle cell disease given its prominence in the current age of technology, in-patient or otherwise. Additionally, engagement of school administrators and educators into DEI training which incorporates information regarding students with chronic illness or disabilities and how this may affect them and their relationships with peers could help mitigate bullying and related physical and mental health repercussions.

Analysis from the parent study will provide guidance for social programming by comparing the experiences and needs of adolescents with sickle cell disease and cystic fibrosis; however, childhood and adolescent social adaptations stemming from chronic health condition extend beyond these two disorders. Future research comparing other conditions with recognized social disruptions, such as congenital heart disease or type 1 diabetes, may be important in determining what aspects of growing up with chronic illness are yielding the most significant challenges (i.e. frequency of hospitalization, disease severity, physical limitations, or upkeep of treatment regimens) and for which of these adversities programming could to mititgate social burden.[55-56] Understanding differences

between each, as well as their intersectionality, will inform how existent programming, for example among young people with cancer, could be adapted as a model.

Strengths & Limitations

Strengths

This analysis adds important knowledge on social network dynamics and adaptation strategies to accommodate the needs of young people living with sickle cell disease, describes engagement with and expectation of virtual communities, and expands on known socioemotional barriers to social connectivity among young people living with chronic illness. The principal investigator engaged in a rigorous qualitative approach inclusive of thorough documentation and deidentification of all participant data, frequent study team debriefs, reflexivity practices, and iterative refinement of materials and protocols from project conception through analysis completion. Additionally, the principal investigator intentionally formed relationships with participants and their families to establish trust and credibility prior to conducting interviews. This allowed for the facilitation of honest and open sharing from participants, yielding rich data for analysis. The participants were recruited from across the United States and had various home life situations and levels of parental and social network involvement, resulting in a more representative sample of adolescents with sickle cell disease broadly.

Limitations

The majority of participants included in this analysis were male, which is not proportional of the population of adolescents with sickle cell disease in the United States. Additionally, at the time of this analysis we were unable to recruit any participants fourteen

or nineteen years of age so any nuances that may exist within those ages are not captured. However, within the study sample, no variation in age was noted. It is also important to consider the positionality of the principal investigator as she is not a member of the population of interest. While she made an effort to express her personal investment in the sickle disease community, avoid stigmatizing language, create an open dialogue, and establish rapport with participants and their parents, she may still have been regarded as an outsider by participants.

Conclusion

The architecture and adaptability of the social networks of adolescents with sickle cell disease are dependent on a variety of factors including the individual's self-relationship and aptitude to socialization, family dynamics, perception of community empathy and understanding, and experiences, expectations, and receptiveness of support. Stability and cohesion within the family units, and consequently their ability to respond to the emotional, medical, and social needs of their child with sickle cell disease is determinate, in part, of the adaptability of their social networks, mediating secondary and tertiary relationships. Our analysis revealed that emotional and instrumental support were the most meaningful among participants during and beyond hospitalization. However, most participants expressed dissatisfaction with some aspect of the support received from their networks during hospitalization, underscoring the need for supplemental and intervention-based in-patient support.

