

Quality of Life and Functioning in Physically Disabled Rheumatic Adolescents

Eman Taher Sayed

Prof.Samia Samy Aziz

Professor of Public Health - Medical Studies Department of Children - Faculty of Postgraduate Childhood Studies - Ain Shams University

Dr.Eman Ahmed Tawfik

Assistant Professor of Physical Medicine - Rheumatology and Rehabilitation - Faculty of Medicine - Ain Shams University

Summary

Physical disability brings a substantial change in a person's life Burchardt, 2003; Compelling evidence shows that growing disabled frequently leads to an expansion in psychological distress. (Choi& Marks, 2008). one of the causes of physical disability is rheumatological disorders. Adolescence can be a time when rheumatological conditions present to the general practitioner for diagnosis and management. It is believed that functioning affects the quality of life of individuals in the way that better functioning leads to better quality of life.

Aim: To assess quality of life and correlation between quality of life and functioning in adolescents with physical disability as a result of rheumatic diseases.

Methods: The study was conducted in the period between 11\ 2015 and 12\ 2017. Number of patients within the age range from 9 to 19 years old and meeting the inclusion criteria of the study were 78 patients with different rheumatic diseases causing physical disability. Functioning was assessed using the Health Assessment Questionnaire while Quality of life was assessed using WHO Quality of Life assessment.

Results: Seventy eight patients were assessed, 48 females and 30 males with age ranging between 9 and 19 years old.

The number of female patients was much higher than that of male patients in the age between 16 and 19 years old, and the level of disability was higher in the female group than in the male group. The male group were found to have poorer quality of life than the female group, 54% of the patients were compliant to drug therapy while 46% were not. The main finding was that there was a negative correlation between quality of life and functioning in adolescents with physical disability due to rheumatic diseases.

Conclusion: Functioning has no effect on the quality of life of adolescents with physical disability due to rheumatic diseases.

نوعية الحياة والأداء الوظيفي لدى المراهقين ذوي الإعاقات البدنية الناتجة عن الأمراض الروماتيزمية

إن حدوث إعاقة جسدية يعد حدثًا كبيرًا في حياة الأفراد غالبًا ما يؤدي إلى زيادة في الضغط النفسي فهو يؤثر سلبًا على فرص العمل ويمكن أن يؤثر بشكل كبير على العلاقات الاجتماعية. إن الأشخاص الذين يواجهون تدهورًا في الصحة البدنية بسبب الإعاقات، يكونون أكثر عرضة لأعراض الاكتئاب ومع ذلك، ليس كل من يواجه إعاقة جسدية يتعرض بالضرورة لهذه الأعراض، ويختلف حجم الأثر النفسي بين الذين يتأثرون سلبًا من جراء هذه الإعاقات. أحد أسباب الإعاقة يكون بسبب الأمراض الروماتيزمية والتي تبدأ في أغلب الأحيان في سن المراهقة. كثير من الناس ذوي الإعاقات الجسدية يشاركون في خدمات إعادة التأهيل من سن مبكرة. ومن أهم الأهداف الرئيسية لإعادة التأهيل هي تحسين الأداء اليومي، والمشاركة في الحياة وتحسين جودة هذه الحياة للأطفال والشباب.

نفترض في هذا البحث وجود علاقة بين مستوى جودة الحياة والأداء الوظيفي عند المراهقين ذوي الإعاقات البدنية.

الأهداف: تقييم مستوى جودة الحياة عند المراهقين ذوي الإعاقات البدنية، وتحليل العالقة بين مستوى جودة الحياة والأداء الوظيفي عند المراهقين ذوي الإعاقات البدنية.

خطة الدراسة: أجريت هذه الدراسة على المراهقين من ذوي الإعاقات الجسدية الناتجة عن الأمراض الروماتيزمية والذين يترددون على وحدة العلاج الطبيعي وعبادة الأمراض الروماتيزمية للأطفال في مستشفى عين شمس في الفترة ما بين 11/ 2015 و 12/ 2017، عدد المشاركين كان 78 مريض.

طرق البحث: خضع المريض إلى ما يلي تحديد التاريخ المرضي الكامل وفحص طبي شامل مع التركيز على أعراض الإعاقة الجسدية، وقياسات نفسية (استبيان تقييم الصحة (HAQ)- تقييم جودة الحياة من منظمة الصحة العالمية).

النتائج: اثبتت النتائج أنه لا توجد علاقة بين مستوى جودة الحياة والأداء الوظيفي عند المراهقين ذوي الإعاقات البدنية.

