QUALITY OF LIFE OF PATIENTS WITH SICKLE CELL DISEASE IN JAMAICA

- VALIDATION OF THE SF-36 AS A MEASURE OF QUALITY OF LIFE IN THIS POPUALTION AND INITIAL RESULTS

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ABSTRACT

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Quality of life assessments are an important aspect of chronic disease management. Sickle cell disease is the commonest genetic disorder seen in Jamaica. No quality of life assessment tool has been validated for use in this population in Jamaica. This study aimed to validate a frequently utilized generic measure of quality of life assessment as well as study predictors of quality of life in patients with sickle cell disease in Jamaica.

A 'cohort' sample (233 participants) and a 'main' clinic sample (256 participants) were administered the SF-36 version 2, WHOQOL-Bref, and Flanagan's QOLS as well as the UCLA Loneliness scales. The SF- 36 showed a completely different factor structure to that developed by its creators in both subgroups. Three factors, accounting for about 46%-56% of the variability in the SF-36 items, were extracted in each sample, and these could be labeled 'physical health', 'mental health' and 'role limitations'. A total SFscore was also calculated from these subscales. The three subscales and the total SFscore all showed good correlations with the WHOQOL-Bref scores and Flanagan's QOLS scores (convergent validity) and weaker correlations with the Loneliness score (discriminant validity).

Multiple regression analyses showed that living in rural areas compared to urban areas (p-value: 0.002), being employed (p-value<0.001), having a tertiary versus a primary education (p-value 0.006), and having SC disease versus SS disease (p-value: 0.001) were all associated with improved quality of life. Even though the physical health scores were the same for the urban and the rural populations, the latter showed less limitation in their daily living activities as a result of their disease. Further work could help elucidate why rural subgroups of people with this disease appear to enjoy much better quality of disease despite limited health care access.

Keywords: quality of life, sickle cell disease, Jamaica, SF 36, rural/urban health, convergent and discriminant validity.