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## Listening to Stories of Peers with Chronic Illnesses: Extracurricular Career Exploration Activity for High School Students

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*Using achievement goal theory and positive youth development frameworks, this exploratory study reports findings of an innovative career exploration experience designed for high school student members of a health science academy (HSA). Students interested in healthcare careers (n = 9) completed two different interaction sessions with adolescents living with complex congenital heart defects or acquired heart disease (n = 9). The adolescents with cardiac conditions shared their medical treatment journey and life experiences with their peers using Beads of Courage, a narrative medicine tool, and a journal that guided their reflection. Post-interaction evaluation indicated that HSA participants ranked interacting with peers with cardiac conditions as the third extremely helpful learning experience out of nine options, next to shadowing in a healthcare setting and attending career informational meetings. This activity helped them reach learning outcomes listed by Health Occupation Students of America, such as increased sensitivity toward patients' stories and motivation toward healthcare career choice. Adolescents with cardiac conditions reported appreciation for the opportunity to teach about their healthcare experiences, and this increased their confidence in speaking about their medical treatment journey to others. The youth development technique of peer listening, advancing high school students' career exploration, and providing a platform to share their experience for adolescents with chronic illness merits further exploration.*

*Keywords:* youth development, health science students, extracurricular learning, adolescents with chronic illnesses, adolescents with complex heart defects

### Introduction

High school is a time of career exploration and planning. As high school students move forward with their academic career, an emphasis is placed on creating goals and career plans.

Extracurricular activities can be strategically utilized to maximize these career exploration efforts. Student engagement in such activities can be linked to continuing education after high school and furthering academic success (Lawson & Masyn, 2015). Much of the curricular and

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extracurricular activities in which students engage are an investment because the skills and knowledge learned through these activities can impact their future careers and lives (Lawson & Masyn, 2015; Swanson, 2002). High school clubs and school organizations offer the opportunity for students to interact with others who share similar interests, receive mentoring and assistance from school faculty, and engage in scholarly activities outside of the classroom (Nwankwo & Okoye, 2015).

This paper reports the investigation of an underexplored career-related activity where high school students interested in healthcare careers learn from interacting with peers living with a chronic illness and listening to their narratives. The rationale for this exploratory study is that high school students may interact with peers with chronic illnesses daily in their classrooms and through other social engagement opportunities, but they may not have the opportunity to learn from their medical treatment journey. Planned interactions with peers who share stories of their unique medical journey allow students interested in a healthcare career the opportunity to better understand the lives and experiences of their peers with chronic illnesses. The experience also creates opportunities for improved listening skills and the development of empathy, which are important for students interested in future healthcare careers. The present research lets students interested in a healthcare career and peers living with a chronic illness interact in a novel structured dyadic manner and reports the findings using outcomes pursued by Health Occupations Students of America (HOSA). To our knowledge, this is the first study that reports this specific type of planned dyadic interaction between these two groups of adolescents, which could have implications for collaboration between high school professionals and psychosocial care providers in pediatric settings toward facilitating positive youth development outcomes.

### **Theoretical Framework**

Achievement goal theory provided a framework for the current study to conceptualize the importance of how an individual understands the learning process, as well as how the context and environment affect learning (Deemer & Ostrowski, 2010). In this theory, the two dichotomous achievement goals of mastery and performance have been identified (Dweck & Leggett, 1988). Our study utilized only the mastery construct, which focuses on learning goals related to task-oriented understanding of concepts. Academic tasks and extracurricular activities can provide meaningful contexts and environments for students to develop competence and continue to improve and master skills. Challenging and novel experiences provide new skills and knowledge, while failures can be conceptualized as opportunities for learning and growth (Deemer & Ostrowski, 2010). Flum and Kaplan (2006) explain that an exploratory orientation describes a situation where school and extracurricular tasks are relevant to students' lives and offer opportunities to build skills and achieve immediate as well as long term goals. This exploratory orientation allows students to process new information, integrate it into their identity, and create meaning from events that are focused on fostering development. Extracurricular activities attended through memberships in high school clubs and organizations provide a

structure for this exploratory orientation and foster student growth and development (Flum & Kaplan, 2006).

Additionally, the positive youth development (PYD) perspective in developmental science (Damon, 2004; Lerner, 2017) suggests that along with individual strengths, there are also resources in the ecology of the youth, within families, schools, neighborhoods, and structured out-of-school activities that can promote positive qualities in adolescents and more desirable outcomes in their later development. The Five Cs model of PYD is recognized as an empirically supported approach to PYD and suggests that when there is an opportunity for alliance between individual strengths and ecological assets that promote healthy development, there is a likelihood for the Five Cs (caring, character, competence, confidence, and connection) to evolve across the course of an individual's development (Årdal, Holsen, Diseth, & Larsen, 2018; Lerner, 2017). Årdal and colleagues (2018) describe the Five Cs as follows: caring (sympathy and empathy for others), character (a moral sense of right and wrong, respect for societal and cultural behaviors, integrity and standards for correct behavior), competence (experienced competence in different life domains, including academic capability, social and interpersonal skills, and cognitive abilities), confidence (an overall positive self-regard, including a positive sense of self), and connection (positive, mutual contributing bonds with people and institutions). In the context of PYD, our study can add to the literature by exploring one learning opportunity that is based on a beneficial relational experience between individuals and their contexts and its feasibility to enhance the Five Cs attributes of adolescents.