References

1. Newacheck PW, McManus MA, Fox HB. Prevalence and impact of chronic illness among adolescents. Am J Dis Child 1991;145: 1367-1373
2. Zarrett, N., & Eccles, J. (2006). The passage to adulthood: Challenges of late adolescence. *New Directions for Youth Development*, *2006*(111), 13–28. https://doi.org/10.1002/yd.179
3. Newacheck PW. Adolescents with special health needs: prevalence, severity, and access to health services. Pediatrics 1989;84: 872-881.
4. Usta, Y. Y. (2012). Importance of social support in cancer patients. *Asian Pacific Journal of Cancer Prevention*, *13*(8), 3569–3572. https://doi.org/10.7314/apjcp.2012.13.8.3569
5. Walker, A. L., Marchi, E., Puig, A., Slayton, W., Dodd, V., McVay, M. A., & Livingston, M. D. (2022). Volunteer-based social support structures and program exposure outcomes in an adolescent young adult Palliative Care Peer Support Program. *Journal of Palliative Medicine*, *25*(8), 1186–1196. https://doi.org/10.1089/jpm.2021.0426
6. Roberts, C. S., Turney, M. E., & Knowles, A. M. (1998). Psychosocial issues of adolescents with cancer. *Social Work in Health Care*, *27*(4), 3–18. https://doi.org/10.1300/j010v27n04_02
7. Silva, M. E., Moura, F. M., Albuquerque, T. M., Reichert, A. P., & Collet, N. (2017). Network and social support in children with chronic diseases: Understanding the child's perception. *Texto & Contexto - Enfermagem*, *26*(1). https://doi.org/10.1590/0104-07072017006980015
8. Silveira AD, Neves ET. The social network of adolescents who need special health care. Rev Bras Enferm. 2019 Mar-Apr;72(2):442-449. English, Portuguese. doi: 10.1590/0034-7167-2018-0543. Epub 2019 Apr 18. PMID: 31017208.
9. Umaretiya, P. J., Fisher, L., Altschuler, A., Kushi, L. H., Chao, C. R., Vega, B., Rodrigues, G., Josephs, I., Brock, K. E., Buchanan, S., Casperson, M., Fasciano, K. M., Kolevska, T., Lakin, J. R., Lefebvre, A., Schwartz, C. M., Shalman, D. M., Wall, C. B., Wiener, L., … Mack, J. W. (2022). "the simple life experiences that every other human gets": Desire for normalcy among adolescents and Young Adults with advanced cancer. *Pediatric Blood & Cancer*, *70*(1). https://doi.org/10.1002/pbc.30035
10. Centers for Disease Control and Prevention. (2022, May 2). *Data & statistics on Sickle Cell Disease*. Centers for Disease Control and Prevention. Retrieved February 24, 2023, from https://www.cdc.gov/ncbddd/sicklecell/data.html
11. *Patient registry*. Cystic Fibrosis Foundation. (n.d.). Retrieved February 24, 2023, from https://www.cff.org/medical-professionals/patient-registry
12. Konstan, M. W., & Berger, M. (1997). Current understanding of the inflammatory process in cystic fibrosis: onset and etiology. *Pediatric pulmonology*, *24*(2), 137-142.
13. Smith, W. R., Valrie, C., & Sisler, I. (2022). Structural racism and impact on sickle cell disease. *Hematology/Oncology Clinics of North America*, *36*(6), 1063–1076. https://doi.org/10.1016/j.hoc.2022.08.008

14. Steinberg, M. H. (2008). Sickle cell anemia, the first molecular disease: overview of molecular etiology, pathophysiology, and therapeutic approaches. *TheScientificWorldJournal*, *8*, 1295-1324.
15. Kanter, J., & Kruse-Jarres, R. (2013). Management of sickle cell disease from childhood through adulthood. *Blood reviews*, *27*(6), 279-287.
16. Quon, B. S., & Aitken, M. L. (2012). Cystic fibrosis: what to expect now in the early adult years. *Paediatric respiratory reviews*, *13*(4), 206-214.
17. Edwards, C.L., Scales, M.T., Loughlin, C. *et al.* A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *Int. J. Behav. Med.* 12, 171–179 (2005). https://doi.org/10.1207/s15327558ijbm1203_6
18. Centers for Disease Control and Prevention. (2022, May 2). *Data & statistics on Sickle Cell Disease*. Centers for Disease Control and Prevention. Retrieved February 24, 2023, from https://www.cdc.gov/ncbddd/sicklecell/data.html
19. Gardner, Renée V. "Sickle cell disease: advances in treatment." *Ochsner journal* 18.4 (2018): 377-389.
20. Smith, W. R., Valrie, C., & Sisler, I. (2022). Structural racism and impact on sickle cell disease. *Hematology/Oncology Clinics of North America*, *36*(6), 1063–1076. https://doi.org/10.1016/j.hoc.2022.08.008
21. Naehrig S, Chao CM, Naehrlich L. Cystic Fibrosis. Dtsch Arztebl Int. 2017 Aug 21;114(33-34):564-574. doi: 10.3238/arztebl.2017.0564. PMID: 28855057; PMCID: PMC5596161.
22. Jia, Shijing, and Jennifer L. Taylor-Cousar. "Cystic Fibrosis Modulator Therapies." Annual Review of Medicine 74 (2023): 413-426.
23. Egan, Marie E. "Non-Modulator Therapies: Developing a Therapy for Every Cystic Fibrosis Patient." Clinics in Chest Medicine 43.4 (2022): 717-725.
24. Zaher, A., ElSaygh, J., Elsori, D., ElSaygh, H., Sanni, A., Elsaygh, H., & Sanni, A. (2021). A review of Trikafta: triple cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapy. Cureus, 13(7).
25. Erikson, E. (1968). Identity: Youth and crisis. New York: Norton; Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge, MA: Harvard University Press; Eccles, J. S., Midgley, C., Buchanan, C. M., Wigfield, A., Reuman, D., & MacIver, D. (1993). Development during adolescence: The impact of stage/environment fit. American Psychologist, 48, 90–101.
26. Eccles, J. S., & Gootman, J. A. (Eds.). (2002). Community Programs to Promote Youth Development/Committee on Community-Level Programs for Youth. Washington, DC: National Academy Press; Eccles, J. S., Templeton, J., Barber, B., & Stone, M. (2003). Adolescence and emerging adulthood: The critical passage ways to adulthood. In M. H. Bornstein, L. Davidson, C. Keyes, & K. A. Moore (Eds.), Positive development across the life course (pp. 383–406). Mahwah, NJ: Erlbaum.

