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Development and validation of a quality of life questionnaire for people living with epilepsy in Ghana

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ABSTRACT

Background: A number of epilepsy quality of life (QoL) questionnaires have been developed in Western and European countries which do not necessarily apply to the sociocultural context of countries in other parts of the world. Some countries developed their own questionnaires whilst others adopted and validated existing epilepsy QoL questionnaires to match their sociocultural context. However, no questionnaire was found to accurately assesses the QoL of people living with epilepsy (PLWE) in sub-Saharan African (SSA) countries, including Ghana.

Aim: The aim of this study was to develop and validate a culturally sensitive QoL questionnaire that is best suited for the accurate and consistent assessment of QoL of PLWE in Ghana.

Methodology: The sequential multimethod study design involving nine steps in three phases was employed in this study. Phase one conceptualised the construct of QoL through a scoping and integrative review as well as a qualitative explorative study with PLWE in Ghana. In phase two, the findings from phase one were integrated to generate a pool of items which were used to develop the first and second drafts of the epilepsy QoL questionnaire through consultation with the supervisors and the experts in a nominal group technique, respectively. The content and face validity of the questionnaire were tested in phase three using eight experts and four PLWE.

Findings: A pool of 64 items under 13 domains were generated from the first phase and refined for the first draft questionnaire named the QOLIE-GH and comprising 41 items and 11 domains. After employing the nominal group technique to establish relevance to the sociocultural context of Ghana, an additional 25 items and 2 domains were created. The second draft then had 66 items under 13 domains. Content validity testing led to the elimination of five items, leaving a remainder of 61 items under 13 domains to form the third draft QOLIE-GH with I-CVI ranging from 0.83 to 1. Face validity testing led to no change, and respondents considered all the items to be relevant and easy to understand.

Conclusion: The results from the study showed that the questionnaire is culturally sensitive to PLWE in Ghana, has good content validity appropriate for assessing QoL of PLWE in Ghana. This will help health workers, researchers and policy makers assess the QoL of PLWE and to plan and make informed interventions to promote the QoL and wellbeing of PLWE in Ghana. Future studies should undertake further validation of the QOLIE-GH to make it applicable to countries in SSA.

Key Words: “Epilepsy”, “Quality of Life”, “Questionnaire”, “People Living with Epilepsy”, “Questionnaire Development and Validation”