

# **JDM Significantly Affects Quality of Life**

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Unfortunately, very little psychological research has been conducted to evaluate the impact of JDM on families. In order to best support families and children affected by JDM, research should be conducted to assess the family impact of JDM, the level of distress consequently experienced by the child's caregiver, and the most common or helpful sources of coping (i.e. religion, friends, family, etc.). This study seeks to identify the quality of life of children with JDM and the psychosocial family impact of JDM.

Participants were recruited from the 2012 CureJM conference along with multiple online support groups worldwide. The study sample consisted of 34 parents of children aged 4-19 with JDM. Participants completed two quality of life measures. Pearson correlations examined the relationship between physical health scores, psychosocial health score, total quality of life scores for the child, parent health-related quality of life scores, family functioning scores, and total family impact scores.

For the purpose of this study, quality of life refers to an individual's perceived satisfaction with their life. Health-related quality of life includes aspects of life that can influence an individual's health. This encompasses both mental and physical facets of an individual's life, including socioeconomic status, social support, medical health status, etc. Family impact refers to various aspects of the family's life, including physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities, and family relationships, that can be directly influenced by caring for a child with JDM.

Data analyses showed significant correlations between every variable. Results revealed that the family impact total score was most associated with the parent's health-related quality of life. Results also showed that the family impact total score was significantly correlated with family functioning, the child's psychosocial health, the child's quality of life total score, and the child's physical health (in order of most strongest to least strongest correlation). Analyses additionally demonstrated that the parent's health-related quality of life (HRQL) was correlated with the child's psychosocial health, with family functioning, with the child's quality of life, and with the child's physical health (in order of most strongest to least strongest). Lastly, results showed that the child's physical health was associated with the child's quality of life, with the child's psychosocial health, with the child's overall quality of life, family functioning, and the child's psychosocial health (in order of most strongest to least strongest correlation). Interestingly enough, the strongest correlation was found between the child's psychosocial health and overall quality of life. These results are remarkable, as they suggest that a child's psychosocial health is just as influential, if not more influential, than the child's physical health when considering the child's overall quality of life.

In conclusion, these results suggest that JDM significantly influences the child's quality of life, the parent's health-related quality of life, along with the family's overall functioning. This study supports the need for additional psychosocial support programs for both pediatric patients and their parents in order to help connect with individuals and families who have other chronic illness, as they also experience quality of life and family impact difficulties.

Want to know more? These results are a small sample of the total results from the described study. Stay tuned for additional data analyses.