27. Ernst, M. M., Johnson, M. C., & Stark, L. J. (2010). Developmental and psychosocial issues in cystic fibrosis. *Child and Adolescent Psychiatric Clinics of North America*, *19*(2), 263–283. https://doi.org/10.1016/j.chc.2010.01.004
28. Benvenuti, Martina, et al. "Teens online: how perceived social support influences the use of the Internet during adolescence." *European Journal of Psychology of Education* (2023): 1-22.
29. Sawicki, Gregory S., et al. "Risk factors for gaps in care during transfer from pediatric to adult cystic fibrosis programs in the United States." *Annals of the American Thoracic Society* 15.2 (2018): 234-240.
30. Tuchman, Lisa, and Michael Schwartz. "Health outcomes associated with transition from pediatric to adult cystic fibrosis care." *Pediatrics* 132.5 (2013): 847-853.
31. Porter, Jerlym S., et al. "Pediatric to adult care transition: perspectives of young adults with sickle cell disease." *Journal of Pediatric Psychology* 42.9 (2017): 1016-1027.
32. Kayle, Mariam, et al. "Transition to adult care in sickle cell disease: a longitudinal study of clinical characteristics and disease severity." *Pediatric blood & cancer* 66.1 (2019): e27463.
33. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull*. 1985; 98(2): 310-357. https://doi.org/10.1037/0033-2909.98.2.310
34. Cohen S, Gottlieb BH, Underwood LG. Social Relationships and Health. Social Support Measurement and Intervention; 2000: 3-26.
35. Lakey, Brian, and Sheldon Cohen. "Social support and theory." *Social support measurement and intervention: A guide for health and social scientists* 29 (2000): 29-49.
36. Uchino, B.N. Social Support and Health: A Review of Physiological Processes Potentially Underlying Links to Disease Outcomes. *J Behav Med* **29**, 377–387 (2006). https://doi.org/10.1007/s10865-006-9056-5
37. Shama, W., & Lucchetta, S. (2007). Psychosocial issues of the adolescent cancer patient and the development of the teenage outreach program (TOP). *Journal of psychosocial oncology*, *25*(3), 99-112.
38. Thompson, A. L., Christiansen, H. L., Elam, M., Hoag, J., Irwin, M. K., Pao, M., ... & Kelly, K. P. (2015). Academic continuity and school reentry support as a standard of care in pediatric oncology. *Pediatric blood & cancer*, *62*(S5), S805-S817.
39. Woodgate, R. L. (2006). The importance of being there: perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, *23*(3), 122-134.
40. Morgan, S., Davies, S., Palmer, S., & Plaster, M. (2010). Sex, drugs, and rock 'n'roll: caring for adolescents and young adults with cancer. *Journal of clinical oncology*.
41. LeBeau, K., Collins, S., Zori, G., Walker, D., Marchi, E., Pomeranz, J., & Hart, M. (2023). Evaluating a novel hospital-based online health community to address palliative and

psychosocial care factors for chronically ill adolescent and young adult patients. *Palliative & Supportive Care,* 1-12. doi:10.1017/S1478951523000147