Introduction:

The onset of a physical disability is a major event in the lives of individuals. Becoming disabled often results in an increase in psychological distress (Burchardt, 2003; Choi & Marks, 2008). It negatively affects job opportunities and can seriously impact one's relationships and social network.

On average, people who faced a structural decline in physical health because of a disability, report lower well-being and more depressive symptoms. However, not everyone who experiences the onset of a physical disability becomes psychologically distressed, and those who are negatively affected by disability differ considerably in the magnitude of the psychological impact (Sharpe & Curran, 2006; Stanton, et al. 2007).

Relatively little is known about the factors that cause some people to be affected very strongly by a disability whereas others appear to cope well and experience no or only small changes in psychological distress. Previous research found that a lack of social support could exacerbate the negative effects of a disability, whereas a supportive social network may alleviate stress (Turner & Noh, 1988). Also psychological resources, such as sense of mastery and locus of control, seem to cushion the impact of a disability (Bisschop, et al. 2004; Turner & Noh, 1988).

In 2001, the World Health Organization published the International Classification of Function disability and health (ICF) (WHO, 2001). The major goal of the ICF is to describe aspects of human functioning that are related to health status in a standardized way to provide a basis for a common language (WHO, 2001). In 2004, this classification was followed by the children and youth version, the ICF-CY (WHO, 2004). The ICF-CY also provides a common language but focuses on the relation between health status and changes that emerge in development from infancy to adolescence.

Being active and involved in freely chosen activities are essential for the development of skill competencies, socializing with peers, exploring personal interests and enjoying life (Simpkins, et al. 2005). Without opportunities to participate in leisure activities, people are unable to explore their social, intellectual, emotional, communicative and physical potential and are less able to grow as individuals' (King et al., 2003). Moreover, participation contributes to the quality of life for children and youth (McManus, et al. 2008). Children and youth with physical disabilities participate less in leisure activities than their able bodied peers (Bult et al., 2010; Engel-Yeger, et al. 2009). Moreover, their leisure activities tend to be more home-based and organized by adults (Majnemer et al., 2008).

Most people with a physical disability are involved in rehabilitation services from an early age. One of the primary goals of rehabilitation is 'to improve and optimize daily functioning, engagement in life and well-being' (Gorter, 2009).

Aim Of Study:

1. To assess quality of life in adolescents with physical disability as a result of rheumatic diseases.

2. To assess the correlation between quality of life and functioning in adolescents with physical disability.

Subjects:

The present study was conducted in the physical medicine and rehabilitation outpatient clinic and rheumatology and hematology pediatrics clinics at Ain Shams University Hospital in the period between 11\ 2015 and 12\ 2017. Number of patients who attended these clinics in this period was 500. patients within the age range from 9 to 19 years old and meeting the inclusion criteria of the study were 80 patients with different rheumatic diseases, namely (juvenile rheumatoid arthritis, SLE, hemophilic arthropathy...) causing physical disability, two of them refused to participate and 78 agreed.

Methods:

All patients were subjected to the following:

1. Full medical history taking and thorough clinical examination.
2. Psychometric Tests:
 - a. The Health Assessment Questionnaire (HAQ) (Wolfe et al., 2004):
The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries, MD, and colleagues at Stanford University. It was one of the first self-report functional status (disability) measures and has become the dominant instrument in many disease areas. It is widely used throughout the world and has become a mandated outcome measure for clinical trials in rheumatoid arthritis and some other diseases.
The HAQ was developed as a comprehensive measure of outcome in patients with a wide variety of rheumatic diseases, including rheumatoid arthritis, osteoarthritis, juvenile rheumatoid arthritis, lupus, scleroderma, ankylosing spondylitis, fibromyalgia, and psoriatic arthritis. It has also been applied to patients with HIV/AIDS and in studies of normal aging. It should be considered a generic rather than a disease-specific instrument. Its focus is on self-reported patient-oriented outcome measures, rather than process measures.
The questionnaire includes 8 sections: dressing, arising, eating, walking, hygiene, reach, grip, and activities. There are 2 or 3 questions for each section. Scoring within each section is from 0 (without any difficulty) to 3 (unable to do).
 - ☒ Score zero represents no disability.
 - ☒ Scores of > 0 to 1 represent mild to moderate disability.
 - ☒ Scores of 1 to 2 represent moderate to severe disability.
 - ☒ Scores of 2 to 3 represent severe to very severe disability.

