

Title: The impact of rare diseases on health related quality of life

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Abstract:

BackgroundOver 80% of Rare Diseases (RDs) are genetic and appear early in life, resulting in a 30% mortality in children diagnosed before their fifth birthday. RDs are chronic and result in a decreased Quality of life (QOL)
MethodsA self-administered Health Related QOL Assessment tool was created, validated by seven experts, and published online. Different patient groups in EU countries and the USA were contacted to invite their members to participate
ResultsTwo hundred responses given by RD patients were statistically analysed. Results revealed USA based patients face a larger accessibility and financial burden than EU RD patients ($P < 0.05$). There is a significant quality of life difference between EU and US RD patients ($P < 0.05$) as the Europeans reported having a better QOL and access to health services. More than 60% of the participants reported anxiety and stress as a result of their RD
ConclusionStrong correlation was established between Accessibility and Quality of life in RDs. Accessibility of ODs depended on pricing, re-imburement policies and product availability. There is a need for improvement in the quality of life of RD patients given the high cost of illness, mental health problems and poor accessibility