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REVIEW ARTICLE

Questioners for assessing quality of life in people with epilepsy

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ABSTRACT

It is generally accepted that health-related quality of life (HRQOL) refers to "an evaluation of one's well-being based on consideration of physical, mental, social, and general health status." In this review, we provide information from current studies on the main and most used QOL measures for both adults and children with epilepsy. Measurement of HRQOL aims at capturing such patient centered effects of therapy. Different epilepsy-specific instruments such as QOLIE-89, quality of life in epilepsy inventory (QOLIE-31), QOLIE-10, quality of life in epilepsy inventory for adolescent (QOLIE-AD48), epilepsy surgery inventory (ESI55), side effects and life satisfaction, Liverpool HRQOL Battery, and Washington psychosocial seizure inventory (WPSI) are used to determine QOL. This concludes that there were instruments that should be preferred for future use. The WPSI will be used for the mental and social measures, ESI-55 for surgery, QOL in Epilepsy QOLIE-31 used for adults, Liverpool QOL Batteries used for frequency and intensity of seizure, and QOLIE-AD-48 used for adults.

KEY WORDS: Epilepsy, Health-related quality of life, Quality of life, Seizure

INTRODUCTION

Numerous factors, including a person's financial situation, relationships, housing, leisure time, health, and other factors, determine the quality of their life. Clinicians are worried about health status as a factor in quality of life (QOL), or QOL that is tied to one's health.[1] Health-related QOL (HRQOL) is conceptually understood to be "an evaluation of one's well-being based on consideration of physical, mental, social, and general health status."[2] The contrast between QOL and HRQOL is more important than just an academic exercise.[3] A recent evaluation of HRQOL measures used in clinical trials found that methods commonly failed to distinguish between general QOL and HRQOL. It is obvious that a survey that asks about global QOL without mentioning health specifically would not provide any information on the estimate's health-related component.[4]

Any HRQOL definition should be able to capture patients' subjective perceptions of the health area that we are interested in assessing.[5] As Gill and Feinstein so eloquently put it, "HRQOL is a uniquely personal view expressing the way that individual patients feel about their health state."[6] Reviewing the health-related QOL tools that are available for epilepsy patients and discussing the issues with assessing it throughout treatment for the illness are the objectives.

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METHODS

Different epilepsy-specific questionnaires, as shown in Figure 1, are QOLIE-89, quality of life in epilepsy inventory (QOLIE-31), QOLIE-10, QOLIE-AD48, epilepsy surgery inventory (ESI55), side effects and life satisfaction, Liverpool HRQOL Battery, and Washington psychosocial seizure inventory (WPSI) are used to determine QOL.[7]

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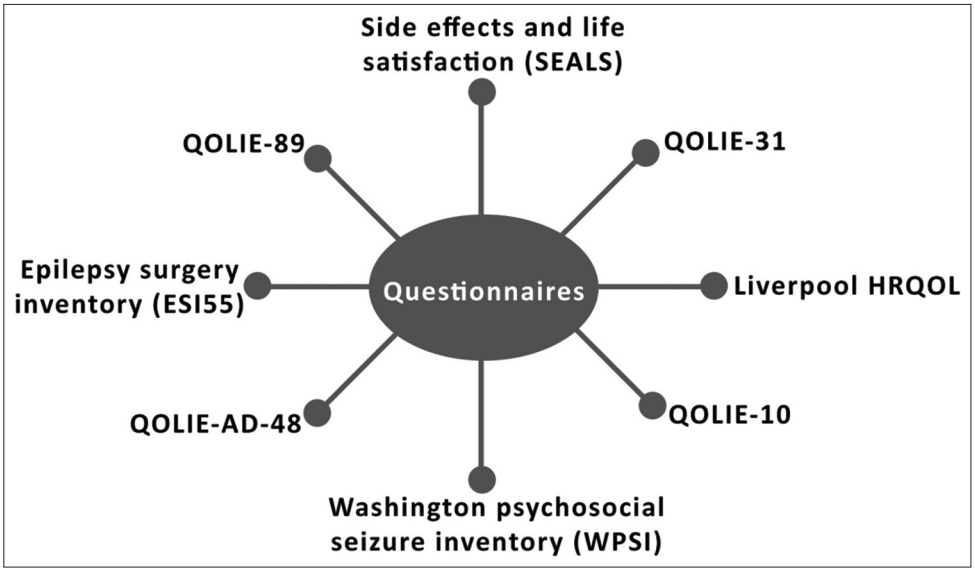

