HEALTH RELATED QUALITY OF LIFE OF PATIENTS WITH SICKLE CELL DISEASE AGED 8-17 YEARS AT KAMUZU CENTRAL HOSPITAL, MALAWI

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Abstract

Background: Sickle cell disease (SCD) is characterized by both acute and chronic complications that affect the daily lives of patients and lower their quality of life. Objective: To describe the health-related quality of life (HRQoL) and the associated factors in children aged 8 to 17 with SCD attending the paediatric haematology clinic at Kamuzu Central Hospital (KCH) in Lilongwe, Malawi. Methods: A mixed methods cross sectional study was conducted at KCH. Patient data was collected with the aid of a standardized case report form. HRQoL was assessed using PedsQL Sickle Cell Disease Module by child's report. Associations between HRQoL scores and independent variables were evaluated by a linear regression model. In-depth interviews were then carried out and the qualitative data was analyzed using content thematic analysis. Results: A hundred and sixty-three children with SCD were enrolled, 52.1% were females. Their median age was 11.2±2.7 years. The mean global HRQoL score of the children was 62±17.3. The highest scores were in the treatment domain (72.5±15.1) while the lowest scores were in the emotions domain (55.2±28.7). The mean pain score was 58.8±16.3. The factors associated with low HRQoL scores were pain (β-coefficient -6.97 CI (-3.07,-15.58); p value 0.034) and low haemoglobin levels (β-coefficient 2.29 CI (0.65-3.91); p value 0.006). Conclusion: The HRQoL of this population is low. Pain and low hemoglobin were significantly associated with low HRQoL scores. A biopsychosocial model of heath care delivery and health campaigns are recommended to improve the HRQoL of the children.

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