For each section the score given to that section is the worst score within the section, i.e. if one question is scored 1 and another 2, then the score for the section is 2. In addition, if an aide or device is used or if help is required from another individual, then the minimum score for that section is 2. If the section score is already 2 or more then no modification is made. The 8 scores of the 8 sections are summed and divided by 8. The result is the DI or FDI,

the disability index or functional disability index. In the event that one section is not completed by a subject then the summed score would be divided by 7.

- b. WHO Quality of Life Assessment: The WHOQOL- 100 quality of life assessment was developed by the WHOQOL Group With the help of 15 collaborating centers around the globe, WHO has developed two instruments for measuring quality of life: the WHOQOL- 100 (World Health Organization quality of life) and the WHOQOL- BREF. These instruments can be used in an assortment of cultural settings while allowing the comparing of the results from different countries and populations (Szabo et.al., 1997).

The WHOQOL- 100 was developed concurrently in 15 field centers around the globe. The vital aspects of quality of life and means of asking about quality of life were composed on the basis of statements made by patients with a range of diseases, by well people, and by health professionals in a variety of cultures (Szabo et.al., 1997).

To assess its validity and reliability in each of the field centers, the instrument rigorously tested, and to assess responsiveness to change, it is currently being tested. An abbreviated 26- item version of the WHOQOL- 100, the WHOQOL- BREF, was developed using data from the field- trial version of the WHOQOL- 100.

Scoring The Whoqol Instruments: The WHOQOL- 100 produces scores relating to specific facets of quality of life (such as positive feelings, social support, financial resources), scores relating to larger domains such as:

- ▣ Physical Functioning.
- ▣ Emotional Functioning.
- ▣ Social Functioning.
- ▣ School Functioning

The physical health summary score is the same physical functioning scale. To create the psychosocial health summary score the mean is calculated as the sum of the items divided by the number of items answered in the emotional, social, and school functioning scales.

The instructions ask how much of a problem each item has been during the past 1 month. A five- point categorical response scale is utilized across child self- report for ages 8 to 18 years (0: Never a problem; 1: Almost never a problem; 2: Sometimes a problem; 3: Often a problem; 4: Almost always a problem)

Items are reverse- scored and linearly transformed to a 0 to 100 scale (0: 100, 1: 75, 2: 50, 3: 25, 4: 0), so that higher score indicate better QoL. Scale scores are computed as the sum of the items divided by the number of items answered

The WHOQOL- BREF does not produce individual facet scores, but produces domain scores. Details on scoring are included in manuals available from The WHOQOL Group, Program on

Mental Health, World Health Organization.

Statistical analysis:

Statistical presentation and analysis of the present study was conducted, using the mean, standard Deviation, unpaired student t- test, Linear Correlation Coefficient, Analysis of variance [ANOVA] test and chi- square tests by (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.): Unpaired Student T- test was used to compare between two groups in quantitative data and Chi- square.

The hypothesis that the row and column variables are independent, without indicating strength or direction of the relationship. Pearson chi- square and likelihood- ratio chi- square. Fisher's exact test and Yates' corrected chi- square are computed for 2x 2 tables.

Linear Correlation Coefficient [r]: Linear Correlation coefficient was used for detection of correlation between two quantitative variables in one group.

Analysis of variance [ANOVA] tests: According to the computer program SPSS for Windows. ANOVA test was used for comparison among different times in the same group in quantitative data.

(>0.05 Non significant <0.05* significant <0.001** High significant)

Results:

In our study we assessed the quality of life and the correlation between quality of life and functioning in adolescents with physical disability as a result of rheumatic diseases. 78 patients were assessed, 48 females and 30 males with age ranging between 9 and 19 years old.

