CORRELATION BETWEEN PAIN ACCEPTANCE AND ANXIETY IN ADOLESCENTS WITH SICKLE CELL DISEASE

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Correlation between pain acceptance and anxiety in adolescents with SCD

Abstract

Sickle cell disease (SCD), an inherited blood disorder, causes a patient's red blood cells to form into a sickle shape and clot in the vessels. Individuals with SCD can suffer from severe pain due to the restricted flow of blood. Pain acceptance is a crucial component of a patient's quality of life. The ability to accept the pain that comes with SCD can enable patients to have more productive and fulfilling lives. Anxiety in adolescents with SCD can have a significant impact on their functionality and overall development. The many factors contributing to anxiety in adolescents can worsen when combined with the stress of having a chronic illness. The aim of the current study was to explore the relationship between pain acceptance and anxiety in a sample of adolescents with SCD. Data for the following study was collected at a children's hospital in the Midwest. Participants included 30 adolescents, aged 12-18 years (M=14.5). The data set included male (46.7%) and female (53.3%) participants. Participants identified as either African American (85.2%) or biracial (14.8%). The Chronic Pain Acceptance Questionnaire (CPAQ) a 20-item self-report measure, was used to gather data on pain acceptance in children. The Spence Children's Anxiety Scale 44-item self-report measure was used to assess anxiety in children. Higher scores represent better ability to accept pain and higher levels of anxiety, respectively. A bivariate correlation between adolescent self-report scores on the CPAQ and SCAS showed no significant association between pain acceptance and anxiety in adolescents with SCD, r=.10, p>0.05. There is insufficient evidence to conclude a significant linear relationship between self-report scores on the SCAS and the CPAQ is present among adolescents with SCD. Limitations to this study included a narrow sample size. The influence of an

unidentified third variable such as the development of strong coping skills or having already come to terms with the reality of their diagnosis could be present. Unknown contributing factors to participants' anxiety could have potentially impacted results. Including, pain levels on the day of the survey and their mindset when taking the survey. Further research regarding contributors to high levels of anxiety in patients with SCD is needed to determine if additional factors influencing anxiety are present in their daily life. Potential examples include participants support systems or the type/severity of their SCD diagnosis.

Chapter I: Introduction

Throughout adolescence children may experience feelings of anxiety as they navigate the world around them. Anxiety is a common experience, especially in adolescent human development. Adolescents who suffer from anxiety disorders are pre-disposed to poor functioning in many areas of life as development progresses such as: performance in school, ability to make social connections, and compatibility in the family system (Barker et.al., 2019). Anxiety can present in several different forms during adolescence, but common signs can appear as crying, irritability, and angry outbursts (Garcia, 2021). These anxious episodes are often initiated by triggers that are typically unique to each adolescent but share common themes, including fear exposure, loss of an attachment figure, or obsessive thinking (Rockhill et.al., 2010). The anxiety symptoms often present in adolescents can be made worse by the presence of chronic illness.

Sickle cell disease (SCD) is a blood disorder in which patients inherit two abnormal copies of the hemoglobin subunit beta gene that occurs in chromosome 11. This causes oxygen-carrying red blood cells to be formed in a hardened "sickle" shape. As these cells move through the blood vessels, they often get stuck or clotted, halting blood flow to specific areas of the body

or organs, contributing to SCD pain crises. The affected cells will subsequently die early, leading to a perpetual shortage of functional red blood cells. Patients are typically diagnosed around five months of age and will experience daily pain that differs in frequency and intensity for each patient but can culminate in "pain crises" requiring hospitalization (Johns Hopkins Medicine, 2019). In the United States, there are an estimated 100,000 people living with SCD, making it the most common inheritable blood disorder (Centers for Disease Control and Prevention, 2022). Although SCD can impact people of any race, according to the CDC, 1 in every 365 Black or African American babies is born with SCD, while the next most affected group is 1 in every 16,300 Hispanic American babies (Centers for Disease Control and Prevention, 2022). In the United States, SCD is predominantly present in the Black and African American community by a significant margin.