### **Health Occupations Students**

HOSA is an extracurricular organization that serves high school and collegiate students who are pursuing careers in the healthcare field (HOSA – Future Health Professionals, 2017). The mission of HOSA is to “enhance the delivery of compassionate, quality healthcare by providing opportunities for knowledge, skill and leadership development of all health science education students, therefore, helping each student to meet the needs of the healthcare community” (HOSA – Future Healthcare Professionals, 2017, p. 1). HOSA provides a list of career-related exploratory activities, including attending professional informational meetings, engaging with doctors and nurses as guest speakers, attending panel discussions, going on field trips to healthcare facilities, shadowing healthcare professionals, and participating in laboratory-based research (HOSA – Future Health Professionals, 2017). These activities are designed to accomplish several outcomes, including setting goals for lifelong planning, being flexible for possible shifts in career goals, managing basic survival skills, leading and using democratic processes, building self-esteem, raising social intelligence levels, taking pride in accomplishments, developing enthusiasm, maintaining motivation, accepting the spirit of competitiveness, communicating more effectively, and helping others without needing recognition (HOSA – Future Health Professionals, 2017). Local HOSA chapters provide opportunities for student members to build leadership and citizenship skills, develop physical

and mental wellbeing, and interact with professionals and other students. These clubs plan activities to help student members become more interested in and familiar with healthcare fields, acquire and practice skills such as critical thinking, experience a wider range of opportunities related to healthcare topics, and fine-tune skills that will be beneficial to future employers (Nwankwo & Okoye, 2015). For example, allowing high school students to participate in laboratory-based research provides them with the opportunity to gain understanding and confidence in scientific topics, increase their interest in scientific careers, and enhance their comprehension of the scientific method. While the benefits are numerous, the opportunities are limited because some researchers are hesitant to include a high school student in their laboratories (Harley, 2013).

Active listening skills allow healthcare professionals to keenly listen to an individual's medical treatment journey, which is important as these skills help them to build rapport and connect with patients, as well as fully understand their medical, treatment, and therapeutic needs (Easton & Atkin, 2011). Charon (2001) states that the effective practice of medicine, nursing, and other human service professions entails narrative competence, which requires authentic engagement and the ability to understand and follow up on the stories of others. Patient narratives allow the medical professionals to listen and imagine the experiences that the patient is sharing; this gives the opportunity for medical professionals to empathize with the viewpoint of the patient (Charon, 2001). This empathy is developed during healthcare education as future healthcare professionals learn how to listen to patients tell their stories. Listening authentically can be a means of generating trust, empowering and affirming the patient, and providing the opportunity for the professional to take on another person's point of view momentarily to better understand the patient's experiences (Haigh & Hardy, 2011).

### **Adolescents with Chronic Illnesses**

Adolescents living with chronic illnesses experience enduring stress associated with extended treatment, recovery, and survivorship; this can contribute to emotional and behavioral problems (Compas, Jaser, Dunn, & Rodriguez, 2012). The impact of illnesses is intensified by stress encountered in other aspects of the adolescent's life. A chronic illness diagnosis can greatly impact an adolescent's development and lead to unique struggles with which the adolescent must cope, including in the school setting. Although they have additional challenges with which to cope, adolescents with chronic illnesses are very similar to their peers in many ways, including the need for guidance and positive influence as they encounter developmental and educational milestones (Suris, Michaud, & Viner, 2004). Thus, it is necessary to understand the ways that adolescents cope with stress to better elucidate processes of adjustment to illness and to develop effective interventions to enhance coping and adjustment (Compas et al., 2012). Medical professionals, school administrators, counselors, and educators can be mindful of these students' challenges and provide therapeutic resources (e.g., journaling, support groups, and specialized coping programs) for opportunities to explore and communicate their unique medical journey.

Adolescents with chronic illnesses exhibit a variety of communication preferences when talking about their diagnosis and treatment. This preference includes the desire for confidentiality and for the listener to be kind, understanding, and participate in the conversation (Klosinski & Farin, 2015; Shearer, Rempel, Norris, & Magill-Evans, 2013). These communication preferences impact the way adolescents with chronic illnesses interact with others, as well as whether and how much they choose to share the story of their medical treatment journey. Adolescents with complex congenital heart defects (CHD) experience frequent medical interventions, physical differences, activity limitations, social exclusion, feelings of isolation in school, and even bullying (Shearer et al., 2013). They also struggle with a variety of psychosocial and emotional issues such as striving for independence or realizing that their life will be different than peers because of their chronic medical condition (Connolly, Rutkowski, Auslender, & Artman, 2002). High school professionals can encourage adolescents with chronic illnesses to participate in narrative medicine opportunities to support the development of their communication skills and encourage positive self-expression, rather than feeling isolated due to their health condition.

