

Quality of Life in Jordanian Children with Cystic Fibrosis as Perceived by Children themselves and their Parents

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Background: Children with cystic fibrosis facing health challenges and negatively affects on their health related quality of life. The management of cystic fibrosis should be carried out on a daily basis, which requires parental monitoring.

Objective: This study assessed the quality of life of Jordanian children with cystic fibrosis as perceived by them and their parents.

Methods: A cross-sectional design was conducted on 200 children with cystic fibrosis aged 6 to 13 years and their parents. The Arabic Cystic Fibrosis Questionnaire Revised (Cystic Fibrosis Questionnaire–Child version (CFQ-Child) and Cystic Fibrosis Questionnaire–Parent version (CFQ-Parent) was used to collect the data from participants who attended a pediatric hospital in northern Jordan between December 2012 and March 2013. Multivariate analysis and Pearson's correlation coefficient were performed to assess children's quality of life.

Results: The total domains mean of the CFQ–Child and CFQ-Parent were 58.1 (SD = 16.3) and 50.6 (SD = 19.0) respectively. Males and children aged 6-11 years had better quality of life digest ($p = 0.011$), emotional ($p = 0.005$), social ($p = 0.007$), body image ($p = 0.005$) domains.

Parents with higher educational level and employed were more likely to perceive that their children had better quality of life. CFQ–Child domains and CFQ-Parent domains were not significantly correlated.

Conclusions: Quality of life of children with cystic fibrosis was poor as perceived by themselves and as perceived by their parents. CFQ–Child domains CFQ and parent domains were not significantly correlated.

Key words: Children, Cystic fibrosis, parents, quality of life.