



**FUNCTIONAL DISABILITY AND HEALTH RELATED QUALITY
OF LIFE AMONG JUVENILE IDIOPATHIC ARTHRITIS
PATIENTS ATTENDING THE PEDIATRIC RHEUMATOLOGY
CLINIC AT TIKUR ANBESSA SPECIALIZED HOSPITAL, A
PROSPECTIVE STUDY**

A RESEARCH PROJECT TO BE SUBMITTED TO ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, PEDIATRICS AND CHILD HEALTH DEPARTMENT IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE SPECIALTY CERTIFICATE PROGRAM IN PEDIATRICS AND CHILD HEALTH.

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I, the undersigned Pediatric and Child Health Resident, declare that I have submitted my original work titled " The assessment of health related quality of life and associated factors in children with juvenile idiopathic arthritis attending Tikur Anbresa Specialized Hospital pediatrics rheumatologic clinic" in Addis Ababa, Ethiopia in partial fulfillment of the requirement for the specialty certificate program in pediatrics and child health.

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ACRONYMS AND ABBREVIATIONS

JIA_____Juvenile idiopathic arthritis

ILAR_____International League of Associations for Rheumatology

RF _____Rheumatoid Factor

PRINTO_____Pediatric Rheumatology International Trials Organization

ANA _____Antinuclear Antibody

HRQOL_____Health Related Quality Of Life

JADAS_____Juvenile Arthritis Disease Activity Score

CHAQ_____Childhood Health Assessment Questionnaire

PedsQL_____Paediatric Quality of Life Inventory

JAQQ_____Juvenile Arthritis Quality Of Life Questionnaire

TASH_____Tikur Anbessa Specialized Hospital

WHO_____World Health Organization

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Abstract

Back ground: Juvenile idiopathic arthritis (JIA) is an idiopathic inflammatory arthritis which includes different types of chronic arthritis and also extra-articular structures. It has a wide presentation and different clinical subtypes. It is a long standing disease associated with many complications including permanent damage to joints with or without joint destruction, interference with bones and growth resulting in disability and loss of function which in turn results in problem in functional ability and health related quality of life of the child.

Methods: 57 JIA patients were included in cross-sectional study at Tikur Anbessa Specialized Hospital (TASH), department of pediatrics and child health pediatrics rheumatology follow-up clinic from September 1- December 30, 2024. A standard questionnaire were used to collect the datas, questionnaire of Paediatric Quality of Life Inventory (PedsQL) and the Childhood Health Assessment Questionnaire (CHAQ) to assess the health related quality of life and functional status of the patient respectively. The collected data using SPSS statistics (25) were checked, organized and analyzed. Descriptive statistics were used for presenting summary data using tables and graphs. Independent variables and outcomes were checked using mean score comparison test. Statistical significance was declared at a p-value of <0.05.

Result: The CHAQ disability index (DI) of the studied patients rang from 0-3 and a mean of 0.82 ± 0.94 (SD). Indicating that, the overall disability index is good. CHAQ (VAS) and (Overall wellbeing) of JIA patients rang from 0 to 9 and a mean of 3.79 ± 2.64 (SD) plus 5.09 ± 2.76 respectively. The overall mean of the total scores of both the parental and child proxy shows that there is an optimal HRQOL 404.53 ± 110.94 and 387.65 ± 145.65 respectively.

Conclusion: The study having small sample size and being single hospital based is a limitation. Male patients, psoriatic subtype and those >10years of illness duration were found to have a lower functional status. The overall mean of the total scores of both the parental and child proxy shows that there is an optimal health related quality of life.

Key words: HRQOL, CHAQ, JIA

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1. Introduction

1.1. Background

Juvenile idiopathic arthritis (JIA) is a heterogeneous group of idiopathic inflammatory arthritis that includes different types of chronic arthritis and also extra-articular structures like eyes, skin, and internal organs. It is defined as idiopathic arthritis that affects those younger than 16 years old and persists for six weeks or more. It is also the most prevalent pediatric rheumatologic disorder having a high association with disability and even mortality.(1, 2)

The clinical presentation and disease course of JIA is very wide and unpredictable. It ranges from a mild self-limiting disease to a persistent disease with joint destruction. It generally presents with widespread of inflammatory joint disease like soft tissue swelling, joint effusion, synovitis with bone edema and erosion and in some patients having a significant systemic manifestations like fever, rash and other constitutional symptoms.(1)

Due to the various presentation of JIA the International League of Associations for Rheumatology (ILAR) divides it into different subgroups based on different factors. These subgroups include oligoarticular (persistent or extended), polyarticular (RF-negative or RF-positive), systemic (sJIA), psoriatic arthritis and enthesitis-related arthritis. Those that does not fit into these divisions or fall into more than one division are considered as undifferentiated(3).

The ILAR classification was revised again in 2019 by the Pediatric Rheumatology International Trials Organization (PRINTO) Consensus. This consensus changed the age of onset to before 18 year of age it also defines JIA as a compile of different disorders and it proposes to identify this complex of features as early onset Antinuclear Antibody(ANA) positive JIA, sJIA, RF-positive JIA and enthesitis/spondylitis-related JIA. Those that persists for more than 6weeks without fulfilling the criteria are labled as ‘other JIA’ and those who falls into more than one criteria labled as ‘unclassified JIA’.(4)

As mentioned above since JIA is a long standing chronic inflammatory disease it is accompanied with many complications including permanent damage to joints with or without joint destruction, interference with bones and growth causing stunted growth, disability and loss of function. It also causes long standing chronic pain with vision problems and anemia(5). But this chronic complications and over all clinical outcome of JIA has improved with the significant advancement of the management especially with the creation of biological treatment agents resulting in disease control and possible remission in most patients. The mortality rate of JIA was reduced by the administration of biological agents from 1 to 4% in the 1970s to 0.3–1% in 2016.(6)

Even with the advancement of JIA treatments a large number of people have an ongoing persistent disease activity leading to complications and requiring active treatment into adulthood from which approximately 30% of them aquire some kind of disability(7). The presence of this ongoing disease process and the fact that they are prone to many complications makes JIA to influence in different

aspects of the child's life and their family's life too. Therefore it is important to focus on improvement of health related quality of life (HRQOL) as a key treatment goal(8).

HRQOL is the term used to describe how a person feels about a particular element of their life in relation to their health or state of health. It contains at least of the physical, mental, and social aspects that the World health organization (WHO) first identified in 1948.(9) As mentioned above HRQOL is highly dependent on the JIA disease activity which is assessed in various measures. The Juvenile Arthritis Disease Activity Score (JADAS), Juvenile Arthritis Functional Assessment Scale, and Juvenile Arthritis Functional Assessment Report are just a few of the several tools that have been developed to measure JIA disease activity. Additionally, evaluations of physical, social, and mental functioning were intended to be incorporated into health assessments through the development of the Paediatric Quality of Life Inventory (PedsQL) and the Childhood Health Assessment Questionnaire (CHAQ), which are most widely used in routine practice(10, 11)

The PedsQL is an instrument for measuring health-related quality of life (HRQOL) in those ages 2 to 18. It has a child self-report and parental proxy-report scales multidimensional questions developed as the generic core to assess the PedsQL.(12, 13) CHAQ is also a disease specific questionnaires that measures functional ability of the children in their daily living routine activities.(14)

Several studies has adapted and used this measurement instruments to determine the HRQOL in patients with JIA. Even though JIA is a prevalent disease in Ethiopia it is not well studied and the patients quality of life are not addressed.(15) Therefore this study will be conducted to assess the health related quality of life of JIA patients on follow up at Black lion hospital pediatrics rheumatology clinic.

1.2. Statement of the problem

Juvenile Idiopathic Arthritis (JIA) is one of the most prevalent chronic rheumatologic disorders in pediatrics that manifests in children who are less than 16 years. It has several presentations ranging from single joint arthritis to wide systemic manifestations. It can also causes severe impairment and disability in some cases. The extent of the severity and cause of impairment with disability depends on the patients socioeconomic status, the disease severity is worsening because of the delay to access health care, rheumatologist treatment to be specific, which this in turn leads to directly affect their over all well-being and their lifequality.(16)

Even with advanced treatments, JIA has an on and off type of presentation with periods of exacerbation and remission. A few children may have symptoms only for a months due to a good response to treatment but others may have a progressive disease with chronic functional impairment and disability. This undulant characteristic of the disease has a great influence on both the children and their family life quality.(17)

In Ethiopia despite the importance of assessing a patient for the quality of life and treating accordingly, there are no studies found focusing on a JIA patient's HRQOL. Therefore, this research aims to study HRQOL of JIA patients on follow up at Black lion hospital pediatrics rheumatology clinic.