### **Narrative Expression**

The opportunity to explore and express their medical treatment journey through narrative medicine provides adolescents with chronic health conditions an outlet to express themselves and to learn coping skills. Narrative expression allows for the revelation of a diagnosis and symptoms, as well as offers the listener the opportunity to better understand the experiences of the individual who is sharing their story (Charon, 2004). As a form of narrative medicine, the Beads of Courage (BOC) program provides children and adolescents with chronic illnesses a unique tool for owning and sharing their medical treatment journey with others. In this program, the individual with a chronic illness is enrolled as a BOC member and receives a specific type of bead for each medical procedure or treatment milestone determined by a bead journal- guide (Beads of Courage, 2015). For example, a BOC member receives a black oval bead for every needle stick, a light green oval bead for radiological procedures, a yellow oval bead for every overnight stay in the hospital, a silver square bead with a heart for a cardiac surgery, or a fish-shaped bead for a transfer to a different medical unit or hospital. Thus, each BOC member creates his or her unique bead strand relevant to his or her unique medical journey and now has a tangible tool to help visualize and narrate his or her story. Additionally, journaling is another effective psychosocial intervention for individuals with chronic illnesses. Reflective journaling about emotional topics can help individuals cope with both psychological and physical healing during their medical treatment journey (Delamare, 2014).

### **Current Study**

In this paper, we report how Health Science Academy (HSA) students interested in a healthcare career and adolescents living with heart disease experienced the process of shared engagement. For the current study, our approach capitalized on the strengths of HSA students' motivation for

learning and matched it with the opportunity to provide adolescents with chronic illnesses an outlet to share their healthcare journeys by using their BOC strands and a reflective journal. This PYD process involved reciprocally influential relations and engagement between both sets of youth to promote their development (Lerner, 2017).

This study's research questions are as follows: (a) Is planned interaction between a health sciences student and a peer with chronic illness deemed helpful for HOSA healthcare career-oriented learning outcomes? (b) What can high school students interested in a healthcare career learn from interacting with peers with a chronic illness such as congenital or acquired heart disease? (c) How do adolescents with heart disease describe the experience of sharing their medical treatment journey with high school peers during a structured dyadic interaction session?

### Methods

The institutional review board of East Carolina University approved this study. This community-engaged research consisted of a collaborative partnership between academic researchers and the community working together for mutual benefit (Ross et al., 2010). The partnership entities were a child life department in a children's hospital, the Health Sciences Academy, and the researchers. This study is part of a three-phase study examining how retrospective enrollment in the BOC program could be helpful for adolescents with heart disease as they are learning to integrate their experience of living with their chronic health condition. Only the components pertinent to the current study are reported in this paper. We collected the HSA students' data during the second phase, and we collected the data regarding the dyadic exchange experience of adolescents with heart disease during the third phase of the study. We obtained appropriate parental consent and adolescent assent from each respondent.

### Participants

Participants in this study included two separate groups of adolescents. The first group consisted of a convenience sample of nine (2 males, 7 females) high school students between 16-18 years old. To be eligible for the study, high school students had to be leadership members of the regional Health Science Academy (HSA) and be interested in healthcare careers. To recruit participants, the HSA program coordinator informed 19 eligible students about the study by mailing study information to their home. Individuals interested in participating in the study were requested to inform the HSA program coordinator, who then compiled the list and provided the list of confirmed participants to the researchers. The nine participants came from three different high schools within a public school district in eastern North Carolina. These students were sophomores ( $n = 1$ ), juniors ( $n = 3$ ), and seniors ( $n = 5$ ). The students' racial/ethnic backgrounds were African American/Black ( $n = 5$ ), Asian Indian ( $n = 1$ ), and White ( $n = 3$ ). Key participant characteristics are reported in Table 1. All HSA participants reported that they were also members of HOSA, as well as other organizations (e.g., the Red Cross), or were involved with other opportunities such as volunteering or shadowing in a clinical setting.

**Table 1. Health Science Academy (HSA) - Participant Demographic Characteristics (n = 9)**

<b>Participant ID</b>	<b>Gender</b>	<b>Age in Years</b>	<b>Grade in School</b>	<b>Future Healthcare Career Aspirations</b>
HSA P1	Female	18	12	Geriatric Physician
HSA P2	Female	18	11	Pediatric Clinical Nurse
HSA P3	Female	16	10	Pediatrician
HSA P4	Female	18	12	Specialized Nursing
HSA P5	Male	17	11	Pharmacist
HSA P6	Female	17	12	Pediatric Nurse
HSA P7	Male	17	12	Physical Therapist and Athletic Trainer
HSA P8	Female	17	12	Labor and Delivery Nurse Practitioner
HSA P9	Female	16	11	Pediatric Cardiologist

The second group of participants consisted of a convenience sample of nine (4 males, 5 females) adolescents between 13-18 years old who are living with a congenital heart defect (CHD) or acquired heart disease. Key participant characteristics of these adolescents are reported in Table 2.

