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Sickle cell disease and adolescents’ perspectives on self-care management resources

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ABSTRACT

Background: Adolescents with sickle cell disease (SCD) face unique challenges, especially during the critical health care transition from pediatric to adult care. The purpose of this study was to gather the perspectives of adolescents living with SCD and to describe their self-care management experiences prior to their move into the adult health care system.

Methods: Guided by the Theory of Self-Care Management for Sickle Cell Disease, this qualitative descriptive study used semi-structured interviews with 11 adolescents with SCD (M = 16.63 years, SD = 1.15). In addition to a demographic survey, adolescents answered interview questions about their perceptions of their self-care management, health care transition readiness, support, and spiritual well-being. Data were analyzed using a template analysis style.

Results: Four major themes were identified: attaining vocational aspirations, maintaining effective self-care management strategies, managing and maintaining social support, and building resilience through spirituality and religion. Maintaining, effective self-care management strategies had three threads: coping behaviors, health care transition needs, and self-care management strengths.

Discussion: Identifying self-care management resources and areas where further attention is needed can be helpful for health care providers when developing age specific plans. A tailored approach to care during this critical health care transition period can also build capacity for a successful transition for adolescents.

1. Introduction

Sickle cell disease (SCD) is a genetic blood disorder affecting approximately 100,000 Americans and millions globally.[1] Medical advances have significantly reduced childhood mortality and lengthened adult longevity, yet morbidity remains problematic for children and adults who may experience significant health complications, including acute and chronic pain, progressive end-organ damage, and mental health challenges.[2,3]

The transition of adolescents to adult care is a vulnerable period for youth living with SCD. The adolescent-to-adult health care transition is the “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.” [4] The process of transitioning to adult care involves planning, transfer, and integration into adult-centered health care.[5] It also includes assessing patients’ resources for self-care management and readiness for the adult health care system.[6] Self-care management incorporates health outcomes as well as lifestyle and vocation outcomes.

The transition from a supportive, high-touch, family-centered care model during adolescence to an individual-centered health care model during adulthood is difficult for many young people with chronic

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conditions.[7] Physical complications, including vaso-occlusive crises, jaundice, acute chest syndrome, acute kidney disease, avascular necrosis,[8] pulmonary hypertension,[8,9] and neurocognitive deficits[10] are some of the chronic conditions reported by adolescents with SCD as they transition to adult care.[8] Adolescents with SCD are especially at risk for anxiety, stress, and depression related to their illness, which can be exacerbated during the transition to adult care.[11–13] These psychosocial challenges may impact adolescents' capacity for self-care management of pain,[14] which can result in emergency department utilization or the need for hospital-based-care.[15]

Transitioning to adult care changes the ways in which adolescents and young adults interact with the health care delivery system. During the time of transition, multiple challenges emerge adding to the complexity of self-care management of SCD, for example previously established schedule for health care visits are stopped and AYA lose contact with their established, trusted health- care providers. Additionally, time needed to establish relationships with new providers, and changes in insurance, income, and living arrangements can also contribute to emerging health disparities, poor health outcomes, and limited access to care and resources.[16–18]

AYA perspectives concerning health care transition issues have been explored.[19–21] They are concerned about their capacity to cope with their SCD[5,21] and need a great deal of support for self-care management of their SCD.[19,22] Support from health care professionals is a critical factor in transition from pediatric/adolescent health care to the adult care system, yet some adolescents and young adults have reported undesirable experiences with providers and are concerned about establishing a relationship with their new adult health care provider.[10]

Use of self-care resources is theorized to impact health care transition readiness[21] and health outcomes.[23,24] Prior research has highlighted the significance of spirituality and religiosity in coping with SCD and health outcomes.[25,26] The Theory of Self-Care Management for Sickle Cell Disease[24] (Fig. 1) is a middle-range theory focusing on relationships among self-care management resources, vulnerability factors, and health outcomes. Self-care management resources are skills, behaviors, and activities that include assertive communication skills, coping behaviors, self-care ability, self-care actions, self-efficacy, and social support (including family, spiritual, and community, etc.) that can improve health outcomes. Self-care management is one's ability to maintain one's health and life in coping with a chronic illness. Vulnerability factors include lack of recognition/response to cues of impending sickle cell crisis, number of complications, number of acute pain episodes per year, and overprotection (providers and parents). Health outcomes include pain management experience, depressive symptoms, self-esteem, and perceived health-related stigma. Vulnerability factors can negatively influence health outcomes. Self-care management resources directly contribute to positive health outcomes and mediate negative vulnerability factors that influence health outcomes.