1.3. Significance of the study

The finding of this study will be used as important input for concerned bodies to strengthen the assessment of health related quality of life of JIA patients and advance the management. First, this study will provide important information for different stakeholders addressing the issues of JIA and its association with health related quality of life. Second, the findings from this study gives information for policy makers to develop strong strategy on management of JIA according to the patients' life quality. The study will show the functionality and health related quality of life of patients and give incite on follow up and on management and follow up improvement. Finally, the study serve as benchmark for other studies in this area.

2. Literature Review

2.1. Health related quality of life in children with juvenile idiopathic arthritis

Juvenile idiopathic arthritis (JIA) is a prevalent chronic illness in children with 1.6 to 23 new cases per 100,000 adolescents annually.(18) But the prevalence of JIA varies from one region to the other because of absence of uniform categorization and difference in disease frequencies at different areas.(10) As mentioned above this highly prevalent disease has a progressive pattern with disabling features in the affected patients causing a significant influence in all aspects of both the child's and their family's life. Therefore, the treatment goal in JIA is not only to decrease the disease progression and activity leading to achievement of clinical remission but also to minimize the side effects of the medications with encouragement of optimal physical activity and reach to a quality of life comparable to their healthy peers with maintaining that status. Therefore, researchers have increasingly recognized health-related quality of life as a major significant treatment goal.(19, 20)

A cohort study was done in multinational level at the international organization of pediatrics rheumatology and the CHAQ assessment of HRQOL of JIA patients showed a significant lower mean and standard deviation on the physical and psychosocial domain in those with JIA than healthy children, concluding that patients with JIA has a significant suboptimal HRQOL in relation to healthy children especially on physical summary.(21)

A study conducted in United States, Cincinnati children's Hospital, including 524 patients resulting 20.6% of them having a suboptimal HRQOL with PedsQL score and suggested that a majority of patients with JIA whether they have clinical symptoms or not they experience suboptimal HRQOL.(8)

In addition, there are also several studies conducted on HRQOL of JIA patients in Europe from which a study done in Norway, Oslo university, on disease progression of JIA into adulthood suggested that there were an active disease progression on 41% of the patients and 28% of them had a high symptom state and noted the low quality of life through adulthood.(20) Plus a study conducted in patients who consulted pediatrics rheumatologist in Amsterdam, Netherlands indicated that both children (6-12years) and adolescents (13-18years) has a significant suboptimal HRQOL in most of the studied domains in relative to controlled groups.(22)

A Germany study also indicated that there is statistically significant problem, low HRQOL, the highest differences is on the pain dimension with (JIA patients 56%; 95%CI). (23) On another angle a study conducted in Serbia on. The regression model emerged with specified variables explaining 63 % of the variance in the PedsQL score ($p < 0.01$) among children.(24)

HRQOL was found to be suboptimal in twenty five (45.4%) of the studied groups in the research conducted in Thailand which included sixty five children, the lowest was found in the school functioning scale score being 60(25-100) as reported by the parents.(25)

There are only few studies conducted in Africa from which a study done in South Africa on Juvenile idiopathic arthritis in two tertiary centers including 78 children showed that the median CHAQ was

0.5(IQR 0.1-0.25) and concluded on the presence of significant challenges secondary to late presentation, different disease characteristics and variable disease courses.(26) Another study done in Morocco used the juvenile arthritis quality of life questionnaire (JAQQ) scoring tool to assess the HRQOL and it demonstrated that the median for the entire sample was 2.6 with significant differences in HRQOL between the age groups of the studied population($P = 0.04$). (27)

2.2. Factors associated with health related quality of life in children with juvenile idiopathic arthritis

2.2.1. Socio-demographic status

In the Morocco study it was indicated that HRQOL was worse in adolescent patients compared to children but gender ($P = 0.95$), age of onset of JIA ($P = 0.81$), and evolution duration ($P = 0.34$) were not significantly related.(27)

In contrary the research conducted in Netherlands, HRQOL was found to be significantly lower in most of the domains in both groups with ages 6-12 years and ages 13-18 years.(22)

2.2.2. Disease related factors

Persistent oligoarthritis patients were found to have better HRQOL than the other subtypes in one multicentered, a multinational cross study (21) And also The study conducted in Thailand suggested that a disease lasting for greater than one year and the presence of high disease activity were significantly associated with suboptimal HRQOL with adjusted odds ratios (ORs) of 5.9 (95% CI 1.2, 33.3) and 20.2 (95% CI 1.4, 291.7) respectively.(25)

Those with delay in diagnosis were found to have a significant association with decrement in HRQOL and those with polyarticular and systemic JIA were also found to have a worse gross motor, fine motor function than oligoarticular JIA subtypes in the study conducted in Morocco.(27)

2.2.3. Treatment related factors

A study conducted in Canada on the effect of treatment and HRQOL in JIA patients showed that two-thirds of children will experience the medication side effects within one year of the diagnosis which has a significant impacting their HRQOL.(28) Another similar study suggested the cause of lower HRQOL in children with JIA being treatment intensity and disease activity.(29)

The research conducted in Germany suggested that in addition to female gender, older age and lower level of education lower HRQOL in JIA patients was related with prolonged duration of rheumatic treatment and the presence of disability.(23)

Different studies also suggest that patients with JIA receiving physiotherapy treatment, targeted physical therapy exercises may help children with JIA with their strength, posture, walking, aerobic conditioning, functional mobility, and pain management.(30, 31)

2.3. Conceptual framework



Fig 1: conceptual framework of factors associated with HRQOL of JIA patients.

3. OBJECTIVES

3.1. General objective

- To assess health related quality of life and associated factors in children with juvenile idiopathic arthritis attending pediatrics rheumatologic clinic, Black lion hospital, Addis Ababa, Ethiopia, 2024.

3.2. Specific objectives

- To determine health related quality of life in children with juvenile idiopathic arthritis attending pediatrics rheumatologic clinic, Black lion hospital, Addis Ababa, Ethiopia, 2024.
- To identify factors associated with health related quality of life in children with juvenile idiopathic arthritis attending pediatrics rheumatologic clinic, Black lion hospital, Addis Ababa, Ethiopia, 2024.

4. METHODS AND MATERIALS

4.1. Study area

The research is conducted in Ethiopia, Addis Ababa, at Tikur Anbessa Specialized Hospital (TASH), department of pediatrics and child health. TASH is the largest referral and teaching hospital located at the capital city of Ethiopia. The pediatrics and child health department in the hospital has emergency, outpatient, follow up clinics, in patient wards and intensive care units. It is the only hospital in the country that has a pediatrics rheumatology follow-up clinic with pediatric rheumatologist. In the clinic there are patients on follow-up with different rheumatologic diseases.

4.2. Study design and period

4.2.1. Study design

- A hospital based cross sectional study was done on patients with juvenile idiopathic arthritis attending TASH pediatrics rheumatologic clinic.

4.2.2. Study period

- The study was conducted from September 1 to December 30, 2024.

4.3. Source and Study population

4.3.1. Source population

- All patients ≤ 18 years attending TASH pediatrics rheumatologic clinic

4.3.2. Study population

- All JIA patients fulfilling ILAR definition of JIA and on follow up at TASH pediatrics rheumatologic clinic were included in the study

4.4. Inclusion criteria

- All JIA patients fulfilling ILAR definition of JIA and on follow up at TASH pediatrics rheumatologic clinic

4.5. Exclusion criteria

- Those patients who were not volunteer to participate in the study,
- Those patients with acute illness requiring urgent medical attention during follow up
- Those patients who did not full fill the ILAR definition of JIA

4.6. Sample size and sampling procedures

4.6.1. Sample size determination

Since the number of patients on follow up at Tikur Anbessa Specialized Hospital (TASH) paediatrics rheumatology clinic is small 66 in total, so we included all the patients that fulfil the inclusion and exclusion criteria's which accounts to be 57.

4.6.2. Sampling method

- Convenience sampling was used to conduct the study

4.7. Variables of the study

4.7.1. Dependent variables

- Health related quality of life in children with juvenile idiopathic arthritis

4.7.2. Independent variables

- Socio-Demographic Factors (Age, sex, Family status, Care giver Educational status, Care giver Occupational status, Income, Living area)
- Disease related factors (The subtype of JIA, Response to treatment On remission or Disease progression, Presence of pain, Presence of deformity, Presence of disability)
- Treatment related factors (What PO medications are they taking?, Medication side effects, the gap between illness and treatment initiation, adherence to medication, physiotherapy)

4.8. Operational definition

JIA- is a disease defined by the presence of arthritis of more than 6 weeks duration in patients who are less than 16years old and with unknown etiology.

HRQOL- is the term used to describe how a person feels about a particular element of their life in relation to their health or state of health.