**Table 2. Adolescents with Heart Disease - Participant Demographic Characteristics (n = 9) and Dyadic Interaction Partners**

<b>Pseudonym</b>	<b>Gender</b>	<b>Age in Years</b>	<b>Grade in School</b>	<b>Heart Disease Diagnosis</b>	<b>Dyadic Interaction Partners</b>
AG	Female	17	11	Single ventricle; 100% pacemaker dependent	HSA P7, HSA P9
Ronaldo	Male	13	8	Pulmonary Atresia	HSA P2, HSA P3
Daddy	Male	17	12	Catecholamine-induced ventricular tachycardia, implantable defibrillator	HSA P9, HSA P5
Swag	Male	13	8	Dextrocardia	HSA P4, HSA P1
David Benz	Male	16	10	Tetralogy of Fallot	HSA P1, HSA P3
Diva	Female	14	8	Hypoplastic Left Heart Syndrome, pacemaker	HSA P6, HSA P8
Alexis	Female	13	8	Tetralogy of Fallot	HSA P2, HSA P8
Lucy	Female	18	12	Hypertrophic cardiomyopathy	HSA P7, HSA P4
Dramatic41	Female	13	8	Heart aneurysm	HSA P5, HSA P6

*Note:* Adolescents with heart disease chose a pseudonym for themselves during the first session which they utilized throughout the research process. These are not their actual names.

To be eligible for the study, these adolescents had to have a diagnosis of a complex CHD or other heart disease acquired during childhood, must have been treated as an inpatient at our study's partnership hospital within the past five years as was verified by their child life specialist, and must have attended a specific camp for children with complex cardiac diagnoses. For the remainder of the paper, we refer to our participants as adolescents with heart disease, which includes both those with complex CHD or heart disease acquired in childhood. The camper list was used to recruit adolescents with heart disease. We mailed study information to the homes of 15 eligible participants, made follow up phone calls to answer further questions, and confirmed interest in study participation. This method resulted in a sample of nine participants. These adolescents were in high school ( $n = 4$ ), and middle school ( $n = 5$ ). Their racial/ethnic backgrounds were African American/Black ( $n = 3$ ) and White ( $n = 6$ ).

## Procedures

To provide the context for the current study, we are briefly listing all three phases of the larger study. In the first phase, we retrospectively enrolled adolescents with heart disease as Beads of Courage members, during which they received their beads to signify their unique medical journey milestones. One parent of each adolescent was actively involved in this step.

During the second phase, which was conducted three weeks after phase one, these adolescents with heart disease interacted with HSA students and used their BOC beads strands and a journal to share their medical journey and story of living with heart disease. Participants met in a large conference room located on the researchers' university campus. The HSA participants completed two sessions of dyadic interactions where they were paired with a different adolescent with heart disease for each session (see Table 2). Each session lasted approximately 40 minutes. To encourage candid discussion, these interactive sessions were not audio recorded. Hence, there is no transcript available for these interactive sessions. The HSA participants were instructed to listen to their peers with heart disease and to ask questions of interest about their diagnosis, their medical treatment journey, experiences of living with a heart disease, and the significance of their beads. The adolescents with heart disease were instructed to share their unique medical treatment journey to the extent they felt comfortable. They used their BOC strands and the companion reflection journal developed by the researchers which served as a concrete memory trigger when sharing meaningful events of their medical treatment journey. The journal provided 14 open-ended reflection sections which encouraged self-exploration in conjunction with their BOC. For example, journal topics included prompts related to living with a cardiac diagnosis, hospital and clinic visits, treatments and procedures, and thoughts about using BOC. The first author, a certified child life specialist with extensive work experience with children and adolescents with heart disease, was present during the facilitated dyadic interactions. She was available to provide support if any adolescents with heart disease became distressed when discussing their treatment journey. Per the research protocol, one parent of the adolescent with CHD remained seated behind the adolescent during the interactive sessions. The

parent was available to assist with remembering information about the medical treatment journey or to provide support as needed while the adolescent with heart disease was sharing his or her story.

To evaluate their extracurricular learning experience, the HSA students completed a questionnaire titled, “HSA Student Feedback of Dyadic Peer Interaction Activity,” immediately after listening to two different stories of the medical treatment journey and life experiences of adolescents with heart disease. Both sets of participants received a \$25 gift card for a general department store for their time and effort in participating in this research study.

In the third phase, using a semi-structured interview tool titled “Experience with Retrospective Enrollment in the Beads of Courage Program,” we interviewed the adolescents with heart disease regarding their entire BOC experience. During this interview, two questions specifically pertained to describing their experience of talking with the HSA peers: “What did you feel when telling your peer about your heart condition and medical treatment journey using your beads?” and “Did the beads and the journal help you process your thoughts about your medical treatment journey and do you think it helped when you talked with your peers?” The interviews were audio recorded. The second author repeatedly listened to the interviews and manually transcribed them verbatim. Another research team member listened to the interviews and verified the accuracy of these transcriptions.

