



POSTER PRESENTATION

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# The self versus proxy report conundrum in juvenile idiopathic arthritis: implications for a cost-effectiveness analysis of integrated podiatry care

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## Background

JIA is associated with impaired health-related quality of life (HRQoL). Proxy reporting of health outcomes such as HRQoL is often required in the paediatric setting. However there is uncertainty regarding whether self- or proxy-reported HRQoL should be used in health economic analyses, as perceptions of well-being may differ between parent and child. The aim of this study was to estimate levels of agreement and association between self- and proxy-reported HRQoL in JIA.

## Methods

The EQ5D is a generic measure of HRQoL commonly used in economic evaluations. It has 2 components; 1) EQ5D profile comprises of 5 domains; mobility, self-care, usual activities, pain, and anxiety (scored as severe, moderate, or no problems); and 2) a 100mm visual-analogue-scale (VAS). EQ5D profiles were used to calculate a weighted utility index (worst health = -0.59, best health = 1) based on a tariff derived from a UK population sample. The EQ5D was self- and proxy-completed independently by JIA patient-parent/guardian pairs in the paediatric rheumatology multi-disciplinary foot clinic (n=40). Agreement for the EQ5D profile items was estimated using Cohen's linear-weighted kappa ( $\kappa_w$ ) (>0.4=moderate agreement) and 95% confidence intervals. Agreement for the utility

index and VAS was estimated using the intraclass correlation coefficient (ICC) ( $\geq 0.4-0.75$ =fair to good agreement) with 95% confidence intervals. Consistency was estimated using Kendall's Tau ( $\tau$ ) and Pearson's correlation coefficient ( $r$ ) ( $\geq 0.4-0.6$ =moderate-strong consistency).

## Results

Self- versus proxy- agreement was moderate for self-care ( $\kappa_w=0.44$ ) and usual activities ( $\kappa_w=0.44$ ), but less than moderate for mobility ( $\kappa_w=0.29$ ), pain ( $\kappa_w=0.29$ ), and anxiety ( $\kappa_w=0.20$ ). There was good agreement for EQ5D VAS (ICC=0.59), but poor agreement for the utility index (ICC=0.23). The consistency of HRQoL reporting was moderate for self-care ( $\tau=0.47$ ) and usual activities ( $\tau=0.44$ ), but weak for mobility ( $\tau=0.31$ ), pain ( $\tau=0.33$ ), and anxiety ( $\tau=0.23$ ). Consistency was good for EQ5D VAS ( $r=0.59$ ) but weak for utility index ( $\tau=0.28$ ).

## Conclusions

The levels of agreement and association between patients with JIA and parent-proxies are at best moderate for all EQ5D measures. This has important implications for cost-utility analyses using QALYs derived from the EQ5D utility index. Further research is required to determine feasibility of using self- and proxy reported outcomes in cost-effectiveness analyses of podiatric interventions.

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