Self-care management resources are modifiable factors amenable to interventions by health care providers and researchers. Assertive communication skills is one's ability for self-advocacy through sharing thoughts, feelings, or information with health care providers.[27] Coping behaviors are cognitive and behavioral strategies used to master conditions of harm, threat, or challenge related to their SCD such as pain, anxiety, or depression. Using coping strategies reinforces the capacity for coping. Self-care ability is the capability to engage in therapeutic behaviors to maintain and/or improve health status and quality of life. Self-care actions through therapeutic activities and actively accessing resources maintain and improve health status and quality of life. Self-efficacy is belief about one's ability to manage their SCD and to achieve desired outcomes. Self-efficacy is directly related to a successful transition from pediatric to adult centric care.[13] Social support is the internal perception of interpersonal transactions, including expressions of positive effect, affirmation of another's behaviors or views, or giving symbolic or material aid. The presence of supportive social networks is associated with health promoting behaviors.[28] Each self-care management resource directly impacts a successful transition from pediatric to adult-centric care,[13,19,29–31] can help mitigate challenges unique to adolescents,[13,19] and can increase stability across the social determinants of health.[32] Based on the Theory of Self-Care Management for Sickle Cell Disease, one would improve transition and health outcomes by addressing vulnerabilities and optimizing self-care management resources.

The current study expands on existing literature by exploring adolescents' perspectives on their experiences with self-care management before their health care transition, specifically considering their access to, and use of, self-care resources. The purpose of this study was to gather the perspectives of adolescents living with SCD and describe their self-care management resources before transitioning to adult care. The focus on resources allowed for a strength-based approach to assessing protective factors, vulnerabilities, and needs. Understanding self-care management resources before transition can help identify needs and provide resources and support to make the process of transition more efficient and less challenging to impact health outcomes positively.

2. Methods

Using a descriptive qualitative design with data collected via semi-structured interviews,[33,34] we explored perspectives of adolescents living with SCD and their self-care management resources before transitioning to adult care. Interviews were conducted between 2018 and early 2020, prior to the onset of the COVID-19 pandemic. The

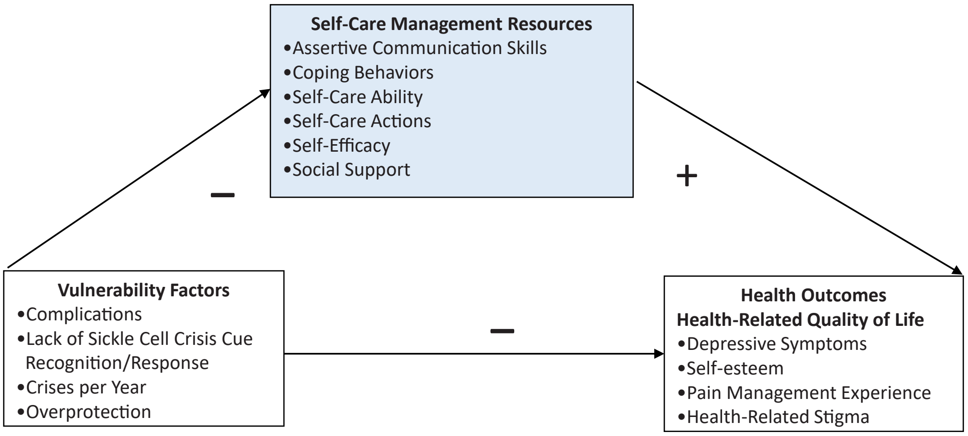

Fig. 1. Theory of self-care management for sickle cell disease. Re-printed from Jenerette, C. M., Brewer, C. A., & Ataga, K. I. (2014). Care seeking for pain in young adults with sickle cell disease. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*,*15*(1), 324–330.

Institutional Review Board approved this study.

Research questions that guided this study were: (a) What are the perspectives and experiences of adolescents in using their self-care management resources before their move into adult care? and (b) Does the Theory of Self-Care Management for Sickle Cell Disease fit with the participants' perspectives and experiences?

2.1. Recruitment

Adolescents living with SCD and residing in the Midwestern region of the United States were recruited with flyers distributed through professional, community, and faith-based organizations. These organizations also assisted with recruitment by email announcements, word of mouth, and social media. Parents of eligible participants interested in the research contacted the principal investigator (PI). Inclusion criteria included adolescents who: (a) had a diagnosis of sickle cell disease, (b) were between the ages of 15 and 18 (to access adolescents who are progressing toward transition to adult centric care), (c) were English speaking, and (d) had not transitioned from pediatric to adult health care. The PI explained the study to the parents and adolescents in person if the adolescent expressed an interest in participating in the study. Parent consent and participant assent were obtained if the adolescent was under 18 years. Participants who were 18 years old provided consent. A total of 21 potential participants were approached, and 11 (52%) were enrolled. Four (19%) adolescents did not enroll due to scheduling difficulty for completing the interview, and seven (33%) adolescents/parents never returned a phone call from the PI to schedule an interview. Interviews for most (64%, $n = 7$) enrolled participants were conducted during the same in-person contact as obtaining the parent consent and participant assent. For four (36%) participants, the interview was scheduled at a separate time.

2.2. Procedures

Participants completed a demographic survey. The demographic survey included age, gender, and hemoglobinopathy type. The demographic survey also included questions to understand better the trajectory of their SCD, such as hospitalizations, vaso-occlusive crises, and number/history of surgeries (Table 1).

The interview guide was created to include concepts from the Theory of Self-Care Management for Sickle Cell Disease. Specifically, as described in Table 2, questions were developed for each of the six self-care management resource concepts of the theory: assertive communications skills, coping behaviors, self-care ability, self-care actions, self-efficacy, and social support. Based on findings in the investigators' prior research,[25] the coping behaviors domain included questions about faith and beliefs. The content validity of the interview guide was evaluated through pilot interviews with two adolescents before finalizing the interview guide. Based on this feedback, the interview guide was revised to improve the questions' flow and incorporate the adolescents' perspectives on contextual influences on SCD and self-management, such as stigma.