## Measures

We developed the HSA Student Feedback of Dyadic Peer Interaction Activity questionnaire after carefully reviewing HOSA’s handbook. The handbook outlined typical activities provided to student members, proposed learning outcomes that HOSA aims to help student members reach, and information regarding how these activities and outcomes are interconnected (HOSA – Future Healthcare Professionals, 2017). Three subject experts (one HSA coordinator, and two social sciences faculty members who have prior experience working with youth) reviewed the tool to establish content validity. This nine-item questionnaire included four close- and five open-ended questions. The four closed-ended questions included (a) perceived helpfulness of prior participation in HSA initiated activities toward preparing for a healthcare career, (b) perceived helpfulness of their experience with this current research, (c) an indication of which healthcare professionals they have previously interacted with in a one-on-one setting, and (d) a report of which of the nine adapted HOSA outcomes they experienced due to their recent interactions with adolescents with heart disease. Using a standard Likert-type scale (1= extremely helpful, 2 = very helpful, 3 = somewhat helpful, 4 = slightly helpful, 5 = not at all helpful), participants rated their perceived level of helpfulness of participating in the nine typical learning opportunities provided through HOSA, as well as the current experience of listening to medical treatment journey stories of peers with heart disease. We provided HSA students with a list of the typical learning outcomes for HOSA programs and asked them to check all that applied to their current

experience of listening to peers' medical treatment journey and experience living with heart disease. The remaining five open-ended questions asked about healthcare club membership, their feelings about interacting with a peer with heart disease, what they learned because of interacting with a peer with heart disease, their understanding of the BOC program, and any additional feedback about their experience interacting with an adolescent with heart disease.

We also developed the semi-structured interview tool used to interview the adolescents with heart disease. Although for this study, we only used data from two interview questions, we are providing a brief description of the tool. The overarching question for the interview was, "Can you tell me what it was like for you to become a member of the Beads of Courage program?" There were 17 subquestions, which we used as further probes to encourage the adolescents with heart disease to share their experiences of receiving their BOC. Examples of these questions ranged from inquiring about what they learned regarding their unique medical treatment journey by being enrolled in the BOC program, to if they planned to use their beads in the future and, if so, in what ways.

### **Data Analysis**

We analyzed the quantitative and qualitative data. We calculated the frequencies for the numeric items on the survey. Guided by van Manen's (1984) highlighting approach, both researchers independently completed content analysis of the open-ended responses from HSA participants and of the relevant interview responses from the participants with heart disease. We reviewed the data several times to understand participants' responses to discern potential themes. We extracted significant statements from the data, eliminated duplications, and used illustrative quotes to describe the results. By using analytic coding, we identified a recurrence of themes regarding what and how the participants experienced meaning in their interaction. We compared the themes and resolved any discrepancies in the interpretation.

### **Findings**

A commonality in the responses of both sets of adolescents was their acknowledgement that this dyadic interaction opportunity was mutually beneficial. This section describes the learning achieved by HSA students in terms of HOSA based outcomes, as well as insights gained into the life of peers living with heart disease. This section also briefly provides insights from adolescents with heart disease regarding their experience of sharing their medical treatment journey with high school peers.

### **Learning Achieved by HSA Students during Current Study Participation**

**Overall HOSA related learning outcomes.** Of the nine learning experiences typically provided through HOSA, which were explored in the HSA student questionnaire, shadowing in healthcare settings was perceived as extremely helpful by all nine (100%) of HSA students. Attending

career informational meetings was rated as extremely helpful by seven (77.78%) students. Notably, along with field trips to healthcare facilities, the learning experience of interacting with a peer with heart disease, which was designed for this research, was rated as extremely helpful by six (66.67%) HSA students. Other HOSA activities rated as extremely helpful by HSA students were observing in healthcare settings ( $n = 4$ , 44.44%); attending panel discussions, listening to guest speakers, or participating in competitive events ( $n = 3$ , 33.34%); and lab-based experiences or project participation ( $n = 2$ , 22.22%).

Additionally, like learning from interacting with peers with a chronic illness, HSA students reported prior participation in other comparable interaction-oriented learning opportunities typically offered through HOSA activities with a variety of healthcare professionals. These included nurses ( $n = 9$ , 100%), doctors ( $n = 5$ , 55.56%), psychosocial service professionals, such as social workers and chaplains ( $n = 3$ , 33.34%), and other healthcare professionals, such as physical therapists and occupational therapists ( $n = 6$ , 66.67%). Participants compared the value of their current learning experience to other HOSA-based interaction-oriented opportunities. For example, HSA P1 stated,

It was a very different experience. I am familiar with interacting with health professionals who explain diseases scientifically; however, hearing a patient describe their personal experience was insightful. Listening to someone my age describing the procedures and hospital visits they had to go through made the disease seem very real, which is something that I did not feel or experience while shadowing at the hospital.

To frame the experience of listening to the medical treatment journey of peers as a meaningful learning experience, the authors adapted HOSA's list of possible outcomes (HOSA – Future Health Professionals, 2017) and explored which of these outcomes were achieved. Of note, all nine HSA participants reported that the experience of interacting with a peer with a chronic illness helped them realize that they have a realistic healthcare career goal. This experience emphasized for them that one needs the ability to communicate effectively and increase their sensitivity to patients' stories and medical treatment journeys. It reaffirmed their belief in the purpose of healthcare services and helped them to understand that everyone is important in his or her own right and deserves to be treated with respect and love. Also, as a result of this experience, eight (88.89%) participants felt a sense of self-esteem, developed enthusiasm, and maintained motivation regarding their healthcare career choice. Several HSA participants ( $n = 7$ , 77.78%) were reminded to be flexible for possible career plan changes. Notably, of the ten possible outcomes that they could have experienced because of participating in this research, six (66.67%) HSA students reported that they experienced all ten possible outcomes, while three (33.34%) reported experiencing at least eight outcomes. Overall, two thirds ( $n = 6$ , 66.67%) reported that this experience of interacting with a peer with heart disease was extremely helpful; one third ( $n = 3$ , 33.34%) reported that the experience was very helpful.