Table (1) Number and percentage of female and male cases

Gender	N	%
Female	48	61.5
Male	30	38.5
Total	78	100.0

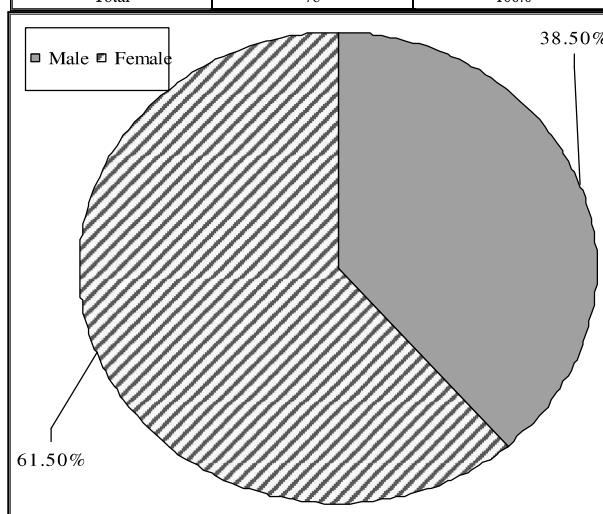


Fig. (1) Number and percentage of female and male cases

Table (2) Gender and age distribution

Age \ Gender	Female		Male		Total		Chi- Square	
	N	%	N	%	N	%	X ²	P- Value
9- 12 Years	15	48.4	16	51.6	31	39.7	4.465	0.107
13- 15 Years	19	65.5	10	34.5	29	37.3		
16- 19 Years	14	77.8	4	22.2	18	23		
Total	48	61.5	30	38.5	78	100.0		

Although this table shows no significant difference between male and female cases among different age groups, there is a big difference between the number of male and female cases in the age of 16 to 19 years old.

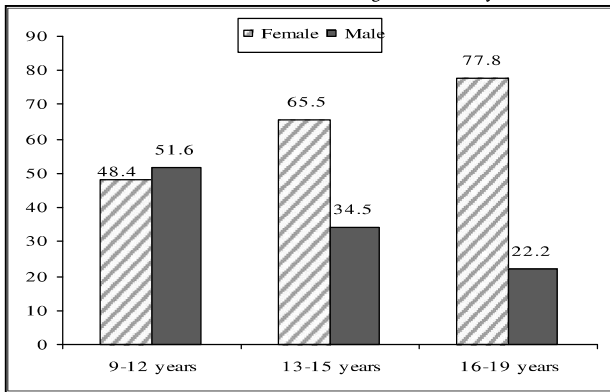


Fig. (2) Gender and age distribution.

Table (3) Number And Percentage Of Compliant And Non- Compliant Cases To The Treatment.

Drug Compliance	N	%
C	42	53.8
NC	36	46.2
Total	78	100.0

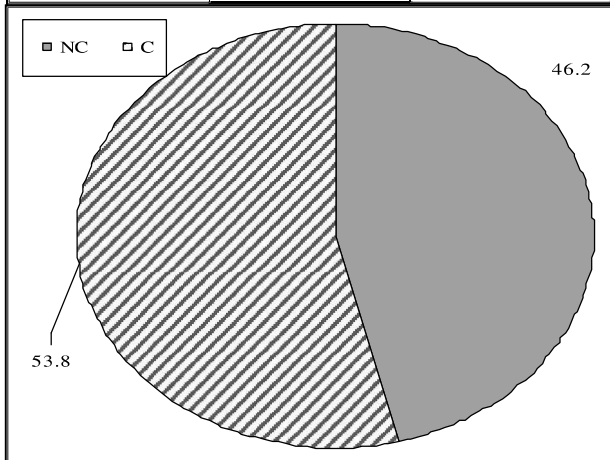


Fig. (3) Number and percentage of compliant and non-compliant cases to the treatment.

Table (4) The relation between the HAQ score and the QoL in each age group.

Age	Haq 0-1		Haq 1-2		Haq 2-3		ANOVA	
	Mean	SD	Mean	SD	Mean	SD	f	P- Value
9-12 Years	86.22	7.05	79.67	15.63	80.00	0.00	0.724	0.494
13-15 Years	74.25	15.75	82.05	11.88	68.00	0.00	1.421	0.260
16-19 Years	77.67	23.03	79.54	10.02	90.00	24.04	0.571	0.577

This table shows no significant difference in the relation between HAQ and QoL among different age groups.

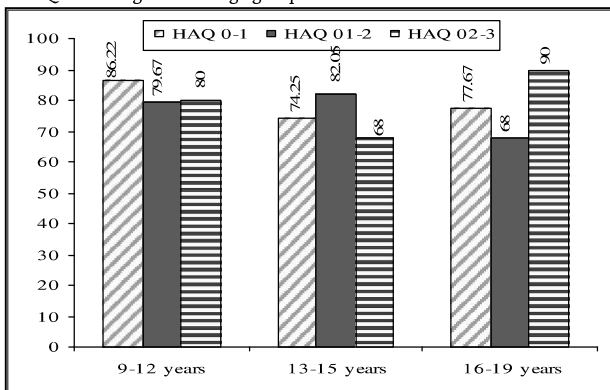


Fig. (4) The relation between the HAQ score and the QoL in each age group.