The principal investigator (PI) and co-investigator (Co-I) conducted semi-structured interviews lasting approximately 45 min each. Interviews were conducted in a private room at a public library (18%, $n = 2$), at a private office within a community organization (18%, $n = 2$), at the participant's home (18%, $n = 2$), or using audio and/or visual technology such as Skype or telephone (45%, $n = 5$). Adolescents were interviewed privately to create a safe atmosphere to discuss their perspectives without reservation. Participants were interviewed to the point of theoretical saturation.[27] Interviews were digitally recorded and transcribed verbatim by a professional transcriptionist.

Table 1
Participant demographics (n = 11).

Demographic	n
Age	
15	2
16	4
17	1
18	4
Gender	
Female	6
Male	5
Race/Ethnicity	
African American	10
Biracial	1
Grade	
8th grade	1
High School	7
Completed High School	1
College	2
Days Missed at School for the Current School Year	
None	
Less than 1 week	1
More than 1 week	9
More than 1 month	1
Type of Insurance	
Medicaid	1
Medicaid and Private Insurance	3
Private	1
Not sure	6
Type of Insurance Planning	
None	10
Yes	1
Employment	
Yes	6
No	5
Hours per Week Worked	
0–10	3
11–20	2
21–30	1
Not applicable	5
Sickle Cell Disease Type	
HbSS	8
HbSC	1
SCBT+	2
Disease Severity	
Mild	8
Moderate	3
Comorbidity	
Depression	2
Heart Murmur	1
Asthma	2
Neurology	1
None	7
Number of Hospitalizations in Past Year	
None	3
1–5	5
10–15	1
> 20	2
Number of Hospitalizations in Lifetime	
0–10	2
11–50	2
> 50	2
> 100	2
> 200	2
> 250	1
Number of Vaso-occlusive Crisis in Past Year	
None	3
< 10	4
10–20	2
60–80	1
365	1
History of Surgeries	
SCD related	11
None SCD related	7
Tonsils	3
Gallbladder	5
Hip Replacement	1

(*continued on next page*)

2.3. Data analysis

The PI is a research faculty member trained in conducting qualitative

Table 1 (*continued*)

Demographic	n
Brain	2
Spleen	3
VP Shunt	1
Back	1
Ear tubes	1
Kidney stones	1
No	2
History of Transfusion	
Yes	9
No	2

research through graduate and post graduate coursework. A Co-I (graduate student) who had training in conducting qualitative research through graduate coursework assisted with data analysis. NVivo 12 was used for data management. The PI read interviews to gain an overall view of data. Data were analyzed using a template analysis style. A coding template was developed a priori using concepts from the Theory of Self-Care Management for Sickle Cell Disease. During the coding process four additional codes were identified and added to the final template which was used to code all eleven interviews.

Concurrent data generation and analyses were completed by the PI and co-investigator. After the PI and Co-I coded two transcripts, additional codes arose from the data and were listed on the coding template. The two researchers then met to compare codes on the template. There were few instances where the PI and the co-investigator lacked agreement. For themes where there was disagreement, consensus was reached through discussion. The template was used to recode the first two transcripts and continue coding the remaining nine transcripts. Coding summaries were made for each code, and thematic analysis was used to identify four final themes that described how adolescents used self-care management resources to prepare for their transition from pediatric/adolescent health care to adult care.

3. Results

Participants included 10 African American adolescents and one biracial adolescent ($M_{Age} = 16.6$ years; $SD_{Age} = 1.1$), 6 (54.5%) females and 5 (45.5%) males as described in Table 1. Twenty-seven percent ($n = 3$) of the participants had been hospitalized more than 10 times in a year. Sixty-three percent ($n = 7$) had 50 or more hospitalizations in their lifetime. One (0.09%) participant had an average of one crisis per day in the past year, and 36% of them ($n = 4$) experienced 10 or more crises in the past year. Four themes were identified that described participants' self-care management resources including attaining vocational aspirations, maintaining effective self-management strategies, managing and maintaining social support, and building resilience through spirituality and religion.

3.1. *Attaining vocational aspirations*

Adolescents shared how having SCD influenced their vocational aspirations. Attaining vocational aspirations included concerns adolescents had with their capacity to transition to resource systems for education and employment. Successful transition to these resource systems would support them in securing employment and establishing the independence expected as a young adult. These vocational aspirations most often included access to higher education and obtaining the necessary accommodations for successful employment.

Many of the adolescents, 73% ($n = 8$), acknowledged that they would not be able to attend school or work daily. They openly discussed their aspirations both with and without perceived limitations regarding their SCD. Most of the adolescents, 64% ($n = 7$), indicated that they would like to attend college; three indicated that they would like to learn a trade, and one was undecided between earning a college degree or a trade. However, 100% ($n = 11$) stated that they would like to establish a career. However, these adolescents expressed some concern about what their college major would be. A 16-year-old female wondered if she should postpone college until she had a definite idea of what she would like to major in, as well as secure a job where the employer would understand and accommodate her SCD:

> Well, I have no idea what I want to do, so that's my concern, and like me making a living, I don't want to be bored. I don't want to wake up every morning and be like, oh, another day. I want to actually like what I want to do. I also want to make sure I find a job where I can

Table 2
Comparison of the relationship of theory concepts to interview questions.