Finally, some participants reported confirmation of future career choices. For example, HSA P6 explained that “this experience made me more firm on my choice to become a pediatric nurse,” and HSA P9 stated that her experience “made me more confident in my goal which is to be a pediatric cardiologist.”

**Learning about peers’ life experiences related to living with heart disease.** Analysis of open-ended responses of HSA participants regarding first-hand understanding of the life experiences of peers with heart disease as a result of interacting with them revealed four themes: (a) learning about the physical limitations that are a result of complex CHD, (b) understanding the unique aspect of each persons’ medical treatment journey, (c) experiencing empathy regarding suffering and resiliency associated with heart disease in adolescents, and (d) gaining new knowledge about heart anatomy or treatment for CHD. Several participants learned that individuals with complex CHD have various levels of physical limitations depending on the type of heart defect. For example, HSA P6 explained, “one may be able to participate in school sports while the other can’t. One may miss a large amount of school time while the other doesn’t. I was fortunate enough to experience this wide range during my interaction today.” HSA P5 stated that “some people with heart defects can play sports but they have to be extra careful on what they do.” When discussing suffering and restrictions, HSA P1 articulated, “patients with heart defects must suffer through a lot more than healthy people because of their disorder.”

The participants also reported that they learned about the unique nature of each person’s treatment journey. HSA P4 articulated how “it’s all a journey; each person will have a different unique and special experience.” HSA P7 realized the resiliency of his peer with heart disease. He stated, “even through being in the ICU, intubated, on the ventilation, being told they might die, and so on, they can still smile.” Insightfully, participant HSA P2 realized that “[the adolescents with heart disease] didn’t let their diagnosis stop them and prevent them from living,” while HSA P4 stated that “interacting with my peers who have this disease opens up my mind to see how they may have a disease, but it doesn’t define them.” Several participants reported increased empathy, such as HSA P4 who learned, “how it affected [my peer with heart disease] socially and mentally,” and HSA P9 hoped that these adolescents with heart disease would, “get a chance to share their stories with their peers because people deserve to know how strong they are.”

Many participants reported new knowledge of heart anatomy and treatment procedures for heart defects. For example, HSA P3 realized that “the peers were born with a certain [heart] defect,” which shows her understanding that CHD is typically a congenital birth defect. HSA P7 also explained how he learned that, “they have pacemakers to help their heart continue to beat.” HSA P9 described her new understanding of defibrillators and “the amount of pain associated with the shock.” She stated that she “never knew that these were necessary for treatment of tachycardia.” Responses of two HSA students revealed some inaccurate understanding of heart function and treatment intentions.

**BOC as a tool for communicating a complex medical journey.** HSA participants reported learning several aspects about the BOC program such as how (a) the beads served as a new type of communication tool and made sharing easier for the adolescents with heart disease, (b) the program provided comfort and encouragement to the BOC members, and (c) each adolescent with heart disease had their own unique medical treatment journey. HSA P7 stated, “each BOC symbolize something that patient has been through,” while HSA P4 said, “the program creates a way for these peers to tell a story and have something they can hold on to and share.” HSA P9 explained, “I learned what different beads meant . . . the abundance of one color made me see what [medical treatment] the child has been through the most.”

**The overall value of interacting with a peer with heart disease.** Analysis of open-ended responses regarding their overall perceptions and feelings about interacting with a peer with heart disease revealed two themes: (a) insight and affirmation related to the experience and (b) comparison of the experiences of adolescents with heart disease to their own life experiences. First, participants reported gaining new knowledge and understanding because of this experience and summarized their experience as “heartwarming,” “insightful,” “informative,” and “helpful.” HSA participants felt that listening directly to the adolescent with heart disease was helpful and allowed for a new level of understanding of their unique medical treatment journeys. HSA participants also realized the resiliency of adolescents with CHD; HSA P6 referred to them as “courageous children.” HSA P7 explained that it was “heartwarming” to know that “even through the pain they suffer, they can still smile.” HSA participants’ comments regarding this extracurricular learning activity revealed that they were grateful for the experience and wanted to listen to more than two peers tell their stories. They hoped other high school students would get a similar experience of listening to peers with chronic illnesses share their stories and noted that this experience reinforced their career goals. For example, HSA P2 stated that “this experience will never be forgotten,” and HSA P4 explained that “I want to encourage and help others like my peers. . . . This only furthers my compassion of going to school to be in the health field.”

Second, the participants compared the experiences of the adolescents with heart disease to their own life experiences and described the emotions associated with that comparison. HSA P5 explained that it “felt good to interact with people with a different journey in life . . . some of the things they told me made me think about my life and things I need to change.” He reinforced again, “there are more things in this world that people should worry about besides themselves.” HSA P7 reported that “it was heartwarming to know how fortunate I truly am.”