Table (5) The relation between the HAQ score and the QoL in male and female

Sex	Haq0-1		Haq 1-2		Haq 2-3		ANOVA	
	Mean	SD	Mean	SD	Mean	SD	f	P- Value
Female	78.45	14.72	82.32	11.65	86.67	17.95	0.627	0.539
Male	82.22	14.08	77.45	14.64	68.00	0.00	0.613	0.549

This table shows no significant difference in the relation between HAQ and QoL among male and female cases.

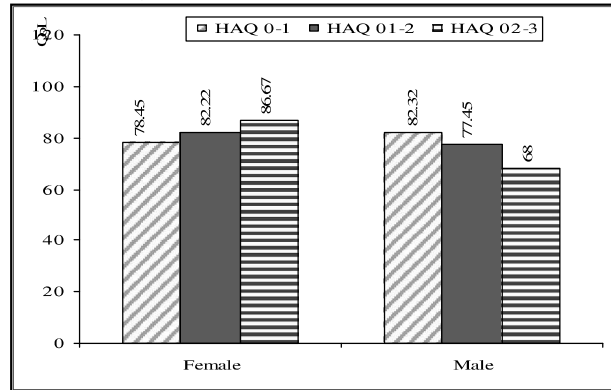


Fig. (5) The relation between the HAQ score and the QoL in male and female.

Table (6) The Relation Between The HAQ Score And The QoL In Compliant And Non-Compliant Cases.

Drug Compliance	Haq0-1		Haq 1-2		Haq 2-3		ANOVA	
	Mean	SD	Mean	SD	Mean	SD	f	P- Value
Compliant	84.64	13.16	79.83	11.56	80.00	0.00	0.651	0.527
Non-Compliant	74.67	14.14	81.38	14.66	82.67	21.22	0.712	0.498

This table shows no significant difference in the relation between HAQ and QoL in compliant and noncompliant cases to treatment but generally it shows that QoL and functioning are higher in compliant cases.

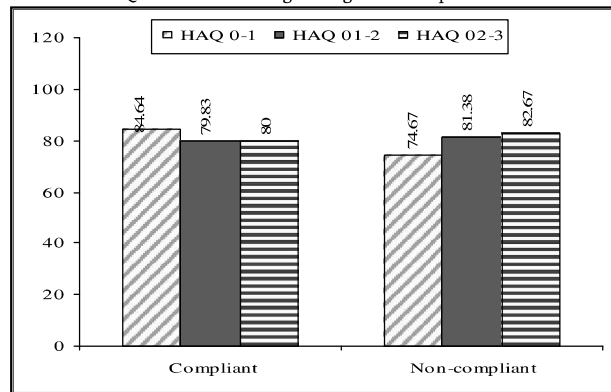


Fig. (6) The relation between the HAQ score and the QoL in compliant and non-compliant cases

Discussion:

Physical disability is a significant event in the lives of individuals. Becoming disabled often results in an increase in psychological distress (Burchardt, 2003; Choi& Marks, 2008). It negatively affects job opportunities and can seriously impact one's relationships and social network.

People with disability, report lower well- being and more depressive symptoms. However, not everyone who experiences the onset of a physical disability becomes psychologically distressed, and those who are negatively affected by disability differ considerably in the magnitude of the

psychological impact (Sharpe& Curran, 2006; Stanton, et.al. 2007).

In 2001, the World Health Organization published the International Classification of Function disability and health (ICF) (WHO, 2001). The major goal of the ICF is to describe aspects of human functioning that are related to health status in a standardized way to provide a basis for a common language (WHO, 2001). In 2004, this classification was followed by the children and youth version, the ICF- CY (WHO, 2004). The ICF- CY also provides a common language but focuses on the relation between health status and changes that emerge in development from infancy to adolescence.

Rheumatic disorders are chronic inflammatory autoimmune diseases with a specific course that cycles between remissions and relapses. These disorders can have a significant adverse impact on a patient's physical, mental and social well-being, resulting in a low quality of life (QoL) (Salaffi, et.al. 2009). Because of the fact that the current available therapy neither prevents nor cures the underlying disease, the main objectives of treatment are achieving and maintaining remission, reducing symptoms and improving the patient's quality of life.

Quality of life of the disabled people has been the subject matter of study by various researchers all throughout the world. Lack of access to health services and medical care is a major problem faced by people with disabilities and this has resulted in associated problems like muscular-skeletal and mental health above the primary disability. The quality of life and psychological health are inversely related. Depression, lack of concentration, feelings of fatigue, loss of interest in daily activities, social isolation, and a sense of worthlessness were common features of people living with disabilities.