CHAQ- a disease specific health instrument that measures functional ability in daily living activities in children.

4.9. Data collection tools and procedures

The HRQOL was assessed using standard structured questionnaire of Paediatric Quality of Life Inventory (PedsQL) and the Childhood Health Assessment Questionnaire (CHAQ). These questionnaires were selected and reviewed because they align with our research objectives and they have been used in a similar research conducted in Africa. After the selection, permission was obtained from the original authors to simply adapt it to our language. The questionnaires were reviewed and

they didn't require cultural and contextual adaptations. In order not to compromise the validity of the original instrument, no questions were added or removed. The questionnaire went through a rigorous forward and back translation which was then reviewed by a bilingual expert to resolve discrepancies. The questionnaire was then given to a data collecting nurse that was trained. . Training was given on the objective of the study and procedure of data collection. The trained nurse conducted the interview under the supervision of the principal investigator. The questionnaire was pilot tested on two patients to test for clarity and comprehension. After feedback collection, there were no improvements made on the questionnaire.

4.10. Data quality assurance

Prior to data collection, the data collector received training on the study's purpose, applicability, confidentiality of information, respondent rights, informed consent, and interviewing techniques. Every day, the data gathering procedure was monitored to ensure that the completed questionnaires were accurate and consistent.

4.11. Data processing and analysis

All information was checked after each data collection for its completeness. Data was entered into Epi info. Software version 7 and was exported and analyzed using SPSS statistical software version 25. Descriptive statistics was used for presenting summary data using tables and graphs. The associations between the independent and outcome variables were checked using independent t-test and one-way ANOVA and statistical significance was declared at a p-value of <0.05 .

4.12. Ethical considerations

Ethical clearance was obtained from the pediatrics and child health department of TASH and Research Ethical Committee. The study participant was informed about the objective, purpose, and anticipated outcome of the study. By reading written Informed consent form, prior to starting of the interview, consent was sought from all study participants. Confidentiality for collected data was ensured throughout the research process.

5. Result

A total of 57 JIA patients were included in this study from which 23(40.4%) were boys and 34(59.6%) girls. The age range from 2 to 18 years was included with the mean of 2.77 ± 1.25 years. Most of the patients 43 (75.4%) are from urban areas and also 87% live with at least one of their parents. From the study participants 78.9% (45) attended formal education and from those who did not attend majority 66.6%(8) of them is because of their illness.

Polyarticular RF negative type of JIA was the most predominant among the studied JIA patients presenting in 43.9% of them followed by oligoarticular 22.8% and Polyarticular RF Positive type systemic type 15.8%. Psoriatic and enthesitis types were found to be rare. The duration of illness were found to be within 1-5years for most of the patients 73.7% with the mean duration of illness being 2.19 ± 0.48 .

Table 1: The basic information of JIA patients

Variables		N	Percent (%)	Mean	Standard Deviation
Sex	Male	23	40.4	1.40	0.495
	Female	34	59.6		
Age	2-4years	4	7.0	2.77	1.254
	5-7years	14	24.6		
	8-12years	23	40.4		
	13-18year	16	28.1		
Living area	Rural	14	24.6	1.75	0.434
	Urban	43	75.4		
Who they live with	Parents	50	87.7	1.88	0.33
	Other guardians	7	12.3		
Paternal educational status	Can't read and write	1	1.8	3.37	1.447
	Primary school	18	31.6		
	Secondary school	19	33.3		
	Diploma/Degree/Above	8	14		
Maternal educational status	Can't read and write	8	14	3.35	1.408
	Primary school	19	33.3		
	Secondary school	20	35.1		
	Diploma/Degree/Above	4	7		
Guardian educational status	Can't read and write	1	1.8	1.32	0.929
	Primary school	2	3.5		
	Secondary school	3	5.3		
	Diploma/Degree/Above	1	1.8		

Attendance of formal education	Yes	45	78.9	1.79	0.411
	No	12	21.1		
Reasons for not attending formal education	Due to illness	8	66.6	1.35	0.719
	Due to age	4	33.4		

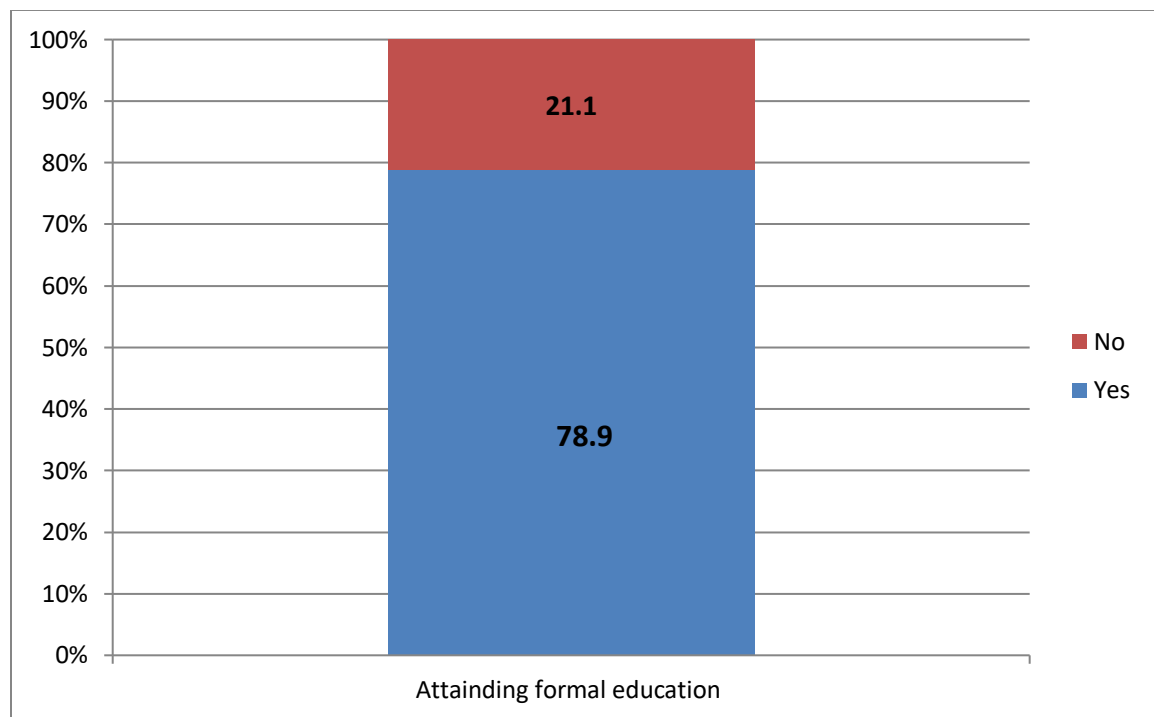


Fig2: A graph showing distribution of formal education attendance

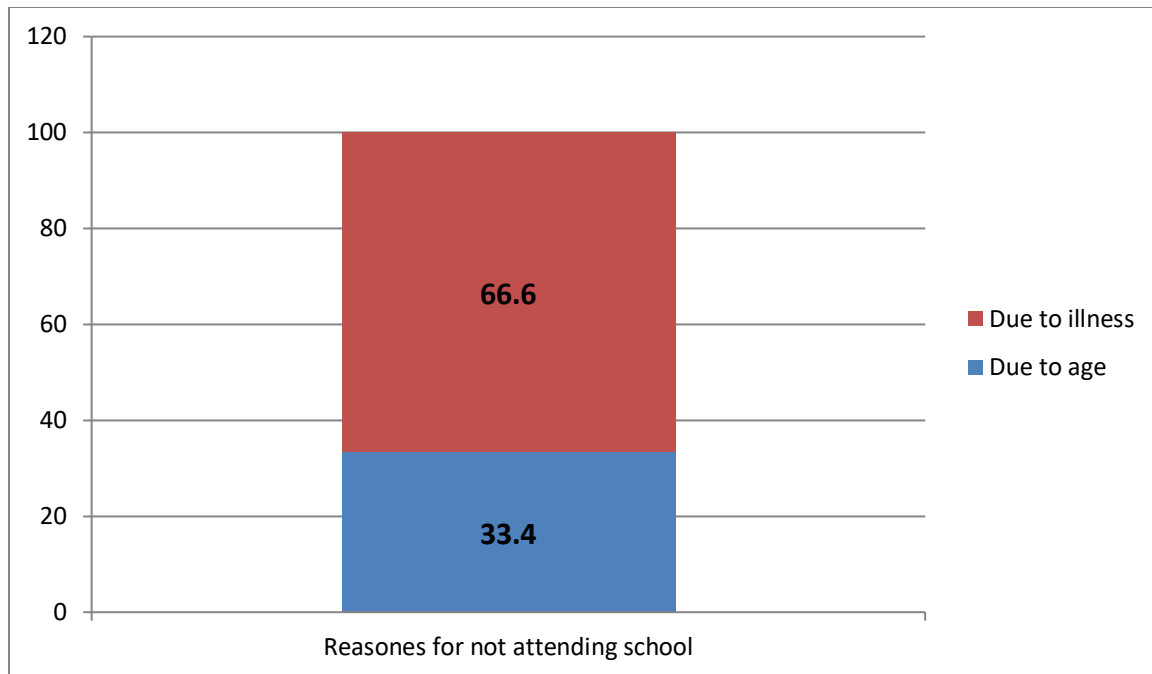


Fig 3: A graph showing distribution of reasons for not attending formal education