Theory Concepts: Self-Care Management Resources (existing skills)	Interview Questions
Assertive Communication skills	– Tell me about your relationship with your current doctor? Do you feel comfortable communicating with him/her about your health/care?
Coping Behaviors	– What types of things do you do that are helpful to yourself? Make you feel good or bring you happiness? How would you describe your faith/beliefs? How does your faith/do your beliefs fit into your life? Or guide you in life?
Self-Care Ability	– -Describe how your appointments have been in the last year. How comfortable are you in scheduling your appointments? What experience have you had with this? Did you miss any? How many? Why? – -How comfortable/or sure do you feel managing/caring for your SCD? Managing pain/other symptoms? Managing your medication? – -Tell me what you know about changing over to adult care. What about changing over to an adult doctor are you looking forward to? When do you think you will change over to an adult doctor? Describe any information you have received about moving over to an adult doctor so far. What do you expect will happen as you change over to an adult doctor? – -How comfortable/or sure are you in managing your SCD to do the things you need to do? Cook? Clean? Use the pharmacy? Use the grocery store? Manage allowance/money? What about things you like to do?
Self-Care Actions	– (Includes all questions under self-care ability)
Self-Efficacy	– How comfortable/or sure do you feel managing/caring for your SCD? Managing pain/other symptoms? Managing you medication? – How comfortable are you in managing your SCD to do the things you need to do? Cook? Clean? Use the pharmacy? Use the grocery store? Manage allowance/money? What about things you like to do? – If you could change something about the preparation you have received up until now for moving over to an adult provider/care, what would it be?
Social Support	– Tell me about those you consider to be supportive. Are there any family members who you consider to be most supportive? Who are helpful? Who you can talk to? Health care providers? Teachers? Coaches? Pastor? People in the community? What have they offered that has been supportive to you? How has this influenced your life?

Note: Interview questions are listed next to theory concepts.

> keep up working full time and everyone understands me, not treat me differently but understand.

An 18-year-old female discussed how she would like to attend school for culinary arts because of her interest in cooking, and believed if she created her own business, she would have greater flexibility to manage her SCD:

> Well, I want to go to school for culinary. So, I really want to be a baker, but they're both cool. I like to cook … I don't know. I don't cook a lot, but when I do I cook …. Sometimes I cook pies. Like, I've cooked pecan pie before. Baking as a business would really let me bake when I feel my best, and others in my business could help fill in when I need to focus on my body.

Adolescents expressed some anxiety around being able to secure a job with an employer who is aware of their sickle cell status. An 18-year-old male wondered if any alternatives would be available for missed days when he may not feel well enough to attend class or go to work or be treated differently if he took a day off for illness:

> I am not sure how all of this will work. Um, like I know I can apply for college or apply for a job, but I don't want a bad record if I miss class or if I miss work. Will I get kicked out of school and will I be in debt after I get kicked out? Will I lose work benefits and then have to try and get benefits all over gain again? I don't really know.

Adolescents also expressed some concern with working full time during the summer and being able to "keep up" with regular activities. Two of the adolescents had prior experiences with job shadowing to learn more about a particular profession or trade.

3.2. Maintaining effective self-care management strategies

In discussing what would be involved in managing their SCD, adolescents were asked to describe self-care actions they would likely need to perform and anticipated future self-care actions. Maintaining effective self-care management supports the capacity of adolescents as they focus on their physical, mental, and social needs during the critical health care transition period. Sub-themes included coping behaviors, health care transition needs, and self-care management strengths.

3.2.1. Coping behaviors

Coping behaviors were the actions adolescents engaged in to support them in managing their SCD and their lives. For the adolescent, developing and using coping strategies can be effective in easing the burden of experiences related to their SCD. When asked what kinds of things they did for self-care management and to better understand their coping behaviors, an 18-year-old female said, "I guess I shop for myself. I drive around. I get to places I need to go. Oh, yes, and I guess when I get my nails done, and hair done and stuff like that." A 16-year-old male adolescent said, "I like to be by myself in my room. It helps me recharge. I enjoy choir. It lifts my mood when I'm down."

3.2.2. Health care transition needs

Adolescents shared that they were not sure what to expect in transitioning over to adult health care. They identified areas that would support them during their last phases of adolescent care. Addressing the needs of adolescents during the critical health care transition period can impact their perception of their SCD and health-related quality of life. In addition, while parents and health care providers mean well, the theory concept overprotection, is a vulnerability factor that may be present for some adolescents. When asked what he thought would change after the health care transition, a 16-year-old male said:

> I'm not going to be connected as much as I am to my one doctor I have right now. Like, I'm going to have to start over, I guess. One question I would have is knowing how to find a good doctor; one that's going to meet my needs. I have concerns that I am not going to be able to do it. Because normally, your mom or your parents just know how to handle it and how to do it for you. That's probably going to be my concern, that I won't have a parent there to help me.