### **The Perceptions of Adolescents with Heart Disease about this Interaction with HSA Peers**

In this section, we report the findings of how adolescents with heart disease described their experience of sharing their unique medical treatment journey with the HSA participants. They were aware that they would interact with high school peers interested in healthcare careers during phase two of the study. They unanimously summarized their interactions with HSA peers

as enjoyable and feeling like their “teachers.” The adolescents with heart disease felt that they had the opportunity to share valuable information with the HSA students, which will be helpful for their HSA peers’ learning and healthcare career goals. While two adolescents with heart disease reported feeling somewhat nervous initially, they both reported talking freely once they realized that their HSA peer “really liked listening [about their experiences]” and felt that “seeing the beads also helped them realize how much we’ve been through.” One participant with heart disease explained that using the beads “made it a lot easier to tell . . . which bead means what, and what color means what, and it just helped me be able to explain, and I think help them understand more.” He also reported that looking through his journal “helped me tell them what my diagnosis was . . . [and] what all my symptoms are.” Another adolescent with heart disease said this interaction showed the HSA students that “people have [medical] conditions right beside them . . . it’s not just when they come to the hospital.” She continued, “I think it really helped them . . . see what other kids go through, like the problems other people have . . . [and] understand us more.”

Overall, adolescents with heart disease appreciated the opportunity to share their medical treatment journey with peers interested in healthcare careers because it helped their peers learn something relevant to their future goals. They also appreciated that the HSA students were genuinely interested in talking with them and were sensitive. They also reported liking their peers’ responses, such as seeing the different facial expressions or reactions of “shock.” All adolescents with heart disease articulated their realization that they could meaningfully share their unique medical treatment journey to sensitize and help peers interested in healthcare careers. They felt a sense of pride in sharing their journey with their HSA peers. For example, a participant with heart disease said, “it was kind of fun to actually have people want to talk to me . . . and it’s helping them . . . and I like teaching people that I know is smarter than me.”

And another adolescent with heart disease expressed his feelings of pride as articulated below,

I think when I was talking to one of them . . . he was shaking his head, and you know he was like thinking . . . gathering up all the information I told him and storing it into his mind so that he can use it. And one of the girls her reaction . . . she was kind of like in a little bit of a shock . . . because she couldn’t believe, you know, how intelligent and smart I was.

The adolescents with heart disease expressed that talking to peers about their medical treatment journey empowered them and that they were able to practice how to share their story in a way that is beneficial to both the storyteller and the listener.

## Discussion

Our study adds to the literature by providing initial support that intentionally structured interactions with peers with chronic illnesses can become a useful career exploration oriented

extracurricular learning activity for high school students who are interested in healthcare careers. Our findings provided further insight regarding the three research questions in understanding (a) if planned interactions between a health sciences student and a peer with chronic illness were considered helpful for HOSA healthcare career-oriented learning outcomes, (b) what high school students interested in a healthcare career learned from interacting with peers with heart disease, and (c) how adolescents with heart disease described the experience of sharing their medical treatment journey with high school peers during a structured dyadic interaction session.

As conceptualized in the achievement goal theory, participation in experiences that engage students in career exploration in a meaningful way can lead to students feeling that they are adept and able to achieve their collegiate and career goals (Deemer & Ostrowski, 2010). In underscoring the connection between research and application, this study supports the PYD perspective on developing youth and promoting positive qualities and outcomes in their development (Lerner, 2017; Theokas & Lerner, 2006). Two-thirds of the HSA participants in our study said that listening to a peer with heart disease's medical treatment journey was a novel activity for them and it provided them with an opportunity to reflect on their career path in a new way. HSA participants reported several benefits including gaining first-hand knowledge, increasing their motivation and drive for their healthcare career goals, and becoming inspired to help others like their peers with heart disease. Participants reported some gains in all nine of the HOSA outcomes through this learning activity (HOSA – Future Health Professionals, 2017).

Through their focused interactions, HSA participants more specifically gained knowledge about CHD and its treatment options, as well as restrictions that can result from living with heart disease. Additionally, they were sensitized to the positive attitudes and resilience of their peers with heart disease. Reflections of HSA participants affirming that listening to peers' stories confirmed their career choices for them or, "made me think about my life and things I need to change," highlighted achievement outcomes such as persistence or choice. We can also speculate that since the participants were HSA students and were already interested in health careers, that interest could be the moderating factor in this mastery goals dynamic. This idea could be examined more specifically in future research. Additionally, after participating in this novel experience, HSA participants showed mastery as demonstrated by their understanding of basic CHD related knowledge, critical thinking (e.g., understanding that all adolescents with heart disease will not have the same level of limitations) or making inferences (e.g., reflecting that heart disease did not define their peers' identity).