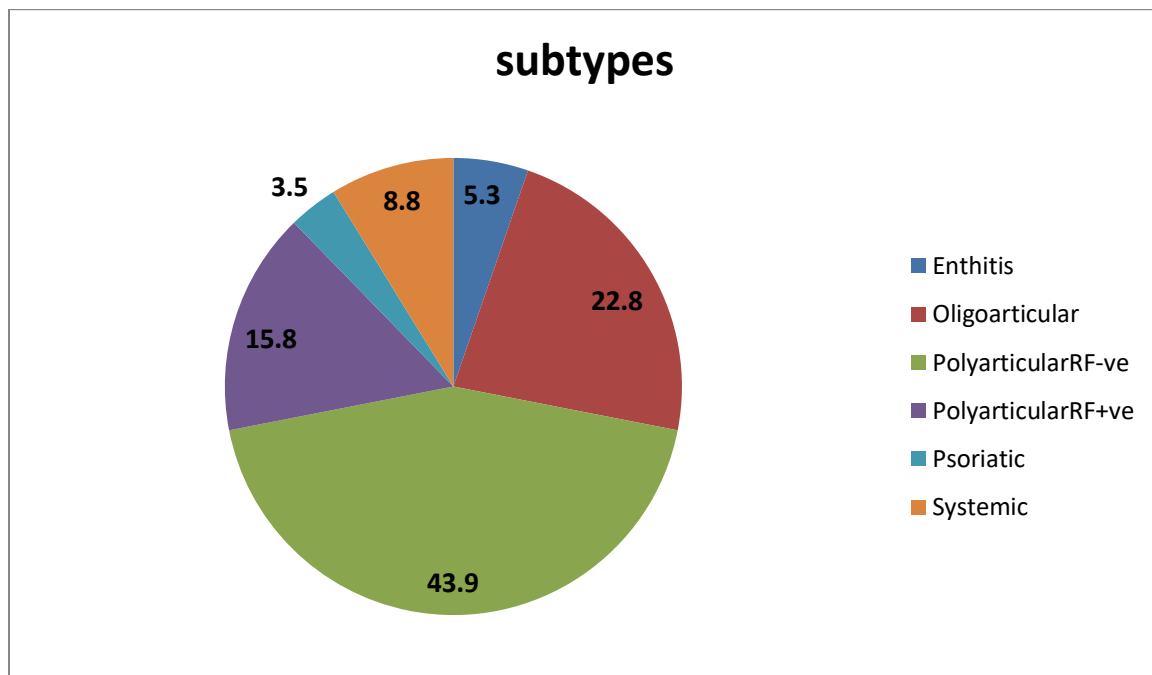


Fig 4: A pie chart showing distribution of the subtypes of JIA

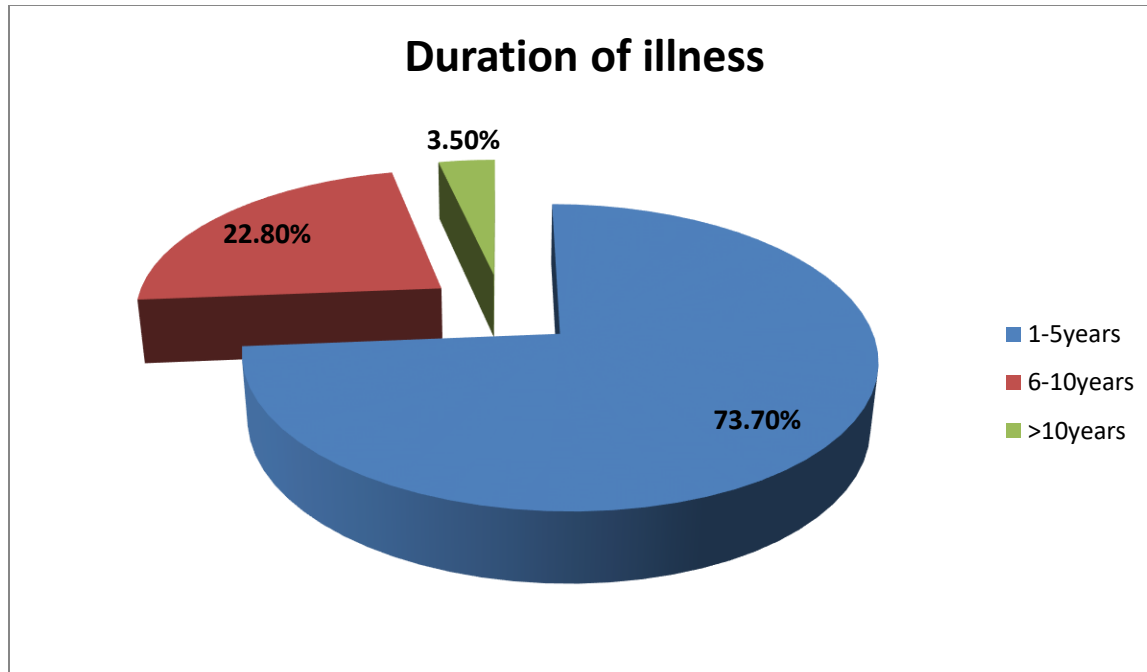


Fig 5: A pie chart showing distribution based on duration of illness

The mean CHAQ-DI scores were 0.61 ± 0.89 Vs. 0.97 ± 0.969 in male and females respectively with insignificant *P* value of 0.15. The mean CHAQ-VAS score were 3.48 ± 2.76 Vs 4.0 ± 2.54 in male and female respectively with insignificant *P* value of 0.46 and also the CHAQ- over all wellbeing score were also found to have an insignificant *P* value of 0.38 with mean scores of 4.7 ± 2.85 for males and 5.35 ± 2.718 for females. Overall result shows that the sex of the child has no significant relation with the functional disability of the patients.

Table 2: The descriptive statistics CHAQ of the studied patients

CHAQ Variables	Mean	Std. Deviation
Dressing	0.75	1.074
Eating	0.56	0.907
Arising	1.05	1.109
Walking	0.95	1.059
Hygiene	0.95	1.025
Reach	0.79	0.901
Grip	0.70	1.034
Activities	0.86	1.008
Disability index	0.82	0.947
VAS	3.79	2.624
Overall wellbeing	5.09	2.766

The CHAQ - (DI) of the studied patients rang from 0-3 with a mean of 0.82 ± 0.94 (SD). Indicating that, the overall disability index is good. CHAQ (VAS) and (Overall wellbeing) of patients rang from 0 to 9 with a mean of 3.79 ± 2.64 (SD) and 5.09 ± 2.76 respectively. CHAQ-DI has a statistically significant association with the subtype of JIA ($P= 0.47$) with the psoriatic subtype having highest CHAQ-DI score with a mean of 2.50 ± 0.71 and the systemic JIA subtype had the lowest mean of 0.20 ± 0.44 . The psoriatic subtype was also found to have the highest score both on the CHAQ-VAS and overall wellbeing score but they were both found to be not statistically associated with the subtypes of JIA with the P -value of 0.077 and 0.135 respectively.

Those patients who were ill for more than 10years were found to have a highest score of CHAQ-DI but there was no statistical significance between the duration of illness and the CHAQ-DI score ($P=0.59$). The CHAQ-VAS and CHAQ-wellbeing scores were also found to have no statistical association with the duration of illness with P -value of 0.595 and 0.837 respectively.

