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Responsiveness of Quality of Life Instruments

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Abstract

Quality of life (QoL) is a phrase that is intuitively meaningful. As a concept it distinguishes between the mere duration of life and a life that is in some sense 'worthwhile'. QoL measurement is thought to be important in the assessment of chronic health conditions and their treatment. It is difficult to create an operational definition of QoL that takes into account different concepts of QoL as well as the heterogeneity of subjects and diseases. Responsiveness is one aspect of instruments which measure QoL. A responsive instrument captures the change in QoL in response to interventions which change underlying health conditions. Internal responsiveness, measured by a variety of standardised mean changes, reflects change in a QoL instrument score measured on subjects who 'should have' changed. External responsiveness relates change in a QoL instrument score to a change in external criteria. Methods of determining external responsiveness include receiver operating characteristic curves, correlation and simple regression. Simple linear regression can be extended using linear mixed models which can estimate parameters either by maximum likelihood or by Markov Chain Monte Carlo methods. This thesis critically examines methods of assessing responsiveness and demonstrates the methodology, including the extension to linear mixed models. The data set used for illustration is based on a study of subjects with rheumatoid arthritis who are assessed before and after a period of inpatient hospital treatment for their condition. Three new QoL instruments, the EuroQol, the Quality of Life Profile and the WHOQoL-Bref were found to be moderately responsive. However the available methodology and the extensions described in this thesis were unable to find any difference in responsiveness. Reasons for this could include that QoL instruments are relatively blunt instruments for the detection of change. The external criteria for change used may not have been ideal. The reasons for a choice of instrument for QoL assessment may be better related to ease of completion, interpretation and analysis, than on sophisticated assessment of responsiveness.
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