A 15-year-old shared more about her needs and said, "Probably just prepare me, like what I'll be seeing more of and what I'll be seeing less of. And just prepare me and talking more about it."

An 18-year-old female expressed some anxiety about being alone, and if something were to happen that no one would be around to help:

> Being by myself. I would never want to be by myself because if it was the situation where it's like 9–1–1, then I wouldn't want to be by myself dealing with that. Also moving. Moving's another one. Sometimes I'm as stiff as a rock. Or sometimes I'm as wobbly as a noodle. You never really know. That's one of the challenges. And I don't know, sometimes my arm won't work, or my leg won't work. And like I said, being by myself is really challenging me.

Some of the adolescents did share concerns about taking their medications. When asked what was challenging about taking medication, a 16-year-old male said:

> When I first start hurting, I don't like to take my medicine until I absolutely need to. Because I usually try to drink water or just lay down. Sometimes I end up going to the hospital. When I take the pill, I always feel like it's still right here. It's kind of stuck, like you can't get it down.

Another 16-year-old male said, "It's a lot of medicine, and they're big." And a 17-year-old female said:

> Making sure I'm taking my hydroxyurea every day. Staying warm would probably be one of them. Um, another one would probably be … yeah. So, staying warm, not getting sick, and taking care of my sickle cell.

3.2.3. Self-care management strengths

Adolescents shared aspects of self-care management where they perceived themselves to be managing their care successfully. In talking with adolescents, they mentioned some strengths that currently support their self-care management. With regard to employment, six (55%) worked part time during the school year. Adolescents shared that they wanted to work to have spending money throughout the year. They had informal roles working for family members or adults they knew, and formal employers outside of their familial and social networks.

Regarding medication management, 55% ($n = 6$) felt they were able to take their medications independently and accurately. Sixty-four percent ($n = 7$) expressed that they could build on their current skills, and benefit from additional support and practice regarding filling a prescription and reordering medication before running low or out of their existing supply. A 16-year-old male said, "I know about my medicines, but my mom takes care of my prescriptions. No, never had to do that part."

Adolescents expressed an interest in learning more. This interest included a desire to know how their insurance impacted their health appointments. Some adolescents maintained a calendar of upcoming appointments and had experience in completing a portion or all the history forms during a clinic or hospital visit. None of them kept an ongoing list or made a list of questions to ask any of their health care providers before their appointments.

Most of the adolescents felt confident about their ability to be in charge of their daily activities. From scheduling haircut appointments to grocery shopping to preparing food and doing laundry/other chores, they felt they had the skills necessary to complete the tasks. They indicated that they could benefit from more practice and receiving additional insight on how to improve on the tasks they are currently involved in, as well as learning new tasks. A 17-year-old female said:

> I think I'm doing this right, but when I have to really do it all by myself I'm like, am I by myself? Will I forget anything? Then I think some practice would help … just in case I don't know it all."

Many adolescents shared that they had some experience in budgeting and managing their own money, and that they were open to learning more in this area.

3.3. Managing and maintaining social support

Managing SCD and maintaining supportive connections can be challenging for adolescents. They discussed supportive relationships and the need for additional social support external to their family. Adolescents described their family members, teachers, coaches, pastors, and friends to be supportive. Most of the adolescents relied on their families for a majority of their general and social support. An 18-year-old female said, "My family and friends, they were just there for me and letting me talk. It's taken off stress. It's made things easier. I feel like I rely on my family quite a bit for a lot of support." When describing how her family has supported her, a 16-year-old female said:

> My dad's been here my whole life. He's probably the main support system I have. My grandma, my auntie, I would say my whole family but probably not, like, being there all the time. I would never consider them unsupportive; they have always supported me, but I would say my dad is my main supporter.

While the adolescents considered family, adults, and peers around them to be supportive, many of them indicated that there were a few instances when information was delayed or not shared for fear of worrying their family members. Whether they believed they were repetitive in discussing the same concern, did not want their loved ones to worry about them, or had difficulty deciding on the timing and amount of information to be shared, they kept some of their concerns to themselves. A 16-year-old male said, "I have things I deal with every day, but so do my parents. So, I try not to bother them, at least not every day." While most adolescents believed they had someone who could be a source of comfort, they also felt there was room for building capacity and support in this area, specifically around community support.

Adolescents shared that it can be challenging to share information with friends. They desire to keep up with their friends and do not want activities to revolve around their SCD. An 18-year-old male said, "None of my friends know I have sickle cell, unless they heard it from someone else. Just trying to live normal …." Adolescents felt comfortable relaying to their peers when they could not participate in an activity but did not feel comfortable sharing reasons why. A 16-year-old female said, "If they know about my sickle cell, they may not include me for things. I see what happens, people get left out." Adolescents also indicated that most of the time they could not talk about their problems with their friends (72%, $n = 8$). For those who had a significant other (27%, $n = 3$), they found their significant other to be the most supportive, followed by family and then friends. Communicating when they were experiencing a problem was still difficult to share with their significant other and often not shared.