Table 3: Childhood health assessment questionnaire (CHAQ) score among studied population

Variables			Mean	Std. deviation	Sig.
Sex	CHAQ-DI	Male	0.61	0.89	0.15
		Female	0.97	0.96	
	CHAQ-VAS	Male	3.48	2.76	0.46
		Female	4.00	2.54	
	CHAQ- Overall wellbeing	Male	4.70	2.85	0.38
		Female	5.35	2.71	
Subtypes of JIA	CHAQ-DI	Polyarthricular	0.88	0.97	0.047
		Oligoarticular	0.62	0.76	
		Systemic	0.20	0.44	
		Enthitis	1.00	1.00	
		Psoriatic	2.50	0.70	
	CHAQ-VAS	Polyarthricular	3.91	2.58	0.077
		Oligoarticular	3.08	2.43	
		Systemic	2.40	1.51	
		Enthitis	5.00	3.60	
		Psoriatic	8.00	1.41	
	CHAQ- Overall wellbeing	Polyarthricular	5.29	2.71	0.135
		Oligoarticular	4.77	2.61	
		Systemic	2.80	1.78	
		Enthitis	5.67	4.04	
		Psoriatic	8.50	2.12	
Duration of illness	CHAQ-DI	1-5years	0.81	0.94	0.593
		6-10years	0.77	1.01	
		≥ 10 years	1.50	0.70	
	CHAQ-VAS	1-5years	3.64	2.66	0.595
		6-10years	4.00	2.67	
		≥ 10 years	5.50	0.707	
	CHAQ- Overall wellbeing	1-5years	4.98	2.78	0.837
		6-10years	5.31	2.95	
		≥ 10 years	6.00	1.41	

The overall mean of the total scores of both the parental and child proxy shows that there is an optimal HRQOL. Both total mean score of the parental and child proxy of PedsQL were not showed to have a statistical significance with the sex of the patient having a *P*- value of 0.29 and 0.52 respectively. But it showed that males have the higher score on both the parental and child proxy of PedsQL where the mean scores were 423.39±95.23 and 402.74±132.02 respectively.

It also showed that the health related quality of life to be suboptimal in the parental proxy related to the pain and hurt category and child proxy also shows that the pain and hurt plus the Worry category has a suboptimal HRQL.

Table 4: Pediatric quality of life inventory 4.0 generic core scales (PedsQL) among studied population

Parental proxy			Child proxy		
IVariables.	Mean.	Std. D.	IVariables	Mean.	Std. D.
Pain and hurt	75.99	25.35	Pain and hurt	75.94	27.74
Daily Activities	83.25	26.80	Daily Activities	84.91	25.04
Treatment	81.25	17.75	Treatment	81.20	18.81
Worry	78.93	28.75	Worry	78.46	31.45
Communication	97.17	11.66	Communication	96.23	14.20
Total score	404.53	110.94	Total score	387.65	145.64

Age and PedsQL scores were found to be statistically associated for both parental (*P*=0.00) and child proxy (*P*=0.00). The same insignificance goes for the duration of the illness, *P*=0.88 for parental proxy and *P*=0.98 for the child proxy, but those patients with a duration of illness greater than 10year old are found to have a lower PedsQL score with a mean score of 375±1.41 for the total child proxy score and 369±9.89 for the total parental proxy.

Study participants who are living with their parents and those who are attending a formal education has a higher PedsQL score in both parental and child proxy even though it was not found to have a statistically significant association. School attending has significant association with both proxies (*P*value-0.00). Psoriatic subtype group had the lowest score on both the parental and child proxy but with no statistical significance (*P*=0.35 and *P*=0.71 respectively).

Table 5: A table showing the highest mean/SD in HRQL of both proxies

Parental proxy	Highest Mean /SD	Child Proxy	Highest Mean/SD
Age(>10Yrs)	30.79±11.5	Age(>10Yrs)	25.4±9.5
Sex (Female)	28.9±13.4	Sex (Female)	23.7±12.5
Duration(1-5yr)	27.3± 14.6	Duration (1-5yr)	22.9±13.1
Living condition (Parents)	27.2± 13.6	Living condition (Parents)	23.7± 12.2
School (Yes)	30.1± 12.2	School (Yes)	26.22± 10.7
Subtypes (Enthitis)	35.0±12.2	Subtypes (Oligoarthicular)	26.3±

The mean CHAQ-DI scores were found to be higher in male than female with mean score of 0.97 ± 0.969 Vs. 0.61 ± 0.89 respectively with insignificant *P* value of 0.15. And also psoriatic subtype and those >10years of illness duration were found to have a higher mean score. The CHAQ-VAS and Overall wellbeing was not also significantly associated with the sex, subtype of JIA and duration of illness. The psoriatic subtype has the highest CHAQ-DI score with a mean of 15 ± 1.41 and the systemic JIA subtype had the lowest mean of 2.8 ± 3.49 . But there was no significant association between the Subtypes of JIA and the CHAQ-DI

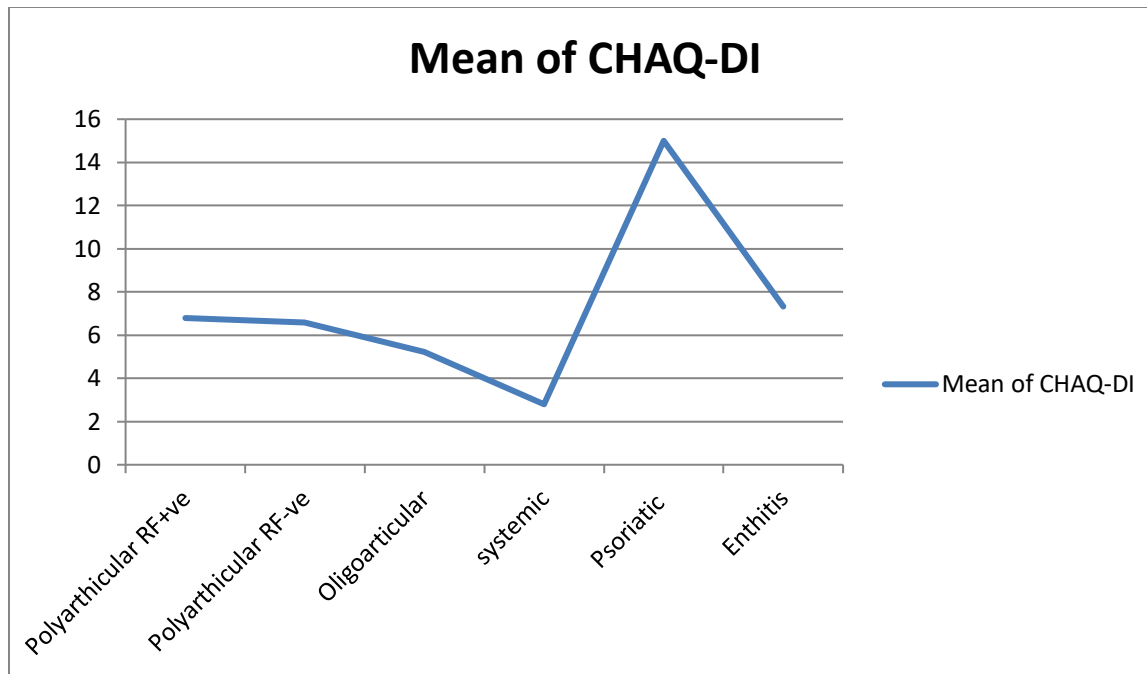


Fig 6: A mean Plot showing association of JIA subtypes with CHAQ-DI

The CHAQ-DI was not found to have a significant association ($P=0.00$) with the PedsQL on both parental and child proxy but it has a negative correlation where the pedsQL score is higher for those with lower disability index.

Table 6: A table showing the association between CHAQ-DI and HRQOL in both proxies

Variables	Mean	SD	Sig
CHAQ-DI	0.83	0.88	
HRQOL Parental Proxy	26.3	14.14	0.00
HRQOL Child Proxy	22.61	12.83	0.00

6. Discussion

Our study showed a mean CHAQ- DI of 0.82 ± 0.947 with VAS score of 3.79 ± 2.624 in the same line a study done on the same parameter of functionality showed that mean CHAQ of patients was 0.28 ± 0.24 (27) and also another study done in Morocco showed that the mean CHAQ of patients was 0.84 ± 0.71 and ranged from 0 to 2.87. The study done Morocco goes in line with the result of this study showing no significance association between the Subtype of JIA and the low HRQOL but oligoarticular subtype indicated that it has the highest mean score meaning that it has a better quality of life than the others.(32)

This study showed that disability index to be higher among males than females but a study in Egypt showed the reverse with P- value of 0.002 indicating that it has significant association. There was no statistical association found between the subtypes of JIA and both CHAQ and PedsQL scores but a study done in Egypt showed that there was statistical difference in both CHAQ($P=0.02$) and PedsQL($P=0.03$) indicating a significant association.

In this study the CHAQ-DI score has no significant association with the subtypes of JIA and same goes for the Egyptian study ($P=0.905$) but the highest HROL is found to be the oligoarticular subtype having the highest mean score while this study the psoriatic subtype has the highest score.(33)

The PedsQL was not associated with any of the studied parameters where p values > 0.05 and the CHAQ was significantly negatively associated with all the parameters of the pediatric quality of life (PedsQL). The same goes for the study done in Egypt.(33)

A study done in china and India showed that the HRQoL improved with the increasing duration of the disease in both proxies and this study showed that those with 1-5yr duration of illness has a higher HRQOL. The study done in India indicated that those patients with systemic JIA has a higher mean score on HRQOL.