Compared to the general population, anxiety disorders are three to four times more frequent in adolescents who are chronically ill (Benton, 2009). In adolescents with SCD, many of the same anxiety symptoms are present, with the addition of passive adherence to SCD treatments. Passive adherence refers to patients who do not show interest in improvements to quality of life but are adherent to their medications (Pitaka et. al., 2007). An example of passive adherence would be a patient whose treatment plan includes taking hydroxyurea, the primary daily medicinal treatment for SCD that helps to reduce the frequency of pain crises, but fails to do so consistently. The use of passive adherence as a coping mechanism can lead to negative medical outcomes and poorer health in SCD patients (Simon et.al., 2009).

The effects of pain caused by SCD in an adolescent's day-to-day life are numerous. SCD causes constant minor pain or discomfort in a patient's day to day life as well as severe pain crises that occur most often in the extremities and can last from an hour up to several days. The

most common effects include a higher likelihood of missing school, social, or recreational engagements (Fuggle et.al., 1996). Even with non-crisis pain, it can be difficult for the patient to do more than complete very basic functions of daily living. A common accompanying symptom of SCD pain is exhaustion resulting in difficulty completing day-to-day tasks, and for adolescents, difficulties going to school and socializing with friends (Ameringer et.al., 2014)

Pain acceptance, as it relates to this study, is the process by which one acknowledges having pain but focuses on living a satisfying life despite that pain (McCracken, 1998). With higher pain acceptance, adolescents could live fuller lives with less pain-related anxiety. Currently in SCD research studies conducted on pain acceptance and effect on day-to-day life for adolescents with SCD suggest that with an increase in pain acceptance, quality of life will improve as well (Wright et.al., 2021). However, the current study focuses on the potential effect on the mental health of adolescents suffering from SCD. The aim of this study is to determine if there is a relationship between levels of pain acceptance and anxiety in adolescent SCD patients. I hypothesize that higher levels of pain acceptance will lead to lower levels of anxiety, resulting in a negative correlational relationship.

The current research study will address the integration of mental health and chronic illness in adolescents with SCD. Results from the study may aid in contributions to the field of SCD research by expanding the focus beyond the barriers of the physical body and incorporating the effects of chronic illness on the mind. In particular, those at a high risk for developing mental health concerns include adolescents who are living with SCD and experiencing frequent pain.

Chapter II: Methods

Participants

The current study uses data collected by Aimee Smith, Ph.D. in the writing of her dissertation. The data was collected at Akron Children's Hospital with SCD patients. Participants included 30 adolescents from the ages of 12-18 (M=14.5). The data set included both male (46.7%) and female (53.3%) participants and the participants identified as either African American (85.2%), or biracial (14.8%). The inclusion of adolescent participants, ages 12-18 years old, ensures that the data will not be skewed by outlying ages as the study only concerns adolescent participants. The even distribution of male and female participants provides inclusive data on both groups, allowing for results that are more accurately representative of the target population.

Measures

Pain Acceptance

The *Chronic Pain Acceptance Questionnaire* (CPAQ) was used to assess patient information on pain acceptance (McCracken, 2004). The CPAQ consisted of approximately 20 questions that were used to gain insight into how patients view their pain. Subjects were asked to answer on a scale from zero to six, zero being "never true" and six being "always true". Examples of questions included, "I lead a full life even though I have chronic pain" or "My life is going well, even though I have chronic pain" (McCracken, 2004).

Anxiety

The *Spence Children's Anxiety Scale* (SCAS) was used to assess patient anxiety levels (Spence, 1998). The scale included 45 questions, with responses ranging from never, sometimes, often, to always. Examples of questions included, "I have trouble going to school in the mornings because I feel nervous or afraid" and "I suddenly start to tremble or shake when there is no reason for this" (Spence, 1998).

