QUALITY OF LIFE AND ADOLESCENTS WITH HEMOPHILIA

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ABSTRACT

Hemophilia is an incurable hereditary bleeding disorder due to the absence or deficiency of clotting factors in the blood. This disease was traditionally classified as mild, moderate and severe based on the level of coagulation factors. Oftentimes, Hemophilia causes flexion deformities of the elbows, knees, and hips interfering with the individuals’ daily activities. The aim of this review was to examine the literature which addressed quality of life for adolescents with Hemophilia. A literature search was conducted using CINAHL and EBSCO databases using the keywords “blood disorders and adolescents”. Search refinement with keywords “quality of life and hemophilia and adolescents” and “nursing” resulted in 30 articles. Refinement of the search occurred using keywords “hemophilia and adolescents and quality of life” and include only full text articles that were dated 2014 – 2019. The result was six articles. However, one article was specific for children and eliminated from the review which resulted in five articles.

METHODS

A literature search was conducted using CINAHL and EBSCO host databases using the keywords “blood disorders and adolescents” and resulted in 600 articles. Search refinement with keywords “quality of life and hemophilia and adolescents” and “nursing” resulted in 30 articles. Refinement of the search occurred using keywords “hemophilia and adolescents and quality of life” and include only full text articles that were dated 2014 – 2019. The result was six articles. However, one article was specific for children and eliminated from the review which resulted in five articles.

RESULTS cont.

of life survey was de-identified prior to data collection and analysis of white associated factors. Study participants were 47 adolescents and 13 adults who had been diagnosed and treated for Hemophilia A, B, or from 2014 to 2019. The sample size was 60. There was a significant difference in the quality of life between adolescents and adults. The quality of life was assessed using the Haemophilia Quality of Life (Haemo-QoL) questionnaire. The results of the Friedman test indicated these boys showed a significant difference in the quality of life for a reduction in the mean number of bleeding events (x²=20.44, P<0.001), referrals to the Hemophilia clinic (x²=28.18, P<0.001), and school absences (x²=40.13, P<0.001) throughout the assessment stages. The study concludes, that the males and also that there is a decrease in physical and mental impacts on the adolescents performing yoga, which resulted in the increase of their quality of life (Beheshitipoor et al.).

DISCUSSION

Findings from this review indicate children and adolescents with Hemophilia have increased financial burden due to expensive medical treatment. There was also a physical activity restriction in order not to suffer any injuries, but this also depends on the severity of the disease and the rate of bleeding during bleeding episodes. The findings also revealed engaging in yoga had a positive impact on adolescents with Hemophilia quality of life (Beheshitipoor et al., 2015) Pain management and education also improved effective in managing Hemophilia in adolescents (McLaughlin, et al.). Studies show that there also is an increased prevalence of Hemophilia in male children and adolescents than females. Also, education and support in physical activity and no change in female children and adolescents with the disease (McLaughlin et al., 2017)

REFERENCES


 INTRODUCTION

Bleeding disorders are a group of disorders that have the inability to form blood clots properly. Improper clotting can be caused by defects in blood components such as platelets and/or clotting proteins, also called clotting factors. Hemophilia is a rare group of bleeding disorders resulting from congenital inherited deficiency, dysfunction, or absence of specific coagulation proteins or factors that cause longer healing, may damage organs, muscle tissue, and joints. Hemophilia is transmitted as an X-linked recessive disorder only sixty percent of affected children have a positive family history for the disease. Though one-third of hemophilia cases may be caused by a gene mutation. There are six different types of bleeding disorders, two common forms are Hemophilia A (classic) Factor VIII and Hemophilia B (Christmas disease) Factor IX. This rare bleeding factor prevents the blood from clotting which leads to prolonged bleeding after injury, surgery or physical trauma and can become deadly if not treated correctly. Bleeding disorders lessen the physical health-related quality of life (Beheshitipoor et al.).

RESULTS

Article 1

Owaidah et al. (2018) conducted a epidemiological based survey among adolescents and young adults (1901 [49%] boys, 1980 [51%] girls) regarding bleeding symptoms. Of these, 1849 (47.6% responded “Yes/Positive” for at least one question about the bleeding symptoms. The Most common bleeding symptom was epistaxis (19.7% of the sample population) detected in Phase I of the study. A tandem survey was conducted among 525 adolescents, who responded “Yes/Positive” to any one of the questions in to any one of the questions inquiring about bleeding symptoms. In this study, they reported for the first time the prevalence of bleeding symptoms in a representative sample of Saudi adolescents and young adults (Owaidah et al.).

Article 2

Neuner, et al. (2016) conducted a cross-sectional study comparing the Health-related quality of life (HcQoL) amongst children and adolescents with a Hereditary Bleeding Disorder to that of adolescents with stroke/TIA. Participants were admitted into 6 specialized treatment centers in Germany. The population was initially 354 participants, 37 of which were older than 17 years old (10.5%). Of the remaining 299 study participants 23 did not fill out the revised KINDer Lebensqualitatsfragebogen (KIND-R) questionnaires. The data set consisted of 144 patients who were with HBDS(51.4%) and 70 who were patients who stroke or TIA(48.6%). In conclusion Group 1 showed no differences in self reported HcQoL, between patients with bleeding disorders and peers. While Group 2 showed differences between patients with stroke/TIA and their healthy peers regarding self-worth and friend-related well being (Neuner et al.).

Article 3

McLaughlin et al. (2017) conducted a cross-sectional study among adolescent and young adults with bleeding disorders. The purpose of their study was to investigate the relationships between pain management and quality of life while increasing awareness, knowledge of treatment and living with rare bleeding disorders. An online 36-item Short Form Health Survey (SF-36) approved by Munson Medical Center institutional review board, and IMPACT quality

C O N C L U S I O N

Adolescents with Hemophilia have a decreased quality of life due to physical regression and restrictions which impacts their physical and mental well being. Yoga, pain management and education among children with Hemophilia can improve the quality of life among adolescents and adults with quality of life. Studies were limited to primarily international communities.

FUTURE RESEARCH QUESTIONS GENERATED FROM THE REVIEW

1. What is the difference in quality of life measures for adolescents with or without Hemophilia?
2. What diversionary activities improve the health related quality of life in adolescents with Hemophilia residing in the United States?
3. What factors predict improved quality of life for US adolescents living with Hemophilia?