3.4. Building resilience through spirituality and religion

Adolescents shared their experiences about their spirituality and their religion. Adolescents shared that they found comfort in their religious beliefs. An 18-year-old female described her introduction to a higher power: "My parents are really religious, to a certain extent, and I appreciate that. I appreciate them for waking me up to God. And I found my way to church, yeah, that's really a support." When asked what compels her to return to church every week, she shared:

> Just their faces. They're really nice people. And they're really good to talk to; really good friends. And like I said, I like teaching, and I like hearing the stories of the Bible, and I like seeing the kids and the babies. So, it's really fun there.

The "words and wisdom shared by members during different times" is what she found to be the most supportive. "They actually help me to live well, not just praying for a miracle." This was common for most of the adolescents. Whether it was wisdom shared about life by a member of the church or words shared to encourage, it supported them in living with their SCD.

Adolescents indicated that they relied on their spirituality as a source of support to include their relationship with self, others, or God. Some made that connection with others. A 15-year-old male described his relationship with his school pastor and the social support he receives:

> Yeah. Our pastor at my school, he is very nice. He has a few kids of his own with some difficulties, with some sicknesses, and he's just been through a lot, too. I know it's hard for him, but he's always kept his head up. He just always has a good attitude towards life and is still trying to help everyone else.

A 16-year-old female shared that while she did not attend a church currently, she does have access to attend mass. She said, "I don't go to church currently. I go to a Catholic school. We have mass sometimes, but I don't have a specific pastor or anything."

4. Discussion

There is limited literature on academic and vocational support for adolescents living with SCD which represents a significant gap in practice. The adolescents in our study provided their perspectives on self-care management needs and resources related to their impending transition to adult care. These perspectives offer valuable information for health care providers seeking actionable interventions. Our results supported that adolescents desire self-care management resources to become more independent. Several self-care management concepts from the Theory of Self-Care Management for Sickle Cell Disease were prominent in their responses. Participants provided descriptions of these resources, conveyed their strengths, and how deficits in resources increased vulnerability to lack of transition readiness. Several self-care management concepts from the Theory of Self-Care Management for Sickle Cell Disease were prominent in their responses.

For theme one, attaining vocational aspirations*,* adolescents would benefit from early exposure and discussion regarding their educational options. This finding is similar to research conducted with caregivers of children living with SCD where caregivers experienced a heightened sense of empowerment following their acquisition of additional information regarding educational options for their child.[43] The scarcity of opportunities to engage adolescents in education and vocation planning can lead to higher levels of stress within this population.[13] Neglecting their needs or concerns regarding vocational attainment can limit their self-management and hinder their capacity for employment and financial independence.[44] Understanding why education options are infrequently discussed is crucial. Adolescents with chronic illnesses transitioning to adult life are less likely to graduate from college, less likely to be employed, and more likely to experience a lower income and receive public assistance.[36,45] Adults with SCD have emphasized the need to address age-specific vocational aspirations and develop resources to further support them.[35] Furthermore, having a clear understanding of vocational experiences and preparation provided to adolescents by school guidance counselors and support services is essential, especially for health care providers.[37,46] Addressing concerns about maintaining employment and promoting awareness in the workplace is warranted.

For theme two, maintaining effective self-care management strategies, adolescents described approaches to managing and living with SCD that revolve around decision-making and having choices. None of the adolescents mentioned learning these approaches from their peers.

Consistent with previous research, providing opportunities for exchanging ideas, celebrating independence achievements, and offering mutual support among peers may be mutually beneficial over time.[46] Life stages and experiences can be helpful topics for peer discussions. Adolescents may benefit from hearing diverse perspectives on addressing similar concerns and gaining additional insights and support. Health care providers can support the development of peer relationships through support groups and social events tailored for adolescents living with SCD.[46]

Adolescents expressed the need for more skills in managing appointments, medications, and tracking health issues. Areas requiring practice included communication with health care providers in various settings (inpatient, outpatient, and emergency departments). While most adolescents felt comfortable talking with their health care providers in general, they indicated having more confidence in managing their daily activities. Health care providers (physicians, mid-level, nurses, social workers) can collaborate with adolescents to identify short-term health care transition goals continuously.[38] Connecting adolescents to existing resources and creating opportunities for them to develop and practice their self-care skills is warranted. Collaborating with school-based health centers can help adolescents identify and achieve self-care goals, thereby improving school support.[39,40] This approach will support adolescents in their self-management with fewer interruptions and enhance overall comfort.