Our study had certain limitations, the modest size of each subtype as a result of the small patient sample. Therefore, it is recommended that future research of functional ability be conducted in bigger, multicenter studies.

7. Conclusion

In conclusion, even though this study is small and single hospital based it does give an important insight on functional status and HRQOL of children with JIA in Ethiopia. Male patients(40.4%), psoriatic subtypes(5.3%) and those >10 years of illness duration (3.5%) were found to have a lower functional status their mean score of CHAQ-DI being 0.61, 2.50, 1.50 respectively.

The overall mean of the total scores of both the parental and child proxy shows that there is an optimal health related quality of life scores being 404.53 and 387.65 respectively. The highest score of health related quality of life was recorded on age >10 (30.79 ± 11.5), female (28.9 ± 13.4), duration of illness 1-5yr (27.3 ± 14.6) and those living with their parents (27.2 ± 13.6) for the parental proxy and also same goes to the child proxy age >10 (25.4 ± 9.5), female (23.7 ± 12.7), duration of illness 1-5yr (22.9 ± 13.1) and those living with their parents (23.7 ± 12.2).

The HRQOL, were found to be statistically associated with the age of the patient ($P=0.00$) but associated with duration of illness ($P=0.88$). And also looking at the subtypes of JIA it showed that the psoriatic subtype had lowest score in the PedsQL (125.4 ± 4.5 in child proxy and 102.4 ± 2.5 in parental proxy) and highest disability index in the CHAQ (8.10 ± 1.41) indicating that they have a low HRQOL.

We advise routinely monitoring JIA patients with CHAQ and PedsQL scores. In addition, we advise conducting additional research on a sizable number of JIA patients. Clinical Improvement of functional abilities and physical performance in children with JIA should also be a focus of developmental and functional follow-up programs.

8. Recommendation

This study raises concerns for pediatricians and pediatric rheumatologists to pay more attention to the quality of life of children when in treating. We also recommend the use of CHAQ and PedsQL in regular follow up for JIA patients to assess their quality of life. This study can be taken as a preliminary reference study for further studies to be conducted in Ethiopia. It is also suggested that future research on HRQOL and functional ability to be conducted in multicenter studies with larger sample size.

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10. Questionnaires

Participant Agreement form

Hello, my name is Etsegenet Bekele. I am a final-year resident specializing in pediatrics and child health at the School of Medicine, Addis Ababa University, College of Health Sciences. Currently, I am conducting research on the Functional Disability And Health Related Quality Of Life Of Children With Juvenile Idiopathic Arthritis Patients Attending The Pediatric Rheumatology Clinic At Tikur Anbessa Specialized Hospital. This is a hospital-based cross-sectional study. I would like to ask you a few questions and your honest answers will help achieve the goals of the study. All the information you provide will remain confidential and private, accessible only to the principal investigator and the interviewer. Your participation is entirely voluntary, and you can choose not to participate or withdraw at any time if you feel uncomfortable. If you have any questions, please feel free to ask. **Thank You.**

Socio-demographic status

Serial No	Item	Description
1	Age of the child	Age less than 1 year -----
		Age between 1yr and 5 year----
		Age greater than 5 year-----
2	Sex of the child	Male -----
		Female-----
3	Residential Area	Urban
		Rural
4	Maternal Educational Status	Cannot read and write
		Can read and write
		Primary school
		Completed secondary school

		Diploma/ Degree/ above
5	Paternal Educational Status	Cannot read and write
		Can read and write
		Primary school
		Completed secondary school
		Diploma/ Degree/ above
6	Family monthly Income	Less than 5000
		5000-10,000
		Greater than 10,000

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

In this section we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response which best describes your child's usual activities (averaged over an entire day) OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS. If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but not because he/she is RESTRICTED BY ILLNESS, please mark it as "NOT Applicable"

Characteristics	Without and difficulty	With some difficulty	With much difficulty	Unable to do	Not applicable
Dressing and Grooming					

Is your child able: to dress including tying shoelaces and doing buttons?					
Wash his/her hair?					
Remove socks?					
Cut fingernails?					
Eating					
Is your child able to: Cut his/her own meat/food?					
Lift up a cup or glass to mouth?					
Open a new cereal box?					
Arising					
Is your child able to: Stand up from a low chair or floor?					
Get in and out of bed or stand up in crib/bed?					
Walking					
Is your child able to: Walk outdoors on flat ground?					
Climb up five steps?					

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:	
Cane	
Walker	
Crunches	
Wheelchair	
Devices used for dressing (button hook, zipper pull, handled shoe horn, etc...)	
Built up pencil or special utensils	
Special or built up chair	
Others; specify:	

Please check any categories for which your child usually needs help from

another person because of illness:	
Dressing and Grooming	
Arising	
Eating	
Walking	

Characteristics	Without and difficulty	With some difficulty	With much difficulty	Unable to do	Not applicable
Hygiene					
Is your child able to: Wash and dry entire body?					
Take a tub bath (get and out of tub)?					
Get on and off the toilet or potty chair?					
Brush teeth?					
Comb/brush hair?					
Reach					
Is your child able to: Reach and get down a heavy object such as a large game or books from just above his/her head?					
Bend down to pick up clothing or a piece of paper from the floor?					
Pull on a sweater over his/her head?					
Turn neck to look back over shoulder?					
Grip					
Is your child able to: Write or scribble with pen or pencil?					
Open car doors?					
Open jars which have been previously opened?					
Turn faucets on and off?					
Push open a door when he/she has to turn a door knob?					

Activities					
Is your child able to:					
Run errands and shop?					
Get in and out of a car or toy car or school bus?					
Ride bike or tricycle?					
Do household chores (eg, wash dishes, take out trash, yard work, clean room)					
Run and play?					

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:	
Raised toilet set	
Bathtub seat	
Jar opener (for jars previously opened)	
Bathtub bar	
Long-handled appliances for reach	
Long-handled appliances in bathroom	

Please check any categories for which your child usually needs help from another person because of illness:	
Hygiene	
Reach	
Gripping and opening things	
Errands and chores	

- ❖ How much pain do you think your child has had because of his/her illness in the past week?
Place a mark on the line below, to indicate the severity of the pain

No pain |—————| 100 very severe pain

- ❖ Global evaluation: considering all the way that arthritis affects your child, rate how he/she is doing by placing mark on the line below.

Very well |—————| 100 very poor

Pediatric quality of life inventory for juvenile idiopathic arthritis

DIRECTIONS: Children with arthritis sometimes have special problems. On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

0 if it is never a problem

1 if it is almost never a problem

2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

❖ PARENT REPORT for TODDLERS (ages 2-4)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or	0	1	2	3	4

spoon					
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books or toys	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

❖ PARENT REPORT for YOUNG CHILDREN (ages 5-7)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise	0	1	2	3	4

causing pain					
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to other people	0	1	2	3	4

❖ Child REPORT for YOUNG CHILDREN (ages 5-7)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4

Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to other people	0	1	2	3	4

❖ PARENT REPORT for YOUNG CHILDREN (ages 8-12)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4

Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to	0	1	2	3	4

other people					
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❖ Child REPORT for YOUNG CHILDREN (ages 8-12)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to other people	0	1	2	3	4

❖ PARENT REPORT for YOUNG CHILDREN (ages 13-18)

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or marker	0	1	2	3	4
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4

Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to other people	0	1	2	3	4

❖ **Child REPORT for YOUNG CHILDREN (ages 13-18)**

In the past ONE month, how much of a problem has your child had with ...