Through their narratives, adolescents with heart disease discussed their diagnoses, symptoms, as well as healthcare experiences and events that changed their lives because of their illness, with the students who were interested in healthcare careers. The narratives allowed the HSA students to build empathy by better understanding the life and medical experience of the adolescents with heart disease. Our study suggests that the narratives of the adolescents with heart disease allowed the HSA students to gain a new perspective regarding how some adolescents with this

chronic health condition defined their illness and how the disease affected their identity. They also realized how their peers are living and coping with heart disease. Our findings support Charon's (2004) observations regarding the importance of narrative medicine, considering that the HSA students were able to authentically engage with the adolescents with heart disease and affirm their experiences. Effective medical professionals must develop the skills required to engage in an authentic manner and genuinely listen to and understand other peoples' stories. These skills allow professionals to build rapport as they learn more about their patients' physical and therapeutic needs, as well as affirm their experiences (Charon 2001; Easton & Atkin, 2011; Haigh & Hardy, 2011). Through this research experience, we provided the HSA students an opportunity to practice crucial listening skills that will become necessary for them when they pursue healthcare careers in the future.

Exploratory orientation is a process in which individuals deliberately engage in internal or external action of seeking and processing information in relation to the self (Flum & Kaplan, 2006). Notably, because of participating in this planned relational dyadic interaction, the HSA students were able to compare their own life experiences with those of peers living with a chronic health condition. This activity can be viewed as an outcome of processing information in relation to self and the creation of self-relevant meaning, which in turn may have an integrative effect that could impact their overall development. Flum and Kaplan (2006) state that in the 21st-century job environment, individuals must have the capability to engage in activities in which they can relate their experiences to their own identity and respond flexibly to future career opportunities. The HSA participants appeared to address their realization of the importance of listening to their future patients. They may have participated in this experience while thinking about their career aspirations, but along with more insight into their future career, they also gained perspective on how it felt to be listening to a peer with a chronic illness.

Through the lens of the achievement goal theory, our findings suggest that HSA students had an increased likelihood of considering the task of listening to peers' medical treatment journey as contextually meaningful. This learning activity posed a mastery goal for them and could contribute toward adaptive motivational patterns, concentrating on developing competence and focusing on continued self-improvement (Deemer & Ostrowski, 2010; Dweck & Leggett, 1988). From the Five Cs model of PYD, our findings suggest that through the structured peer dyadic exchanges with peers living with chronic illnesses, high school students can become meaningfully engaged in a healthcare career exploration activity to promote their sense of caring, competence, and connection. On the other hand, the adolescents with chronic illnesses can practice communication skills toward reducing their isolation in school, and thus potentially enhancing their confidence and sense of connection with peers.

### **Implications for High School Professionals and Psychosocial Healthcare Providers**

By providing more guidance and deliberating how the relationship of this type of learning activity (i.e., listening to peers' medical treatment journey and living with a chronic illness) and insights gained from it relates to their future career aspirations, HSA coordinators can more proactively help high school students recognize these meaningful connections. For example, it could be reinforced to the HSA students that to better serve their future patients, they must be able to actively listen to their clients, as well as engage with their stories in a genuine and nonjudgmental way (Easton & Atkin, 2011). It is also critical for them to develop empathy as they learn to see the world from someone else's perspective (Haigh & Hardy, 2011).

Health science organization administrators in high schools can create more organized and intentional opportunities for their student members to interact with peers with chronic illnesses. Collaboration between school-based professionals (e.g., HSA coordinators, school counselors, school nurses), and pediatric psychosocial providers (e.g., child life specialists, social workers) to identify adolescents with chronic health conditions willing to participate in such peer dyadic exchange opportunities could be mutually beneficial for both the HSA students and the adolescent with the chronic condition. In the same token, child life specialists could reach out to HSA coordinators to create similar dyadic exchange experiences for their patients who might benefit from it. Also, if high school administrators, counselors, and educators are aware of narrative medicine tools, it allows these school staff to potentially discuss the benefits of such resources to students with chronic healthcare needs. School staff could partner with psychosocial healthcare providers, such as child life specialists working at local children's hospitals, to help their students access such resources.

### **Limitations and Research Implications**

While the findings of this novel extracurricular learning activity are noteworthy, the small sample recruited through convenience sampling techniques limits generalizability to other populations. A pre-post intervention study design with greater randomized sampling of student dyads could increase the generalizability of this type of extracurricular learning activity. The one-time intervention and its immediate evaluation did not allow for measuring a sustained impact and level of commitment to healthcare career preparation due to this learning activity. Another limitation is that researchers did not bring the HSA participants together with their HSA high school coordinator after their individualized interactions for a group discussion regarding what each participant learned from their peer interactions. This approach would allow for further processing and consideration of career goals in a focused educational environment as well as assist with clarifying any misconceptions the students may have. Including adolescents with different illnesses or disabilities to share their medical journey experiences could provide new information and understanding for HSA students.

## Conclusions

To summarize, our innovative approach of pairing HSA students who are motivated to learn about healthcare careers with adolescents who have chronic illnesses and are open to sharing their healthcare journeys appears to benefit both sets of youth. Our findings merit the awareness and efforts of high school professionals to consider planned peer dyadic exchanges between students interested in healthcare careers and adolescents with chronic illnesses as a potential healthcare career exploration activity toward cultivating more sensitive healthcare practitioners. Also, high school professionals and psychosocial healthcare providers can collaboratively facilitate planned dyadic exchanges to allow adolescents with chronic illnesses to practice communication skills toward reducing their isolation in school and empowering them to take ownership of their unique medical treatment journeys.

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