



Health-Related Quality of Life Assessment in Juvenile Idiopathic Arthritis

Thesis

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By

Mahmoud Ramadan Hassan

Master Degree in Paediatrics, Faculty of Medicine, Ain Shams University

Under the Supervision of

Prof. Elham Mohammad Hossny

Professor of Pediatrics

*Head of the Pediatric Allergy and Immunology Unit
Children's Hospital, Ain Shams University*

Dr. Amira Fouad El-Hattab

Lecturer of Pediatrics

*Pediatric Allergy and Immunology Unit, Children's Hospital,
Ain Shams University*

Dr. Batoul Mohamed Abdel Raouf

Lecturer of Pediatrics

*Pediatric Psychiatry Unit, Children's Hospital,
Ain Shams University*

*Faculty of Medicine
Ain Shams University*

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

قَالَ

سُبْحَانَكَ لَا عِلْمَ لَنَا
إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ
الْعَلِيمُ الْعَظِيمُ

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List of Abbreviations

Abb.	Full term
<i>ALPS</i>	<i>Autoimmune lymphoproliferative syndrome</i>
<i>CAHP</i>	<i>Childhood Arthritis Health Profile</i>
<i>CALI</i>	<i>Child Activity Limitations Interview</i>
<i>CHAIMS</i>	<i>Childhood Arthritis Impact Measurement Scales</i>
<i>CHAQ</i>	<i>Childhood Health Assessment Questionnaire</i>
<i>CHIP</i>	<i>Child Health and Illness Profile chip</i>
<i>CHQ</i>	<i>Child Health Questionnaire</i>
<i>CMAS</i>	<i>Childhood Myositis Assessment Scale</i>
<i>CYP</i>	<i>Children and young people</i>
<i>DACH</i>	<i>Division of Adult and Community Health</i>
<i>EuroQOL</i>	<i>EQ5D</i>
<i>FSM</i>	<i>Functional Status Measure</i>
<i>HCFA</i>	<i>Health Care Financing Administration</i>
<i>HEDIS</i>	<i>Health Plan Employer Data and Information Set</i>
<i>HLH</i>	<i>Hemophagocytic lympho histocytosis</i>
<i>HRQOL</i>	<i>Healthy related quality of life</i>
<i>IBD</i>	<i>Inflammatory bowel disease</i>
<i>ILAR</i>	<i>International League of Associations for Rheumatology</i>
<i>ISOQOL</i>	<i>International Society for Quality of Life Research</i>
<i>JAFAR</i>	<i>Juvenile Arthritis Functional Assessment Report</i>
<i>JAFAS</i>	<i>Juvenile Arthritis Functional Assessment Scale</i>
<i>JAFI</i>	<i>Juvenile Arthritis Foot disability Index</i>

List of Abbreviations cont...

Abb.	Full term
<i>JAFS</i>	<i>Juvenile Arthritis Functionality Scale</i>
<i>JAQQ</i>	<i>Juvenile Arthritis Quality of Life Questionnaire</i>
<i>JASI</i>	<i>Juvenile Arthritis Functional Status Index</i>
<i>JIA</i>	<i>Juvenile idiopathic arthritis</i>
<i>MCS</i>	<i>Mental Component Summary</i>
<i>MTX</i>	<i>methotrexate</i>
<i>NCCDPHP</i>	<i>National Center for Chronic Disease Prevention and Health Promotion</i>
<i>NSAIDs</i>	<i>Non steroidal anti inflammatory drugs</i>
<i>PCS</i>	<i>Physical Component Summary</i>
<i>PedsQL</i>	<i>Pediatric QOL Inventory generic and rheumatology module</i>
<i>SF-20</i>	<i>Short-Form General Health Survey SF-36 and Short Form-20</i>
<i>SMILEY</i> ®.....	<i>Simple Measure of Impact of Lupus Erythematosus in Youngsters</i> ®
<i>TACQOL</i>	<i>TNO AZL Children's Quality of Life questionnaire</i>

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INTRODUCTION AND AIM OF THE WORK

Juvenile idiopathic arthritis (JIA) is a type of arthritis that causes joint inflammation and stiffness for more than six weeks in a child aged 16 years or younger (*Akioka, 2016; Giannini, 1997*).

