

## 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.