Data analysis

All analyses were conducted using SPSS v28 (IBM, 2021). Descriptive statistics were collected to provide the mean and frequencies of the data set. A correlation analysis was completed to determine the relationship between the variables and determine if the hypotheses of a negative correlation between pain acceptance and anxiety in adolescents with SCD would be supported.

Chapter III: Results

Descriptive statistics were collected on primary study variables and are displayed in Table 1. The correlation revealed that there is insufficient evidence to conclude a significant linear relationship exists between self-report scores on the SCAS and the CPAQ among adolescents with SCD ($r = .10$, $p = .73$).

Table 1

	N	Minimum	Maximum	Mean	Std. Deviation
Participant Number	31	1.00	38.00	17.1774	10.66501
CPAQ_tot_am	14	.30	4.75	3.0429	1.09945
SCAS_tot_AM	28	.05	1.45	.7557	.33389
Valid N (listwise)	14				

Chapter IV: Discussion

In this study examining the relationship between pain acceptance levels in adolescents with SCD and anxiety, the variables were examined through a bivariate correlation. From the results yielded, there was not a significant statistical relationship between the included variables.

In Table 1, the descriptive and preliminary anxiety and pain acceptance statistics are listed. Participants in the study scored in the normal adolescent range for anxiety and above average in the scores for pain acceptance (Spence, 2021). What this means is that the adolescents anxiety levels were consistent with their agemates, on average, and that they had a more developed pain acceptance than their peers as well.

One potential explanation for these findings is that there may be an additional influence on the factors or the necessity for a change in the data collection process. This may include reviewing and adapting the survey questions to yield more specific results, adjusting one or both variables to gain a different point of view on the issue of adolescent anxiety in chronic illness, or using a different method of data collection to decrease the detrimental effects of the self-report measures. In future studies, it may be beneficial to broaden the scope of the study to include more of the common chronic illnesses that effect the adolescent population. With the expansion of research on this topic into other illnesses there will be a broader view of the issue of adolescent anxiety and how it may have different severity across diagnoses.

Limitations to this study included a small sample size. The influence of an unidentified third variable such as the development of strong coping skills or having already come to terms with the reality of their diagnosis could be present. Unknown contributing factors to participants' anxiety could have potentially impacted results, for example, pain levels on the day of the survey or their level of fatigue when taking the survey. Further research regarding contributors to high levels of anxiety in patients with SCD is needed to determine if additional factors influencing anxiety are present in their daily life.

More knowledge on how chronic illness effects adolescent anxiety can help mental health practitioners as well as physicians to better understand their patients' behaviors and needs. With

this knowledge mental health practitioners will be able to adjust and form treatment plans specifically to target adolescent anxiety that is comorbid to their chronic illness and potentially improve their quality of life. The inclusion of pain acceptance data in these findings means that the treatment plans formed to help patients with SCD-related anxiety, specifically, can use the strengthening of pain acceptance to improve mental health.

Chapter X: Conclusion

In summary, this study examined the relationship between anxiety and pain acceptance levels in adolescents with sickle cell disease. The initial hypothesis theorized that higher levels of pain acceptance would lead to lower levels of anxiety, resulting in a negative correlational relationship. Results from this study indicate that there is not enough evidence to declare a significant relationship between the variables. Further research on the subject is needed to gain insight into each variable such as factors contributing to anxiety and how pain acceptance is affected by a lifelong diagnosis. The implications of this study in raising awareness of comorbid anxiety in chronic illness remain significant, as this could help to improve information on treatment plans used by mental health practitioners and understanding of this specific mental health issue.