Figure 1: Questionnaires used to determine quality of life in epileptic patients

Frequency and intensity of seizure

For a very long time, seizure frequency has been used to evaluate how well epilepsy therapies are working. Later, it was discovered that not all seizure types had the same consequences on the people who experienced them, particularly in the context of antiepileptic drug trials.[8] Liverpool Seizure Severity Scale used to assess seizures severity.[9,10] A seizure as indications of treatment control is the portion with this supplement that describes both development as well as cumulative experience with their usage.[11]

Liverpool QOL Batteries: Although many QOL difficulties would be pertinent to all PWE, others would be unique to the particular point in the clinical trajectory at which they were positioned, led to the development of the Liverpool batteries.[7] According to their suitability in regard to this and the specific research topic to be addressed, the battery technique allows for the inclusion or deletion of individual domain subscales.[12] For instance, individuals with freshly diagnosed seizures may find it challenging to effectively react to items pertaining to seizure severity because they have had fewer episodes and are unable to recognize patterns of seizure shape or occurrence.[13] Although some subscales, such as the Liverpool Seizure Severity Scale, Liverpool Adverse Events Profile, the Impact scale, and the negative stigma scale, are being employed extensively as well as themselves, the method's negative effects are the fact that this can make it difficult to cross-compare findings.[14]

Mental and social measures

The early discovery that epilepsy causes substantial psychological harm to its sufferers was essential to the development of disease-specific HRQOL tools. This section examines the conceptual development that produced the present understanding of HRQOL. In first attempt, Lennox developed theories on the effects of epilepsy on a patient's life, family, interictal behavior, and career as early as the middle of the 20th century.[15] Twenty years later, Taylor presented a ground-breaking epilepsy paradigm that is still incorporated into HRQOL models today. It makes a distinction between the disorder's biological expression, the illness's experience, and the situation (its effect on psychosocial status). The conceptual underpinning for the subjective perception and impact of epilepsy in contemporary HRQOL tests is provided by Taylor's "disease" and "predicament."[16] For three decades, disparate psychological and functional tools were applied in a rather haphazard manner, focusing on particular aspects of epilepsy such as driving, returning to work, affective status, cognitive function, and personality profiles, without attempting a comprehensive assessment of HRQOL. The 132-item of self-administered WPSI was established by Dodrill which the first comprehensive psychosocial evaluation specifically for epilepsy patients in 1980.[17] The WPSI has 132 items spread over eight scales, including family history, emotional, interpersonal, and occupational adjustment, financial situation, seizure adjustment, medical treatment, and overall functioning.[18,19] For use with teenagers, there is a 139-item version. There is evidence that the WPSI has strong internal consistency, test-retest reliability, and is sensitive to modification. It also has content and constructs validity. Although WPSI was widely utilized, its popularity may have decreased recently as other rival metrics have grown more well-liked. The WPSI has a limited scope, it might not be able to differentiate between individuals with severe and moderate epilepsy, and it might overlook subtle but substantial changes brought on

by medication.[20-22] However, this method made cross-cultural research easier and paved the way for accurate HRQOL models for epilepsy.