Pain and Hurt (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Aches in joints and/or muscles	0	1	2	3	4
Having a lot of pain	0	1	2	3	4
Trouble sleeping because of pain or aching in joints and/or muscles	0	1	2	3	4
Feeling stiff in the morning or when he/she sits too long	0	1	2	3	4

Daily activities (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty turning on water faucets	0	1	2	3	4
Difficulty turning door handles	0	1	2	3	4
Trouble eating with a fork and/or spoon	0	1	2	3	4
Difficulty drawing a crayon or	0	1	2	3	4

marker					
Difficulty carrying books	0	1	2	3	4

Treatment (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Medicines making him/her feel sick	0	1	2	3	4
Physical therapy or daily exercise causing pain	0	1	2	3	4
Getting anxious about having blood drawn	0	1	2	3	4
Getting anxious about having needle sticks/shots	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4

Worry (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Worry about side effects from medicines	0	1	2	3	4
Worry about whether or not medicines are working	0	1	2	3	4
Worrying about his/her arthritis	0	1	2	3	4

Communication (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
Difficulty asking the doctors or nurses questions	0	1	2	3	4
Difficulty explaining his/her illness to other people	0	1	2	3	4

መጠይቅ

የተሳታፊዎች ስምምነት ቅጽ

ሰላም እፀገነት በቀለ እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ በጤና ሳይንስ ኮሌጅ የሕክምና ትምህርት ቤት በሕፃናት ሕክምና እና የሕፃናት ጤና ላይ የመጨረሻ ዓመት ተማሪ ነኝ። በአሁኑ ወቅት በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል የሕፃናት <የሩማቶሎጂ> ክሊኒክ የሚከታተሉ <ጁቨኒል ኢዲዮፓቲክ አርትራይተስ> ያለባቸው ሕፃናት በተግባራዊ የአካል ጉዳት እና ከጤና ጋር ተዛማጅነት ባላቸው ሕፃናት የሕይወት ጥራት ላይ ጥናት እያደረግሁ ነው። ይህ በሆስፒታል ላይ የተመሰረተ አቋራጭ ጥናት ነው። ጥቂት ጥያቄዎችን ልጠይቅህ እፈልጋለሁ እና የአንተ ታማኝ መልሶች የጥናቱን ግቦች ለማሳካት ይረዳሉ። ሁሉም የሚያቀርቡት መረጃ ሚስጥራዊ እና ሚስጥራዊ ሆነው ይቆያሉ፤ ለዋናው መርማሪ እና ለቃለ መጠይቅ አድራጊው ብቻ ተደራሽ ይሆናሉ። የእርስዎ ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው፤ እና ምችነት ከተሰማዎት በማንኛውም ጊዜ ላለመሰተፍ ወይም ላለመሰተፍ መምረጥ ይችላሉ። ማንኛውም ጥያቄ ካለዎት እባክዎን ለመጠየቅ ነፃነት ይሰማዎልኝ። አመሰግናለሁ።

ማህበረ-ሕዝብ ሁኔታ

ቁጥር	ክፍሎች	መግለጫ
1	የልጁ ዕድሜ	እድሜ ከ1 አመት በታች
		እድሜ ከ1 አመት እስከ 5 አመት
		እድሜ ከ5 አመት በላይ
2	የልጁ ጾታ	ወንድ
		ሴት
3	የመኖሪያ አካባቢ	ከተማ
		ገጠር
4	የእናት የትምህርት ሁኔታ	ማንበብና መጻፍ ማትችል
		ማንበብ እና መጻፍ የምትችል
		የመጀመሪያ ደረጃ ትምህርት ቤት ያጠናቀቀች
		ሁለተኛ ደረጃ ትምህርት ቤት ያጠናቀቀች

		ዲፕሎማ / ዲግሪ / በላይ
5	የአባት የትምህርት ሁኔታ	ማንበብና መጻፍ ማይችል
		ማንበብ እና መጻፍ የሚችል
		የመጀመሪያ ደረጃ ትምህርት ቤት ያጠናቀቀ
		ሁለተኛ ደረጃ ትምህርት ቤት ያጠናቀቀ
		ዲፕሎማ / ዲግሪ / በላይ
6	የቤተሰብ ወርሃዊ ገቢ	ከ 5000 በታች
		5000-10,000
		ከ10,000 በላይ

የልጅነት ጤና ግምገማ መጠይቅ

በዚህ ክፍል ውስጥ የልጅዎ ህመም በእለት ተእለት ህይወት ውስጥ የመሥራት ችሎታውን እንዴት እንደሚጎዳ ለማወቅ ፍላጎት አለን። እባክዎ በዚህ ገጽ ላይ ማንኛውንም አስተያየት ለማከል ነፃነት ይሰጣዎታል። በሚከተሉት ጥያቄዎች፣ እባክዎን ባለፈው ሳምንት የልጅዎን የተለመዱ ተግባራት (በአማካይ ሙሉ ቀን) በተሻለ ሁኔታ የሚገልጸውን አንድ ምላሽ ያረጋግጡ። በህመም ምክንያት የሆኑትን ችግሮች ወይም ገደቦችን ብቻ ልብ ይበሉ። በልጅዎ ዕድሜ ውስጥ ያሉ አብዛኛዎቹ ልጆች የተወሰነ እንቅስቃሴ እንዲያደርጉ የማይጠበቅባቸው ከሆነ፣ እባክዎን «ተፈጻሚ አይሆንም» ብለው ምልክት ያድርጉበት። ለምሳሌ፣ ልጅዎ አንድን እንቅስቃሴ ለማድረግ ቢችግረው ወይም እሱ/ሷ በጣም ትንሽ ስለሆነ ማድረግ ካልቻሉ፣ ነገር ግን እሱ/ሷ በህመም የተገደበ ካልሆነ፣ እባክዎን "አይተገበርም" ብለው ምልክት ያድርጉበት።

ባህሪያት	ያለ ምንም ችግር	በተወሰነ ችግር	በብዙ ችግር	ማድረግ አለመቻል	አይተገበርም።
ልብስ መልበስ እና ማስጓጉ					
ልጅዎ፡ የጫማ ማሰራያዎችን እና ቁልፎችን ማድረግን ጨምሮ መልበስ ይችላል?					

ፀጉሩን ይታጠባል?					
ካልሲውን ማውለቅ?					
ጥፍር ይቆርጣል?					
መብላት					
ልጅዎ የሚከተሉትን ማድረግ ይችላል: የራሱን ስጋ/ ምግብ ይቆርጣል?					
አንድ ኩባያ ወይም ብርጭቆ ወደ አፍ ማንሳት?					
አዲስ የእህል እሽግ ይከፍታል?					
መነሳት					
ልጅዎ: የሚከተሉትን ማድረግ ይችላል: ከዝቅተኛ ወንበር ወይም ወለል መነሳት?					
ከአልጋ ላይ መውጣት እና መውረድ?					
መራመድ					
ልጅዎ: የሚከተሉትን ማድረግ ይችላል: ጠፍጣፋ/ለጥ ያለ መሬት ላይ ከቤት ውጭ መራመድ?					
አምስት ደረጃዎች መውጣት?					

እባኮትን ከላይ ለተዘረዘሩት ተግባራት ልጅዎ ብዙውን ጊዜ የሚጠቀመውን ማንኛውንም ማገዣ ወይም መሳሪያ ያረጋግጡ፡	
ዱላ	
ከዘራ	
ክራንች	
ተሽከርካሪ ወንበር	
ለመልበስ የሚያገለግሉ መሳሪያዎች (የአዝራር መንጠቆ፣ ዚፐር መጎተት፣ የጨማ ቀንድ፣ ወዘተ...)	
የተሰራ እርሳስ ወይም ልዩ እቃዎች	
ልዩ ወይም የተገነባ ወንበር	
ሌሎች፣ ይግለጹ፡	

እባክዎን ልጅዎ በህመም ምክንያት ከሌላ ሰው እርዳታ የሚፈልግባቸውን ማንኛውንም ምድቦች ያረጋግጡ፡	
ልብስ መልበስ እና ማስጌጥ	
መነሳት	
መብላት	
መራመድ	

ባህሪያት	ያለ ምንም ችግር	በተወሰነ ችግር	በብዙ ችግር	ማድረግ አለመቻል	አይተገበርም።
ንጽህና					
ልጅዎ፤ የሚከተሉትን ማድረግ ይችላል፡ መላውን ሰውነት ማጠብ እና ማድረቅ?					
የመታጠቢያ ገንዳ ይውሰዱ (ከመታጠቢያ ገንዳ ይውጡ እና ይውጡ)?					
ከመጻዳጃ ቤት ወይም ፖፖ ላይ መቀመጥ እና መነሳት?					
ጥርስ መቦረሽ?					
ፀጉርን ማበጠር/መቦረሽ?					
መድስ					
ልጅዎ፤ የሚከተሉትን ማድረግ ይችላል፡					

ከጭንቅላቱ በላይ ያሉ መጨመሪያዎችን/መፀሀፍት ማንሳት?					
ከወለል ላይ የልብሶችን ወይም ወረቀት ለመውሰድ ማጎንበስ?					
በጭንቅላቱ ላይ ሹራብ መጎተት?					
ወደ ትከሻው ለመመለስ አንገትን ማጠፍ?					
መያዝ					
ልጅዎ፤ የሚከተሉትን ማድረግ ይችላል: በብዕር ወይም እርሳስ መፃፉ ወይም ማስመር?					
የመኪና በሮች መክፈት?					
ከዚህ ቀደም የተከፈቱ ብልቃጦችን ይከፈታል?					
ቧንቧዎችን መክፈት እና መዝጋት?					
እሱ/ እሷ የበሩን ቋጠሮ መታጠፍ ሲኖርባቸው በሩን ገፍተው ይከፍታሉ?					
ተግባራት					
ልጅዎ፤ የሚከተሉትን ማድረግ ይችላል: የታዘዙትን ማድረግ እና መላላክ?					
ከመኪና ወይም ከአሻንጉሊት መኪና ወይም የትምህርት ቤት አውቶቡስ ወቶ መውረድ?					
ብስክሌት ወይም ባለሶስት ብስክሌት መንዳት?					
የቤት ውስጥ ሥራዎችን መሥራት (ለምሳሌ፤ ሰሃን ማጠብ፣ቆሻሻ መጣያ ማውጣት፣የዳሮ ሥራ፣ ንጹህ ክፍል)?					
መሮጥ እና መጨመት?					