JIA is classified into seven categories; systemic-onset type, persistent and extended oligoarthritis, polyarthritis with rheumatoid factor negative, polyarthritis with rheumatoid factor positive, psoriatic arthritis, enthesitis-related arthritis and undifferentiated arthritis (*Akioka, 2016*).

Joints are typically affected in symmetrical pattern. The distribution of joint affection includes small joints, which are involved most often, and larger joints that may become involved later in the disease (*Guillemin, 2000*).

Children and adolescents with juvenile idiopathic arthritis deserve special attention because juvenile idiopathic arthritis affects not only the individuals with the disease, but also their caregivers, thereby altering the family routine and the quality of life of all involved family members (*Stelmach et al., 2012*). Thus, it is necessary to characterize quality of life in children and adolescents with juvenile idiopathic arthritis. The understanding of the extent to which juvenile idiopathic arthritis can affect quality of life will help establish therapeutic,

environmental, and behavioral strategies, resulting in increased awareness within the health care system, so that interventions allowing a favorable disease outcome are promoted (*Bugatti et al., 2018*).

Quality of life is defined as the perception that individuals have of their position in life, in the context of the culture and system of values in which they live and in relation to their objectives, expectations, standards, and concerns. Quality of life can change according to the environment and the experiences, as well as in response to certain diseases (*puchner et al., 2015*).

Pediatric Quality of life inventory version (pedsQL Generic Core Scale) Child – Report the PedsQL has 23 items and covers Physical, emotional, social, and school functioning and wellbeing (*Varni et al., 2001*).

We sought to assess the health-related quality of life of a group of children with juvenile idiopathic arthritis. The ultimate objective is to alleviate morbidity in these children and help them lead a normal life.

HEALTH RELATED QUALITY OF LIFE (HRQOL)

"Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity (*Parrish, 2010*).

Well-being

Well-being is a positive outcome that is meaningful for people and for many sectors of society, because it tells us that people perceive that their lives are going well. Good living conditions (e.g., housing, employment) are fundamental to well-being. Tracking these conditions is important for public policy. However, many indicators that measure living conditions fail to measure what people think and feel about their lives, such as the quality of their relationships, their positive emotions and resilience, the realization of their potential, or their overall satisfaction with life. (*Diener et al., 2006*).

Well-being generally includes global judgments of life satisfaction and feelings ranging from depression to joy (*Diener et al., 2006*).

Well-being integrates mental health (mind) and physical health (body) resulting in more holistic approaches to disease prevention and health promotion

Well-being is a valid population outcome measure beyond morbidity, mortality and economic status that tells us how people perceive their life is going from their own perspective (*Diener et al., 2006*).

Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life (*Bhagat et al., 2014*). What makes it challenging to measure is that, although the term "quality of life" has meaning for nearly everyone and every academic discipline, individuals and groups can define it differently. QOL is now increasingly being recognized as an end point, perhaps in importance with survival. There is often a compromise between disability and survival, and it is this compromise which justifies the assessment of HRQOL in the evaluation of healthcare, and perceived QOL reflects the size of gap that the individuals see between their actual situation and that to which they aspire (*Sharma, 2004*).

HRQOL was adapted from the more general and wide – ranging concept QOL. Because this is such a broad concept, there is no universally accepted definition for QOL. In this study we adopted the WHO definition of multidimensional concept of QOL; an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological

state, level of independence, social relationships and their relationships to salient features of the environment (*WHOQOL, 2004*).

Due to the multidimensionality of the concept, it is not practical (or perhaps not possible) to assess all that is meant by QOL simultaneously. Therefore, a more limited and focused assessment should be undertaken. With regard to chronic illness, QOL should be determined by health parameters, and not by more general parameters such as economic status or environment since these are often distant from health or medical concerns (*McGee, 2004*).

Although health is one of the important domains of overall quality of life, there are other domains as well for instance, jobs, housing, schools, the neighborhood. Aspects of culture, values, and spirituality are also key aspects of overall quality of life that add to the complexity of its measurement. Nevertheless, researchers have developed useful techniques that have helped to conceptualize and measure these multiple domains and how they to each other (*Mollaoglu, 2013*).

The concept of health-related quality of life (HRQOL) and its determinants have evolved since the 1980s to encompass those aspects of overall quality of life that can be clearly shown to affect health either physical or mental (*Selim et al., 2009*).