The comparison of one's actual state with one's ideal state that the serious epileptic patients were tasked to score their own HRQOL in relation to that of others, assess the importance of each issue, and list their own personal priorities in each category of health-related quality. The distinction between the desired and desired health condition was, therefore, profiled, or its validity, reliability, and responsiveness all appear to be sufficient. Despite the measure's small history, it demonstrates that the disparity between self-status and esteem is a strong predictive predictor of psychosocial well-being.[23,24]

Health-related QOL in epilepsy

Due to the importance of assessing patients' centered health status and well-being in epileptic seizures, there exists an expanding body of research on the issue since 1990, in addition to the development of health-related QOL instruments tailored to people with epilepsy. In addition to general HRQOL measurements like the sickness impact profile, Nottingham health profile, and short form-36 (SF36), clinicians now have access to a variety of epilepsy-specific HRQOL measures such the closely related QOLIE-89 and ESI-55, as well as Liverpool Scales.[9,24,25] Since they focus on a particular condition, patient, symptom, demography, or function, these tools may be more changeable than broad ones. As a result, the comprehensiveness can be diminished and it might be more challenging to assess various situations or programs.[12,26] For example, movement and pain, which are frequently assessed using general tools, are less important to epilepsy patients. On the other hand, epilepsy-specific tests are used to determine the stigma or cognitive function, both of which are crucial in this condition.[27,28] Combining broad and specific tools typically results in a good medium ground. The QOLIE-89 (and its condensed counterparts, the QOLIE-31 and QOLIE-10), and ESI55, closely similar sets of epilepsy-specific instruments, do this by introducing epilepsy-specific components to the SF-36, a popular general instrument. This is accomplished utilizing a set of several independent generic and epilepsy-specific scores in the Liverpool HRQOL model.[29]

The QOLIE-89 evaluates 86 factors over 17 scales and 3 single items to evaluate the QOL of individuals with low- to moderate-risk epilepsy or a seizure. The quality of life in epilepsy inventory for adolescent (QOLIE-AD-48) assesses the QOL of adolescents and adults with well-controlled epilepsy or low-to-moderate seizure frequency. It asks questions on the impact of epilepsy on physical functioning, mental and social functioning, stigma, school behavior, attitude toward epilepsy, and health views.[30] When assessing the QOL of adults and people with low- to moderate-risk epilepsy or seizures, the QOLIE-31 considers seizure fear, general QOL, emotional wellness, energy/fatigue, cognitive, pharmaceutical impact, and social function. Their Cronbach's alpha ranges from 0.78 to 0.92, indicating strength. Excellent construct validity can be employed in people who do not merely have persistent epilepsy, and the flaw is studies on its validity have shown conflicting results, such as the fact that self-reported neuropsychological functioning does not correspond well with neuropsychological measurements.[31]

ESI-55 is a 55-item assessment that uses the SF-36 as a framework and includes 19 additional questions that examine memory, mental abilities, and views of one's own health that are unique to people with epilepsy. Each subscale consists of two to ten items, with the past 4 weeks encompassed as the recommendation period. For the SF-36 base measure, each subscale score is converted into a score from 0 and 100, with higher scores denoting better functions.[32] In validating tests, that ESI-55 proved to have excellent internal coherence, powerful discriminated reliability, and solid content, but also some issues with ceiling effects. The scale's responsiveness to change has been validated by subsequent investigations, although it has been emphasized that this was mostly due to changes in the general subscale (i.e., SF-36) scores rather than those that are disease-specific.[33]

CONCLUSION

This review concludes that there were instruments that should be preferred for future use. The WPSI will be used for the mental and social measures, ESI-55 for surgery, QOL in Epilepsy QOLIE-31 used for adults, Liverpool QOL Batteries used for frequency and intensity of seizure, and QOLIE-AD-48 for adults.

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AUTHORS CONTRIBUTIONS

Dr. Amit Sharma and Mr. Hardik Kumar collected data in ongoing study and writing the manuscript, data analysis. Dr. Amit Sharma and Mr. Hardik Kumar are major contributor in writing, drafting, and referencing the manuscript. Dr. Amit Sharma and Mr. Hardik Kumar are major contributor in writing and drafting the manuscript as well as all authors read and approved the final manuscript.

CONFLICTS OF INTEREST STATEMENT

The authors have declared that no competing interests exist.

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