እባክትን ከላይ ለተዘረዘሩት ተግባራት ልጅዎ ብዙውን ጊዜ የሚጠቀመውን ማንኛውንም ማገዣ ወይም መሳሪያ ያረጋግጡ፡	
ከፍ ያለ የመጻዳጃ ቤት ለመቀመጥ	
የመታጠቢያ ገንዳ መቀመጫ	
ብልቃጥ መክፈቻ (ቀደም ሲል ለተከፈቱ ብልቃጥ)	
የመታጠቢያ ገንዳ	
ለመድረስ ረጅም እጅታ ያላቸው እቃዎች	
በመታጠቢያ ቤት ውስጥ ረጅም እጅታ ያላቸው እቃዎች	

እባክዎን ልጅዎ በህመም ምክንያት ከሌላ ሰው እርዳታ የሚፈልግባቸውን ማንኛውንም ምድቦች ያረጋግጡ፡	
ንጽህና	
መድረስ	
ነገሮችን በመያዝ እና በመክፈት	
ስራዎች	

- ❖ ባለፈው ሳምንት ልጅዎ በህመም ምክንያት ምን ያህል ህመም አጋጥሞታል ብለው ያስባሉ? የህመሙን ክብደት ለማመልከት ከታች ባለው መስመር ላይ ምልክት ያድርጉ

ህመም የለም(0) |-----| 100 በጣም ከባድ ህመም

- ❖ አለምአቀፍ ግምገማ:- አርትራይተስ በልጅዎ ላይ የሚደርሰውን ጉዳት ግምት ውስጥ በማስገባት ከዚህ በታች ባለው መስመር ላይ ምልክት በማድረግ እሱ/ሷ እንዴት እየሰራ እንደሆነ ገምግሙ።

ህመም የለም(0) |-----| 100 በጣም ከባድ ህመም

የሕጻናት ሕይወት ጥራት መጠይቅ ለጂኒዲያ ኢዲዮፖሊቲክ አርትራይተስ ታካሚዎች

መመሪያ: አርትራይተስ ያለባቸው ልጆች አንዳንድ ጊዜ ልዩ ችግሮች ያጋጥሟቸዋል። በሚቀጥለው ገጽ ላይ ለልጅዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር አለ። እባክትን በመክበብ ባለፈው አንድ ወር ውስጥ እያንዳንዳቸው ለልጅዎ ምን ያህል ችግር እንደፈጠሩ ይንገሩን።

- ❖ 0 በጭራሽ ችግር ካልሆነ
- ❖ 1 ጭራሽ ችግር ነው ብለው ካላሰቡ
- ❖ 2 አንዳንድ ጊዜ ችግር ከሆነ

- ❖ 3 ብዙ ጊዜ ችግር ከሆነ
- ❖ 4 ሁልጊዜ ማለት ይቻላል ችግር ከሆነ

ትክክለኛ ወይም የተሳሳቱ መልሶች የሉም። ጥያቄ ካልገባዎት፣ እባክዎ እርዳታ ጠይቁ።

❖ የወላጆች ሪፖርት ለታዳጊዎች (ዕድሜያቸው ከ2-4)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበር እጅታዎችን ማዘር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክንያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4

ደም ስለመስጠት መጫነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጫነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጫነቅ	0	1	2	3	4

❖ የወላጅ ሪፖርት ለወጣት ልጆች (ከ5-7 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበር እጅታዎችን ማዘር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጫወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክንያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4

ደም ስለመስጠት መጨነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድሃኒቶች የጎንዮሽ ጉዳቶች መጨነቅ	0	1	2	3	4
መድሃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለይክተኞች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ይክተኞችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4
ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4

❖ የልጅ ሪፖርት ለወጣት ልጆች (ከ5-7 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበር እጅታዎችን ማዘር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክኒያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4
ደም ስለመስጠት መጨነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድኃኒቶች የጎንዮሽ ጉዳዮች መጨነቅ	0	1	2	3	4
መድኃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለይክተሮች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ይክተሮችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4

ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4
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❖ የወላጅ ሪፖርት ለወጣት ልጆች (ከ8-12 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበር እጅታዎችን ማዞር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክንያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4
ደም ስለመስጠት መጨነቅ	0	1	2	3	4

በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድሃኒቶች የጎንዮሽ ጉዳቶች መጨነቅ	0	1	2	3	4
መድሃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለዶክተሮች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ዶክተሮችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4
ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4

❖ የልጅ ሪፖርት ለወጣት ልጆች (ከ8-12 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
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የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበረ እጅታዎችን ማዞር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክኒያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4
ደም ስለመስጠት መጨነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድሃኒቶች የጎንዮሽ ጉዳቶች መጨነቅ	0	1	2	3	4
መድሃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለይክተሮች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ይክተሮችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4
ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4

❖ የልጅ ሪፖርት ለወጣት ልጆች (ከ13-18 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4
የበር እጅታዎችን ማዞር አስቸጋሪነት	0	1	2	3	4
በሽካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንዴ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክንያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4
ደም ስለመስጠት መጨነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድሃኒቶች የጎንዮሽ ጉዳቶች መጨነቅ	0	1	2	3	4
መድሃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለይዘት/ሮች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ይዘት/ሮችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4
ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4

❖ የወላጅ ሪፖርት ለወጣት ልጆች (ከ13-18 አመት)

ባለፈው አንድ ወር ውስጥ፣ ልጅዎ ምን ያህል ችግር አጋጥሞታል...

ህመም እና ጉዳት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም	0	1	2	3	4
ብዙ ህመም መኖር	0	1	2	3	4
በመገጣጠሚያዎች እና/ወይም በጡንቻዎች ህመም ወይም ህመም ምክንያት የመተኛት ችግር	0	1	2	3	4
ጠዋት ላይ ወይም እሱ / እሷ በጣም ረጅም ሲቀመጡ የመደንዘዝ ስሜት	0	1	2	3	4

የዕለት ተዕለት እንቅስቃሴዎች (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
የውሃ ቧንቧዎችን ማብራት አስቸጋሪነት	0	1	2	3	4

የበር እጅታዎችን ማዞር አስቸጋሪነት	0	1	2	3	4
በሹካ እና/ወይም በማንኪያ የመብላት ችግር	0	1	2	3	4
ማርከርን ለመሳል አስቸጋሪነት	0	1	2	3	4
መጽሐፍትን ወይም መጨወቻዎችን ለመያዝ አስቸጋሪነት	0	1	2	3	4

ሕክምና (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
መድኃኒቶች ምክኒያት የሚመጡ ህመሞች	0	1	2	3	4
ህመም የሚያስከትል የአካል ብቃት እንቅስቃሴ ወይም የዕለት ተዕለት እንቅስቃሴ	0	1	2	3	4
ደም ስለመስጠት መጨነቅ	0	1	2	3	4
በመርፌ ስለመወጋት መጨነቅ	0	1	2	3	4
ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ መድኃኒቶች የጎንዮሽ ጉዳዮች መጨነቅ	0	1	2	3	4
መድኃኒቶች እየሰሩ ስለመሆኑ ይጨነቁ	0	1	2	3	4
ስለ አርትራይተስ መጨነቅ	0	1	2	3	4

ግንኙነት/መግባባት (ችግሮች ከ...)	በጭራሽ	በጭራሽ ማለት ይቻላል	አንዳንድ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
እሱ/ሷ ምን እንደሚሰማቸው ለዶክተሮች እና ነርሶች መንገር መፍራት	0	1	2	3	4
ዶክተሮችን ወይም ነርሶችን ጥያቄዎችን መጠየቅ መቸገር	0	1	2	3	4
ህመሙን ለሌሎች ሰዎች ለማስረዳት መቸገር	0	1	2	3	4