42. Wendy Shama MSW, RSW & Sonia Lucchetta MSW, RSW (2007) Psychosocial Issues of the Adolescent Cancer Patient and the Development of the Teenage Outreach Program (TOP), Journal of Psychosocial Oncology, 25:3, 99-112, DOI: 10.1300/J077v25n03_06
43. Sengbusch, — Melissa. (n.d.). *Home - welcome to 13thirty cancer connect - syracuse & rochester*. 13thirty Cancer Connect. https://13thirty.org/
44. Brooks, J., McCluskey, S., Turley, E., & King, N. (2015). The Utility of Template Analysis in Qualitative Psychology Research. *Qualitative research in psychology*, *12*(2), 202–222. https://doi.org/10.1080/14780887.2014.955224
45. Collins, W. A., & Steinberg, L. (2006). Adolescent development in interpersonal context. In N. Eisenberg (Ed.) & W. Damon (Series Ed.), Handbook of child psychology: Vol. 3. Social, emotional, and personality development (6th ed., pp. 1003–1067). New York: Wiley
46. Dishion, T., Patterson, G., Stoolmiller, M., & Skinner, M. (1991). Family, school, and behavioral antecedents to adolescent involvement with antisocial peers. Developmental Psychology, 27, 172–180.
47. Lewis P, Jordens CFC, Mooney-Somers J, Smith K, Kerridge I. Growing Up With Cancer: Accommodating the Effects of Cancer Into Young People's Social Lives. Journal of Pediatric Oncology Nursing. 2013;30(6):311-319. doi:10.1177/1043454213513839
48. Collins DE, Ellis SJ, Janin MM, et al. A Systematic Review Summarizing the State of Evidence on Bullying in Childhood Cancer Patients/Survivors . Journal of Pediatric Oncology Nursing. 2019;36(1):55-68. doi:10.1177/1043454218810136
49. Woodgate RL. The Importance of Being There: Perspectives of Social Support by Adolescents with Cancer. Journal of Pediatric Oncology Nursing. 2006;23(3):122-134. doi:10.1177/1043454206287396
50. Taylor, R. M., Gibson, F., & Franck, L. S. (2008). The experience of living with a chronic illness during adolescence: a critical review of the literature. *Journal of clinical nursing*, *17*(23), 3083-3091.
51. Steineck, A., Lau, N., Fladeboe, K. M., Walsh, C. A., Rosenberg, A. R., Yi-Frazier, J. P., & Barton, K. S. (2022). Seeking virtual support: Digital technology use in adolescent and young adults with advanced cancer. *Pediatric blood & cancer*, *69*(11), e29938. https://doi.org/10.1002/pbc.29938
52. Poku, B. A., Caress, A. L., & Kirk, S. (2018). Adolescents' experiences of living with sickle cell disease: An integrative narrative review of the literature. International Journal of Nursing Studies, 80, 20-28.
53. Dale, J. C., Cochran, C. J., Roy, L., Jernigan, E., & Buchanan, G. R. (2011). Health-related quality of life in children and adolescents with sickle cell disease. *Journal of Pediatric Health Care*, *25*(4), 208-215.
54. Engelen, V., Koopman, H. M., Detmar, S. B., Raat, H., Van De Wetering, M. D., Brons, P., ... & Grootenhuis, M. A. (2011). Health-related quality of life after completion of successful treatment for childhood cancer. *Pediatric blood & cancer*, *56*(4), 646-653.

55. Tye, S. K., Kandavello, G., Wan Ahmadul Badwi, S. A., & Abdul Majid, H. S. (2021). Challenges for Adolescents With Congenital Heart Defects/Chronic Rheumatic Heart Disease and What They Need: Perspectives From Patients, Parents and Health Care Providers at the Institut Jantung Negara (National Heart Institute), Malaysia. *Frontiers in psychology*, *11*, 481176. https://doi.org/10.3389/fpsyg.2020.481176
56. Skinner, T. C., John, M., & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Pediatric psychology*, *25*(4), 257-267.

APPENDIX

Appendix A: Recruitment Materials

Appendix B: Interview Guide

Social Networks of Adolescents with Chronic Illness: An Exploration of Social Support During Hospitalization

Interview Guide: Adolescents with Sickle Cell Disease and Cystic Fibrosis

Note: Interviews may be conducted in person, by phone, or via Zoom, depending on current safety guidelines and participant preference.

Introduction

1. **Welcome**

   Hello! My name is Kaitlyn and I will be interviewing you today. This interview is part of a study about relationships and how you experience support from these relationships while you are in the hospital.

2. **Background and Disclosures:**

   As a reminder, this study is being conducted as part of a master's thesis through Emory University's Rollins School of Public Health under the Emory Palliative Care Research Center This research is about patients with Sickle Cell Disease or Cystic Fibrosis aged 14-19 who have experienced a recent hospitalization. We are interested in hearing about how you experienced support during this time. By learning about the experiences of people like you, we hope to build programs to better support patients during their time in the hospital.

   I will be recording our conversation today. The purpose of this recording is not to identify you, but to be able to create an accurate written record of what we talked about. No one's real name will be used in this research, nor will details about you or anyone we talk about that would help people identify you.

   Our conversation today will be no more than an hour. No formal breaks have been added into this schedule, but anytime you would like to use the restroom or take a break for any reason please let me know and you are more than welcome to do so.

   I am interested in hearing your true experiences and opinions, so there are no wrong answers to any questions that I will ask you today. That being said, we have a lot of things I'd like to talk abo9ut today, so if I push to move the conversation along it is not to be rude, just to be sure we get to all of our topics within the time we have today.

   Do you have any questions? [Ask for permission to record and begin recording].

Fantastic, first I just want to get to know a little bit about you and the people you spend most of your time hanging out and talking with.