In our study we assessed the quality of life and the correlation between quality of life and functioning in adolescents with physical disability as a result of rheumatic diseases. 78 patients were assessed, 48 females and 30 males with age ranging between 9 and 19 years old.

We found that the number of female patients was much higher than that of male patients in the age between 16 and 19 years old, and that the level of disability was higher in the female group than in the male group. This finding is in agreement with that in the study by Radha et.al. (Shankar et.al. 1995) but in contrast with that in the study by Chaves et.al. (Chaves et.al. 1993)

On the other hand the male group were found to have poorer quality of life than the female group. A significant difference in the levels of QoL and disability was found between the genders in a study done by Nishi et.al. Females were found to be more disabled and having poorer QoL than males.

In his study he explained that the of QoL is centered on the social and cultural environment of the individual. With regard to the components of disability, the lower status of occupation can be included, since most of the men were holding jobs, and the young women were dependent on their families for financial support. Rajeev et.al.(Krishnadas, et.al., 2007) reported that family support and employment can reduce disability.

It was noticed in our results that 54% of the patients were compliant to drug therapy while 46% were not. Although compliance to medication represents a key requirement for successful treatment, it was believed that poor compliance was common in rheumatic disorders (Harrold, et.al., 2009). This was also true for other chronic disorders (DiMatteo, et.al., 2004).

In general, it was estimated that during long-term medication therapies, the compliance rate was between 40% and 50% (DiMatteo, et.al., 1995). Likewise, the mean compliance rate stated by the World Health Organization is 50% for chronic conditions (Sabate, et.al., 2003). Nevertheless, the difference in treatment outcomes between high and low compliant patients was shown to be 26% (DiMatteo, et.al., 2002).

We also found in our study that the number of non-compliant patients was much higher than that of compliant patients in the age between 16 and 19 years old and that the quality of life and functioning of patients who were compliant to drug therapy was higher than that of the non-compliant ones. These results were in contrast with that in the study by Hromadkova et.al. who found that patients with higher quality of life seem to comply less.

Our main finding in this article was that there was a negative correlation between quality of life and functioning in adolescents with physical disability due to rheumatic diseases. Children with poorer functioning showed higher levels of perceived quality of life.

Relatively little is known about the factors that cause some people to be affected very strongly by a disability whereas others appear to cope well and experience no or only small changes in psychological distress. Previous research found that a lack of social support could exacerbate the negative effects of a disability, whereas a supportive social network may alleviate stress (Turner& Noh, 1988). Also psychological resources, such as sense of mastery and locus of control, seem to cushion the impact of a disability (Bisschop, et.al. 2004; Turner& Noh, 1988).

A study among Adolescents with physical disabilities in Korea reveals that acceptance of society about their existing problem is very helpful in having a normal life for the disabled persons. A study conducted by Centres for Disease Control and Prevention (National Adolescent Student Health Survey 1987), It was found that if the disabled are motivated to appraise their health situation positively the adverse impact of disability could be reduced. (Kim et.al. 2003)

In one of the study present that the satisfaction of having a relationship, self achievement, self worthiness, recognition are all expected by a grown up disabled person. In the case of adolescent disabled persons his self-rating of health is related to various aspects, both social and psychological, which including his achievement in schools, involvement in sports and exercise, income of family, psychological wellbeing, relationship with parents, self-esteem etc. and quality of life is not much related to his physical wellbeing. (Patrick., 1997)

In his study he put forward a model for promoting quality of life of people with disabilities by giving importance to changing environment

giving more opportunities to perform independence and autonomy. It is also pertinent to state that financial implications of disability in a child on the family is also very significant. Studies conducted in Delhi revealed that loco motor disabilities is causing serious financial burden on parents of the disabled positive self-appraisal of health may mitigate the deleterious children. (Laskar, et.al. 2003).

Most people with a physical disability are involved in rehabilitation services from an early age. One of the primary goals of rehabilitation is 'to improve and optimize daily functioning, engagement in life and well-being' (Gorter, 2009).

Since rehabilitation services are aimed at children and youth of all ages it is important for rehabilitation professionals to know which factors are related to optimal participation and functioning in each developmental stage and whether there is a relation between perceived quality of life and functioning in order to provide effective interventions and programs.

Limitation of our study include the Refusal of parents or subjects to participate.

Conclusion:

Functioning has no effect on the quality of life of adolescents with physical disability due to rheumatic diseases.

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