For theme three, managing and maintaining social support, adolescents shared that they often did not want to fully disclose specific SCD experiences to their friends. Individuals with SCD commonly report negative reactions from family and friends when they disclose their SCD status. Negative stigma regarding their personality, pain tolerance, and abilities often leads to regret over disclosure.[41,42,47] Adolescents expressed a willingness to connect with peers living with SCD. However, it remains unclear whether they have had the opportunity to develop relationships with other adolescents living with SCD, either within or outside of the clinic setting. Creating experiences for planned interactions among peers can promote social support for adolescents living with SCD. These interactions can take the form of support groups, providing a safe and understanding environment where adolescents can connect with others facing similar challenges. Planned social activities that encourage relationship building can lead to increased comfort with sharing experiences and concerns. Furthermore, ongoing awareness campaigns within school and community settings, addressing health-related stigma, can create more welcoming, supportive, and less isolated environments.[39,40]

For theme four, building resilience through spirituality and religion, adolescents indicated having a relationship with a Higher Being, a sense of purpose when supporting younger adolescents, and connectedness with activities that promote a sense of meaning and purpose. Spirituality is the capacity to experience meaning and purpose in life,[48,49] while religion involves a commitment to beliefs and practices related to established religious organizations. [50];[51] Introduction to having a relationship with a Higher Being often came from parents or interactions and content at a parochial school. However, the activities that may promote coping behaviors were not as diverse for this group of adolescents. Involvement in activities that promote positive youth development and spiritual connectedness has been shown to impact coping behaviors, self-efficacy, and social support progressively among adolescents.[25,52,53] This may be particularly significant during the critical health care transition period when adolescents are also working on establishing a sense of identity and purpose. Further exploration of the lack of spiritual involvement among adolescents is warranted. A deeper examination may help understand whether this is related to complications of their sickle cell disease or other factors and address any existing barriers. Spirituality and religion can serve as sources of comfort and strength.[25] Additionally, spirituality and religion may motivate adolescents to engage in self-care strategies that support them in managing their SCD.[25]

Each of the study subthemes were in alignment with Theory of Self-care Management for Sickle Cell Disease resource concepts to include Theme 3.2.1 coping behaviors (coping behaviors concept), Subtheme 3.2.2 health care transition needs (self-care ability concept), and Subtheme 3.2.3 self-care management strengths (self-care ability and self-care actions concept). The concept assertive communication did not emerge as a theme, The desire for greater independence reflects several concepts from the Theory of Self-Care Management for Sickle Cell Disease. Adolescents presented with self-care management resources, such as learning to manage prescriptions. This involves enhancing self-care ability, self-care actions, and overall self-efficacy, all crucial aspects of successful living with SCD. Health care providers can use the Theory of Self-Care Management for Sickle Cell Disease as a guide in addressing specific interventions relative to the four themes. (Table 3).

Of the vulnerability factors, assessing overprotection among caregivers and pediatric providers is warranted. Sources of overprotection may stem from the nurturing pediatric environment and well-meaning caregivers. For example, Anonymous (2010)[54] report that maternal caring during childhood may promote self-efficacy in adults with SCD, and this is an area that needs further exploration. While the concept vulnerability factors was not included in the interview guide or the coding scheme, the concept emerged and is significant when considering health care transition processes.

Limited or lack of availability and access to self-care management resources during the critical health care transition period adds greater complexity to any existing vulnerability factors. For example, an adolescent not learning how to best communicate with health care providers can result in poor health outcomes, such as health-related stigma, depressive symptoms, challenges with self-esteem, and poor pain managementexperiences, as indicated in the Theory of Self-Care Management for Sickle Cell Disease.[24,55]

4.1. Limitations

This study provides background information regarding potential vulnerabilities and resources for adolescents with SCD, yet despite the important insights into self-care management, some limitations must be acknowledged. A small convenience sample of adolescents with SCD was used; therefore, selection bias may have impacted this study's validity. Additionally, because self-care management skills were not directly observed and were based on self-report, recall bias may have led to overreporting or underreporting. All but one of the adolescents who participated in this study received care from the same comprehensive SCD center. Their responses may not reflect the experiences of adolescents who participate in other comprehensive SCD centers or receive care outside of centers. Lastly, using a theory-guided approach to questions only allowed for exploration of concepts relevant to the theory. A broader exploration without theoretical constraints may uncover other themes related to self-management in adolescents preparing to transition to adult care.

4.2. Conclusion

Future research on self-care management and readiness to transition in SCD and applying the Theory of Self-Care Management for Sickle Cell Disease to transition in SCD are warranted. This research will add to existing literature addressing self-care management and health care transition needs for adolescents and young adults living with SCD. Addressing self-care management from a theory-based approach with the incorporation of cultural strengths can be beneficial. Providing culturally appropriate, evidence-based wraparound support before the critical health care transition is essential for success and future health outcomes. Adolescents living with SCD have unique needs related to SCD and have many of the same needs as their peers. Providing age-specific care with consideration of specific assets and resources, as well as factors that place them at a greater risk for poor health and

Table 3

Comparison of the relationship of theory concepts to themes, subthemes, and clinical implications.