References

American Society of Hematology. (n.d.). *Sickle cell disease*. Hematology.org. Retrieved October 1, 2022, from https://www.hematology.org/education/patients/anemia/sickle-cell-disease

Ameringer, S., Elswick, R. K., Jr, & Smith, W. (2014). Fatigue in adolescents and young adults with sickle cell disease: biological and behavioral correlates and health-related quality of life. Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 31(1), 6–17. https://doi.org/10.1177/1043454213514632

Barker, M. M., Beresford, B., Bland, M., & Fraser, L. K. (2019). Prevalence and incidence of anxiety and depression among children, adolescents, and young adults with life-limiting conditions. JAMA Pediatrics, 173(9), 835. https://doi.org/10.1001/jamapediatrics.2019.1712

Benton, T. D., Ifeagwu, J. A., & Smith-Whitley, K. (2009). Anxiety and depression in children and adolescents with sickle cell disease. Current Psychiatry Reports, 9(2), 114–121. https://doi.org/10.1007/s11920-007-0080-0

Centers for Disease Control and Prevention. (2022, May 10). Complications of sickle cell disease. Centers for Disease Control and Prevention. Retrieved December 5, 2022, from https://www.cdc.gov/ncbddd/sicklecell/complications.html#Pain

Centers for Disease Control and Prevention. (2022, May 2). *Data & statistics on Sickle Cell Disease*. Centers for Disease Control and Prevention. Retrieved October 1, 2022, from https://www.cdc.gov/ncbddd/sicklecell/data.html

Fuggle, P., Shand, P. A., Gill, L. J., & Davies, S. C. (1996). Pain, quality of life, and coping in sickle cell disease. *Archives of Disease in Childhood*, *75*(3), 199–203. https://doi.org/10.1136/adc.75.3.199

Garcia, I., & O'Neil, J. (2021). Anxiety in adolescents. *The Journal for Nurse Practitioners*, *17*(1), 49–53. https://doi.org/10.1016/j.nurpra.2020.08.021

IBM Corp. (2020). IBM SPSS Statistics for Windows (Version 27.0) [Computer software]. IBM Corp.

Johns Hopkins Medicine. (2019, November 19). Sickle cell disease. Sickle Cell Disease | Retrieved December 5, 2022, from https://www.hopkinsmedicine.org/health/conditions-and-diseases/sickle-cell-disease

McCracken, L. M. (1998). Learning to live with the pain: Acceptance of Pain predicts adjustment in persons with chronic pain. *Pain*, *74*(1), 21–27. https://doi.org/10.1016/s0304-3959(97)00146-2

McCraken, L. M., Vowles, K. E. & Eccleston, C. (2004). Acceptance of chronic pain: component analysis and a revised assessment method. Pain, 107, 159-166.

Pitkala, K. H., Strandberg, T. E., & Tilvis, R. S. (2007). Interest in healthy lifestyle and adherence to medications: Impact on mortality among elderly cardiovascular patients in the debate study. *Patient Education and Counseling*, *67*(1-2), 44–49. https://doi.org/10.1016/j.pec.2007.01.016

Rockhill, C., Kodish, I., DiBattisto, C., Macias, M., Varley, C., & Ryan, S. (2010). Anxiety disorders in children and adolescents. *Current Problems in Pediatric and Adolescent Health Care*, *40*(4), 66–99. https://doi.org/10.1016/j.cppeds.2010.02.002

Simon, K., Barakat, L. P., Patterson, C. A., & Dampier, C. (2009). Symptoms of depression and anxiety in adolescents with sickle cell disease: The role of intrapersonal characteristics

and stress processing variables. *Child Psychiatry and Human Development*, *40*(2), 317–330. https://doi.org/10.1007/s10578-009-0129-x

Spence, S. H. (1998). A measure of anxiety symptoms among children. Behaviour Research and Therapy, 36(5), 545-566. doi: 10.1016/S0005-7967(98)00034-5

Spence, S. (2021, August 24). *SCAS Translations*. The Spence Children's Anxiety Scale. Retrieved April 19, 2023, from https://www.scaswebsite.com/

Wright, L. A., Cohen, L. L., Gise, J., Shih, S., Sil, S., & Carter. (2021, June 15). Pain and Qol in pediatric sickle cell disease: Buffering by resilience processes. OUP Academic. Retrieved December 7, 2022, from https://academic.oup.com/jpepsy/article/46/8/1015/6299975