Overview of friends and family within the social network

1. Can you tell me about the people you are closest to?
   Probes: Friends? Family members? Others?
2. What other social circles are you a part of?
   Probes: Church community? Online health community? Online gaming community? School peers? Teachers? Disease specific community?
3. What do your friends and family know about your [CF/SCD]?
   Probes: How comfortable are your friends/family talking about your condition? What kinds of things do you share with them? How do the things you share differ with each? How comfortable are you sharing with them about your condition? Why? In what ways does your [CF/SCD] make your relationship different than with their other friends/your other siblings?
4. In doing these interviews, some people have told me their friends are really uncomfortable hearing about their [CF/SCD]. Other people have told me they have friends who get really invested and remind them to do their treatments. When you think about your friends, where do they fall on that spectrum?"
   Probes: How has this changed now that you're older/friends play a larger role in your life in general?
5. When you are in the hospital, how do you keep in contact with your friends and family?
   Probes: How often do you keep in contact over the phone? How/what apps? How does this differ from when you are not in the hospital?
6. When you are in the hospital, which friends/family members visit you in person?
   Probes: If so, how often and for how long? If not, why? Are they at work? School? Another reason? *For those 17-19* How has visitation changed now that you're older?

Thank you so much for sharing all of that with me. Now I would like to talk about your relationships and interactions with hospital and medical personnel.

Overview of community and healthcare professionals within the social network

7. How do you feel about the hospital staff that you've met?
   Probes: Have they been friendly? Do you have a consistent team each time you are hospitalized?
8. Some people have told me that they feel like they have an emotional connection with their hospital staff and others have mentioned that they don't like to share their

feelings with them. What is your relationship with hospital staff like while you're there?
Probes: Just informational/transactional? Lean on them for support? Support in addition to friends/family or in place of due to absence?

For those 17-19

9. Around your age people generally begin to transfer from their pediatric care team to adult care. Have you begun this transition and if so, how has it been so far?
Probes: How comfortable are you with your new team? How did you meet your new team? (i.e formal meeting, just had a new team one day, etc) How has your communication with hospital staff changed as you've shifted to adult care?

Thank you again for sharing. I'd like to ask a few questions about your last in-patient hospital stay for SCD/CF treatment.

Narrative of most recent hospitalization and hospitalization effects in general

10. You were recently in the hospital; can you tell me about what happened and what it's like when you're there?
Probes: How long was the stay? How did this stay compare to others? I.e. was it similar? Why or why not?

11. When you are in the hospital, what challenges do you have keeping up with school and relationships?
Probes: How do you address these challenges? How do you use social media to communicate/stay up to date with friends/your life outside the hospital?

12. Of all the people we've talked about so far, who visited you during your last hospitalization?
Probes: How many times? Who messaged you? Played online games with you? Checked in in some way?

13. Was there anyone you wanted to hear from or visit that didn't?
Probes: How did that make you feel? Why did they not come?

14. How do your friends and family make you feel supported during your hospital stays?
Probes: What ways do you not feel supported?

15. How do you express when you feel lonely or upset during hospitalization?
Probe: Who do you express it to? If you don't express these feelings, why not?

16. Who do you lean on for support most when in the hospital?
Probes: What does this look like? Having them call or visit? Is this different than who you would reach out to outside the hospital?

Thank you. I would like to move to our final set of questions to wrap up everything we have discussed so far today.

<u>Closing Question Set</u>

17. Let's say that someone has just befriended someone with SCD/CF, what are some things you might tell them that would help them support their new friend?

18. We have talked a lot about who you talk to and how you connect with them. Given all of that, what would you like people outside of your circle to know about your time within the hospital and the kind of support you do or don't receive?

19. What would you want to tell your friends/family about your experience that maybe you haven't openly shared with them?

20. What do you want people to understand about your experience with SCD/CF?

21. Some hospitals have peer support networks where people around your age can come visit while you are in the hospital, have you ever experienced one of these programs?
    Probe: [If no] Is it something you would be interested in/you think could be beneficial? [If yes] What was your experience like? How could it have been improved?

Thank you and next steps.

Thank you so much for talking with me today. We've talked about so much and it has been wonderful getting to know a little bit more about you. As mentioned, I will send you a gift card by email this week for your time. I want to remind you that all information you shared with me today about yourself and your experiences will remain anonymous and if you change your mind about sharing your experiences with this project, please let me know within two weeks so I may remove your information. Once I transcribe our conversation and it is analyzed with others it will become difficult to separate it out, although I will try to do so. Before we close is there anything else you'd like to share about anything we've discussed today, or do you have any final questions?