Theory Concepts: Self-Care Management Resources (existing skills)	**Themes**	**Clinical Implications (health care professionals, educators, caregivers)**
Coping Behaviors Cognitive and behavioral strategies used to master conditions of harm, threat, or challenge when a normal or routine challenge is not available.	**Maintaining Effective Self-care Management Strategies (Theme 3.2)** Coping Behaviors (Subtheme 3.2.1)	Assess psychological, social, and physical aspects of their coping strategies.[35] Work with individuals living with SCD to develop a resource book with a network that supports development of diverse coping strategies.
	Building Resilience Through Spirituality and Religion (Theme 3.4)	Assess spiritual and religious aspects of their coping strategies.[36] Work with individuals living with SCD to identify, support, and integrate spirituality-based coping strategies (interconnecting with others, interconnecting with creative arts/activities) and religious-based coping strategies (interconnecting with God, scriptural stories/references, finding meaning/purpose).
Self-Care Ability The capability to engage in therapeutic behaviors to maintain and/or improve health status and quality of life.	Attaining Vocational Aspirations (Theme 3.1)	Vocational aspiration endeavors can be built beginning in elementary school. Using Social Cognitive Career Theory (SCCT)[41] based career programming, individuals living with SCD can learn to develop their career decision making ability and how to overcome challenges during career exploration. A collaboration between teacher, caregiver, and school counselor is warranted.
	Maintaining Effective Self-care Management Strategies (Theme 3.2) Self-Care Management Strengths (Subtheme 3.2.3)	Individuals living with SCD stressed the importance of making independent choices in life. One of the independent living skills is the ability to develop self-efficacy in making choices. Individuals living with SCD need to be empowered and provided with options during the decision-making process. Instead of providing one advice or suggestion, individuals can be presented with or provided with informed choices by health care professionals, caregivers, and educators. Programming and health care approaches that promote the development of self-determination skills among individuals living with SCD is crucial for them to make purposeful decisions and choices.[37]
Self-Care Actions Engaging in therapeutic activities and actively accessing resources to maintain or improve health status and quality of life.	Attaining Vocational Aspirations (Theme 3.1)	Pre-vocational program or a SCD pre-vocational counselor/coach. Pre-vocational programs include: Promoting using company's Employee Assistant Program (EAP) to navigate employment issues and their SCD related conditions/concerns to sustain the employment status. Joseph et al.[38] reported that EAP was effective in increasing the employees' level of presenteeism within the company. Promote using Human Resources department. Individuals would learn to familiarize themselves with the organization's diversity and inclusion policy and principles of equal employment opportunity. Education on resources such as workplace omnibus can be a valuable resource when encountering conflict in the workplace. More organizations have adapted inclusion policy as a social responsibility[39] (Gould et al., 2020).
	Maintaining Effective Self-care Management Strategies (Theme 3.2) Self-Care Management Strengths (Theme 3.2.3)	Acquire informed choices, ask for 2nd or 3rd opinions. Identify and build relationships with supportive allies/mentors to face the outcomes of the choice that they made. Accept mistakes as learning moments
Social Support The internal perception of interpersonal transactions, including expressions of positive effect, affirmation of another's behaviors or views, or giving symbolic or material aid.	Managing and Maintaining Social Support (Theme 3.3)	Strengthen social capital. A person's social capital consists of social support and environmental support. Social support comes from family, friends, and significant others.[40] Environmental support consists of access to health and mental health services, rehabilitation or social services, and community living supports. Emphasize the importance of evaluating social determinants of health.[41] An evaluation of social capital is essential when developing a plan for self-care management.
	Building Resilience Through Spirituality and Religion (Theme 3.4)	Work with individuals living with SCD to build their spiritual and religious support network. In addition to family and friends as mentioned previously, consider their pastor, religious leader, youth ministry fellowship/activities/volunteer service, focused church led support groups, or visiting a friend's church[36]
Theory Concepts: Vulnerability Factors	**Themes**	**Clinical Implications**
Overprotection	**Maintaining Effective Self-care Management Strategies (Theme 3.2)** Health Care Transition Needs (Subtheme 3.2.2)	Health care providers such as nurses can serve as a buffer of overprotection from caregivers. Researchers showed that when nurses engaged in difficult conversations with caregivers regarding the importance of the patient's ability in self-care management, this facilitates the caregivers' coping[42]. Psychoeducational sessions facilitated by health care

(continued on next page)

Table 3 (*continued*)

	providers regarding capability and desire to engage in self-care management for caregivers is necessary.

health care outcomes, is vital. Collaborative, comprehensive assessments and care that include the medical team, caregivers, and adolescents are significant in supporting the adolescent through the health care transition period. Adolescents provided their perspectives on self-care management prior to their transition to adult health care. Both elements impact the capacity for self-management, health outcomes, and transition readiness. Understanding the unique context for each adolescent is critical during the period of transition from pediatric to adult health care. Use of the Theory of Self-Care Management for Sickle Cell Disease may be helpful in addressing the needs of adolescents and supporting them with the development of age-specific interventions.

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Ethical conduct of research

The study associated with this protocol was conducted ethically. It was reviewed the Marquette University Internal Review Board and received a notice of approval IRB: #1805024069.

CRediT authorship contribution statement

Dora L. Clayton-Jones: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Visualization, Writing - original draft, Writing - review & editing. **Jill B. Hamilton:** Formal analysis, Writing - review & editing. **Kristin Haglund:** Writing - review & editing. **Lee Za Ong:** Visualization, Writing - review & editing. **Kalen C. Kennedy**: Formal analysis, Investigation, Writing - review & editing. **Sylvia Pena:** Visualization, Writing - review & editing. **Latoya Stamper:** Writing - review & editing. **Coretta Jenerette:** Writing - review & editing.

Declaration of Competing Interest

The authors have no conflicts of interest to declare.

Data availability

The data that has been used is confidential.

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